

UNDERSTANDING QUALITY OF LIFE IN ADOLESCENTS LIVING WITH  
ADVANCED CANCER

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Submitted to the faculty of the University Graduate School  
in partial fulfillment of the requirements  
for the degree  
Doctor of Philosophy  
in the School of Nursing,  
Indiana University

April 2011

Accepted by the Faculty of Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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## DEDICATION

I dedicate this dissertation work to my grandma, Maggie Moore, who always saw the best in me, and taught me how to love unconditionally.

I would also like to thank the many adolescents and children diagnosed with cancer who have made such a difference in my life. If I could list you each by name, and all of the lessons I have learned; it would fill the pages of this book. When I think of you, I smile with gratitude. You have taught me how to live each day with a purpose, how to love my family and friends more deeply, how to let go and forgive more often, and how to fight with determination.

You have helped me to become a better person, and I am forever changed.

## ACKNOWLEDGEMENTS

I would not be where I am today without the loving support of my family and friends, and the incredible guidance and insight from my dissertation committee. To my dissertation chair and undaunted leader, Dr. Victoria Champion, words will never adequately describe my gratitude for all you have done for me. You are an amazing mentor! Thank you for seeing the big picture and the value of end-of-life research for such a vulnerable population. Thank you for believing in me and for investing countless hours in my training and development as a research scientist. With your help, I was able to decipher a complex phenomenon and develop a logical framework for the study of end-of-life research. To my committee, you are la crème de la crème. I could not ask for a better committee. I have great respect for each of you and I am honored to be guided under your tutelage. Dr. Marion Broome, thank you for suggesting the case study method for my dissertation research. Your foresight was instrumental for the development of this entire study, and your pediatric expertise has been a valuable resource for my professional development. Dr. Rose Mays, you have helped me in ways you probably don't even realize, particularly in times of great transition. You have a quiet strength that speaks volumes. Thank you for your investment in me, especially during my Leadership Education in Adolescent Health (LEAH) Fellowship. Dr. Anna McDaniel, I still remember some of your undergraduate lectures. You were one of my favorite professors, and have been a great role model in my life. Thanks for being the case study expert on my committee and for providing wisdom and insight for the methodology section of this study. You are a wealth of knowledge. Last but not least, Dr. Greg Zimet, my minor advisor, who played a major role in my sanity and my development as a research scientist. Thank you for your support during my LEAH Fellowship, for contributing your expertise in adolescent psychology, and for walking with me on this quest to help adolescents with incurable cancer. You were always right there to give me the encouragement I needed to keep pressing on to study such a difficult, but much needed research topic.

I would also like to thank the Walther Cancer Foundation, the American Cancer Society, the Oncology Nursing Foundation, LEAH, and Indiana University School of

Nursing (Research Incentive Fellowship), who provided generous financial support during my doctoral education.

I am very grateful for the expert training I received during my pre-doctoral fellowship with the Mary Margaret Walther Program for Cancer Care Research. I began to eagerly anticipate, (and cherish) the critical feedback I received each year at the annual conference from the senior scientists of the Behavioral Cooperative Oncology Group as I continued to mold and develop my program of research. That was one of the many benefits of the Fellowship. I am also deeply indebted to Peggy Weber and Sandi Fowler. You have made the journey so much smoother. I appreciate your administrative help, your organization, and your friendship. No matter how busy you are, you always find time to provide a listening ear. I will always remember you and smile, when I think of my Walther Fellowship.

A special thanks to Dr. Don Orr and the faculty and staff in Adolescent Medicine and the LEAH program at IU. I am one of many people who passionately desire to address the needs of the adolescent population, and have benefitted from your dedication, time, energy, and expertise in adolescent health and research.

I am deeply grateful to Melissa Lee, Marcie Sherman, and Cindy Davis, pediatric oncology research staff at Riley, for being the eyes and ears for recruitment. I am also thankful for the many physicians who supported this study from its inception through SRC and IRB. Thank you Joni Vaughan, World's best manager, for your encouragement and for providing the flexibility for me to maintain a position on Stem Cell while working on this study. To my academic colleagues Andrea Maners and Dr. Jodi Skiles, data analysis and writing articles may have brought us together but compassion and understanding made us friends. I am so glad our paths have crossed!

I would like to extend a BIG thank you to the American Cancer Society and especially Gary McMullen, Erin, and all the folks at the Great Lakes Division. I was inspired by the Relay for Life volunteers and staff at the National Summit in Houston and the Regional Summit in Michigan. You will never know how much your encouragement cheered me on as I was writing the final chapters of my dissertation.

To my parents and grandparents who have taught me what to do and what *not* to do in life- thank you. You have passed down an excellent work ethic, along with some

stubbornness and determination which have come in handy with the endless hours I have invested in my dissertation research.

To my sisters and life-long friends, Paulette, Jann, Katie, and Mernie, and to my oldest and dearest friends Margo Breininger and Jan Sloan, what can I ever say that will adequately capture the words of my heart? We have been through everything together. I appreciate your support more than words could ever say. Thank you for always standing by me! As I venture into the next chapter of my life's story, I know you will still be there...and that speaks volumes! True friendship is a rare gift, and I cherish the bond I have with each of you. I am honored that you have walked beside me on this journey.

To my three sons, Mike, Mark and Ryan, I will always believe that being your mother is my greatest accomplishment. I could never be more proud of the young men you have become. You have been, and continue to be my greatest teachers in life.

Mike, you have been my voice of reason at so many instrumental points of my life. I appreciate your savvy insight, your creativity, and how you somehow always manage to remind me not to settle for the easy way out. To my lovely daughter-in-law Lara, you have encouraged me in so many ways, and I appreciate the many times you have sent the kids for a "Grandma-fix" at just the right time.

Mark, you have been a source of stability and strength through this whole process. You are also a great observer of life. You have helped me to pay better attention to the details that sometimes get lost along the way. And you always know how to make me smile. I am so thankful for your encouragement and belief in me. To my future daughter-in-law Ashley, you are a beautiful addition to our family. I have been so thankful for the times you and Mark come to visit, bringing a refreshing break in my sometimes overzealous concentration.

Ryan, what can I say? A big thank you for all the hours you invested in listening, transcribing, bouncing ideas, perfecting power points and conceptual models, tutoring me through hand calculations in Biostatistics, and most of all, for really understanding why I am passionate about what I do. You are amazing! I am certain you will find your niche and turn the academic and business world upside down, while simultaneously making a difference for the sake of humanity.

To my grandchildren, Jarred, Ava and Ivy, you are the sunshine of my life. You have provided hugs and kisses, joy and laughter, and you constantly remind me of *all* that is good and beautiful in life. To my dog Hoosier, thank you for hanging in there to the very end!

Last but certainly not least, I want to thank my husband, Leon for walking with me on this marathon of a journey. You have been my sounding board, my companion, my chef, my diversion (when I just couldn't take it anymore), and my very best friend. I really owe a big part of my accomplishment to you. I know there were times when you thought your wife might not ever return, even though we were living in the same house. But I did! And we survived! And I am convinced that you and me together...we can do anything. I love you!

I am so thankful for the adolescents who participated in this study, who took *their* time and energy to invest in this research so that *we* can better understand what it is like to be *living* with advanced cancer. I thank God for giving me the compassion to invest in end-of-life research, for the opportunity over the years to help others at the end-of-life, and for giving me the inner strength to be present with those who are hurting. To all who read this, may you have the courage to dance with those who are facing an unknown future while living with cancer that is not cured.

PREFACE  
COME DANCE WITH ME

*Cynthia J. Bell*

My life is a dance between living and dying

between knowing what is real and pretending it is not

between accepting my destiny and rejecting my fate

between celebrating the moments...

and grieving my time is running out

My life is a dance between Hoping and Believing

that *my* life actually does matter

I AM LIVING

Come dance with me

## ABSTRACT

Cynthia J. Bell

### UNDERSTANDING QUALITY OF LIFE IN ADOLESCENTS LIVING WITH ADVANCED CANCER

The **purpose** of this study is to advance theoretical understanding of how an adolescent with incurable cancer prepares for end-of-life (EOL). A theoretical model was developed to link awareness, acceptance, and willingness to take action to EOL preparedness (knowledge about EOL, acknowledgement of grief and emotion, identification of the meaning of death and spirituality, and conceptualization of personal plan) and communication about EOL preferences and priorities; and to determine impact on quality of life (QOL).

**Method:** Case study research method was used to guide data collection and analyses on two adolescent cases across two time points. The theoretically-based model was developed prior to data collection and based on research studies conducted in adult and pediatric EOL literature. Multiple sources of data were collected and triangulated to assess relationships between qualitative and quantitative data. Through an iterative process of pattern matching, data were compared to constructs in the conceptual model for both across cases, and across time.

**Results:** Results indicate awareness (cognitive recognition of incurable prognosis) and acceptance (emotional acknowledgement of incurable prognosis) are both fluid concepts and varied within each time point and across time. Contextual factors (demographic, environmental, personal, and social support characteristics) influenced awareness, EOL preparedness, and willingness to take action; and directly influenced

QOL. Level of awareness influenced involvement in EOL preparedness. Information preference and willingness to engage in discussions regarding knowledge about EOL were incongruent with actual knowledge about EOL. Adolescents demonstrated a willingness to discuss potential disease progression in order to conceptualize an EOL advanced care plan regardless of emotional acceptance of incurable prognosis. In contrast, acknowledgment of grief and emotions, and identification of the meaning of death and spirituality were related to acceptance of incurable prognosis and further determined conceptualization of immediate EOL priorities. Social constraint or lack of ability to discuss prognosis, was identified as an important construct that influenced communications.

**Implications:** This study provides increased theoretical understanding of how adolescents living with advanced cancer confront EOL. Insight led to theory modification and expansion which may serve as a guide for future research to assist clinicians caring for adolescents living with incurable cancer.

Victoria L. Champion, PhD, RN, FAAN, Chair

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## LIST OF ABBREVIATIONS

AAP:	American Academy of Pediatrics
AYA:	Adolescent/Young Adult
CM:	Centimeter
CT:	Computed tomography
CPS:	Control Preferences Scale
EFAT:	Edmonton Functional Assessment Tool
EOL:	End-of-Life
HCP:	HCP
ICCC:	International Classification of Childhood Cancers
ICD-O:	International Classification of Diseases for Oncology
IOM:	Institute of Medicine
IV:	Intravenous
KG:	Kilogram
MPNST:	Malignant Peripheral Nerve Sheath Tumor
MSPSS:	Multidimensional Scale of Perceived Social Support
NF1:	Neurofibromatosis type 1
NIH:	National Institutes of Health
NPCR:	National Program of Cancer Registries
PEACE:	Peace, Equanimity and Acceptance in the Cancer Experience Scale
QUAL-E:	Quality of life at end-of-life scale
QOL:	Quality of life
TPN:	Total Parenteral Nutrition
WHO:	World Health Organization

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## CHAPTER 1: THE NATURE OF THE STUDY

### Introduction and Background

Cancer is the leading cause of death by disease in the adolescent population 10-21 years of age (Bleyer, 2005; Jemal, et al., 2008). Improvements in cancer treatment protocols have led to an overall cure rate of 75% in this population (Hinds, Pritchard, & Harper, 2004; Jemal, et al., 2008). Still one-fourth of all adolescents with cancer will ultimately die from their disease (Jemal, et al., 2008). Additionally, adolescents 15 to 19 years old have a significantly lower survival rate compared to other pediatric age groups (Bleyer, 2005).

Fewer adolescents participate in clinical trials which are a major method for improving disease outcome and thus directly related to death rates of adolescents with cancer in the United States (Bleyer, Budd, & Montello, 2006). In addition, a disproportionate number of older adolescents and young adults (18 to 24 years old) are without health insurance in our country and tend to be the least likely to access health care, thus presenting with a more advanced stage of cancer (Martin, et al., 2007). Each of these factors may contribute to the markedly lower improvements in 5-year survival rates and mortality reduction rates in adolescents with cancer (Bleyer, 2007).

End-of-life (EOL) research studies in adults have shown that most individuals dying of cancer prefer to die at home (Gomes & Higginson, 2006; Higginson & Sen-Gupta, 2000; Tang, 2003). Similarly family members often want children with cancer to be cared for at EOL in the home (Davies, et al., 1998; Hannan & Gibson, 2005; Surkan, Dickman, Steineck, Onelov, & Kreicbergs, 2006). However, approximately 45-60% of children and adolescents dying from cancer spend their last hours in a hospital setting and nearly 50% of those hospitalized, die in an intensive care unit (ICU) with aggressive treatments directed at sustaining life (Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005; Drake, Frost, & Collins, 2003; J. Wolfe, Grier, et al., 2000). In a recent adolescent study, 78% of adolescent cancer deaths occurring between 2000 and 2005 were in a hospital setting with 41% of those hospitalized dying in ICU (C. J. Bell, Skiles, Pradhan, & Champion, 2010).

Since children and adolescents with cancer are treated in an acute-care medical model focusing on curative treatments across the cancer trajectory (Bradshaw, et al.,

2005; Brandon, Docherty, & Thorpe, 2007; McGrath, 2001), HCPs find it difficult to transition to an EOL, palliative-care focus when cure is no longer possible. In one pediatric study, palliative care interventions (defined as documented interventions of pain management, counseling, support groups, or comfort care such as oxygen, fluids or nutrition) were documented in only 23% of the medical records; and EOL interventions (defined as documented family counseling around the time of death, making memories, debriefing and grief management interventions) were documented in only 6% of the medical records (N = 460), of pediatric deaths resulting from complex chronic conditions, such as cancer, in the United States (Brandon, et al., 2007).

There are many barriers in the current provision of hospice services to children in the home. For example, in all but 3 states in the United States, a parent must forego curative treatment options for their child before services can be offered by a licensed hospice provider (Morris, 2008). Hospice regulations limit the use of blood products, intravenous (IV) fluids or total parenteral nutrition (TPN) at EOL. Insufficient access to pediatric hospice services in rural areas may also inhibit hospice referrals in children or adolescents with cancer.

Although the American Academy of Pediatrics endorses the World Health Organization's integrated model of providing palliative care from the time of diagnosis throughout the illness trajectory (AAP, 2000; WHO, 1990), our nation falls short of integrating palliative care services to address the complex emotional and psychosocial needs of the dying adolescent and his/her family during advanced cancer and at EOL. Parents or family members may also have difficulty accepting when medical science can no longer offer a cure. Therefore many adolescents are dying in an acute-care, curative system without the psychosocial support to face the emotional, spiritual, and existential issues that are a normal part of dying. As a result, adolescents face the uncertainty of an incurable cancer unprepared and without adequate support, resources, knowledge or skills.

The Institute of Medicine has defined a good death as “one that is free from avoidable distress and suffering for patients, families and caregivers, is in general accord with patients' and families' wishes and is reasonably consistent with clinical, cultural and

ethical standards” (IOM, 2001). Yet few studies have examined how adolescents dying with cancer communicate their wishes about living out the remainder of their lives.

Bell, Skiles, Pradhan, and Champion (2010) found physicians initiated discussions about death with dying adolescents an average of 30 days before death. In a study of 103 adolescents with cancer, significant differences in the timing of EOL discussions were noted across diagnostic groups. For adolescents who died with leukemia/lymphoma compared to adolescents with central nervous system tumors or solid tumors, initial EOL discussions were more likely to occur in the last 7 days of life, leaving very little time to psychologically prepare for death (C.J. Bell, Skiles, Pradhan, & Champion, 2010). Drake and colleagues reported 58% of parents whose child died in the hospital were approached for the first time about whether or not to initiate a Do Not Resuscitate (DNR) status on the last day of their child’s life (Drake, et al., 2003). Similarly in a study of 77 children who were known to be terminally or chronically ill, the median time from DNR decision to death was less than 24 hours (range < 1 day to 30 days before death) and 83% died in the ICU (McCallum, Byrne, & Bruera, 2000). Each study was limited by its retrospective design. There may have been discussions that occurred but were not documented. However, the evidence clearly documents there are a significant number of discussions that occur very close to death and quite possibly in the midst of a crisis situation.

Kunnin (1997) describes the ethical struggles that many parents and healthcare providers face particularly when communicating with adolescents about an incurable prognosis. While each brings his/her own coping and communication styles to the relationship, parents in particular may exercise their right to protect their child from the intense emotions associated with death and separation, by waiting until the last possible moment to talk about death (Kunin, 1997). Feudtner et al. (2003) suggest exploring ways for more timely access to pediatric palliative care services not only within the hospital setting but also within the familiarity of community settings (Feudtner, DiGiuseppe, & Neff, 2003).

### *Description of the Problem*

Adolescents prefer to be informed about their cancer diagnosis, treatment and prognosis, and desire a participatory role in decisions about their care (Palmer, Mitchell, Thompson, & Sexton, 2007; Young, Dixon-Woods, Windridge, & Heney, 2003). Research indicates adults dying from cancer and their caregivers feel unprepared for EOL (Babow, Hanser, & Adams, 2004; Barry, Kasl, & Prigerson, 2002; Hannan & Gibson, 2005; Herbert, Prigerson, Schultz, & Arnold, 2006); and adolescents are no exception (Bluebond-Langner, 1978; Palmer, et al., 2007; Young, et al., 2003).

In a retrospective study of adolescent cancer survivors, Dunsomore & Quine (1995) found adolescents desire information even when the prognosis is poor or treatment is ineffective. Almost all of the adolescents, (49 of the 51 participants in their study), stated they wanted to be told if they were going to die (Dunsomore & Quine, 1996). Although few prospective studies have been conducted on adolescents with incurable cancer, documented encounters from clinical experts suggest EOL preparation is less than optimal (Bartholome, 1993; Beale & Baile, 2005; George & Hutton, 2003; McCulloch, Comac, & Craig, 2008; Nitschke, et al., 2000; Perilongo, et al., 2001; Postovsky & Arush, 2004; L. Wolfe, 2004). Preparation for EOL is necessary to help reduce suffering and improve quality of life (QOL). Adolescents who are prepared for EOL would have the opportunity to complete tasks that are important to them, make memories, communicate with loved ones and find closure prior to death, benefitting both the adolescent, their family and professional caregivers.

This chapter will describe the concept of EOL preparedness within a conceptual model that articulates the dimensions of preparedness in relation to QOL at EOL, focusing on adolescents with incurable cancer. The significance of EOL preparedness, the research questions for the study, the limitations of the study and the significance to nursing will be addressed. It is proposed that an adolescent's level of EOL preparedness will affect the quality of how, and where, an adolescent spends his/her final days.

#### *Definition of End-of-Life Preparedness in Adolescents with Incurable Cancer*

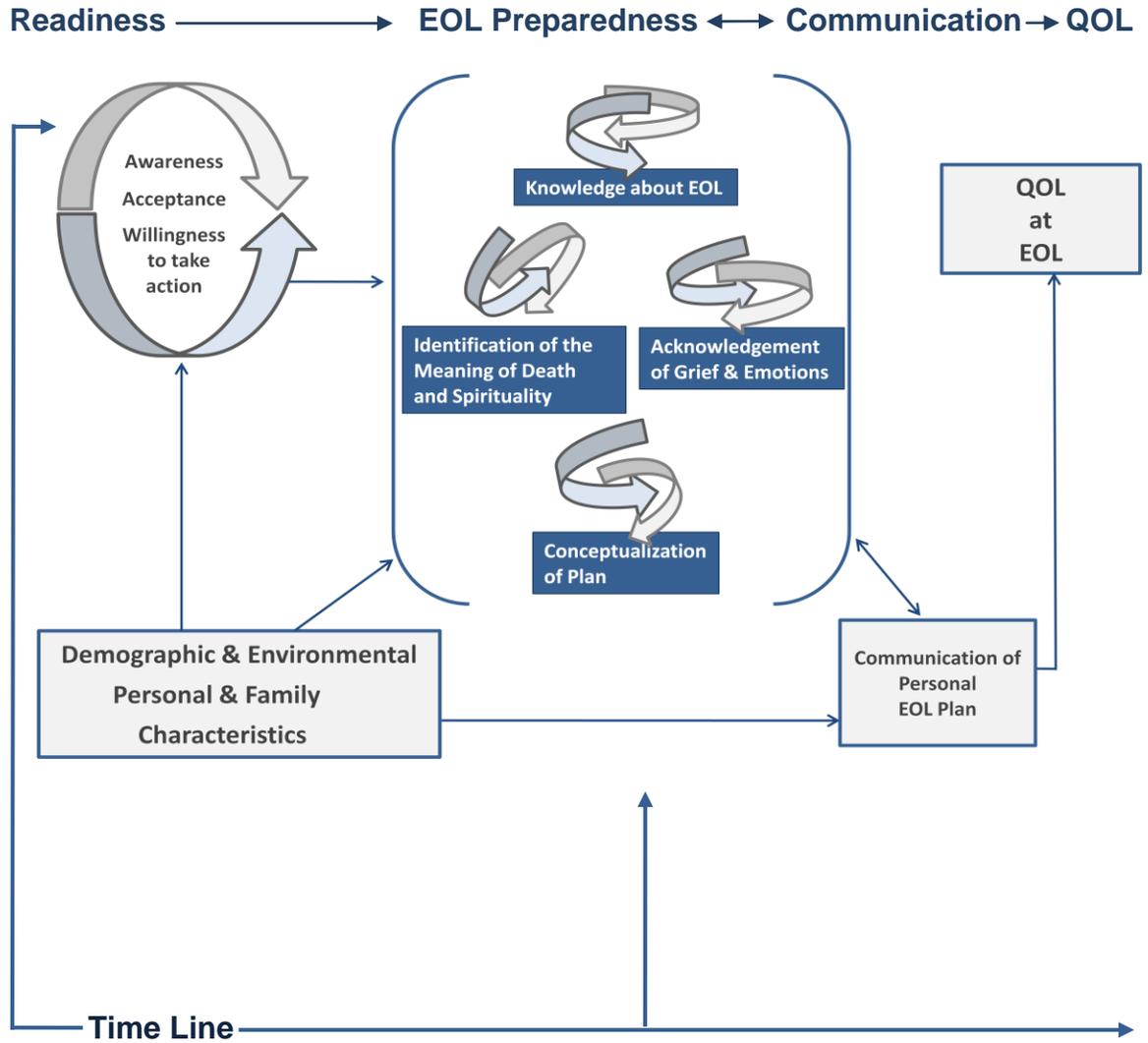
End-of-life preparedness is a process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for the end of life consistent with his/her desires; communicates the desires to family and caregivers; and experiences

a satisfactory end of life (Bell & Champion, 2008). There are 4 defining attributes in EOL preparedness. They are: 1) knowledge about EOL, 2) acknowledgement of grief and emotions, 3) identification of the meaning of death and spirituality, and 4) conceptualization of an EOL plan. Collectively the process of cognitive, emotional, spiritual and practical EOL preparedness leads to communication about an adolescent's EOL beliefs and preferences with his/her parents and/or HCP to assure mutual consensus between what an adolescent desires and what actually occurs at EOL. The process of EOL preparedness is not sequential. The adolescent may address each domain in any order and may move back and forth between domains as the process develops, as demonstrated in Figure 1 on page 6.

#### *The End-of-Life Preparedness Conceptual Model*

The conceptual model shows the proposed relationship between antecedent and outcome variables which is mediated by the process of EOL preparedness. The relationship of each variable within the conceptual model and its origin in research or theory are described more thoroughly in Chapter 2. The conceptual model shows the proposed relationship between antecedent and outcome variables which is mediated by the process of EOL preparedness. Conceptual definitions of each component in the model are discussed in this chapter. The relationship of each variable within the conceptual model and its origin in research or theory are described more thoroughly in Chapter 2. Operational definitions will be included in Chapter 3. Briefly, the process of readiness is an antecedent to EOL preparedness and consists of awareness, acceptance, and a willingness to take action to prepare for EOL. Readiness is influenced by demographic, environmental, personal, and family characteristics. These characteristics also influence EOL preparedness. Additionally the variable "time" influences the readiness and EOL preparedness processes. There are two consequences or outcomes that are a result of EOL preparedness: 1) communication about EOL personal plan to parent(s) and/or HCP, and 2) improved QOL at EOL. The bi-directional arrow between the process of EOL preparedness and communication of EOL personal plan demonstrates how an individual's plan may be modified or adapted over time depending upon disease progression and proposed length of time before death.

**Figure 1: Conceptual Model.**



(Bell and Champion, 2008)

### *Purpose of the Study*

This study will use a multiple-case study methodology to explain how the process of EOL preparedness impacts quality of life (QOL) in adolescents with incurable cancer. In this study, the “case” is defined as the adolescent with incurable cancer. The theoretical predictors (readiness and preparedness) of QOL at EOL will be examined within the context of living with incurable cancer. Data from multiple sources and multiple time points will be collected to measure convergence of concepts within the conceptual model, and to explain the process of EOL preparedness and its impact on the adolescent’s quality of life.

### *Overarching Research Questions*

This multiple-case study will answer the following research questions:

1. How do adolescents with incurable cancer become ready to engage in EOL preparedness?
  - a. What demographic, environmental, personal, and family characteristics influence the process of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) for adolescents with incurable cancer?
  - b. How are the dimensions of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) interrelated?
  - c. How does time influence the process of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) in adolescents with incurable cancer?
2. How does an adolescent’s Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) impact the process of EOL preparedness including the dimensions of: knowledge about EOL; acknowledgement of grief and emotions; identification of the meaning of death and spirituality; and conceptualization of personal EOL plan?
3. How do adolescents with incurable cancer prepare for EOL?
  - a. How is each dimension in the process of EOL preparedness (knowledge about EOL; acknowledgement of grief and emotions; identification of the

meaning of death and spirituality; and conceptualization of personal EOL plan) interrelated?

- b. How does time influence EOL preparedness?
  - c. How do demographic, environmental, personal, and family characteristics influence EOL preparedness in adolescents with incurable cancer?
4. How does the process of EOL preparedness relate to the adolescent's communication of personal EOL plan to his/her parent(s) and/or healthcare provider?
  5. How do demographic, environmental, personal, and family characteristics influence an adolescent's communication of personal EOL plan to parent(s) and/or healthcare provider?
  6. How is an adolescent's quality of life at the end of life influenced by communication of his/her personal EOL plan?
  7. How is an adolescent's quality of life at the end of life influenced by EOL preparedness?

#### Model Components and Conceptual Definitions

Conceptual definitions of this study and rationale for inclusion within the conceptual model are described in the following section. Constructs in the theoretical model include context (demographic, environmental, personal, and family characteristics), readiness (awareness, acceptance, willingness to take action), EOL preparedness (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of a personal plan), communication of personal plan and quality of life at the end of life.

##### *Demographic, Environmental, Personal, and Family Characteristics*

The context is defined as the demographic, environmental, personal, and family characteristics that create the atmosphere of the study. There are several demographic, environmental, personal, and family characteristics that may influence the process of EOL preparedness as well as impact other components in the model. Since multiple-case studies are based on replication logic, demographic, environmental, personal, and family characteristics will assist in case selection. When multiple-case studies are conducted, each case is selected in order to either predict similar results (literal replication); or

predict distinctly different results for predictable reasons (theoretical replication) (R. K. Yin, 2003b). Certain demographic, environmental, personal, and family characteristics will be used for case selection criteria. This will be explained more in Chapter Three.

### *Demographic Characteristics*

There are many demographic factors that may influence an adolescent's understanding of the gravity of their disease and therefore impact the processes of readiness and EOL preparedness. These factors include age, sex, education, disease status and race/ethnicity.

Adolescence is a dynamic period of physical, psychological and social change. This study defines an adolescent as any individual 10-21 years of age (Strasburger, et al., 2006). The process of adolescent development is more accurately described as a gradual process, rather than a series of discrete stages. However, heuristically, it can be useful to characterize adolescent development as occurring over three stages in order to highlight salient features of the process. These stages are loosely defined as early, middle and late adolescence (IOM, 2007; Strasburger, et al., 2006). During early adolescence the key issue is the quest for autonomy. Adolescents show less interest in family activities and more interest in activities with their peers, especially members of the same sex. As adolescents are developing physically, uncertainties about appearance are common. Concrete thinking is still very typical during early adolescence. Lack of impulse control with little understanding of consequences results in high risk-taking behaviors during this stage (Strasburger, et al., 2006).

During middle adolescence peer conformity is important. Peer friendships include both sexes. Relationships are sometimes experimental and being attractive to one's peers is important. Conflict with parents is more prevalent. Believing one is omnipotent and immortal leads to risk-taking behaviors in this stage. Abstract reasoning begins to emerge allowing adolescents to consider possible outcomes or consequences to actions (Strasburger, et al., 2006).

In late adolescence parental relationships are renegotiated and generally become more positive. Adolescents become more comfortable with their own values and identities as peer conformity is less important. Mutual understandings are achieved in partner relationships. In late adolescence the ability to compromise and set realistic limits

occurs. During this stage adolescents generally demonstrate abstract reasoning (Strasburger, et al., 2006).

Although Strasburger et al. (2006) categorize early, middle and late adolescence by age (i.e. early adolescence 10-13 years old; middle adolescence 14-17 years old; and late adolescence 18-21 years old) (Strasburger, et al., 2006) there are many variations in the biopsychosocial processes of adolescent development. So a caveat for health care professionals, educators and researchers is to be aware of the progression of development that occurs on multiple levels (physical, psychological, social, and spiritual) during adolescence; and to be attuned to the individual variations which may not necessarily coincide with age.

In recent years, there has been interest among medical and legal professionals to support the adolescent's right to be actively involved in decisions that affect their medical care, particularly decisions affecting EOL (Freyer, 2004; Freyer, et al., 2006; Hartman, 2004; Nitschke, et al., 2000; Weir & Peters, 1997). State courts are recognizing that an adolescent's experience with a life-threatening disease escalates maturity level for an individual of minor age and is a reliable indicator for decision making capability (Hartman, 2004). Therefore age as well as disease status (i.e. length of cancer experience, type of cancer and prognosis associated with his/her original diagnosis) will be collected as demographic variables.

Age, education and gender may influence preference in decision-making which in turn, may influence an adolescent's involvement in the process of EOL preparedness. In an adult study conducted by Degner and Sloan (1992) female individuals with cancer preferred more decisional control than men. Similarly individuals with more education and those who were younger adults preferred more decisional control (Degner & Sloan, 1992).

The length of time an adolescent knows of his/her incurable prognosis may influence psychological adaptation. Studies conducted by Andershed and Ternstedt have described that individuals with a very rapid illness trajectory feel less prepared for death as described by participants and their caregivers during qualitative interviews (Andershed & Ternstedt, 2001). Additionally Herbert (2006) found that education and race were significant predictors of EOL preparedness for adult caregivers. Preparedness was

measured subjectively with a one item measure “To what extent were you prepared for the care recipient’s death?” Responses were “not at all; somewhat; or very much” Results showed individuals with higher education were better prepared. African-American participants reported less preparedness than White participants. There were no significant differences in reported preparedness between Hispanic versus non-Hispanic White participants in Herbert’s study. (Herbert, Dang, & Schultz, 2006). However, evidence shows cultural beliefs impact EOL practices, particularly open communication among family members (Herbert & Schultz, 2006; Hern, Koenig, Moore, & Marshall, 1998; Shrank, et al., 2005).

The following **Demographic Characteristics** will be included in this study:

- Age: defined as the life interval of the adolescent with cancer.
- Sex: defined as the classification of an individual into an exclusive group of male or female based on typical reproductive function.
- Education: defined as level of formal schooling an adolescent has received (last grade completed; and current grade enrolled in school).
- Disease Status: defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis, as well as the trajectory of the illness.
- Race: defined as adolescent’s perception of belonging to a distinct group of the human population distinguishable from others based on shared biological traits.
- Ethnicity: defined as adolescent’s perceived affiliation with group of individuals sharing common customs, language, or history.

#### *Environmental Characteristics*

The process of dying is influenced by the social environment where an adolescent spends his/her final days. Environmental characteristics that may influence the processes of readiness and EOL preparedness include place of care such as hospital, hospice, or home care environment; focus of care, i.e. whether care is directed from an acute-care context or a palliative care context; continuity of staff; EOL training, including hospice or palliative care certification of nursing staff; experience of nursing staff; and EOL discussions with HCP.

Most adolescents diagnosed with cancer are initially treated in a tertiary care center with experts specializing in pediatric oncology. Over the course of months and sometimes years the individual and his/her family share mutual joys from the successes of treatment as they develop deep and trusting relationships with HCPs within an acute-care medical environment. Yet when cure is no longer possible, adolescents and their families must face the painful reality of death. The relationships previously developed between health care professionals, the adolescent and family have a crucial influence on the adjustment and adaptation to a life-limiting prognosis. This transition is very difficult. Nursing professionals who have additional training in hospice, palliative or EOL care provide an added resource for this transition.

Place of care and relationship with the HCP can influence how an individual and family accept the process of advanced or incurable disease. For example, if an adolescent and/or parent chooses aggressive or experimental treatment in light of an incurable prognosis, the focus will be on prolongation of life in an acute-care setting, with little focus on preparation for death. In contrast, if an adolescent and/or parent chooses palliative EOL care or a hospice environment, the primary focus becomes quality living while confronting and preparing for death. Health care professionals in a hospice environment are trained to support individuals holistically; however, few adolescents dying of cancer enter a hospice program prior to death (Fowler, et al., 2006). Additionally, specialty certification of nurses has been linked to personal and professional benefits as well as positive performance outcomes for patients (Cary, 2001; Niebuhr & Biel, 2007; Weeks, Ross, & Roberts, 2006). It is proposed that conversations about EOL and preparedness will occur more frequently and more comfortably among adolescents who are cared for by a proficient or expert nurse. Based on Benner's work from novice to expert (P. Benner, 1982; PE Benner, 1984), the length of time spent in oncology nursing may influence the ease in which a nurse addresses the psychosocial needs of the dying adolescent as well as EOL conversations.

End-of-Life discussions within the health care environment influence awareness, acceptance, and willingness to engage in EOL preparedness. Adolescents in this study will not be recruited until an initial conversation about the adolescent's life-limiting prognosis has been discussed with the adolescent and his/her family by the physician.

Timing of EOL discussions can influence the processes of readiness and EOL preparedness. Discussions that occur too close to death make it difficult for the adolescent and family to accept the reality of death and to psychologically prepare for EOL. Additionally, ongoing discussions as opposed to a one-time discussion facilitate a better understanding of what to expect and how to prepare for EOL.

The following **Environmental Characteristics** will be included in this study:

- Place of care: defined as the environment where adolescent is living with advanced and incurable cancer.
- Focus of care: defined as adolescent's perception of specific purpose for care delivery (palliative versus curative).
- Continuity of staff: defined as continuation of familiar nursing and medical staff (oncologist, psychologist, primary attending physician, etc.) while transitioning to EOL.
- EOL discussion: defined as a conversation about impending death or incurable prognosis with the adolescent or adolescent and his/her parent(s).

#### *Personal Characteristics*

Personal characteristics are factors pertaining directly to the adolescent with incurable cancer that may impact the processes of readiness and EOL preparedness. This would include physical or psychological symptom distress; and preferences for decisional control.

#### **Physical Symptom Distress**

It has long been understood that symptom distress variables interfere with an individual's ability to socially engage with others. Managing distressing physical symptoms that interfere with quality of life are necessary before psychological and emotional needs can be addressed in the process of EOL preparedness. The most common physical symptoms reported at EOL in cancer patients include: pain, fatigue, weakness, dyspnea, weight loss, anorexia, vomiting, constipation, and diarrhea (Bradshaw, et al., 2005; Goldman, Hewitt, Collins, Childs, & Hain, 2006; J. Wolfe, Grier, et al., 2000).

## **Psychosocial Symptom Distress**

Prominent psychosocial symptoms at EOL reported in the literature include: depression, sadness, anxiety, nervousness, worry, guilt, loneliness, and fear (Drake, et al., 2003; Georges, Onwuteaka-Philipsen, van der Heide, van der Wal, & van der Maas, 2005; Potter, Hami, Bryan, & Quigley, 2003; Theunissen, et al., 2007). In a large prospective EOL adult study, feelings of loneliness and anxiety interfered with a peaceful death (Georges, et al., 2005).

## **Decisional Control Preferences**

Some of the key developmental tasks during adolescence include achieving independence, developing a sense of autonomy and maintaining individuality (Balk, 2008; Ritchie, 2001; Strasburger, et al., 2006). Participatory decision-making honors the adolescent by providing the opportunity to be actively involved in decisions affecting treatment and care. Studies conducted throughout cancer treatment for adolescents with cancer have demonstrated adolescents want to be involved in treatment decisions (Dunsomere & Quine, 1996; Hinds, et al., 2001; Palmer, et al., 2007). Furthermore guidelines have been developed that recommend adolescents have the opportunity to be actively involved in decisions about their care, even at end of life (Masera, et al., 1999; Spinetta, et al., 2003).

The following **Personal Characteristics** will be included in this study:

- Physical symptom distress: defined as perceived physical symptoms that interfere moderately or severely with daily activities.
- Psychosocial symptom distress: defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities.
- Decisional control preferences: defined as adolescent's preferred level of involvement in decisions about care and treatment.

## *Family Characteristics*

In pediatric oncology the family is an integral part of the treatment process. In the United States if an adolescent is under the age of 18 at diagnosis, a parent or legal guardian must consent for treatment. Therefore from the point of diagnosis, adolescent and healthcare provider discussions are initiated within the context of the family unit. At times this may create a strain on the patient-provider relationship if the adolescent is not

given an equal opportunity to contribute to the plan of care. This dynamic becomes even more complex as disease progresses and the adolescent and his/her family faces an incurable prognosis. Acceptance of prognosis and willingness to discuss the emotional and psychological stressors that are part of dying are influenced by family communication; family coping mechanisms; family support and cultural and spiritual practices. For this study family characteristics that will be measured include perceived family and social support, family communication and family cultural and spiritual practices.

Each family has its own unique culture. Sometimes culture is influenced by the country of origin, or an individual's ethnic heritage. In the United States there are unique cultures across regions (i.e. Midwest, South, West and East). There are also unique cultures within the same city depending upon each unique family. There are many beliefs, ceremonies and rituals that surround the death of a loved one, and researchers are striving to understand how to better provide culturally competent care. For this study information will be collected on the cultural and spiritual practices that may influence EOL preparedness.

The following **Family Characteristics** will be included in this study:

- Family and other social support: defined as adolescent's perception of family and other sources of encouragement, support, and help during difficult times.
- Family communication: defined as the degree of open discussion among family members about difficult topics such as EOL.
- Family cultural and spiritual practices: defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent's personal and family life.

### *Readiness*

Readiness is an antecedent to EOL preparedness. In this study Readiness is defined as a process of becoming ready over time. It involves cognitive awareness of impending death, emotional acceptance of death as a realistic threat, and finally willingness to take action or begin the process of EOL preparedness.

### *Awareness*

Awareness of death in the pediatric literature has shown that individuals know they are dying from cancer even before their physician or parent has discussed the topic with them (Bartholome, 1993; Beale & Baile, 2005; Nitschke, et al., 2000). In Myra Bluebond-Langner's classic work, *The Private Worlds of Dying Children*, the stages of awareness are described as children and adolescents become more cognizant through socialization (Bluebond-Langner, 1978). Children and adolescents pick up non-verbal and verbal cues as they are dying to confirm or discredit their preconceived notions. In Bluebond-Langner's ethnographic study, adolescents would seek out their peers with similar diagnoses to determine what would happen next if they could not get honest answers from their parents or HCP (Bluebond-Langner, 1978). Their awareness context followed the stages of Glaser and Strauss who conducted some of the earliest research on awareness of death (Glaser & Strauss, 1965).

Glaser and Strauss conducted a grounded theory research study and determined there are four awareness contexts evidenced during interactions with dying individuals. The first context is closed awareness. This is where the HCP and family are cognitively aware of impending death but the dying individual gives no indication of awareness and therefore information about death is not discussed. The second context is suspicion awareness. Here the dying individual suspects that he/she is dying but the suspicion is not validated by the HCP or family. The third context is mutual pretense where the dying individual, family member and healthcare provider are all aware of impending death but continue to act under the pretense that the individual is not really dying. This becomes a delicate balancing act and if one member breaks the rules for maintaining this context, such as discussing prognosis, then open awareness ensues. In the final context of open awareness all parties are aware of the individual's impending death and discussions about death and dying are addressed openly (Glaser & Strauss, 1965). Bluebond-Langner's

study showed dying individuals, their parents and HCP would go to great lengths to maintain the mutual pretense context; even after an open awareness context occurred some individuals felt more comfortable returning to a mutual pretense context (Bluebond-Langner, 1978).

### *Acceptance*

Acceptance is defined as the emotional acknowledgment that death is a realistic threat. Even after adolescents and their parents are cognitively aware of the incurable prognosis, an emotional acceptance of the inevitability of death must occur. In recent literature several studies have been conducted on prognostic awareness and acceptance of impending death (Barnett, 2006; Barry, et al., 2002; Herbert, Dang, & Schulz, 2006; Mack, et al., 2008; Ray, et al., 2006; Robinson, et al., 2008; Surkan, Dickman, et al., 2006). There appears to be an emotional component of peace or resolution that contributes to positive acceptance with minimal distress. So there is both acceptance and peaceful acceptance, where the latter is associated with lesser psychological distress.

### *Willingness to Take Action*

Awareness of death and acceptance are not enough to prepare an individual for EOL. One must also be willing to take action to prepare for EOL. One way to do this is by engaging in EOL discussions to address EOL issues. In a study conducted by Dalton and Gottlieb (2003), the desire to change and take action determined an individual's degree of readiness. In addition, certain factors were found to trigger readiness, including 1) perception that a health concern is not going to resolve, 2) a change in physical condition which takes on new meaning, 3) confidence to manage stress, 4) sufficient energy and 5) adequate support. The presence of one or more of these factors triggered an individual's readiness to consider change (Dalton & Gottlieb, 2003).

End-of-life preparedness is a change in mindset, from focusing on cure and treatment to planning for EOL. This change allows the individual to weigh the costs and benefits of every decision in light of a limited life span. Living life to the fullest while confronting death requires social support, energy and Readiness. Willingness to take action is the third step in the process of Readiness. It is an agreement or intent to take action, having weighed the pros and cons of moving in this new direction.

The following components of **Readiness** will be included in this study:

- Awareness: defined as the level of cognitive recognition of an incurable prognosis. Open awareness will be based on a patient-physician discussion regarding the open acknowledgment of the medical limitations to cure the adolescent's cancer which will ultimately result in death.
- Acceptance: defined as the level of emotional acquiescence of an incurable prognosis.
- Willingness to Take Action: defined as the level of intent or desire to take action to prepare for EOL. It involves a willingness to discuss issues pertaining to EOL questions and concerns; emotional aspects of EOL; the meaning of death, spiritual and cultural aspects of death and dying; and EOL plans or goals to accomplish while living out the remainder of life.

#### *End-of-Life Preparedness*

In this study, EOL preparedness in adolescents with incurable cancer is defined as a process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end-of-life consistent with his/her desires; communicates the desires to family and caregivers; resulting in a satisfactory end of life (Bell & Champion, 2008). The defining attributes include knowledge of EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan. Each of these factors is defined below. Ideally, through the process of EOL preparedness, the dying adolescent has the opportunity to address the physical, psychological, spiritual and practical issues that are a normal part of dying with the social support of their family and an interdisciplinary team. The components of each factor are briefly listed below. A more thorough discussion of EOL preparedness will be included in the literature review of Chapter 2.

#### *Knowledge about End-of-Life*

Knowledge about EOL includes comprehensive information about EOL. This includes knowledge about the process of dying, knowledge about symptoms, and knowledge about EOL options that are available when one is dying.

### *Acknowledgement of Grief and Emotions*

Acknowledgement of grief and emotions includes discussing emotions, grief and sadness with family, friends or healthcare provider; acknowledging feelings of sadness for not having a normal life; acknowledging grief about leaving family and friends and expressing emotionally what those relationships have meant.

### *Identification of the Meaning of Death and Spirituality*

Identification of the meaning of death and spirituality includes exploring and discussing spirituality and the certainty of death; spiritual concerns and beliefs; describing the purpose of life and the meaning of death; and recognizing sources of spiritual support.

### *Conceptualization of End-of-Life Plan*

Conceptualization of EOL Plan includes defining goals for the remainder of one's life, prioritizing tasks to complete before death; identifying preference of location for living remainder of life, planning opportunities to create meaning and make memories with friends and family, and describing preferences about EOL such as advanced directives, DNR, or management of symptoms.

The following components of **EOL preparedness** will be included in this study:

- Knowledge about EOL: defined as a comprehensive understanding of the process of dying, including physical and psychological symptoms and options available at EOL.
- Acknowledgement of grief and emotions: defined as the adolescent's recognition of grief and emotional expression of the meaning of loss.
- Identification of the meaning of death and spirituality: defined as the adolescent's recognition of the meaning of death and exploration of spirituality and existential beliefs.
- Conceptualization of an EOL plan: defined as a comprehensive list of goals, priorities and preferences for living with incurable cancer.

### *Outcomes*

There are 2 outcomes that are a result of EOL preparedness: 1) communication of personal EOL plan, and 2) improved quality of life at the end of life. Each outcome is described in the following section.

#### *Communication of Personal End-of-Life Plan*

Once an adolescent has conceptualized a personal plan, the next step is to communicate that plan with parent(s) and/or HCP. Communication of personal EOL plan is defined as adolescent's written or verbal expression about conceptualized plan which includes goals, priorities and EOL preferences. It may include describing how the adolescent wants his/her death to be (such as preferred location of death, DNR, pain and other symptom control measures), planning funeral arrangements or making a will. It includes prioritizing goals and expressing formulated beliefs about EOL with family, and/or HCP. It is proposed that communication of personal EOL plan will lead to better quality of life at the end of life by assuring the adolescent's EOL goals, priorities and preferences are respected and upheld whenever possible by parent(s) and members of the health care team.

#### *Quality of Life at the End of Life*

Quality of life at the end of life is defined as the adolescent's subjective estimation of the quality of symptom control, relationships with others, the meaningfulness of life, and resolution of impending death. It is proposed that as an adolescent is more prepared, his/her quality of life at end of life will also improve. The following **Outcome Variables** will be included in this study:

- Communication of EOL Plan: defined as a written or verbal expression about adolescent's conceptualized plan- this includes goals, priorities, and EOL preferences to parents and/or HCP.
- Quality of life at the end of life: defined as the adolescent's subjective estimation of the quality of symptom control, relationships with others, and the meaningfulness of life, and resolution of impending death.

## Significance of the Study

Knowledge about EOL preparedness in adolescents with incurable cancer is an essential component for providing the best care of EOL to adolescents and their families. First EOL preparedness provides an individual with the necessary knowledge about the dying process and options that are available at EOL. Preparedness implies a readiness to plan for an event that one is not prepared for. Since developmentally an adolescent is not prepared for death, preparedness will address the essential need for knowledge on what to expect physically and psychologically, and the options that are available at EOL.

Secondly, EOL preparedness is important for the adolescent who is dying because there are many losses that the adolescent faces while dying. There is the loss of a future, the loss of dreams, and the loss of planning for one's occupation, future relationships or family. There is the anticipatory loss of current relationships; having to say good-bye to friends and family members. There is the loss of normalcy. There is nothing normal about dying during adolescence. There is also loss of strength and independence at a critical time in the adolescent's life when strength and independence are crucial aspects of normal growth and development. Each of these losses is a type of grief, and facing multiple losses makes this a very complex emotional time. An important component of EOL preparedness is acknowledgment of grief and emotions.

Third, EOL preparedness is important for the adolescent who is dying because there may be spiritual, cultural or existential needs that surface when one is facing death. Studies in adults have shown the benefit of supporting spiritual and cultural beliefs in the dying individual which help to give meaning to life and death (Crawley, Marshall, Lo, & Koenig, 2002; Kagawa-Singer & Blackhall, 2001; Kitzes & Berger, 2004; Lobar, Youngblut, & Brooten, 2006). Additionally, death-related fears are typically associated with the dying process (Penson, et al., 2005; Steihauser, Christakis, et al., 2000; Theunissen, et al., 2007) Some of these fears may be relieved through discussions about what to expect, however, some fears are addressed better in light of one's spiritual or cultural beliefs. Identification of the meaning of death and spirituality is filtered through an individual's spiritual and cultural beliefs and is an important aspect of EOL preparedness.

A critical component of EOL preparedness is individuality. As one is preparing for EOL, it is important to maintain individuality. In a study conducted by Steinhauser et al, being known as an individual was important (Steinhauser, Christakis, et al., 2000). EOL preparedness allows the adolescent to conceptualize and individualize a plan that uniquely represents his/her goals/desires for living out the remainder of life. Preparing for EOL is really about living. After confronting the inevitability of death, an adolescent can focus on living life and making the most of today and tomorrow. An EOL plan is the byproduct of EOL preparedness and can help the individual achieve a sense of control over a situation that feels very unmanageable.

Finally EOL preparedness is important for the adolescent with incurable cancer because it opens the door for communication of one's conceptualized plan. When an adolescent has the opportunity to communicate his, her desires prior to death, especially with a trusted individual, such as a parent or HCP, there is reassurance that decisions will be honored through end of life.

#### Limitations of the Study

The proposed study is an empirical inquiry that will investigate and ultimately explain the process of EOL preparedness in adolescents with incurable cancer within the real-life context of living with cancer. Case study method offers the strength of adaptability to meet both practical and ethical considerations of studying the complexity of end of life research. However, case study method also has the following limitations in this study: 1) the boundaries between the phenomenon of EOL preparedness and the context of living with an incurable disease are not clearly defined and therefore will not be controlled, 2) the individual cases in this proposed study are not generalizable to populations however, the proposed case study will be generalizable to theoretical propositions, 3) the process of dying affects the adolescent and his/her family, however, this study will limit its focus to understanding EOL preparedness as it pertains to the adolescent with incurable cancer.

## Assumptions

The assumptions for this study are:

1. Adolescents will honestly report their perspectives about EOL.
2. Self-report questionnaires that are administered to adolescents are valid and reliable.
3. Dying is an individual process that can be investigated systematically.
4. EOL preparedness is a subjective experience.
5. Dying does not occur in isolation and therefore the social context influences the dying process.
6. Narratives from individual experiences are an effective way to describe the processes of Readiness and EOL preparedness.
7. Theory development prior to data collection provides the essential foundation for case study research.

## Significance to Nursing

There is increasing empirical evidence that supports the need to address the palliative/EOL needs of the dying adolescent and his/her family. However, EOL research is laden with methodological, practical and ethical challenges. Dying adolescents are vulnerable individuals and may not be able to withstand traditional methods of research. Additionally the sample available for a prospective EOL study at a single university site is small. Case study research method is a rigorous research strategy that will reduce the research burden on the adolescent while collecting data from additional sources, such as medical chart reviews, and observations. This study will contribute to our knowledge of adolescent preparation for EOL. Descriptions from this study of EOL preparedness and its impact on QOL will contribute theoretical support for addressing adolescent EOL issues in practice and research. Nurses have an integral role in supporting adolescents and their families at EOL. Knowledge about how adolescents acclimate to the dying process and how they construct meaning and hope will provide tangible benefits to clinicians providing EOL nursing care.

Many qualitative and quantitative EOL research studies have been conducted and will be discussed more thoroughly in the next chapter. These studies have provided the foundation for the development of the conceptual model that guides the current study.

Case Study Research Method will provide the framework to examine the theoretical propositions within the proposed conceptual model. This will build theoretical knowledge in addressing the complex needs of adolescents who are dying of cancer. Furthermore the prospective design will permit study of adolescents with advanced disease while capturing transitions during the dynamic and challenging experience of facing end of life. Life and death are part of human development and existence. Expanding our understanding of the process of EOL preparedness will provide insight for the development of interventions that will support adolescents with cancer and their families to live more fully as they address the physical, psychological, emotional, spiritual and existential issues associated with EOL.

#### Summary

Theoretical advancement of quality of life at the end of life though extremely important has been neglected in adolescent EOL research. This multi-case study will describe and analyze the process and effects of EOL preparedness on quality of life at the end of life. A conceptual model based on analysis of the EOL literature will provide the framework to guide this study. This multi-case study will answer research questions related to the constructs within the model to inform theoretical propositions and advance the knowledge and theory of adolescent EOL research.

## CHAPTER 2: LITERATURE REVIEW

This chapter will present a review of the literature in three main sections: 1) an overview of adolescent cancer, 2) the effect of cancer on adolescent development, and 3) theoretical perspectives supporting the conceptual framework.

### SECTION ONE: ADOLESCENT CANCER STATISTICS

#### Adolescent Cancer

This chapter begins with an overview of adolescent cancer, including the effect of cancer on adolescent development. In this study an adolescent is defined as an individual between the ages of 10 and 21 years of age (Strasburger, et al., 2006). However, one of the difficulties in reporting adolescent cancer statistics stems from the lack of a consistent definition for an adolescent. The second obstacle to reporting accurate adolescent cancer statistics stems from the way in which data is categorized by age. For example, the National Program of Cancer Registries (NCPDR) provides data to the Centers for Disease Control (CDC) and Prevention which can be broken down by 5 year increments, i.e. 10 to 14, 15 to 19, 20 to 24, etc. Information on adolescents between the ages of 10 and 19 can be reported without difficulty; however, the information on adolescents who are 20 and 21 is lost in the 20 to 24 year-old age group (*United States Cancer Statistics: 1999-2005 Incidence and Mortality Web-based Report* U.S. Cancer Statistics Working Group, 2009). Similarly, the National Cancer Institute (NCI) provides data from the Surveillance, Epidemiology, and End Results (SEER) program which reports information on individuals in five year increments across the lifespan (Ries, et al., 2008). In addition, each year the American Cancer Society publishes data on cancer statistics. Data is collected from various sources including SEER, experts in epidemiology, the US Mortality Data and National Center for Health Statistics, at the CDC. This data reports cancer trends on children under the age of 15 or for individuals from birth to age 19. Again, the statistics for the younger adolescent (10-14 years old) or older adolescent (20-21 years old) are mixed with statistics for either children or adults (Jemal, et al., 2008). Adolescent cancer statistics are not clearly defined and are often buried within the reports on children or adults.

Similarly, in clinical practice, research, and education, the age boundary for adolescence is not universally defined. This was evident when a committee of adolescent

experts convened to discuss the challenges in adolescent health care (IOM, 2007). Depending on the source, adolescence does not begin before the age of 10 and it ends somewhere between 19 and 25 years of age, depending upon the source. Some cancer studies have combined older adolescents and young adults (AYA) to report AYA findings for 15-29 year-olds (A. Bleyer, M. O'Leary, R. Barr, & L. A. G. Ries, 2006), or more recently 15-39 year-olds (Hayes-Lattin, et al., 2006). In an effort to capture all of the available data about the adolescent age group (10-21 years old), statistics are reported for this study using data classification systems for individuals 10-14 years old, 15-19 years old and 20-24 years of age.

In summary, the lack of clear age boundaries to define adolescence contributes to incongruent reporting of adolescent cancer statistics. In addition, age classifications for reporting cancer statistics vary according to cancer data base sites. Five year increments for reporting cancer statistics are only conducive to the definition of an adolescent within the pre-determined 5-year increments (i.e. 10 to 19 years, 10 to 24 years, 15 to 19 years, or 15 to 24 years).

#### *Classification of Adolescent Cancer*

The method for reporting adolescent cancer is also inconsistent. Cancer statistics for adolescents are reported two different ways. First, cancer can be reported in adolescents by using the International Classification of Diseases for Oncology (ICD-O). This classifies cancer based on primary site (i.e., gastrointestinal, genitourinary, breast, etc.) and morphology; and is commonly used in adult oncology. The second way adolescent cancer is reported is by using the International Classification of Childhood Cancer (ICCC) system. Childhood cancer is often classified based on histology or tissue of origin, (Li, Thompson, Miller, Pollack, & Stewart, 2008). Unlike adult cancers which tend to originate in specific locations or organs in the body, childhood cancers tend to be widely dispersed at diagnosis (i.e. lymphohematopoietic, connective tissue, peripheral nervous system, etc.) (Bleyer, Hag-Alshiekh, Pollock, & Reis, 2006). Therefore identifying the histology is more effective in determining specific cancer treatment protocols. The ICCC allows for a more accurate characterization of childhood cancers. Cancer data in adolescents is sometimes reported using the ICCC and other times reported using ICD-O since adolescents may be treated at either a pediatric or adult

cancer institution. This lack of congruency can be problematic when trying to make comparisons and track improvements across the adolescent age groups.

Refinements are proposed for the classification of cancers that are specific to the AYA population (Birch, Alston, Quinn, & Kelsey, 2003; A. Bleyer, M. Hag-Alshiekh, et al., 2006). Nevertheless, registration and classification issues impact the concise reporting of adolescent malignancies (Pollock & Birch, 2008), particularly for those individuals in middle and late adolescence.

In the United States, an adolescent may be treated by a pediatric oncologist at 21 years of age or may be seen by an adult oncologist at age 15. Perhaps this relates back to the lack of a universal definition for an adolescent and/or the lack of guidance on where and by whom the adolescent with cancer should be treated.

Information about cancer, staging, morphology, etc. varies across different population-based cancer registries. Detailed information is sometimes limited, for example, if individuals have not given full consent to collect information as part of a clinical trial. In these circumstances data are not collected (Pollock & Birch, 2008).

In summary, since diagnostic classification and reporting procedures vary across registries it becomes more difficult to track and compare adolescent diagnoses with outcomes (Pollock & Birch, 2008). Also adolescents are treated at both pediatric cancer centers and adult cancer centers in the United States. This influences enrollment in clinical trials and impacts consistency of protocol-driven adolescent cancer treatments (K. H. Albritton & Eden, 2008; Ferrari, Montello, Budd, & Bleyer, 2008). Additionally adolescent-specific cancer units don't exist in the United States. One exception is the Dana Farber Cancer Institute and the Oregon Health and Science University which have created clinics dedicated to treating AYAs with cancer (McGoldrick, Neal, & Whiteson, 2008). Consistent treatment centers for adolescents with cancer and more specific classifications in cancer registries, based on morphology, will provide better tracking of adolescent outcomes and facilitate more timely response to the disparities reported in the adolescent population.

### *Incidence of Cancer*

Cancer, although relatively uncommon in younger age groups in the United States, affects roughly 7,000 adolescents 10-19 years old and 6800 adolescent/young adults between the ages of 20-24 each year (A. Bleyer, M. O'Leary, R. Barr, & L. Ries, 2006; *United States Cancer Statistics: 1999-2005 Incidence and Mortality Web-based Report* U.S. Cancer Statistics Working Group, 2009). Data from the National Program of Cancer Registries (NPCR) from 2001-2005 indicate 69,995 individuals 10 to 24 years old were diagnosed with cancer. During this same 5-year time-frame, the incidence of cancer markedly increased with each 5 year age increment beginning with 13,688 cases reported in individuals 10-14 years old; 21,968 cases reported in individuals 15-19 years old; and 34,339 cases reported in individuals 20-24 years old ("United States Cancer Statistics: Incidence and Mortality: 2001-2005. Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion," National Program of Cancer Registries, 2009).

### *Types of Cancer*

The type of cancer varies according to the age of the adolescent. The following section reports the changes in primary cancer types among adolescents 10-14 years old, 15-19 years old and 20-24 years old.

#### *Primary Cancers Reported in Adolescents 10-14 Years Old*

The top three cancers reported for adolescents 10-14 years old from the 2001-2005 NPCR data using ICCC are: 1) leukemias, 2) central nervous system (CNS)/brain tumors, and 3) lymphomas. The most prevalent cancers reported for adolescents 15-19 years old are: 1) lymphomas, 2) malignant epithelial neoplasms/melanomas (which include thyroid carcinomas and malignant melanomas), 3) leukemias, 4) germ cell tumors (particularly malignant gonadal germ cell tumors), and 5) CNS/brain tumors.

#### *Primary Cancers Reported in Adolescents 15-19 Years Old*

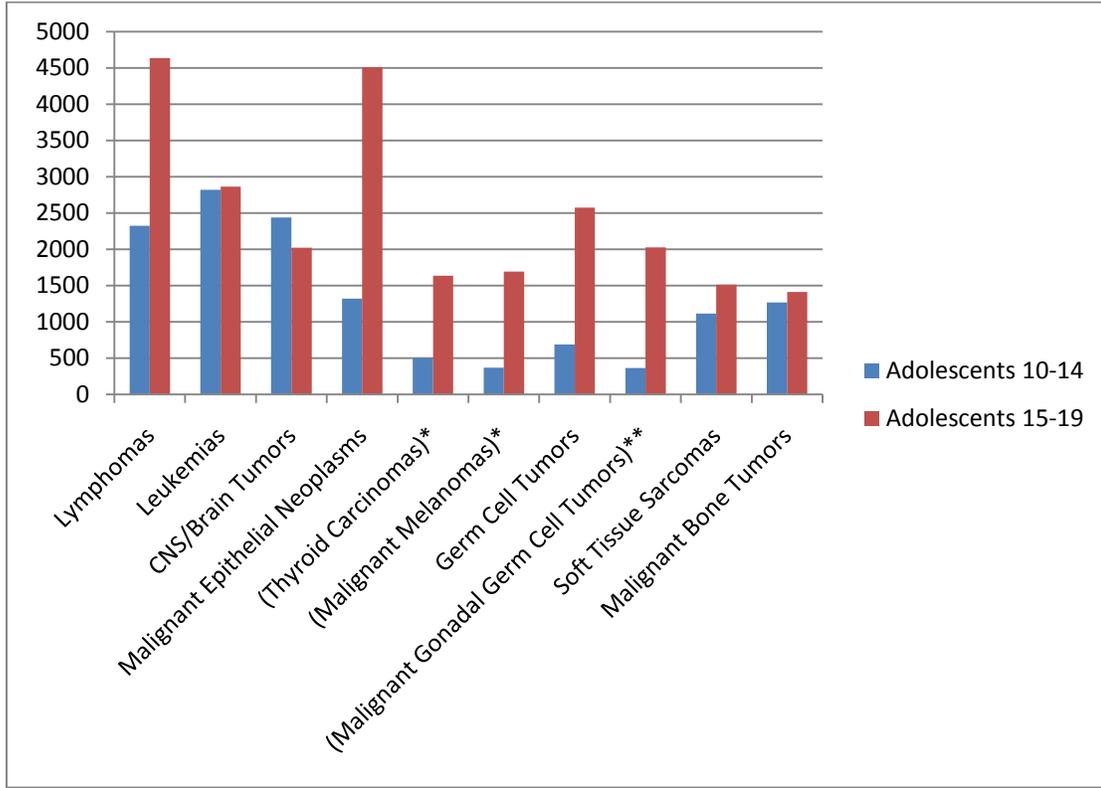
Malignant bone tumors and soft tissue sarcomas are prominent in the adolescent 10-14 and 15-19 age groups compared to children under the age of 10. However, this is representative of only a small percent of the overall cancer incidence in adolescents. Adolescents diagnosed with cancer between 15 and 19 years-old show a marked increase in lymphomas, malignant melanomas, thyroid carcinomas, and malignant gonadal germ-

cell tumors. Leukemias and CNS/brain tumors in the 15-19 year age group remains consistent with the 10-14 age group ("United States Cancer Statistics: Incidence and Mortality: 2001-2005. Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion," National Program of Cancer Registries, 2009).

*Cancer Comparison across Age Groups (10-19 Years Old)*

Comparison of the most common cancers diagnosed in adolescents between the ages of 10 to 14 years old versus adolescents diagnosed with cancer between the ages of 15 to 19 years old is displayed in Table 1. Data used for this analysis was classified according to the International Classification of Childhood Cancer (ICCC) coding system.

Table 1: Comparison of Cancer among Adolescents 10-19 years old<sup>a,b</sup>.



\*Thyroid Carcinoma and Malignant Melanomas are subgroups of Malignant Epithelial Neoplasms;  
 \*\*Malignant Gonadal Germ Cell Tumors are a subgroup of Germ Cell Tumors

<sup>a</sup>Source: U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2005 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2009. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs). 2001-2005 Childhood Cancer, detailed by ICCG group.

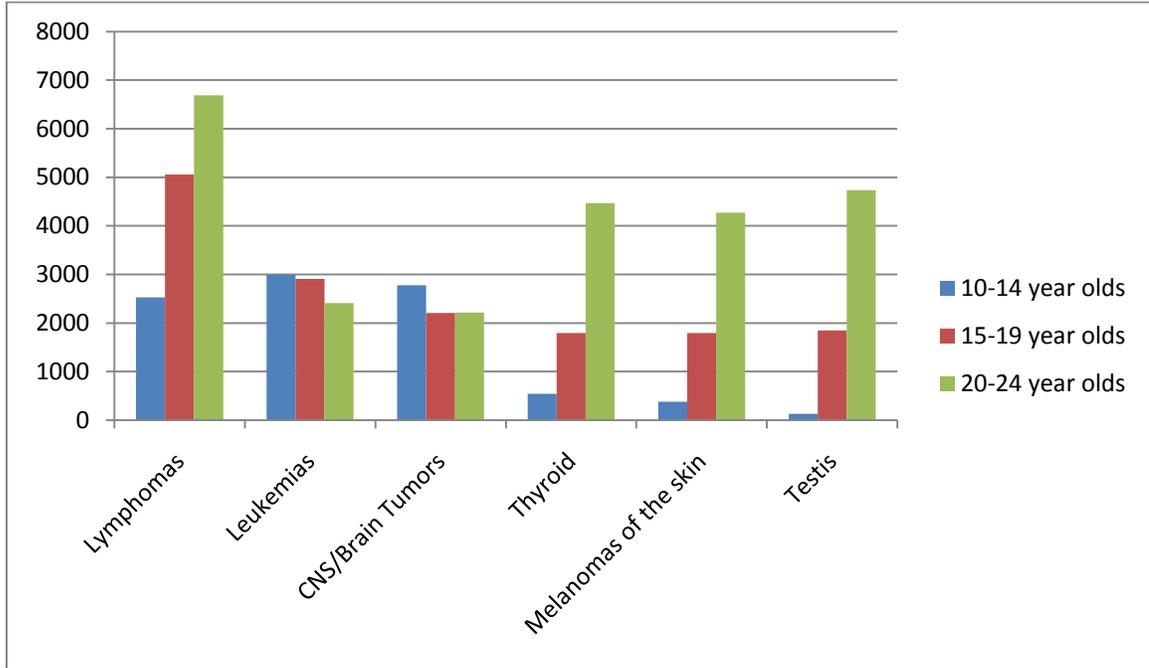
<sup>b</sup>United States Statistics for 2001-2005

*Primary Cancers Reported in Adolescent/Young Adults 20-24 years old*

There were not data in the 20-24 year-old age group classified by the International Classification of Childhood Cancer. Therefore, the incidence of cancer reported from the 2001-2005 NPCR data was examined by primary cancer site. Comparisons were made across all three groups of adolescents/young adults between 10 to 24 years of age in the United States. The most common cancers are recorded according to primary site, in Table 2. The most prevalent cancers reported in the 20-24 age group are: 1) lymphomas, 2) testicular cancer, 3) thyroid cancer, 4) melanomas, 5) leukemias, and 6) CNS/brain tumors ("United States Cancer Statistics: Incidence and Mortality: 2001-2005. Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion," National Program of Cancer Registries, 2009).

Bone tumors and soft tissue sarcomas were not differentiated in the 2001-2005 data set. However, statistics reported from SEER data in 2000 show a steady increase in diagnosis of soft tissue sarcomas (excluding Kaposi Sarcoma), among adolescent and young adult age groups. Incidence dramatically increases as a function of age, from 15 years until a peak at age 35-39, then slowly declines (Casillas, Roll, Keohan, Bleyer, & Malogolowkin, 2006). Bone tumors on the other hand, are not quite as prevalent in young adults and peak in the 15-19 year age group according to the 2000 SEER data (Mascarenhas, et al., 2006). Malignant bone tumors are more common in males than in females in the AYA population, yet still only account for 7.5% of all neoplasms in the 15-19 age group and 2.5% of all neoplasms in the 20-24 age group (Mascarenhas, et al., 2006).

Table 2: Comparison of Cancer among Adolescents 10-24 years old<sup>a,b,c</sup>.



<sup>a</sup>Source: U.S. Cancer Statistics: Incidence and Mortality: 2001-2005 Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health promotion; 2009. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).

<sup>b</sup>United States Statistics for 2001-2005

<sup>c</sup>Soft tissue sarcomas and bone tumors were not defined in this data set

### *Addressing Inconsistent Reporting of Adolescent Cancer*

The inconsistent reporting of adolescent cancer is a barrier to understanding morbidity, mortality and survival trends in this population. Addressing the disparities and improving adolescent outcomes begins with consistent and accurate reporting of adolescent cancer statistics.

To address inconsistent comparisons among adolescents with cancer, Birch et al., (2003) proposed a classification system that incorporates both cancer site and morphology for malignancies that more specifically affect adolescents (Birch, et al., 2003). In a retrospective study on malignant tumors that occurred in individuals between the ages of 12 and 24 in England, Birch and colleagues (2003) examined data over 18 years (1979-1997) and classified malignancies by cancer type, age group (12-14, 15-19, 20-24) and gender. They developed algorithms for selecting tumor types. Then, using the ICD-Oncology codes, they converted cancer data to a detailed morphological type rather than the site of origin.

In this study, based on statistics in England, the most common types of cancer in 12-14 year olds were leukemias, lymphomas, CNS/brain tumors and bone tumors; whereas soft tissue sarcomas, germ cell tumors, melanoma and carcinomas were relatively uncommon in this age group.

Adolescents 15-19 years old had a similar incidence of leukemias, CNS/Brain tumors and bone tumors (compared to the 12-14 year old age group). However, the incidence of lymphomas doubled. For adolescents/young adults in the 20-24 year old group there was a marked increase in lymphomas and a decrease in leukemias. In addition, there was a substantial increase in rates for carcinomas (i.e. thyroid), germ cell tumors and melanomas. The most common cancer in the 20-24 age group was lymphomas followed by carcinomas, germ cell tumors and melanomas. Incidence of CNS tumors remained similar across all 3 groups (Birch, et al., 2003). These findings are remarkably similar to the statistics reported in the United States above.

Researchers are currently collaborating nationally and internationally to address adolescent and young adult cancer disparities (K. Albritton, Caligiuri, Anderson, Nichols, & Ulman, 2006). Having a consistent method of reporting cancers in this population, which addresses the specific biology and response to treatment, will facilitate a better

understanding of how to improve cancer outcomes (K. Albritton & Bleyer, 2003; K. Albritton, et al., 2006; Pollock & Birch, 2008).

#### *Comparing Adolescent and Childhood Cancer*

Li et al. (2008) examined cancer incidence in children and adolescents according to gender, age, race, ethnicity and the US census region (Li, et al., 2008). Data from 2001-2003 were examined from 39 National Program of Cancer Registries and 5 SEER statewide registries (representing more than 90% of the US population). The results showed the incidence rate of all cancers combined is significantly higher in adolescents 15-19 than in children 0-14 years of age ( $p < .05$ ). However, certain cancers in children were significantly higher than in adolescents and include: leukemias, CNS neoplasms, neuroblastomas, retinoblastoma, renal tumors and hepatic tumors ( $p < .05$ ) (Li, et al., 2008). Adolescents 15-19 years old had significantly higher rates of lymphomas, malignant bone tumors, soft tissue sarcomas, germ cell neoplasms, other epithelial neoplasms and other unspecified malignant neoplasms compared to children 0-14 years ( $p < .05$ ). Additionally, the most common type of cancer across all age groups 0-19 years of age, was leukemia, with CNS/Brain tumors second and lymphomas ranking third.

In Li's study (2008) overall, boys were more likely than girls to be diagnosed with cancer, RR: 1.11 [95% CI: 1.09-1.13]. There were variations in race and ethnicity of children and adolescents diagnosed with cancer. White children had the highest incidence of cancer in any race and non-Hispanic children had a higher incidence of cancer than Hispanic children. The highest incidence rate of childhood/adolescent cancers occurred in the Northeast census region of the United States (Li, et al., 2008).

In summary, just as adolescence marks the transition from childhood to adult life, there appears to be a transition from the specific types of cancers that are more traditionally seen in younger children, to a new set of cancers that become more prominent in the second and third decade of life. There appears to be a distinct change in morphology and in the pattern of malignancies seen particularly in older adolescents and young adults (K. Albritton, et al., 2006; Bleyer, et al., 2008; Archie Bleyer, et al., 2006; A. Bleyer, M. O'Leary, et al., 2006; Li, et al., 2008). Lymphomas markedly increase, and malignant epithelial neoplasms, particularly thyroid cancer and malignant melanoma become more prominent during middle and late adolescence. In addition, malignant

gonadal germ cell tumors emerge in the AYA population with an increase in soft tissue sarcomas (Bleyer, et al., 2008). Acquiring a better understanding of the morphology and patterns of malignancy as well as the response of adolescent cancers to specific treatment protocols is an important first step to improving outcomes.

#### Outcomes of Adolescent Cancer

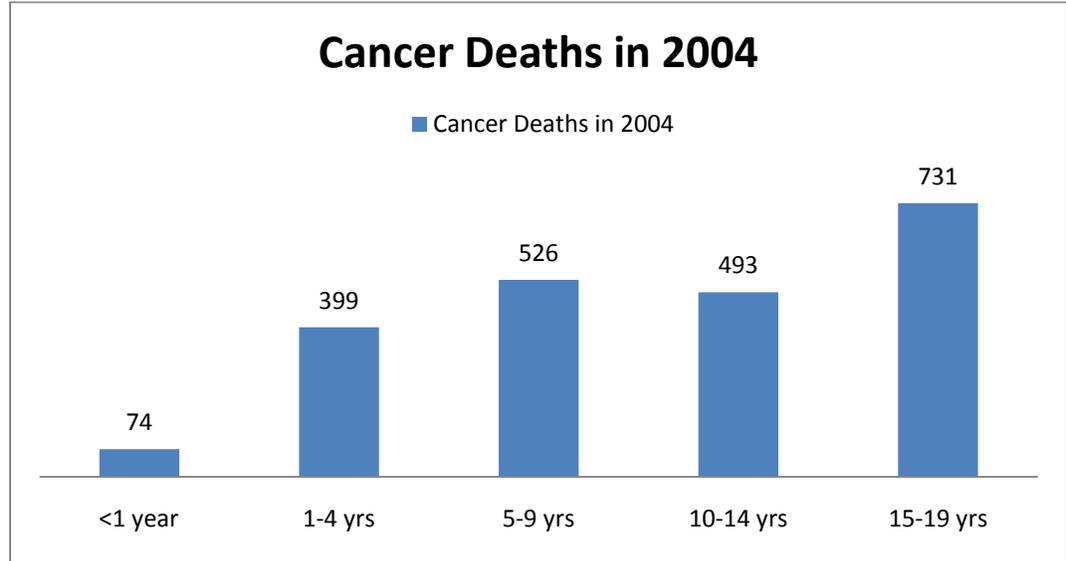
Cancer remains the number one cause of death by disease in adolescent and young adult age groups 10-25 years of age (A. Bleyer, M. O'Leary, et al., 2006; Jemal, et al., 2008). Despite significant progress in the treatment of childhood cancer, the same progress is not seen in the adolescent population, particularly in older adolescents and young adults (K. Albritton, et al., 2006; Bleyer, 2005; A. Bleyer, M. O'Leary, et al., 2006).

#### *Adolescent Cancer Mortality*

In 2004, there were 2,223 pediatric cancer deaths with 1,224 deaths occurring in adolescent 10-19 years of age (*United States Cancer Statistics: 1999-2005 Incidence and Mortality Web-based Report* U.S. Cancer Statistics Working Group, 2009). Although it is not fully understood, older adolescents with cancer, 15-19 years old, have the highest number of deaths compared to other pediatric age groups, see Table 3. More adolescents die of lymphomas, leukemias, epithelial & malignant melanomas and CNS brain tumors than of other types of cancers (*United States Cancer Statistics: 1999-2005 Incidence and Mortality Web-based Report* U.S. Cancer Statistics Working Group, 2009).

Mortality, morbidity and survival statistics vary according to morphology, age, race, gender and time since diagnosis. The following section will provide a summary of the cancer outcomes prevalent in the adolescent population.

Table 3: Adolescent and Pediatric Cancer Deaths<sup>a</sup>.



<sup>a</sup>U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2004 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2007. Available at: [www.cdc.gov/uscs](http://www.cdc.gov/uscs).

### *Cancer Morphology*

The morphology of cancer changes during adolescence and young adulthood. As previously mentioned malignant epithelial carcinomas and germ cell tumors become more prevalent. However, there are also biological and genetic changes that occur within diagnostic groups. For example, three types of lymphoma begin to emerge in the AYA population: follicular (nodular) lymphoma, diffuse small cell lymphoma, and mantle cell lymphoma. Lymphoblastic lymphoma and Burkitt lymphoma decrease as a function of age during this time (O'Leary, Sheaffer, Keller, Shu, & Cheson, 2006). The incidence of Acute Lymphoblastic Leukemia (ALL) begins to decline, however in the 15-19 age group less favorable cytogenetics are found such as, t(12;21) and a higher incidence of Philadelphia-positive chromosome (Mattano, Nachman, Ross, & Stock, 2006). The incidence of Acute Myelogenous Leukemia (AML) increases during adolescence. This has significant implications for the adolescent since the prognosis for AML is not as favorable in this population. In summary changes in cancer histology and cytogenetics during adolescence are linked to poorer prognostic outcomes for some cancer types.

### *Age*

The incidence of all invasive cancer in the United States increases substantially with age from 10 to 60 years. Since most cancer before the age of thirty is not linked to environmental carcinogens, this suggests a biological mechanism that is age-dependent (A. Bleyer, M. O'Leary, et al., 2006). There are certain types of cancer that increase more dramatically with age. For the adolescent these include lymphomas, malignant melanomas, thyroid carcinomas and gonadal germ cell tumors ("United States Cancer Statistics: Incidence and Mortality: 2001-2005. Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion," National Program of Cancer Registries, 2009). According to SEER statistics from 1975-1999, the mortality rate for lymphoma doubled in the 20-24 year old group compared to the 15-19 year old group (O'Leary, et al., 2006).

### *Race*

Race does not appear to impact cancer mortality for adolescents under the age of 15 (A. Bleyer, M. O'Leary, et al., 2006). However, African Americans/blacks had the worst survival rates for individuals diagnosed with cancer overall between 15 and 29

years of age. Non-Hispanic whites had the best survival in this age group (A. Bleyer, M. O'Leary, et al., 2006).

There were also discrepancies noted in adolescents diagnosed with leukemia. From the 1990-1999 SEER data, more Hispanics 10-24 years old were diagnosed with leukemia. Hispanics also experienced the highest mortality rate for individuals diagnosed with leukemia under the age of 25 (Mattano, et al., 2006).

### *Gender*

During adolescence, there is a 10-25% greater chance for young men to be diagnosed with cancer than young women (A. Bleyer, M. O'Leary, et al., 2006). Additionally more male adolescents die of cancer than females (K. Albritton, et al., 2006; A. Bleyer, M. O'Leary, et al., 2006; Bleyer, Viny, & Barr, 2006). Researchers are examining distinct biological differences in cancers during this time period as well as differences within the host. For example, researchers are examining the correlations between adolescent growth spurts, androgens or other male hormones and the potential impact on specific types of cancer and their treatment. In addition hormonal and metabolic changes may affect pharmacological distributions thus impacting response dose of chemotherapeutic agents or radiation during adolescence (Bleyer, et al., 2008; Capra, et al., 2003).

Females 15-29 have a higher incidence of thyroid cancer than males. Since the response to treatment is so effective, few AYAs die of thyroid cancer. Five-year survival rates for thyroid cancer exceed 99% in 15-29 year olds (Waguespack, Wells, Ross, & Bleyer, 2006).

The incidence of Hodgkin's lymphoma is also higher in females, specifically the 15-19 year old age group. For all other lymphomas, the incidence of lymphoma is higher in males than females. This does not impact mortality rates by gender. More young men die of lymphoma than young women 15-29 years of age (O'Leary, et al., 2006).

In summary, outcomes associated with adolescent cancer vary according to demographics such as gender, age and race. More males than females are diagnosed with cancer during adolescence. In addition more adolescent males die of the disease. The diagnosis of cancer increases substantially with age. Mortality also increases with age. More adolescents 15-19 years old die of cancer than adolescents 10-14. Non-Hispanic

whites have the best survival rate, in 15-29 year olds and African-American Blacks have the worst survival rate. Race does not appear to impact cancer mortality overall, on individuals under the age of 15.

#### *Late Mortality*

Unfortunately, the overall survival rates for adolescents and young adults diagnosed with cancer has not changed over a 25 year period tracked by the NCI-SEER data (1975 to 1999). The survival rates for children under the age of 15 has markedly improved for most cancers during this same time period (A. Bleyer, M. O'Leary, et al., 2006).

#### *5 year Survival Rates*

Five year survival rates are relatively good for children and adolescents diagnosed with cancer. For individuals diagnosed with ALL from birth to 18 years, the 5- year survival rate is around 80% (Silverman, et al., 2001). The 5-year survival rate for adolescents diagnosed with Hodgkin lymphoma is around 90% (O'Leary, et al., 2006). There has also been a steady improvement in the 5-year survival rates of adolescents diagnosed with CNS tumors with the survival rate near 70% (Bendel, Beaty, Bottom, Bunin, & Wensch, 2006).

#### *10-20 year Survival Rates*

Unfortunately the 10-year survival rates and 20-year survival rates dramatically decrease in the adolescent and young adult population. This varies according to the type of cancer and morphology. Some of the worst 20-year survival rates for adolescents occur in individuals diagnosed with AML. The 20 year survival rate for individuals 15-29 years of age diagnosed with AML is only 20-27% (Mattano, et al., 2006).

The twenty year survival rate for adolescents with ALL is also poor. Adolescents 10-14 years old diagnosed with ALL have a 20 year survival rate of 60%. The 20-year survival rate decreases to 40% for adolescents 15-19 years old compared to a 75-80% 20-year survival rate in children under the age of 9 (Mattano, et al., 2006).

Certain brain tumors have a particularly poor long-term outcome. The adolescent brain tumors projecting the worst long-term outcome occur in individuals diagnosed with astrocytomas (20 year survival rate = 40%); and PNET (20 year survival rate = 40-45%) (Bendel, et al., 2006).

### *Long-term Morbidity*

Findings indicate childhood cancer survivors fare well psychologically (Zeltzer, et al., 2008), however, there are some distinct medical challenges, including cancer recurrence, diagnosis of a subsequent malignancy, cardiac and vascular abnormalities, pulmonary complications and late mortality (Mertens, et al., 2008). The Childhood Cancer Survivor Study (CCSS) is an ongoing study which examines outcomes of childhood and adolescent cancer survivors who have survived at least 5 years from diagnosis. Several publications have reported findings from CCSS data (Lown, et al., 2008; Mertens, et al., 2008; Mertens, et al., 2001; Mulrooney, Dover, et al., 2008; Mulrooney, Ness, et al., 2008; Nathan, et al., 2008; Zeltzer, et al., 2008). Survivors 5 years or more from diagnosis had mortality rates that were 8 times higher than age-, sex-, and year-matched U.S. population statistics. The highest rate of mortality for the childhood cancer survivor cohort was within 5 years of entering the study or 5-9 years from diagnosis (Mertens, et al., 2008).

Despite significant risks for cancer recurrence, late medical effects and increased mortality risk, few childhood cancer survivors (31.5%) reported seeking medical care that focused on their prior cancer experience. And only 17.8% reported care that focused on their prior cancer experience plus ways to reduce risk, such as screening tests, etc. (Nathan, et al., 2008). Addressing the needs of adolescents and young adult cancer survivors including modifiable behaviors is a much needed area of study and goes beyond the scope of the current study.

In summary, adolescent and young adults diagnosed with cancer continue to die disproportionately in relation to children under the age of 15. The steady increase in survival rates seen in the pediatric population is not shared by the adolescent and young adult population. The 10-20 year survival rate is particularly poor for adolescents diagnosed with Leukemias and certain CNS Brain tumors. Morbidity and mortality of childhood cancer survivors 5 years or more from diagnosis is significantly higher than age-matched controls.

### *Disparities in Adolescent Cancer Population*

The lack of progress in effective treatment outcomes for adolescents diagnosed with cancer is cause for significant concern among adolescent HCPs and researchers alike (K. Albritton, et al., 2006; Bleyer, 2005). The disparities seen in the adolescent population have been linked to a number of factors including delays in diagnosis (Martin, et al., 2007); ineffective access to care (K. H. Albritton & Eden, 2008), lack of health insurance (Martin, et al., 2007); lack of participation in clinical trials (Bleyer, Montello, Budd, & Saxman, 2005; Ferrari, et al., 2008); inconsistent registration and/or classification of cancer in the adolescent and young adult population (Pollock & Birch, 2008); inconsistent treatment and follow-up (Freyer & Brugieres, 2008; Freyer & Kibrick-Lazear, 2006; Hudson, 2008; Hudson & Patte, 2008; Mulrooney, Neglia, & Hudson, 2008); and insufficient research on adolescent-specific issues such as cancer biology (Bleyer, et al., 2008; Capra, et al., 2003; Pollock & Birch, 2008), and psychosocial support (Ishibashi, 2001; Palmer, et al., 2007) including communication and care at EOL (Hurwitz, Duncan, & Wolfe, 2004; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Perilongo, et al., 2001; Tadmor, Postovsky, Elhasid, Ben Barak, & Arush, 2003; J. Wolfe, Grier, et al., 2000; Young, et al., 2003). Questions on compliance are also considered a possible factor affecting adolescent cancer outcomes (Windebank & Spinetta, 2008).

Efforts are underway to address the disparities in the AYA population. The Children's Oncology Group formed an AYA Committee in 2000 to evaluate obstacles including treatment regimens selected for AYA with cancer (Bleyer, 2005). In 2006, an International Working Group was established with a commitment to work on the disparities identified in the adolescent/young adult age group (Barr & Eden, 2008). The Teenage Cancer Trust an advocacy group in the United Kingdom has developed unique teen-specific units for the specialized treatment of adolescent cancer patients (Whiteson, 2003); and advocates for improved training and research in the AYA population (McGoldrick, et al., 2008). In the United States one of the biggest advocacy groups is the Lance Armstrong Foundation who have partnered with the National Cancer Institute to assemble the AYA Progress Review Group (Hayes-Lattin, et al., 2006; McGoldrick, et al., 2008). A strategic plan has been developed to address the recommendations of the

Adolescent and Young Adult Oncology Progress Review Group so that researchers and the oncology community can align priorities, design clinical trials and support training opportunities in response to the recommendations (Hayes-Lattin, et al., 2006). The AYA oncology Progress Review Group has identified 5 key areas for improving outcomes in adolescents and young adults with cancer.

**The 5 key areas for improving outcomes in AYAs with cancer:**

1. Identify characteristics that distinguish the unique cancer burden in the AYA patient.
2. Provide education, training and communication to improve awareness, prevention, access, and quality cancer care for AYAs.
3. Create the tools to study the AYA cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).
5. Strengthen and promote advocacy and support the AYA cancer patient (K. Albritton, et al., 2006).

The current study will address item number 4 “Ensure excellence in service delivery across the cancer control continuum”, particularly at EOL.

In summary, significant disparities are seen across the adolescent and young adult population. Several factors have been identified and described that contribute to these disparities. Although outcomes are less than favorable for many adolescents diagnosed with cancer, committed stakeholders have identified needs and have outlined recommendations to improve the physical and psychosocial outcomes of this vulnerable population.

## SECTION TWO: ADOLESCENT DEVELOPMENT AND CANCER

### Adolescent Development

The impact of cancer on adolescent development is a significant concern for all those involved in the adolescent's care. Before addressing the specific ways cancer may impact development, a review of normal adolescent development is addressed.

Adolescence is a time of dynamic development with rapid physical changes (Strasburger, et al., 2006). Adolescence is sometimes thought of as the transition from childhood to adulthood. Growth occurs in four domains: 1) the Physical Domain, including sexual maturation, 2) the Psychological Domain, including cognitive, emotional and moral development, 3) the Social Domain, including expansion of extra-familial relationships (larger friendship networks and more relationships with adults outside of the family) and 4) the Spiritual Domain, including the search for identity and meaning in life (Rew, 2005b; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Several factors influence adolescent development including hormones, environment, culture and social relationships.

Hormones play a key role in sexual maturation and the physical development of secondary sexual characteristics that occur during puberty (Patton & Viner, 2007; Pinyerd & Zipf, 2005; Rosen, 2004; Strasburger, et al., 2006). Despite variations in the onset of puberty; the progression of physical development through puberty is fairly predictable (Rosen, 2004).

Environment, culture and relationships influence adolescent psychosocial development. Developmental theorists such as Erik Erikson, Sigmund Freud, Jean Piaget, Albert Bandura and Lev Semonovich Vygotsky each have influential theories that describe and explain the process of psychological development.

Adolescence is an extremely complex time of development characterized by dynamic changes from one individual to the next. Adolescents mature at different rates and at different levels across each domain. For example, one 14 year old may not be as mature as another 14 year old. Furthermore, an individual may be more mature physically and less mature socially or psychologically. Age is somewhat arbitrary in determining the maturity of an adolescent however, the central message here is that development occurs along a continuum. So it is especially helpful to have a general understanding of the

progression of physical, psychological, social, and spiritual development that occurs for each adolescent.

Central issues that are important during adolescence include establishing autonomy and independence from parents; developing deeper, more intimate friendships or relationships with peers; developing a strong sense of self-identity; development of higher cognitive thinking from concrete to abstract reasoning; and making important decisions about education and employment (Rew, 2005a; Strasburger, et al., 2006; Turner-Henson, 2005; Vygotsky, 1978; Whiteson, 2003).

In summary, adolescence is a biopsychosocial process with changes taking place simultaneously in physical, psychological, social, and spiritual domains, but at different rates within each individual (Rew, 2005a; Strasburger, et al., 2006). As adolescents develop to mature adults, relationships within the family change. Autonomy and control are important developmental milestones. Adolescents strive to become more independent from their families and form tighter bonds within their peer groups. Psychological development is particularly important and prepares the adolescent for future roles and relationships within society.

#### *Impact of Cancer on Adolescent Development*

The diagnosis of cancer is an unexpected interruption in adolescent development. Adolescents who are transitioning away from their dependence upon parents are often forced back into a dependent parent-child relationship. Social interactions with their peers and negotiating interpersonal relationships which have become increasingly more important are disrupted by hospitalizations and medical treatments (Bleyer, 2005; Hinds, 2004; Kathleen Neville, 2000; Palmer, et al., 2007). Side effects from treatments, such as alopecia, medication-related weight change (rapid weight gain or loss), may alter body image. This can be particularly difficult at first since adolescents are acutely aware of physical changes that are occurring at this point in life (Strasburger, et al., 2006). Disruption in education and social interactions due to diagnosis and treatment of cancer can adversely affect social and career development (Ritchie, 2001; Whiteson, 2003). Furthermore, the effects of chemotherapy and radiation can affect risks for cognitive impairments (Birch, et al., 2003).

Adolescents with cancer have a strong need to be normal (Ritchie, 2001). During cancer treatments, they have also expressed a strong desire for information (Dunsomore & Quine, 1996; Palmer, et al., 2007; Young, et al., 2003) which along with social support has been shown to decrease uncertainty and distress (Haluska, Jessee, & Nagy, 2002; K. Neville, 1998).

During cancer treatments, many adolescents cope by shifting their perspectives from an active awareness of cancer to an active focus on being a normal adolescent. Klopfenstein & Young-Saleme (2002) refer to this as a denial of the existence of cancer, whereas Hinds (2004) describes this as a selective focus- where adolescents choose to stay focused on the well aspects of their lives, despite the fact they are diagnosed with cancer (Hinds, 2004; Klopfenstein & Young-Saleme, 2002). Adolescents who survive their cancer experience fare well psychologically. Levels of psychological and or social dysfunction are no greater in children and adolescents diagnosed with cancer than comparison groups in the general population (Noll & Kupst, 2007). A study conducted by Brown et al. (2003) on adolescent cancer survivors, their mothers and healthy controls showed that significantly more mothers of adolescent cancer survivors met the DSM-III-R diagnostic criteria for post traumatic stress disorder (PTSD) than matched controls ( $p < 0.001$ ). However, none of the adolescent cancer survivors met clinical criteria for a PTSD diagnosis. Erickson et al. (2008) believe psychological functioning is related to a repressive adaptive coping style found in this population (Erickson, Gerstle, & Montague, 2008).

#### *Interaction of Development and Cancer Mortality*

There are four elements that represent a complete developmental understanding of death. These include: irreversibility (or understanding that dead things will not live again), finality (understanding all life-defining functions end at death), universality (understanding all living things die), and causality (realizing what causes death) (Corr, 1995; Himmelstein, 2006). As children develop their understanding of death also increases. Table 4 is adapted from Hurwitz et al. (2004) with insights from Corr (1995), Himmelstein (2006), and Hinds et al. (2005). It describes developmental understanding of death using age as an approximate guide (Corr, 1995; Himmelstein, 2006; Hinds, Oakes, Hicks, & Anghelescu, 2005; Hurwitz, et al., 2004).

Table 4: Developmental Understanding of Death.

Age	Developmental Understanding	Death Concept	Examples & Explanations of Psychological Impact
1-3 years old	Death often seen as continuous with life. Death and Life are like Awake and Asleep	Does not understand irreversibility or permanence	The dead person is sleeping but will wake up.
4-5 years old	Death is seen as temporary and reversible; may also see death as a punishment	Does not fully comprehend the concept of <b>irreversibility or permanence</b> ; Believes in magical thinking or that you can wish someone dead	<p>“Once you are dead are you always dead?”</p> <p>“How long do you stay dead?”</p> <p>“I have been bad so now I have to die”</p> <p>A dying child may struggle with guilt because he/she is dying.</p>
6-9 years old	Understands death is permanent. Begins to realize people he/she knows will die and that dying means living functions will stop.	Understands irreversibility and begins to understand <b>finality or nonfunctionality</b> : heart stops, you do not breathe, etc.	<p>“Will dying hurt?”</p> <p>“Is dying scary?”</p> <p>“What do you do when you are dead?”</p> <p>A dying child may continue to experience guilt and shame for dying.</p>
10-13 years old	Understands death is permanent and that living functions cease. Begins to understand death is universal	Understands irreversibility, nonfunctionality, and begins to understand <b>universality</b> .	<p>Universality requires understanding 3 sub-concepts: 1) death is all inclusive, it occurs with all living things, 2) it is inevitable- eventually every living thing will die, and 3) it is unpredictable. The timing of death is not always certain. It is an unpredictable outcome in living things.</p> <p>“I am worried my mom will break down”.</p>

Age	Developmental Understanding	Death Concept	Examples & Explanations of Psychological Impact
14-18 years old	Thinking becomes more abstract. One can objectively examine death. An adult understanding of death develops. However, death may be viewed as an enemy that can be fought against. Therefore dying may be viewed as a failure.	Understands irreversibility, nonfunctionality, universality and <b>causality</b>	Causality requires an abstract and realistic understanding of internal and external events that cause death.  Events that cause death may be accidental or intentional, but often they are beyond the control of the dying individual.  “I can’t believe I am dying...why is this happening to me?”

Corr (1995) explains children can understand death in stages. Based on Nagy's work (1948) there are 3 stages. In the first stage children do not understand the finality of death. It may be like traveling or going somewhere else to live. In the second stage, children understand the finality of death however, it is something that can be overcome, outwitted or avoided. In the third stage children understand that death cannot be avoided, it is final and universal (Corr, 1995).

Bluebond-Langner (1978) describes how experience with a life-threatening illness helps a child or adolescent to understand death and dying. Children/adolescents become aware of the seriousness of their disease through the process of socialization. As awareness of disease progresses, so does the child/adolescent's self concept about living and dying (Bluebond-Langner, 1978). This is displayed in Table 5.

Table 5: Awareness and Understanding of Death<sup>a</sup>.

<b>Stages</b>	<b>Information About Disease</b>	<b>Changes in Self Concept</b>
1 <sup>st</sup> Stage: Diagnosis	It is a serious illness	I am seriously ill.
2 <sup>nd</sup> Stage	There are medications for the illness with side effects	I am seriously ill and will get better.
3 <sup>rd</sup> Stage	There are special procedures needed to administer drugs; there may be additional treatments required because of side effects from the drugs. Each treatment and each procedure is a unique event	I am always ill and will get better
4 <sup>th</sup> Stage	The disease is a series of relapses and remissions. The medicines are not lasting as long as they are supposed to.	I am always ill and will never get better
5 <sup>th</sup> Stage	The disease is a series of relapses and remissions. There are a finite number of drugs that can be used for treatment. When drugs are no longer effective, death occurs.	I am dying (terminally ill)

<sup>a</sup>Based on Myra Bluebond-Langner's ethnographic study: The Private Worlds of Dying Children

Significant psychological and social issues have been found in dying adolescents. Individuals facing EOL describe many fears, including inadequate pain control and death itself (Penson, et al., 2005; Steinhauser, Clipp, et al., 2000; Theunissen, et al., 2007). Developmental stage greatly influences psychological response to a terminal or life-threatening illness (Block, 2006). Similarly, developmental age influenced the use of anti-anxiety medications in a retrospective study conducted by Bell et al, (2010). There was a significant difference in the use of anxiolytics among adolescent developmental groups at EOL. Relatively more individuals in late adolescence used anti-anxiety medications ( $p = 0.037$ ) (Bell, et al., 2010).

Likewise, a retrospective study by Theunissen (2007) on the physical, psychological, and social symptoms of children and adolescents at EOL as reported by their parents revealed a significant difference in psychological symptoms for adolescents over the age of 12 compared to children under the age of 7. The most frequently reported psychological symptoms at EOL in the adolescent age group (over 12 years old) were sadness, loss of perspective, loss of independence, fear of physical symptoms, and fear of death (Theunissen, et al., 2007). Older adolescents with cancer reported in a recent study that because of some misconceptions about their cancer or treatment, they had lost at least some of their friends (Palmer, et al., 2007).

In summary, adolescents diagnosed with cancer have the same developmental needs as healthy adolescents which include the need to be independent while establishing stronger more intimate relationships with their peers. A diagnosis of cancer and particularly the progression of cancer require the adolescent to become more dependent upon parents and/or healthcare providers for physical, psychological and social support. Adolescents with cancer adapt well psychologically. However, adolescents facing death have an increase in psychological symptoms such as loss of perspective, sadness, fear of pain and fear of death. Understanding of death is a developmental process that increases with age; however, children and adolescents may understand their own dying process based on socialization to illness, which is independent of developmental understanding of death. Adolescents facing the possibility of death have complex needs as they adapt to the reality of death. Personal support systems and a multidisciplinary approach to health care will benefit this vulnerable population (Freyer, et al., 2006).

## SECTION THREE: THEORETICAL PERSPECTIVES

### Overview of End-of-Life Preparedness Theory

The multiple-case study for this dissertation is based on a theory of EOL preparedness. The proposed theory suggests an individual goes through a process of Readiness prior to EOL preparedness. The process of Readiness enables the dying individual to progress through the process of becoming cognitively aware of their prognosis, emotionally accepting of their condition, and willing to take action to prepare for EOL. After Readiness the individual progresses to the process of EOL preparedness. The process of EOL preparedness has several dimensions. An individual becomes prepared for EOL through knowledge on what to expect, through acknowledgement of grief and by addressing the emotional aspect of dying, through identifying the meaning of life and death, (this includes addressing existential issues and spirituality), and then finally conceptualizing a personal plan. The personal plan serves as a guide to focus priorities, set goals and accomplish what is really important with the time that remains in life.

The theory proposes that the process of EOL preparedness will facilitate the communication of the adolescent's personal plan to a family member or healthcare provider. Communication of the adolescent's plan allows others to know what the adolescent wants to accomplish or how the adolescent wants to live out the remainder of life. This important step incorporates the adolescent's support system and allows parents, family members or HCPs to advocate on the adolescent's behalf. The theory proposes that the outcome to EOL preparedness is quality of life at end of life. Time, as well as the Demographic & Environmental, and Personal & Family Characteristics influence the processes of Readiness and EOL preparedness.

The following section describes each of the main constructs within the conceptual model. Studies from both the pediatric and adult literature have been synthesized to support the proposed EOL preparedness theory.

#### *Readiness*

Readiness is an antecedent to EOL preparedness. It is considered a process, so there will be variations in an adolescent's degree of readiness. Readiness has been written about in the disaster preparedness literature (Rebmann, 2006). It taps into the overall

intent of the individual to prepare. Dalton and Gottlieb (2003) describe the many ways readiness has been used in research, such as readiness to change a high-risk behavior, or readiness to perform a specific skill, or readiness for an event such as discharge from the hospital (Dalton & Gottlieb, 2003). Readiness has been studied as a state and as a process. The current study defines Readiness as a process of becoming ready over time. There are 3 defining attributes that pertain to Readiness in relation to preparing for EOL: Awareness, Acceptance, and a Willingness to Take Action to prepare for EOL.

#### *Awareness*

The first step in the process of Readiness is called Awareness. In this study, it is defined as the level of cognitive recognition of an incurable prognosis. Awareness has been studied in EOL literature and has been addressed in both pediatric and adult oncology. In pediatric oncology some of the most prominent work on awareness of death has been documented by Myra Bluebond-Langner (1978). At the time of Bluebond-Langner's study, very few honest conversations about death took place within the family unit or the health care setting yet children and adolescents still became aware of impending death. Bluebond-Langner (1978) describes how children and adolescents became aware of impending death through social cues and interactions with peers who were diagnosed with cancer (Bluebond-Langner, 1978).

In the adult literature, seminal work by Glaser and Strauss (1965) contributes to our understanding of the awareness contexts for dying individuals (Glaser & Strauss, 1965). The context of awareness affects communication about death. For example, in a "closed awareness" context, a parent and HCP have knowledge about impending death, yet the adolescent is unaware he/she is dying so information about death may not be openly communicated. On the other hand, if all parties, (the adolescent, his/her parent(s), and the HCP), have openly discussed the fact that there are no more options for cure and that death is a realistic probability, then everyone is free to operate in an "open awareness" context. Communication about issues of death and dying or issues pertaining to living life fully can be freely exchanged.

In pediatric oncology, awareness of death appears to occur over time and the factors that influence awareness are largely unknown. Additionally, awareness of death may occur at different times for the patient, the family member and the physician or

nurses caring for the dying individual. In a study conducted by Wolfe and colleagues (2000), 103 parents of children who died of cancer and 42 pediatric oncologists were surveyed to determine when parents and physicians become aware that a child had no realistic chance for cure. The timing of parental understanding lagged behind the physician by 3-4 months (J. Wolfe, Klar, et al., 2000). However, when both parent and physician awareness of incurable prognosis was concordant 50 days or more prior to death, there was earlier institution of a do not resuscitate order ( $p = 0.2$ ), earlier discussion of hospice ( $p = .01$ ), less use of cancer-directed treatment in the last month of life ( $p = .04$ ), better parental ratings of quality of care delivered by home care team ( $p = .03$ ) and a higher likelihood that parent ( $p = .01$ ) and physician ( $p = .002$ ) identified the primary goal of treatment was to lessen suffering (J. Wolfe, Klar, et al., 2000). Similarly, in a study conducted in Sweden, parents who reported getting information about incurable prognosis a month or more before death were 2.7 times more likely to have their child die at home (OR 2.7; 95% CI: 1.5, 4.9) (Surkan, Dickman, et al., 2006).

Awareness of prognosis influences treatment preferences. A realistic prognosis can help patients to define goals and plan for the future in a way that is consistent with patient values (Robinson, et al., 2008). Some argue that individuals may not want to be aware of prognosis, because it may cause emotional distress or destroy hope. In a recent study conducted by Mack and colleagues (2006), 194 parents of children with cancer were surveyed to determine if prognostic information was “preferred”, “important”, and “helpful” for such things as determining treatment decisions, preparing for the future, maintaining hope and coping. Parents were also asked if prognostic information was “upsetting”. Responses ranged from “extremely” to “not at all”. There were 68 parents (36%) who reported prognostic information was extremely or very upsetting. These parents were also more likely to desire more information ( $p = .01$ ). Reporting that “prognostic information was upsetting” did not affect hope for a cure nor acknowledging that prognosis was important and helpful in decision-making (Mack, Wolfe, Grier, Cleary, & Weeks, 2006).

One of the gaps in our knowledge of awareness involves the perspective of the dying adolescent. Few prospective studies have been conducted in adolescents who are dying of cancer. Retrospective studies involving parents of dying children have provided

some limited insight. For example, in a large retrospective study conducted in Sweden, 449 parents were surveyed to determine if awareness of child's impending death influenced whether or not the child would be cared for at EOL in the home (Surkan, Dickman, et al., 2006). Four questions in the survey addressed parental awareness of impending death: 1) "When did you realize intellectually that your child was going to die?" 2) "When did you realize emotionally that your child was going to die?" 3) "When do you think your child realized that he/she was going to die?", and 4) "When did you get the information that your child's illness was incurable?" In this sample, place of death occurred 36% of the time at home. Parents who reported intellectually or emotionally realizing their child was going to die were twice as likely to have the child die at home (OR 2.2; 95% CI: 1.3, 3.8 and OR 2.0; 95% CI: 1.2, 3.4), respectively. The Odds Ratio increased to 4.7% when the parent sensed their child was aware of impending death (95% CI: 2.3, 9.7).

A second publication on this same sample reported whether parents talked to their children about death. Parents were asked after death if they had regretted talking or not talking about death with their child (Kreicbergs, et al., 2004). Parents were also asked whether or not they felt their child was aware of impending death. The specific question used for this analysis was "When do you think your child realized he or she was going to die?" Response alternatives ranged from "never realized" to "3 years or more before he/she died". Of the 429 parents in the study, 147, or 34% had talked about death with their child. None of these parents regretted their decision. The remaining 282 or 66% had not talked about death with their child, and 27% of this group regretted their decision. In the overall sample, only 54% of the parents sensed their child was aware of impending death. However, parents who sensed their child was aware of his/her imminent death, were more likely to talk about death with their child. In addition, those who sensed the child's awareness but did not talk to their child about death were more likely to regret it (Kreicbergs, et al., 2004).

Although communication about EOL between a parent, adolescent and their physician may enhance awareness, it is not the only method of gaining awareness. In the Swedish study described above the researcher asked when the parent "sensed" their child was aware of death (Kreicbergs, et al., 2004). Parents are able to connect with their child

in a way that allows them to pick up cues that help in their development of awareness. This is confirmed in other pediatric EOL studies. In Australia, 24 parents were interviewed about their experiences of transitioning to EOL care (Monterosso & Kristjanson, 2008). Several parents described becoming aware of impending death prior to direct communication with their child's physician from either physical deterioration in their child's condition, or a direct comment from their child indicating the treatments were not working or the child was not getting better. Hinds (2005) reports awareness of death is enhanced for parents who not only receive detailed interpretations by physicians, nurses and other members of the health care team but who also see changes in their child's body and physical appearance (Hinds, et al., 2005). This was validated in Wolfe et al.'s study (2000). Although 95% of the parents reported having a discussion at some point with their healthcare team about the child's incurable prognosis, only 49% said their awareness or understanding of this prognosis was a result of a discussion with the medical team. Wolfe and colleagues did not say whether the other 51% of the parents came to this understanding before or after the EOL discussion. However, 30% of the parents became aware that their child had no realistic chance for a cure from a perceived change in the child's appearance or actions and another 9% had a feeling or dream prior to awareness (J. Wolfe, Klar, et al., 2000).

In summary, awareness appears to occur over time in individuals with cancer. Studies show healthcare provider awareness generally occurs before patient or parent awareness. Communication between physician and patient/family about prognosis is related to awareness. However, it is not the only method of becoming aware of impending death. Studies have shown adolescents and children pick up social cues to indicate their cancer is incurable. Parents also pick up cues from reported changes in behavior or appearance. Some parents have an intuition or sense their child is going to die. They have also reported revelations through dreams. Cognitive awareness is a necessary step toward acceptance of death and dying.

### *Acceptance*

The second attribute of Readiness is acceptance. Acceptance is defined as the level of emotional acquiescence of an incurable prognosis. It implies a deeper step to cognitive awareness. Surkan and colleagues (2006) alluded to this from the study above

when researchers asked parents: 1) “When did you realize *intellectually* that your child was going to die?” and then, 2) “When did you realize *emotionally* that your child was going to die?” Studies that have addressed acceptance tap into emotions, such as fear, quiet sadness, or peace (Hinton, 1999; Mack, et al., 2008; Ray, et al., 2006).

Hinton (1999) conducted a longitudinal study on 77 Hospice patients and their unpaid caregivers. Weekly interviews occurred to determine patient and caregiver awareness and acceptance (Hinton, 1999). There was not a significant correlation between patient awareness and depression ( $r = 0.11$ ,  $p = 0.3$ ), however, there was a significant relationship between patient awareness and anxiety ( $r = 0.26$ ,  $p < 0.05$ ). The opposite was true of caregivers. Caregiver awareness was associated with increasing depression ( $r = 0.27$ ,  $p < 0.05$ ) but not significantly correlated with anxiety ( $r = -0.10$ ,  $p = 0.4$ ) (Hinton, 1999). In this study, acceptance generally increased over time and some awareness was necessary before acceptance would occur (Hinton, 1999)

Ray and colleagues (2006) recruited a sample of 280 adults with advanced cancer as part of an ongoing multi-site longitudinal study from 2002-2005 (Ray, et al., 2006). Their intent was to explore psychological well-being in relation to peaceful awareness (Ray, et al., 2006). Peaceful awareness taps into the emotional construct of acceptance. In Ray et al.’s study (2006) multiple measures were collected, in addition to conducting Structured Clinical Interviews for DSM-IV diagnoses. Two questions helped to categorize patients into 4 specific groups. The first question asked, “How would you describe your current health status?” Possible responses were: 1) relatively healthy, 2) seriously but not terminally ill, and 3) seriously and terminally ill. Those who selected “seriously and terminally ill” were considered “aware”. The other two groups were considered unaware. Peacefulness was measured by 1 item, “I feel deep inner peace or harmony” rated on a scale of 1 - 6 (1 = many times a day, 3 = most days, 6 = never or almost never). Patients who rated peacefulness as occurring “most days” or more often were categorized as “peaceful”. Findings indicated patients who were aware were significantly more likely to have EOL care discussions with their physician (OR 2.79), complete DNR orders (OR 3.45), have living wills or durable power of attorney (OR 2.01), and less likely to desire heroic measures (OR .45 versus 2.01) (Ray, et al., 2006).

Patients were then categorized across 4 groups to examine psychosocial outcomes (- aware, - peace; - aware, + peace; + aware, + peace; and + aware, - peace). The peacefully aware subgroup was significantly more likely to have a higher overall quality of death as reported by caregivers in a postmortem survey. The aware without peace group was significantly more likely to feel “sad” and “terrified”. No other significant differences were noted (Ray, et al., 2006). This study suggests there is a difference between awareness on a cognitive level and peaceful awareness or acceptance on an emotional level.

Based on the study above, Prigerson and colleagues (2008) developed a tool to measure emotional acceptance of terminal illness (Mack, et al., 2008). The Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) questionnaire measures extent of acceptance and inner peace as well as the extent of existential struggle with illness. In light of impending death powerful emotions emerge while patients and family members confront loss on multiple levels (Mack, et al., 2008). By helping patients to come to terms with death emotionally, the difficult but necessary transition to emotional acceptance of death should occur. The Peace Scale has 2 subscales: The Peaceful Acceptance of Illness Subscale and The Struggle with illness subscale. Mack et al., (2008) administered the scale to 160 patients with advanced cancer. Older patients had lower struggle with illness scores and higher Peaceful Acceptance of Illness scores. There was no relation in subscale scores to any other demographic variable (sex, race, ethnicity, marital status, income, religious affiliation, or education. In addition cognitive awareness was not associated with peaceful acceptance scores (Mack, et al., 2008). Outcomes of the study showed higher peaceful acceptance scores were related to decreased use of feeding tubes at EOL. Higher struggle with illness scores were more likely to have a durable power of attorney, healthcare proxy or living will (Mack, et al., 2008).

In summary, emotional acceptance of a terminal illness is different from cognitive awareness. Awareness of death involves a cognitive understanding that death may occur. Awareness of death can occur without acceptance of death, but acceptance of death cannot occur without awareness of death. Awareness without acceptance was linked to higher struggle scores in one study. Studies show acceptance, like awareness, also occurs over time (Mack, et al., 2008; Ray, et al., 2006).

### *Willingness to Take Action*

The third and final step in the process of Readiness is Willingness to Take Action. This is defined as the level of intent or desire to take action to prepare for EOL. This step builds on cognitive awareness and emotional acceptance by addressing the desire and intent of an individual. This taps into the behavioral component of one's actions. Before an individual engages in EOL preparedness, he/she must be willing to begin this process.

There is not specific information in the EOL literature that addresses willingness to prepare for EOL however, significant research has been done to address the theories of behavioral change in other areas of cancer research (Champion, et al., 2002; Rawl, et al., 2002; Russell, Champion, & Perkins, 2003; Skinner, et al., 2007). In disaster preparedness literature the intent to prepare is recognized as an important step in the whole process of preparedness (Rebmann, 2006).

In a longitudinal study by Dalton and Gottlieb (2003), five middle-aged individuals living with multiple sclerosis were interviewed during 42 client encounters (Dalton & Gottlieb, 2003). The purpose of the study was to understand the patient's perspective on the concept of "Readiness" in relation to adjusting to illness and disability. Specific factors triggered the process of becoming ready. First there was an awareness that something needed to change. The next step involved an appraisal process of envisioning what life would be like if change occurred and then weighing the costs and benefits to the change. This step includes considering skills, energy, competence and support during the transition. Nurses play an important role in the whole process of Readiness.

In summary, although Willingness to Take Action is under-developed in the EOL literature, there is still a separate behavioral component that is essential before adolescents move into the active role of preparing for EOL.

### *End-of-Life Preparedness*

End-of-life preparedness is the main phenomenon of study. It is defined as a process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for EOL consistent with his/her desires; communicates the desires to family and caregivers; resulting in a satisfactory end of life (Bell and Champion, 2008). The process of EOL preparedness is based on Herbert et al.'s article

(2006) which claims that EOL preparedness is a multidimensional construct that has never been fully defined or conceptualized (Herbert, Prigerson, Shultz, & Arnold, 2006). Herbert et al. (2006) identified that preparedness consists of cognitive and emotional components that affect medical, psychosocial, spiritual and practical aspects of an individual's life. Bell and Champion further delineated the process of preparedness to address 4 components that are consistently identified in the literature: 1) Knowledge about EOL, 2) Acknowledgement of Grief and Emotions, 3) Identification of the Meaning of Death and Spirituality, and 4) Conceptualization of an EOL Plan (Bell and Champion, 2008). Each of these components will be described within the context of EOL literature.

#### *Knowledge about End-of-Life*

The first attribute of EOL preparedness is knowledge about EOL. In numerous EOL studies that query "a good death" or "quality death", knowledge or information about what to expect at EOL is a common theme (Emanuel & Emanuel, 1998; Hendrickson & McCorkle, 2008; Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003; Steinhauser, Clipp, et al., 2000; Widger & Wilkins, 2004). Many of the projects, funded by The Robert Wood Johnson Foundation in a national program called Promoting Excellence in EOL Care, address some aspect of communication or information exchange. Across all projects only 4.6% of patients dropped out prior to death or completion of the project. Satisfaction data reports showed positive responses from patients and families who were grateful for opportunities to discuss their concerns about serious illness (Byock, Twohig, Merriman, & Collins, 2006).

A focus group study of adolescents diagnosed with cancer identified areas of unmet physical, psychological, and social needs (Palmer, et al., 2007). One of the main themes that arose involved communication. Adolescents described their frustrations with how information was disclosed during treatment. Some younger adolescents felt like information about their cancer was not fully disclosed. Others reported feeling excluded from the conversation because the physician spoke directly to parent(s) even though the adolescent was present in the room (Palmer, et al., 2007). This theme was echoed in Young et al.'s study, (2003). Semi-structured interviews were conducted on 13 patients (8 - 17 years old) and their parents (Young, et al., 2003). Although most parents felt their

role was to protect their child, and therefore took an executive approach to communication by controlling and directing information; the child/adolescent reported feeling excluded or marginalized during parent-doctor-patient encounters. In addition, children and adolescents interpreted their social position in health care settings as a subordinate rather than a co-participant in care. Children and adolescents in Young et al.'s study (2003) depended upon their parents to represent their interests since most did not feel they had direct access to a participatory role in decision-making. Age did not appear to be a factor in how much information children/adolescents desired. Some of the youngest participants in this study wanted detailed information whereas one of the oldest adolescents wanted only basic information (Young, et al., 2003).

Knowledge about EOL is gained mainly through discussions with physicians, nurses, and parents of the dying adolescent. Other discussions that address psychosocial and spiritual aspects of dying may involve psychologists, social workers or clergy. Talking about death to children or adolescents with cancer has been identified by healthcare providers as one of the most difficult things to do (Bagatell, Meyer, Herron, Berger, & Villar, 2002; Khaneja & Milrod, 1998; Serwint, et al., 2002; Vazirani, Slavin, & Feldman, 2000) and many report feeling inadequately trained (Meraviglia, McGuire, & Chesley, 2003; Ogle, Mavis, & Thomason, 2005; Schwartz, Goulet, Gorski, & Selwyn, 2003; Sullivan, Lakoma, & Block, 2003). Talking about death provokes strong emotions which can interfere with effective EOL communication (Fryer-Edwards, et al., 2006; Jackson, et al., 2008; Khaneja & Milrod, 1998; Serwint, et al., 2002). Self-reflection and awareness are essential skills for HCPs when discussing EOL concerns among adolescents with cancer. Indeed Bartholome, (1993) argues that “many of the problems involved in responding to the needs of dying children belong to the ‘big’ people involved” (Bartholome, 1993). Caring for a dying child forces providers to face their own mortality and possibly even the fear of losing one’s own child. Addressing existential struggles is a necessary ongoing process for professional caregivers in order to be authentically present with a child through EOL and fully present for a parent who is facing the death of a child.

In a study conducted by Newborg (2008), pediatric oncology professionals (N = 180; 93 Mental Health Professional, 53 Nurses, and 36 Physicians) shared their insights

on the perceived risks and benefits of communicating openly with children (6 - 12 years old) dying of cancer (Newborg, 2008). Open communication was defined as verbal and non-verbal expression of positive and negative thoughts and feelings about death, dying and other illness experiences (fears, questions, concerns related to illness, treatment, prognosis, and death & dying). Through an on-line survey, participants in the study reported feeling unprepared to handle their own emotions or to answer the questions asked by the parents or child. Professionals believed most children are aware of impending death and experience thoughts and feelings of anxiety related to the dying process which are alleviated through open communication. The majority of professionals stated benefits of open communication outweighed the risks. The most common perceived risks involved in open communication were the possibility of increasing parental or child distress, taking away hope, misinterpreting the child's cues to discuss EOL issues or misunderstanding family's needs (spiritual or cultural). Training needs were identified by the participants and primarily focused on how to interpret child cues, how to initiate discussions with the child or parent and how to better understand the emotional burden of not talking with a child who wanted to discuss EOL issues (Newborg, 2008).

Knowledge about EOL prepares an individual psychologically by allaying fears and equipping the individual with important information to address EOL decisions. Herbert et al, (2006) suggest previous research conducted by Mishel (1988) on uncertainty in illness can provide insight for understanding preparedness (Randy S Herbert, Holly G. Prigerson, et al., 2006). Mishel's original work focused on acute uncertainty (Mishel, 1981, 1983, 1984, 1988). Mishel's uncertainty in illness theory proposes that high levels of uncertainty that accompany an illness such as cancer create a stress response which results in anxiety, fear and distress (Levi, Marsick, Drotar, & Kodish, 2000; Mishel, 1981, 1983, 1988; K. Neville, 1998; Stewart & Mishel, 2000). Uncertainty is present when there is: 1) ambiguity regarding the state of the illness, 2) complexity regarding treatment and system of care, 3) lack of information related to the diagnosis and severity of the disease, and 4) when the course of the disease and prognosis is unpredictable (Mishel, 1988). Studies have shown a strong correlation between acute uncertainty in illness and psycho-emotional distress (Mishel, 1999; Stewart & Mishel,

2000). The management of uncertainty through social support and knowledge empowerment help to lessen the negative impact of acute uncertainty in the initial diagnosis and treatment phase of cancer (Mishel, 1990; K. Neville, 1998; Parry, 2003; Stiegelis, et al., 2004). Logically the principles of Mishel's theory on uncertainty in illness seem applicable when treatment focus has recently changed from curative to palliative care although studies have not been conducted at EOL using Mishel's theory. Although knowledge may decrease some of the acute uncertainty associated with EOL, the dying individual and his/her family will most likely continue to wrestle with questions that have no answers. It is somehow through the process of chronic uncertainty where dying individuals and their families struggle to derive meaning from their illness experience.

In Steinhauser et al.'s study (2000) participants described feeling empowered by participating in treatment decisions (Steinhauser, Clipp, et al., 2000). Participatory decision-making at EOL may particularly benefit the adolescent by providing a sense of autonomy within the context for shared decision-making and control. There are many things that a dying individual cannot control which in turn, may influence self-worth and the ability to die with dignity. Providing the adolescent with information about the trajectory of illness, options available for pain or symptom control, and supportive services within the community allow the adolescent to explore options and make decisions that are congruent with personal values and goals. In a study conducted by Hinds, (2001), dying adolescents describe the importance of being well-informed by both parents and healthcare providers in making decisions about EOL care (Hinds, et al., 2001).

In summary, Knowledge about EOL is an important component of EOL preparedness. Knowledge is obtained by sharing information and communicating openly about EOL. Barriers identified in the literature to open communication and the facilitation of knowledge about EOL include the parent's perceived need to protect their child; and lack of professional training to discuss EOL issues and to deal with the emotional response of such discussions. Information about what to expect as cancer progresses and options available during the palliative phase of treatment may have

several benefits: 1) to help decrease acute uncertainty, 2) allow adolescents to stay actively involved in decisions about their care, and 3) better prepare adolescents for EOL.

#### *Acknowledgement of Grief and Emotions*

Acknowledgement of grief and emotions is the second attribute of EOL preparedness. Adolescents living with incurable cancer must eventually confront the reality of death. The prospect of death initiates grief related to anticipated loss, such as the loss of a future, the loss of dreams, the loss of new experiences, or the loss of separation from family and friends. Anticipating loss or grief initiates a gamut of emotions, some of which are very painful. Parents may try to shield adolescents from the painful emotions associated with anticipatory grief, by not talking about death. This in turn may cause more distress by forcing the adolescent to face death emotionally isolated from people they care about the most (Beale & Baile, 2005; Bluebond-Langner, 1978; Himmelstein, 2006; Newborg, 2008).

Doka (1995) recommends considering three questions when participating in difficult discussions about illness with a child: What does a child need to know? What does a child want to know? What can a child understand? (Doka, 1995). Adolescents generally want to know and deserve to know what is happening with their illness and the progression of their disease. They can understand developmentally what death is, and therefore have a greater need to process the emotions that accompany this reality.

In a study conducted by Jones (2006), 131 pediatric oncology social workers participated in a survey concerning the needs of dying children (0 - 14 years of age), adolescents (15 - 21 years of age), and their families. The survey was developed based on results from a focus group study previously conducted with pediatric oncology social workers. Each participant was asked to rate predetermined list of psychosocial needs of children, adolescents and their families at the end of life (Jones, 2006). The most significant psychosocial needs identified for dying adolescents were: 1) pain control and symptom management, 2) ability to talk freely about fears and feelings, 3) control over treatment decisions, 4) choice of where to die, and 5) companionship. Content analysis was used for narrative responses to an open-ended question on the survey: "How would you describe the needs of children with cancer and their families facing end of life?"

Results showed the need for individualized care to meet the many physical, spiritual and emotional needs of dying children/adolescents and their families (Jones, 2006).

Sharing one's grief and emotions generally requires an authentic and trusting relationship. Kane (2004) suggests HCPs have a dual obligation to cure disease and relieve suffering (Kane, Hellsten, & Coldsmith, 2004). Pediatric cancer is a life-threatening disease which requires intense treatment for cure. During the process of cancer treatment relationships are built among children/adolescents, their families and HCPs. As disease progresses to an incurable state, there is not only physical suffering but also emotional and psychological suffering that occurs (Theunissen, et al., 2007; J. Wolfe, Grier, et al., 2000). Kane (2004) suggests healthcare providers can play a key role in the reduction of suffering at EOL by maintaining meaningful relationships with patients and their families (Kane, et al., 2004). Adolescents need the opportunity to explore the grief and emotions associated with death and dying. Adolescents who are dying can experience tremendous suffering particularly if they are left to process their thoughts, feelings and fears about EOL alone (Beale & Baile, 2005). Alexander (1995) states,

There is no one perfect way to walk the road of life-threatening or terminal illness with a child. Yet there are ways. Keep walking and keep talking and listen patiently. Walk always with your eyes and ears open to the child. Look and listen and respect that on conscious and unconscious levels the child is very involved in the process...Be supportive. Be there. The child will lead you (P. Alexander, 1995).

In summary, acknowledgment of grief and emotions is an important part of EOL preparedness. It requires an honest and trusting relationship with the dying adolescent. Parents and HCPs are in a key position to help alleviate the emotional suffering associated with death and dying by being authentically present and encouraging the adolescent to express feelings, fears, emotions and grief.

#### *Identification of the Meaning of Death and Spirituality*

The third attribute in EOL preparedness addresses the meaning of death and spirituality. People find meaning, purpose, and value in life and death through spiritual and cultural beliefs. Steihauser et al. (2000) conducted 12 different focus groups with nurses, social workers, chaplains, hospice volunteers, physicians, patients and bereaved family members to identify attributes of a good death (Steihauser, Clipp, et al., 2000).

The focus groups were stratified by roles. In 11 out of 12 focus groups spirituality or meaningfulness was a theme that was recognized as deeply important at EOL (Steinhauser, Clipp, et al., 2000).

Similar to adults, children and adolescents with chronic illnesses search for meaning and purpose (Himmelstein, 2006). This was brought to light in Hinds et al. (2004) study. The domains of quality of life in pediatric patients receiving active treatment for cancer were explored (Hinds, Gattuso, et al., 2004). Two qualitative studies were conducted on a total of 36 participants 8 to 18 years old to determine the quality of life perspectives of children and adolescents receiving active treatment for cancer. Two open-ended questions were asked consistently across each study: 1) “What makes a good day for you?” and 2) “How has being sick been for you?” or alternately “What is it like being sick?” The first study was a cross-sectional study where an interview was conducted with the participant one time. The second study was a prospective longitudinal study where 4 interviews were conducted on each participant over a 2 year period. A semantic content analysis was used for data analysis. The perspectives reported by children and adolescents in this study showed that the meaning of being ill was something children and adolescents philosophically thought about and processed throughout the course of their treatment. Examples of responses include: “I hope it never happens to my friends”; “It is like being a genie in a jar and I cannot get out”; “I wonder why I am the one to get leukemia but...I tell myself it is better that I get it than my little sister”. Participants in both studies offered existential responses reflecting upon self and life (Hinds, Gattuso, et al., 2004).

Doka (1993) identified tasks that are involved in living with life-threatening illness. In the terminal phase of illness, preparing for death, saying good-bye and finding meaning in life and death are important (Corr, 1995). Supporting the spiritual development of adolescents is of utmost importance while providing EOL care. Himmelstein (2006) explains spiritual concerns may include “forgiveness, hope, security, legacy, loneliness, unconditional love, and loss of age-appropriate roles” (Himmelstein, 2006). Benson and Roehlkepartain (2008) recognize spiritual development in adolescents has not received the attention needed in order to address the adolescent’s needs holistically (Benson & Roehlkepartain, 2008). Spiritual development is an ongoing

dynamic process that combines the adolescent's inward journey and outward journey. "It presses [the individual] to look inward to accept or discover potential to grow, contribute, and matter, and to look outward to connect with life including being in relationship with family, community, the world, and for many, the sacred, divine, or some form of universal reality" (Benson & Roehlkepartain, 2008).

Kane (2004) suggests HCPs can help to alleviate suffering in dying patients and their families by understanding and supporting their use of spiritual resources to seek a sense of order amidst their suffering (Kane, et al., 2004). According to Kane (2000) spiritual support is a process whereby an individual finds order and transcendent meaning. Creating an atmosphere that supports social and spiritual interactions can be particularly meaningful for the dying child/adolescent and family (Kane, et al., 2004).

In a survey sent out to 100 pediatric faculty and 65 residents to explore pediatricians' attitudes toward spirituality and religion in the practice of pediatrics, Siegel et al. (2002) found 46% of the sample identified themselves as "not at all" spiritual and religious or "not very strong" in their spiritual or religious orientation. However, 90% of the sample said it was appropriate to pray with patients if asked to do so, although only 76% said they would actually feel comfortable doing so (Siegel, et al., 2002). In addition, most pediatricians agreed that giving bad news, discussing a life-threatening illness, and discussing issues of death and dying or life of the deceased warrant discussion about spirituality and religion (Siegel, et al., 2002). Overall, the study found a positive attitude about spirituality and religion when addressing concerns for pediatric patients.

Feudtner et al. 2003 conducted a survey on pastoral care providers to determine the spiritual care needs of hospitalized children and their parents (Feudtner, Haney, & Dimmers, 2003). The greatest patient need identified by pastoral care providers was "feeling fearful or anxious". For parents there were several needs that were identified including feeling fearful or anxious, difficulty coping with child's pain or other symptoms, desiring more medical information about the illness, questioning the meaning or purpose of suffering and feeling guilty (Feudtner, Haney, et al., 2003). There were 3 main barriers identified that impacted the provision of spiritual care in pediatric settings: 1) inadequate training of HCPs to detect spiritual needs, 2) insufficient staffing of

pastoral care workers, and 3) being called too late to address the many needs of the individual and family (Feudtner, Haney, et al., 2003).

Spiritual and cultural beliefs can affect the quality of living at end of life by shaping the way an individual makes meaning out of illness, suffering and dying (Kagawa-Singer & Blackhall, 2001; Kitzes & Berger, 2004; Lobar, et al., 2006; Nishimoto & Foley, 2001; Taylor, 2001). Although ethnic groups may share similar norms, beliefs or practices; there may also be diversity within ethnic groups. The key is to embrace each person as an individual within the unique culture of his/her family. An adolescent may or may not embrace their family's cultural and spiritual beliefs, so it will be up to the HCP to assess and support the adolescent's spiritual and cultural belief system when providing EOL care.

Open communication about death and dying is very much a Western value. This same value is not shared among all cultures. In American Indian and Asian American populations the family prefers to act as a filter to protect against emotional distress (Kitzes & Berger, 2004; Nishimoto & Foley, 2001; Taylor, 2001).

In summary, identification of the meaning of death and spirituality is part of the process of EOL preparedness. HCPs are in a key position to assess and support spiritual and cultural beliefs and rituals that bring meaning to living with advanced and incurable disease.

#### *Conceptualization of an End-of-Life Plan*

Conceptualization of an EOL plan is the final attribute in EOL preparedness. It provides the adolescent with a concrete mechanism to communicate goals and desires for living the remainder of life. Only recently has goals of care been written about in the EOL literature (Weiner & Roth, 2006). Conceptualizing a personal EOL plan will help the adolescent to prioritize goals for living. In addition, decisions about place of care and advanced directives prior to a crisis situation can be beneficial to HCPs and parents as well. The personal EOL plan can be communicated to parents and HCPs verbally or in writing.

### *Outcomes of End-of-Life Preparedness*

There are primarily 2 outcomes to EOL preparedness: 1) communication of personal EOL plan, and 2) quality of life at the end of life. The current literature pertaining to each construct will be described in the following text.

#### *Communication of Personal End-of-Life Plan*

The communication of a personal EOL plan is defined as an adolescent's written or verbal expression of a conceptualized plan which includes goals, priorities, and EOL preferences. The EOL personal plan is communicated to a trusted adult, such as a parent or HCP who will be able to advocate on the adolescent's behalf, if needed. Multiple factors influence an adolescent's communication of personal EOL plan. Context of care, open awareness, family communication, perceived social support, energy level, symptom distress, protection, time until death, relationship with HCP, and the degree of involvement in EOL preparedness all influence the adolescent's ability and desire to communicate his/her EOL personal plan.

#### *Quality of Life at the End of Life*

The second outcome of EOL preparedness is QOL at the end of life. It is defined as the adolescent's subjective estimation of current quality of life. Quality of life will be measured by the QUAL-E a 25 item measurement scale which has 4 subscales: 1) symptoms impact, 2) life completion, 3) relationship with HCP, and 4) preparation for EOL (Steinhauser, et al., 2004). Within the four domains, the QUAL-E measures symptoms, sense of control, participation in decisions, relationship with HCP, knowledge on what to expect, acknowledgement of grief and emotions, worry about family, the meaning of life, resolution of impending death, and perceived social support. The components of QOL will be briefly discussed in the paragraphs that follow.

The symptom impact subscale on the QUAL-E will allow the adolescent to identify the 3 most problematic symptoms and describe the frequency and severity of the symptom within the past week and how much the symptom interfered with the ability to enjoy life.

All individuals dying of a cancer-related death will benefit from routine assessment of the presence, intensity and bother of symptoms (Hinds, et al., 2005). Pain is a significant problem at EOL in children and adolescents dying of cancer (Cynthia J.

Bell, et al., 2009; Bradshaw, et al., 2005; Goldman, et al., 2006; Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006; Theunissen, et al., 2007; J. Wolfe, Grier, et al., 2000). Managing pain at EOL is particularly challenging (Dougherty & DeBaun, 2003; Miller, Miller, & Jolley, 2001). Pain can rapidly escalate at EOL and is often under-treated in children dying of cancer (Hinds, et al., 2005). Other physical and psychological symptoms are also problematic at EOL. In two recent quality of life studies of children and adolescents who are in active treatment of cancer, six themes or domains defined quality of life (Hinds, Gattuso, et al., 2004). The first domain addressed symptoms and the physical and mental reactions to disease or treatment. The second domain addressed the ability to participate in usual activities and to be in a preferred place. The third domain addressed social and family interactions and the ability to feel cared about or acknowledged by others. The fourth domain addressed health status and receiving positive treatment-related news or ability to do self-care activities. The fifth domain addressed mood (being worried, angry, scared, bored, seeing others upset or crying, etc.). The sixth domain addressed the meaning of being ill and exploring “why he or she has cancer but assuming that there must be an important reason” (Hinds, Gattuso, et al., 2004). Although Hinds et al.’s studies (2004) were not addressing QOL at EOL there are common themes that resonate with the adult QOL at EOL literature, as well as the domains within the QUAL-E which will be used to capture QOL at EOL for adolescents in this study.

Management of symptoms (physical and psychological) impacts QOL at EOL. In addition, the suffering that is caused by symptoms that are not adequately controlled has reportedly affected the emotional well-being of parent survivors (Surkan, Kreicbergs, et al., 2006), and has caused distress among professional caregivers as well (Mack, et al., 2005; Papadatou, Bellali, Papazoglou, & Petraki, 2002; Rushton, et al., 2006; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000).

The life completion subscale incorporates how an individual finds meaning while living with advanced cancer. It focuses heavily on the significant impact of our relationships with others. This component of QOL includes the ability to find meaning and peace in one’s life. It addresses important things such as, making a positive

difference, helping others, sharing your deepest thoughts, or saying the things that need to be said to the people you love.

Relationship with health care provider subscale captures involvement in health care decisions as well as relationship between the adolescent and his/her HCP. The need for supportive relationships in EOL care has been identified in the literature (Block, 2001; Heller & Solomon, 2005; Kane, et al., 2004; Steinhauser, 2005). Within supportive relationships trust is developed, which facilitates communication about difficult or painful issues related to death and dying. Studies have shown that supportive communication by the physicians caring for pediatric patients at EOL significantly influences parental and family assessment of quality EOL care (Heller & Solomon, 2005; Mack, et al., 2005; Surkan, Kreicbergs, et al., 2006). Likewise in Wolfe et al.'s study (2000), parents were more likely to report significantly more suffering from pain when they also perceived a lack of active involvement by the oncologist in EOL care (OR 2.6; 95% CI 1.0 to 6.7) (J. Wolfe, Grier, et al., 2000). Likewise being known as an individual by HCPs is important to adult patients facing EOL (Steinhauser, Christakis, et al., 2000). Similarly parents have emphasized the importance of knowing their child as a person in providing quality EOL care (Heller & Solomon, 2005).

Preparation for end of life in the QUAL-E is a subscale that captures life regrets, fear of death, worry about burdening family, worry about financial impact of illness, and worry that family members are not prepared for death. Preparation for EOL in the QUAL-E is conceptually different from EOL preparedness, as defined in the current study. EOL preparedness is a much broader construct that includes components of grief and emotion, knowledge, spirituality and existential concerns and the conceptualization of a plan.

## Summary

Most individuals dying from cancer and their families feel unprepared for EOL. There are many factors that contribute to the lack of preparedness. Those who provide support to the dying adolescent, struggle with knowing when to introduce EOL issues. It is particularly difficult for adults, such as parents and HCPs to talk about death because of the fear of causing more distress. Primarily, HCPs and parents desire to protect adolescents from the emotional pain associated with death and dying. Fear of causing more distress or of destroying hope are factors that may interfere with EOL discussions.

Preparation for EOL is necessary to reduce uncertainty and improve QOL at EOL by giving the adolescent the opportunity to fulfill important goals, make memories communicate with loved ones and find closure prior to death. There is not enough known about how we can prepare adolescents and their families for EOL. Adolescents have an understanding of what is happening and need support for optimal QOL while living with advanced and incurable disease.

There are many methodological and ethical challenges in conducting pediatric EOL research. This dissertation study will address the gap in our current knowledge about EOL preparedness and its impact on quality of life. It will also address the methodological challenge of studying advanced cancer in adolescents by using a case study research method. This method will facilitate a better theoretical understanding of the EOL preparedness process in adolescents living with advanced and incurable cancer.

## CHAPTER 3: METHODOLOGY

### Case Study Method

This chapter describes Case Study as a research strategy for understanding the complexity of EOL preparedness. The first section of the chapter provides an overview of Case Study Method and its application to EOL preparedness. This includes several components of case study research design as well as design challenges. The chapter describes the importance of theory in case study research. The second section of the chapter describes the case study design for this dissertation, including unit of analysis, research questions, propositions, eligibility, sources of evidence, and data collection procedures. The third section of the chapter is devoted to analysis. It describes how qualitative and quantitative data will be analyzed through deductive content analysis and triangulation of data. The strategy of pattern matching to analyze individual cases; examine within case changes across time; and compare within case changes across case one (C1) and case two (C2) will be addressed. The chapter concludes with a fourth section explaining the protection of human subjects.

#### SECTION ONE: OVERVIEW OF CASE STUDY METHOD

Case Study Research provides a comprehensive approach for understanding the complex process of EOL preparedness in adolescents with incurable cancer. There are many strategies that can be used in behavioral oncology research to study a phenomenon. One of the advantages of using Case Study as a research method for EOL research is that it allows the investigator to holistically retain the meaningful characteristics of human interactions while studying the EOL preparedness phenomenon. In addition the context of how the EOL experience occurs is not altered. The contextual conditions related to the phenomenon become an important part of inquiry for the case study approach (Hentz, 2007). Yin describes a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (R. Yin, 2009). Finally the case study method allows a rigorous and challenging strategy that is grounded in theory.

A recent literature review using Medline, CINAHL and PsychINFO provided examples of case study research within public administration and hospital systems (Jenson & Rodgers, 2001; Pare, 2002); psychology (Borckardt, et al., 2008; Brinegar,

Salvi, Stiles, & Greenberg, 2006; Osatuke, et al., 2005; Stiles, 2007); and nursing with a particular focus on palliative EOL care (Bergen, 1992; Cowley, Bliss, Mathew, & McVey, 2002; Lee, 2002; Mahmood-Yousuf, Munday, King, & Dale, 2008; McGrath & Joske, 2002; Skilbeck, et al., 2002). There were many variations within each of these case studies. As Hentz (2007) points out, there are no “hard and fast rules” or standardized ways for conducting case study research (Hentz, 2007). Although some may think of this as a weakness, it is actually the very quality that strengthens each unique case under study. By having the flexibility to study a phenomenon from several different angles, the researcher opens up a world of observations that help to expand theoretical understanding of how or why things happen.

Yin (2009) identifies different applications of case study method resulting in exploratory, descriptive and explanatory case studies (R. Yin, 2009). Case studies can also be used for evaluative purposes (Clark, et al., 2002; Cowley, et al., 2002; Seymour, et al., 2002; Skilbeck, et al., 2002). Case Study Research can be used as a method of inquiry to: 1) explore situations where an intervention has occurred, with multiple explanations requiring evaluation, 2) describe an intervention within the real-life context of where it occurred, 3) explain causal links within a theory for a phenomenon that is being studied, or 4) evaluate the effectiveness of a program or community service (R. Yin, 2009). According to Yin (2009) the most important application of case study research is to explain the presumed causal links within a real life context that is too complex for survey or experimental strategies (R. Yin, 2009). The current study will use an explanatory case study approach to explain the causal links within a conceptual model that addresses EOL preparedness and quality of life at the end of life in adolescents with incurable cancer. See the Conceptual Model for this case study on page 6, Figure 1.

Another variation in case study research method is the design. There are four major designs: 1) Single-Case Study holistic design, 2) Single-Case Study embedded design, 3) Multiple-Case Study holistic design, and 4) Multiple-Case Study embedded design (R. Yin, 2009). In single and multiple holistic designs the focus is on the global nature of the organization, program, situation or phenomenon being studied. The embedded design maintains the orientation or original focus of inquiry for the case study while involving more than one unit of analysis. Multiple-case designs regardless of

whether they are holistic or embedded are generally stronger than single case designs (R. Yin, 2009). The current study will use a multiple-case study holistic design across time to explain how the process of EOL preparedness occurs and its impact on quality of life at the end of life.

### *Components of Case Study Design*

A research design is essentially a plan which conceptualizes the structure of the relationships among variables in a research study (Kerlinger & Lee, 2000). Yin (2009) describes it as the logical sequence linking the data to the initial research questions and ultimately to the study's conclusions (R. Yin, 2009). So the design also guides the analysis.

In case study research, there are five components that are especially important in design. Each component will be addressed briefly in this section and include: 1) Case study research questions, 2) Propositions of the study, 3) Unit(s) of analysis, 4) Logic of linking the data to the propositions, and 5) the Criteria for interpreting the findings.

Case study research questions are appropriate for answering how and why questions when the researcher has little control over events in the phenomenon being studied. The need for case study research stems from a desire to understand a complex phenomenon within its real-life context. One of the difficulties in studying EOL preparedness arises out of the desire to understand the phenomenon without disrupting any positive interactions or support that may occur as the adolescent faces EOL. Case study method allows the researcher to study the phenomenon within the real-life context, without changing or controlling variables in the study. This being said, the case study questions become an important guide to facilitate the collection of relevant data. The questions in this study will help to focus the study so that the end result will contribute to knowledge and understanding of how adolescents with incurable cancer prepare for EOL, and how preparing for EOL will improve quality of life at the end of life. The specific questions for this study are outlined in Section Two.

Propositions of the study are another important component of case study design. Propositions of the study provide expected outcomes and are similar to hypotheses (Gangness & Yurkovich, 2006). They guide the researcher in the direction of what should be studied. In essence, propositions guide the case study analysis and help

organization. Propositions help the researcher to focus on certain data while ignoring other data (R. Yin, 2009). During analysis the propositional statements will be either supported or rejected (Gangeness & Yurkovich, 2006); giving way for theory expansion or modification (Sandelowski, 1993; Stiles, 2007). In the current explanatory case study, propositions will identify specific variables that suggest the cause and effect relationships within the process of EOL preparedness. Propositions for this study are outlined in Section Two.

Unit of analysis is the third component integral to the development of case study design. The unit of analysis defines what the case is. In the current study the unit of analysis is the adolescent with incurable cancer. Relevant information about the adolescent will be collected as described in Section Two. After the data is analyzed, theoretical generalizations regarding EOL preparedness will be specific to adolescents with incurable cancer.

The logic of linking data to the propositions within the theoretical framework is the fourth essential component of case study design. This can be done in any number of ways and will be discussed more in the analysis section of this chapter. One approach that is used in case study research is pattern matching where several pieces of information from the same case are related to a theoretical proposition. A researcher might describe two potential patterns and then show how the data from the case study matched one pattern better than the other. Other ways of linking data to propositions include: explanation building, time-series analysis, logic models and cross-case synthesis (R. Yin, 2009).

A criterion for interpreting a study's findings is the fifth and final significant component in case study design. This component is not well developed in case study research. There is no precise way of setting criteria for interpreting findings. However, Yin (2009) suggests interpreting findings by relying on theoretical propositions or by identifying rival explanations during the design phase of a study (R. Yin, 2009). Data for the current study will be interpreted in light of the proposed theoretical propositions. This component will be discussed more in the analysis section of this chapter.

### *Addressing Design Challenges*

In case study research, the credibility of the research is enhanced by incorporating certain strategies into the design. Each strategy helps to improve the quality of case study research. Quality is monitored by four conditions: 1) construct validity, 2) internal validity, 3) external validity, and 4) reliability (R. Yin, 2009).

#### *Construct Validity*

The following section will describe the strategies that can be incorporated into the case study design to enhance the integrity of the study. The specific strategies used for this study will be addressed under the Design and Analysis sections of this chapter. Construct validity assures the correct operational measures are used for the concepts being studied. This is mainly established in case study research using multiple sources of evidence based on any mix of qualitative and quantitative evidence and by establishing a chain of evidence (R. Yin, 2009). The latter strategy allows an external observer to trace the evidence from research question to conclusion or from conclusion back to research question. These strategies will be incorporated during data collection.

#### *Internal Validity*

The next strategies address internal validity and are incorporated into the data analysis. An explanatory case study with internal validity shows how certain conditions lead to other conditions; and distinguishes true relationships from spurious ones. Internal validity can be obtained through pattern-matching, explanation-building, logic models and by addressing rival explanations (R. Yin, 2009). The specific strategies addressing internal validity for this study will be explained more thoroughly in the data analysis section of the chapter.

#### *External Validity*

The third group of strategies addresses external validity. External validity is important for generalizing the study findings beyond the immediate case study. Strategies involve incorporating theory and replication logic into the research design. This allows the researcher to make analytic generalizations (R. Yin, 2009). In summary, explanatory case studies expand, refine and generalize theories.

### *Reliability*

The last group of strategies that aim to enhance the integrity of case study research address reliability. A reliable case study demonstrates the operations of the study. Developing detailed case study procedures and incorporating a case study database are two ways to assure the same case study could be repeated with the same results. The intent for developing detailed case study procedures is to minimize errors and biases in the study. This is particularly helpful for multiple-case studies. A case study database also contributes to the reliability of case study research by having the raw data that led to the case study's conclusions readily available for other investigators to view. This would include *case study notes* (on interviews, observations or document analysis); *case study documents* (or summary of data retrieved from documents); *tabular materials* (quantitative data results); and *narratives* (R. Yin, 2009).

### *Role of Theory in Case Study Research*

The development of a theoretical base prior to data collection is a defining characteristic of case study research. Some qualitative methods, such as ethnography, grounded theory and phenomenology avoid specifying any theoretical propositions at the beginning of the research study (Munhall, 2007; Sandelowski, 1993). Although ethnography may use some theory of social interaction or culture to guide the development of the research study (Sandelowski, 1993). In case study research, theory development is integral to the research design. One of the goals for an explanatory case study approach is to have a preliminary conceptual model at the onset of the study, that is appropriately supported by research literature so that findings from the case study can advance knowledge and understanding of a given topic (R. K. Yin, 2003a). Based on a thorough review of EOL studies reported in the literature, the conceptual model developed for this research study will assist with: 1) defining the process of EOL preparedness, 2) determining case eligibility, 3) collecting data, 4) specifying propositions, 5) analyzing results, and 6) generalizing findings to theoretical propositions.

Case study method relies on theory to guide data collection. Due to the complexity of EOL research, the phenomenon of interest (EOL preparedness) and context, (within the daily lives of adolescents with incurable cancer), are not clearly separable. Understanding the process of EOL preparedness encompasses an in-depth

understanding of contextual conditions. Therefore the development of this study's conceptual model incorporates demographic, environmental, personal and family characteristics that tap into important contextual variables.

Case study method relies on theory for data analysis. Case study research illuminates where theories need to grow (Stiles, 2007). The researcher's task is to systematically observe a phenomenon and determine where observations correspond to the theory and where there are deviations, or new and different discoveries. Observations that show where the theory doesn't work can be just as important scientifically.

When conducting case study research, it is helpful to have multiple points of contact between the case and the theory so that detailed links between theory and observation can occur (Stiles, 2007). The researcher must be familiar enough with the theory to determine where observations converge and where observations fail to fit the proposed theory. Stiles (2007), describes theory as a "growing and changing way of understanding". The author makes the analogy to diffusion, where new observations permeate the current theory to expand it (Stiles, 2007). Acknowledging where observations deviate from the theory is an important component of theory building. This requires careful examination and re-examination of the findings and the confidence to identify and describe how the theory needs to be modified; as well as the humility to accept one's thinking may be mistaken (Stiles, 2007). Case studies that allow for theory-building, not merely theory application give rise to significant scientific contributions. Theory guides data collection, analysis and conclusions. In the end, recognizing modification or refinement of theory may be a necessary result.

## SECTION TWO: DESIGN

The following section will describe the case study design for this dissertation study. It will include: 1) the specific design used for this case study, including unit of analysis, overarching research questions and propositions, 2) eligibility criteria, 3) sources of evidence, and 4) the case study procedure, including detailed information on how data will be collected. Section Three will address analysis.

### *Specific Design for Current Study*

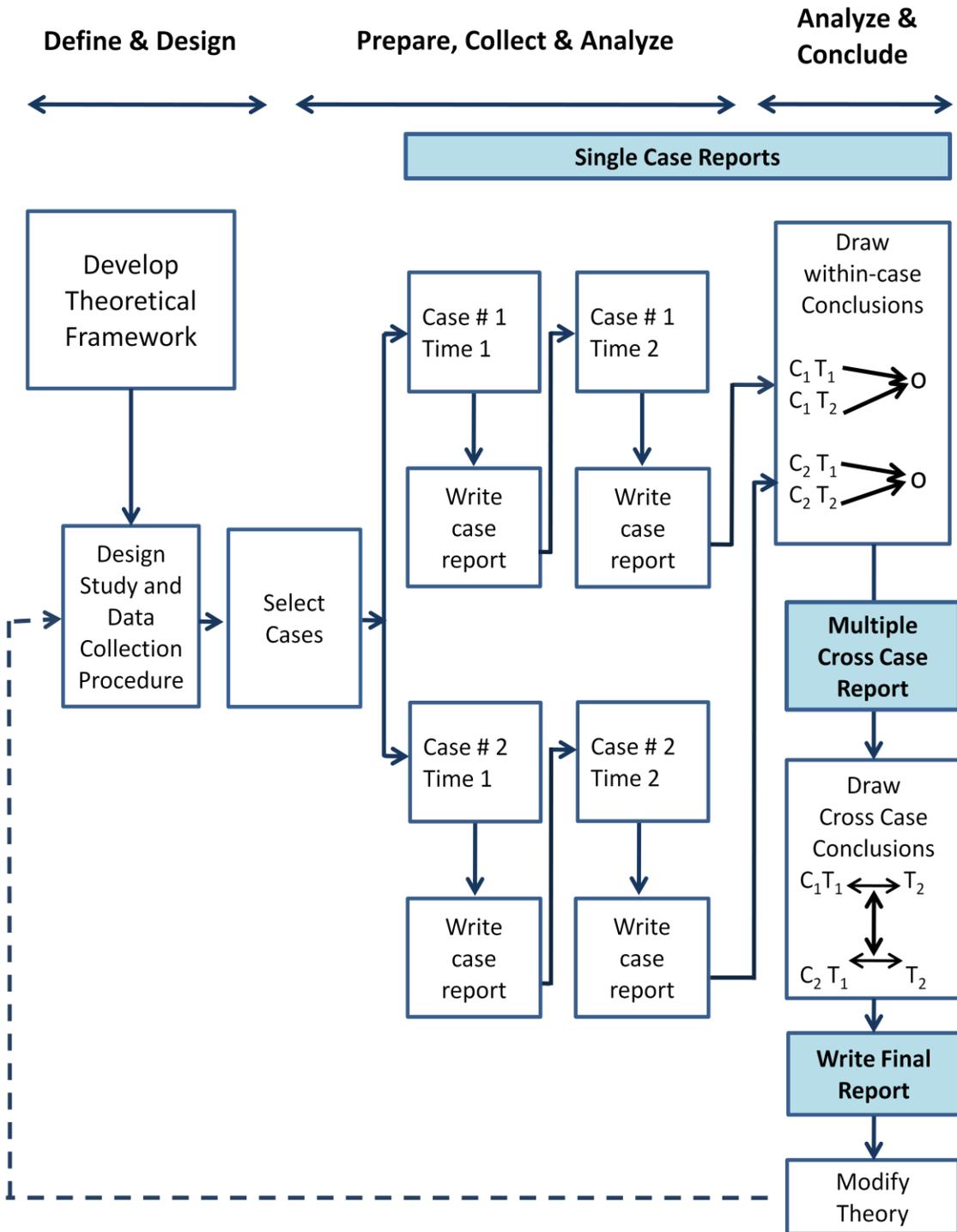
#### *Multiple-Case Study: Explanatory Holistic Design*

The current case study will use a multiple-case study holistic design to explain the process of EOL preparedness in adolescents with incurable cancer. Two cases: Case One (C1) and Case Two (C2) will be selected and studied across time (T1 and T2), providing a robust study to holistically examine the process of EOL preparedness. Yin (2009) considers a multiple case design to be two or more cases (R. Yin, 2009). The EOL Case Study Model in Figure 2 on page 81 demonstrates the current plan for preparing, collecting and analyzing data in this case study. The Conceptual Model described in chapter one provides the theoretical constructs that will guide the collection and analysis of data for the current study. See Figure 1 in Chapter 1, page 6.

#### *Unit of Analysis: Adolescent with Incurable Cancer*

The planned case study will include two adolescents between the ages of 14 and 21 years of age, diagnosed with incurable cancer, who are willing to engage in the process of EOL preparedness. Multiple sources of data will be collected at two time points, pertaining to the adolescent with incurable cancer. Demographic, environmental, personal and family characteristics as well as information about Readiness, EOL preparedness, Communication and QOL in adolescents will be collected.

Figure 2: End-of-Life Case Study Schematic.



### *Overarching Research Questions*

This multiple-case study will answer the following research questions:

1. How do adolescents with incurable cancer become ready to engage in EOL preparedness?
  - a. What contextual factors (demographic, environmental, personal, and family characteristics) influence the process of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) for adolescents with incurable cancer?
  - b. How are the dimensions of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) interrelated?
  - c. How does time influence the process of Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) in adolescents with incurable cancer?
2. How does an adolescent's Readiness (awareness, acceptance, and willingness to take action to prepare for EOL) impact the process of EOL preparedness including the dimensions of: knowledge about EOL; acknowledgement of grief and emotions; identification of the meaning of death and spirituality; and conceptualization of personal EOL plan
3. How do adolescents with incurable cancer prepare for EOL?
  - a. How is each dimension in the process of EOL preparedness (knowledge about EOL; acknowledgement of grief and emotions; identification of the meaning of death and spirituality; and conceptualization of personal EOL plan) interrelated?
  - b. How does time influence EOL preparedness?
  - c. How do demographic, environmental, personal, and family characteristics influence EOL preparedness in adolescents with incurable cancer?
4. How does the process of EOL preparedness relate to the adolescent's communication of personal EOL plan to his/her parent(s) and/or healthcare provider?

5. How do demographic, environmental, personal, and family characteristics influence an adolescent's communication of personal EOL plan to parent(s) and/or healthcare provider?
6. How is an adolescent's quality of life at the end of life influenced by communication of his/her personal EOL plan?
7. How is an adolescent's QOL at EOL influenced by EOL preparedness?

#### *Case Study Propositions*

There are six main propositions that will guide the collection of data and analysis:

1. **Contextual factors** (*demographic, environmental, personal and family characteristics*) **will be related to Readiness**, (*awareness, acceptance, and willingness to take action*); **EOL preparedness**, (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); **and communication of personal plan.**
2. **Readiness** (*awareness, acceptance, and willingness to take action*) **precedes EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*).
3. **EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) **is related to communication of personal plan.**
4. **EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) **is related to QOL at EOL.**
5. **Readiness** (*awareness, acceptance, and willingness to take action*); **EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); **and communication of personal plan are related to time.**
6. **There will be similarities and differences within case changes across C1 and C2.**

### *Eligibility*

Adolescents will be considered eligible if they are: 1) referred by a physician, 2) have had a discussion with their physician about incurable prognosis, and are able to acknowledge and recall this discussion, 3) are between the ages of 14 and 21 years of age, 4) have an estimated time frame of at least five months before death, 5) are willing to talk with an interviewer, and 6) are able to give informed assent/consent.

Although it is difficult to know the length of time an individual has before death, there are certain prognostic indicators that are used by physicians to estimate time to death. This information varies according to specific cancer diagnosis and other individual factors. The researcher will request that physicians attempt to refer adolescents who have greater than five months to live, in order to avoid undue burden on adolescents participating in the research study at EOL. This will also help to decrease potential attrition once enrolled in the research study.

Upon referral from the physician, the adolescent will be approached in person or by phone to see if he/she is willing to answer a few questions to determine eligibility for a research study. The adolescent will be asked:

- *“Are you between the ages of 14 and 21 years old?”*
- *“Do you remember talking to your doctor about your cancer and what would be happening?”*
  - *Probe: “What do you understand is going to happen as far as treatment options?”*
- *“Are you willing to talk with me about what you are currently going through?”*
  - *Probe: Would you be okay with sharing your thoughts and feelings with me as you face the weeks and months ahead?*

Once eligibility is established the researcher will obtain informed consent for the adolescent if he/she is at least 18 years old. Adolescents under the age of 18 will provide assent and will also need the consent of a parent or legal guardian. This will be explained thoroughly in Section Four of this chapter. There are a few other inclusion/exclusion criteria worth noting. The adolescent must be able to understand and speak in English. Due to the researcher’s own limitations in understanding languages other than English, participants in this study must be able to speak and understand English which will

exclude adolescents who speak fluently in another language but cannot communicate in English. There may be cultural or ethnic differences that will not be represented in this sample because of this limitation. Other criteria considered essential for study inclusion are: 1) ability to hear a normal conversation, 2) current medical diagnosis of incurable cancer, and 3) documentation of EOL prognostic discussion with physician describing incurable condition.

### *Sources of Evidence*

In case study research, multiple sources of evidence are used to study a phenomenon. By collecting multiple sources of evidence, the researcher is able to address behavioral and attitudinal issues broadly (R. Yin, 2009). During analysis, triangulation of the data provides support from multiple sources of data to show corroboration of evidence.

The evidence most commonly used for case studies comes from interviews; direct observation; participant observation; documentation; archival records (this may include service records, such as number of clients served over a given period of time, or the listing of pediatric oncology deaths at a given hospital); and physical or cultural artifacts.

The following section will describe the sources of evidence that will be used for this case study. Data will mainly be obtained through qualitative interviews along with quantitative measures about the EOL preparedness phenomenon. Direct observation and documentation will be additional sources of evidence that will be utilized. Archival records and physical or cultural artifacts are probably the least likely sources that will be drawn upon for this case study. However, their use will not be excluded as a source of evidence. For example if an adolescent uses a physical or cultural artifact to describe his/her religious or cultural beliefs about EOL, this will be described in the field notes and incorporated into the analysis.

Each variable or model component within the conceptual model has a conceptual definition and an operational definition. In Case Study Method, multiple sources of evidence will be used to measure each variable or model component within the conceptual model. The measurement definition for each variable will be a result of the triangulation of multiple sources of evidence. In other words, the triangulated data for each construct will become the operational definition. Table 6 provides potential sources

of evidence for each model component or variable in this study. The specific way that each source of information will be collected and analyzed will be addressed under each specified section and in the analysis section of this chapter.

Table 6: Sources of Evidence for Operational Definitions.

<b>Model Component Variable</b>	<b>Conceptual Definition</b>	<b>Sources of Evidence-Operational Definitions</b>
<i>Demographic Characteristics</i>		
Age	Defined as the life interval of the adolescent with cancer	Will be measured by: 1) Self Report Demographic Sheet [Current Age in Years] 2) Medical Record
Sex	Defined as the classification of an individual into an exclusive group of male or female based on typical reproductive function	Will be measured by: 1) Self Report Demographic Sheet [Male or Female]
Education	Defined as level of formal schooling an adolescent has received (last grade completed and current grade enrolled in school)	Will be measured by: 1) Self Report Demographic Sheet [Last grade completed in School ____; Current Grade: ____]
Race	Defined as adolescent's perception of belonging to a distinct group of the human population distinguishable from others based on shared biological traits	Will be measured by: 1) Self Report Demographic Sheet [Race ____]
Disease Status	Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness	Will be measured by: 1) Medical Record Review 2) Demographic & Environmental Flow Sheet lists the specific information that will be obtained for this study 3) Information about disease and trajectory will also be obtained from adolescent during semi-structured interview

<b>Model Component Variable</b>	<b>Conceptual Definition</b>	<b>Sources of Evidence-Operational Definitions</b>
<i>Environmental Characteristics</i>		
Place of Care	Defined as environment where adolescent is living with advanced and incurable cancer	Will be measured by: 1) Location of interview 2) Direct Observation during interview
Focus of Care	Defined as adolescent's perception of specific purpose for care delivery	Will be measured by: 1) Semi-structured interview 2) Medical record review
Continuity of Staff	Defined as continuation of familiar nursing and medical staff while transitioning to EOL	Will be measured by: 1) Self Report Demographic Sheet to obtain primary doctors and nurses [Primary Doctor ____; Primary Nurses _____] 2) Information will be obtained from Medical Record
Initial EOL Discussion	Defined as a conversation about impending death or incurable prognosis with adolescent or adolescent and his/her parent(s)	Will be measured by: 1) Physician and adolescent acknowledgement of conversation 2) Recollection of discussion 3) Medical Record Review
Ongoing EOL Discussions	Defined as ongoing discussions with physician/HCP about death or EOL issues	Will be measured by: 1) Medical Record Review 2) Semi-structured interview

<b>Model Component Variable</b>	<b>Conceptual Definition</b>	<b>Sources of Evidence-Operational Definitions</b>
<i>Personal Characteristics</i>		
Decisional Control Preferences	Defined as adolescent's preferred level of involvement in decisions about care and treatment	Will be measured by: 1) Semi-structured interview 2) Control Preferences Scale (CPS)
Physical Symptom Distress	Defined as perceived physical symptoms that interfere moderately or severely with daily activities	Will be measured by: 1) EFAT-2 2) Semi-structured interview 3) Direct observation 4) Medical record review
Psychosocial Symptom Distress	Defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities	Will be measured by: 1) EFAT-2 2) Semi-structured interview 3) Direct observation 4) Medical record review
<i>Family Characteristics</i>		
Family and other Social Support	Defined as adolescent's perception of family and other sources of encouragement, support, and help during difficult times	Will be measured by: 1) Semi-structured interview 2) MSPSS 3) Direct observation
Family Communication	Defined as the degree of open discussion among family members about difficult topics such as EOL	Will be measured by: 1) Semi-structured interview 2) One item on the MSPSS which states "I can talk about my problems with my family" 3) Direct observation
Family Cultural and Spiritual Practices	Defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent's personal and family life	Will be measured by: 1) Semi-structured interview 2) Adolescent may have cultural artifacts that he/she shares

<b>Model Component Variable</b>	<b>Conceptual Definition</b>	<b>Sources of Evidence-Operational Definitions</b>
Readiness	<p>Defined as <b>Awareness</b> (the level of cognitive recognition of an incurable prognosis); <b>Acceptance</b> (the level of emotional acquiescence of an incurable prognosis); and <b>Willingness to Take Action</b> (level of intent or desire to take action) to prepare for EOL</p>	<p><b>Awareness</b> Will be measured by:</p> <ol style="list-style-type: none"> <li>1) Physician and adolescent acknowledgement of EOL discussion</li> <li>2) Semi-structured interview will help to determine level of awareness</li> </ol> <p><b>Acceptance</b> Will be measured by:</p> <ol style="list-style-type: none"> <li>1) Peaceful Awareness of Illness Subscale from PEACE Scale</li> <li>2) Semi-structured interview</li> <li>3) Direct observation during Interview</li> </ol> <p><b>Willingness to Take Action</b> Will be measured by:</p> <ol style="list-style-type: none"> <li>1) Semi-structured interview</li> <li>2) Direct observation during interview</li> <li>3) Three items that address Willingness</li> </ol>
<i>Phenomenon</i>		
EOL Preparedness	<p>Defined as a process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for EOL consistent with his/her desires; communicates the desires to family and caregivers; resulting in a satisfactory end of life</p> <p>Attributes include:</p> <ul style="list-style-type: none"> <li>• Knowledge about EOL</li> <li>• Acknowledgement of Grief and Emotions</li> <li>• Identification of the Meaning of Death and Spirituality</li> <li>• Conceptualization of an EOL Plan</li> </ul>	<p>Will be measured by:</p> <ol style="list-style-type: none"> <li>1) Semi-structured interview</li> <li>2) Direct observation</li> <li>3) Cultural or Physical Artifacts</li> </ol>

<b>Model Component Variable</b>	<b>Conceptual Definition</b>	<b>Sources of Evidence-Operational Definitions</b>
<i>Outcomes</i>		
Communication of Personal EOL Plan	Defined as adolescent's written or verbal expression about conceptualized plan which includes goals, priorities and EOL preferences	Will be measured by: 1) Semi-structured interview 2) Direct observation during interview 3) Adolescent may have written plan for researcher to see
Quality of life at the end of life	Defined as adolescent's subjective estimation of the quality of symptom control, relationships with others, the meaningfulness of life and resolution of impending death	Will be measured by: 1) Semi-structured interview 2) Direct observation during interview 3) QUAL-E

### *Qualitative Interviews*

An interview is one of the most important sources of information for case studies because it provides information from the human perspective of those directly involved with the phenomenon of study (R. Yin, 2009). In the current study, each case will have two interviews. An adolescent will be initially interviewed at Time 1 and then approximately one month later at Time 2. All interviews will be audio recorded and transcribed verbatim.

A semi-structured interview approach will be used to better understand the phenomenon of EOL preparedness. Semi-structured interviews provide a flexible approach for inquiry to reveal in-depth views and experiences while being open to new information from participants (Payne, Field, Rolls, Hawker, & Kerr, 2007). Semi-structured interviews also use open-ended questions which help to facilitate the collection of contextual data (Fallon, 2008; Gugiu & Rodriguez-Campos, 2007). A pre-determined set of questions will guide the discussion to assure information is gathered about contextual factors as well as each of the constructs in the EOL preparedness model. This will help to focus the data collection and maximize the comprehensiveness of the interview (Gugiu & Rodriguez-Campos, 2007).

During semi-structured interviews, researchers use probes to explore perceptions and opinions about complex or sensitive issues (Barriball & While, 1994). During the interview, once the adolescent has responded to initial questions, the researcher will use the adolescent's own language to ask follow-up questions. This allows the researcher to probe more deeply and invites the participant to freely express and clarify opinions and perspectives (Barriball & While, 1994; Hancock & Algozzine, 2006). Constructs within the conceptual model serve to categorize the interview questions as demonstrated in Table 7. Examples of interview questions and hypothetical probes are included in the table.

Table 7: Semi-Structured Interview Guide.

<b>Construct:</b>	<b>Questions and Probes:</b>
Opening Question	<p>Thank you again for being willing to be a part of this study. And I'm very interested in knowing what it's like to be an adolescent or a teenager that is living with advanced cancer. By learning about this from experts like you, I think that we'll be able to help other adolescents cope with this part of their life. So would you please start by telling me what it's like to be a 15 year old adolescent guy living with advanced cancer?</p> <p>What sorts of things have you found helpful in dealing with advanced cancer?</p> <p>What has not been helpful?</p>
Theoretical Constructs	
<b>Contextual Factors</b>	<b>Questions and Examples of Probes</b>
<i>Demographic Characteristics</i>	<p>Do you think the <i>length</i> of time since your diagnosis of cancer has made any difference in how you are doing now?</p> <p>Is there a time where you knew your cancer was getting worse?</p> <p><b>Probe:</b> Did that help to prepare you in any way to be ready for today?</p>
<i>Environmental Characteristics</i>	<p>(Home Environment) Tell me about your family and the people who live here with you.</p> <p>(Health Care Environment) Tell me about where you have gone for your cancer treatments. What sorts of things can you think of that have helped you deal with your life and the challenges you are currently facing?</p> <p><b>Probe:</b> "It sounds like Dr._____, or your nurse_____ was very supportive, can you try to describe for me how they specifically helped you? How long have you known him/her? Do you see your HCPs often?"</p> <p>Tell about some of the conversations you have had with your physician to prepare you for what you are going through now.</p>

<b>Construct:</b>	<b>Questions and Probes:</b>
	<p><b>Probe:</b> Are there others, like nurses, social workers, psychologists, that have helped you to a talk about these things?</p> <p>“How would you like your physician or nurse to help you in your current situation?”</p>
<i>Personal Characteristics</i>	<p>Tell me about some of the major things that have happened in your life and how have you been able to handle them?</p> <p><b>Probe:</b> Tell me more about how you coped with hard times in the past? So tell me what are your <i>strengths</i> and the things that help you during hard times? What sorts of things might interfere with you handling your illness?</p> <p>What are the biggest problems affecting you now?</p> <p><b>Probe:</b> How is your cancer affecting you physically? Psychologically or emotionally? Socially?</p> <p>How is your energy level?</p> <p>Who are the people you can turn to for support?</p> <p><b>Probe:</b> Tell me more about them</p>
<i>Family Characteristics</i>	<p>Who are the important people in your life now?</p> <p><b>Probe:</b> Of the people you identified, who do you trust most when you get news you <i>need</i> to share?</p> <p>How does your family talk about the tough things you are going through?</p> <p><b>Probe:</b> Tell me about how you are able to bring up conversations with your family, to discuss what you are thinking and feeling?</p>
<b>Readiness</b>	<b>Questions and Probe</b>
<i>Awareness</i>	<p>Tell me how you came to realize the doctors were running out of treatment options for your cancer.</p>

<b>Construct:</b>	<b>Questions and Probes:</b>
	<p><b>Probe:</b> You said that things have gotten more serious for you. Can you tell me what you mean by more serious?</p> <p><b>Probe:</b> So there was a change in your physical condition, tell me what that means to you?</p> <p>Tell me about how you think your illness will affect you in the future</p> <p>How is it affecting you now?</p>
<i>Acceptance</i>	<p>Tell me a little bit about how it was for you to be diagnosed with cancer and then come to realize that the treatments were not working...</p> <p><b>Probe:</b> What events or circumstances have helped you to accept your current condition?</p>
<i>Willingness to Take Action to prepare for EOL</i>	<p>On a scale of one to four (not at all, to a slight extent, to some extent, or to a large extent how willing are you to discuss the things that you're worried about or the concerns that you may have?</p> <p>The second question is: how willing are you to talk about your feelings and those are the things that make you sad or afraid.</p> <p>And then the last question, it talks about your willingness to find out more information. So how willing are you to find out more information about what will be happening if your cancer progresses?</p>
<b>End-of-life Preparedness</b>	<b>Questions and Probe</b>
<i>Knowledge about EOL</i>	<p>Do you ever wonder about what is ahead?</p> <p>Do you worry about pain or other kinds of physical suffering?</p> <p><b>Probe:</b> It must be difficult for you as you anticipate all of the "what-ifs? Tell me where can you go with all your questions?</p> <p>When you think about getting information about your illness, which of these categories fits you best?" (Display responses on cards and let adolescent choose)</p> <p>a. You want all possible</p>

<b>Construct:</b>	<b>Questions and Probes:</b>
	<p>information whether it's good news or bad news.</p> <ul style="list-style-type: none"> <li>b. You prefer to ask what you want to know.</li> <li>c. You want all good news.</li> <li>d. You would rather not have too much detail.</li> <li>e. You don't want to know anything at all.</li> </ul> <p><b>Probe:</b> So you say you want all good news... what if there is bad news to share- how would you want your doctor or family to go about sharing that with you?</p>
<i>Acknowledgement of Grief &amp; Emotions</i>	<p>Tell me, how are the important people in your life handling your illness?</p> <p><b>Probe:</b> So do you worry about your family's emotions?</p> <p>Have you told your <i>parent</i> how hard it is to think of leaving him/her?</p> <p>Do the important people in your life know what they mean to you?</p> <p>Do you feel something important has been left unsaid?</p>
<i>Identification of Meaning of Death and Spirituality</i>	<p>Tell me, how have you made sense of why this is happening to you?</p> <p>What role does faith or spirituality play in your life?</p> <p><b>Probe:</b> Has faith or spirituality been important in your life before this illness?</p> <p>Do you have traditions or beliefs that can help you deal with your illness?</p> <p><b>Probe:</b> So if I understand you correctly then your spiritual/cultural belief or tradition is very important to you and your family, how can your doctors or nurses help to support that belief or tradition for you?</p>

<b>Construct:</b>	<b>Questions and Probes:</b>
<i>Conceptualization of Plan</i>	<p>Have you thought about the things you want to accomplish in the weeks and months ahead?</p> <p>Have you thought about the people you want to spend time with in the weeks and months ahead? What sorts of things would you like to do with them?</p> <p>“Are there important people in your life that you need to talk with?” What information do you hope they remember about you?</p> <p><b>Probe:</b> “Have you thought about developing a personal plan to outline your goals and things you want to accomplish, or who you need to talk to, or the memories you want to make together?”</p>
<b>Outcomes: Measured at Time 2</b>	<b>Questions and Probe</b>
<i>Development of EOL Plan</i>	<p>Last time we met, we discussed the possibility of developing a personal plan that would describe your goals and desires about things you want to accomplish or ways that you would like to see things happen in the months ahead. Were you able to develop such a plan?</p> <p><b>Probe:</b> How did you go about developing your plan?</p>
<i>Communication of EOL Plan</i>	<p><b>Time 2:</b> Have you been able to put any of this in writing or have you had the opportunity to verbally communicate your goals and desires?</p> <p><b>Probes:</b> How could we help you to develop this plan?</p> <p>Tell me about the things that may have interfered with communication of your goals/plan ...<i>or the development of your goals/plan?</i></p>
<i>QOL at EOL</i>	<p>Quality of life means different things to different people. I am interested in knowing how you would describe the quality of your life right now?</p> <p><b>Probe:</b> - will vary based on adolescent response.</p>

### *Quantitative Measures*

There are several quantitative measures that will be collected during Time 1 and Time 2. This section will describe each measure and provide information about reliability and validity of the instruments used in this study. The exact use of each instrument will be described in the procedure section that follows.

#### New Edmonton Functional Assessment Tool (EFAT-2) (Kaasa & Wessel, 2001)

The New Edmonton Functional Assessment Tool (EFAT-2) will be used to measure physical and psychosocial functioning of the adolescents participating in this study. Participation in a research study may be too burdensome for adolescents who have high levels of physical or psychosocial symptom distress. Therefore adolescents will be screened prior to Time 1 and Time 2 using the New Edmonton Functional Assessment Tool (EFAT-2) (Kaasa & Wessel, 2001) to capture adverse physical and psychosocial symptoms. The EFAT-2 is used in advanced cancer patients to measure degrees of functional performance from 0 = Functional to 3 = Severe Dysfunction.

Symptom distress interferes with an individual's ability to engage in the emotional and psychological tasks of EOL. The EFAT-2 was developed to describe the changing functional status that occurs in cancer patients during the palliative/EOL phase. The EFAT-2 measures an individual's ability to interact and mobilize even when severely limited by the progression of cancer (Kaasa, Wessel, Darrah, & Bruera, 2000). This instrument was developed based on the palliative care and rehabilitation literature by therapists working with palliative care cancer patients (Kaasa & Wessel, 2001; Kaasa, et al., 2000).

The EFAT-2 (a 10-item measure) was tested for use in the palliative care oncology population. It was administered to 275 patients, diagnosed with cancer and admitted to an acute palliative care unit. Internal consistency reliability was good (Cronbach  $\alpha = 0.86$ ). A principal-components factor analysis with varimax rotation was performed on a random subset of the sample ( $n = 125$ ) and then on the remaining individuals ( $n = 150$ ). There were 3 factors generated. Physical activity items loaded on Factor 1 (ADL, balance, locomotion and mobility), accounting for approximately 50% of the variance. Cognitive/Affective items loaded higher on Factor 2 (communication, mental status and motivation), accounting for approximately 12% of the variance. Fatigue

loaded pretty evenly on both factors, which may indicate the construct has both physical and cognitive/affective elements that it measures. Dyspnea loaded slightly higher on Factor 1 in both samples (0.494 and 0.405 respectively). The third Factor consisted only of pain with a loading of 0.988 in the first sample and 0.971 in the second sample, accounting for approximately 10% of the variance (Kaasa & Wessel, 2001).

One of the features that make this instrument attractive for the current case study is that it is relatively short (the entire assessment can be completed in 15 - 20 minutes), and it measures a combination of subjective and objective functional performance items. Pain, mental status, fatigue and motivation are measured subjectively. Since some of the mobility measures will not be assessed for the current Case Study, it is estimated that assessment time for administration of the EFAT-2 will be significantly reduced.

In a study conducted by Kaasa et al., (2000), inter-rater reliability for the EFAT-2 was compared between formally trained raters and self-trained raters. Interclass correlation coefficients (ICC) were high and standard errors of measurement (SEM) were low indicating good inter-rater reliability for both formally trained and self-trained raters. The ICC for self-trained raters was 0.97 with a confidence interval of 0.94 - 0.99 and SEM 1.09. For the formally trained raters the ICC was 0.95, CI = 0.90 - 0.98, and SEM 1.44 (Kaasa, et al., 2000). The high ICC shows consistency between raters in both groups. In addition, the narrow confidence interval and low standard error of measurement indicate random error has little influence on the observed ICC score. Classical Measurement Theory assumes that every observed score consists of a true score and an error score (Waltz, Strickland, & Lenz, 2005). A low standard error of measurement indicates less error therefore the observed score is closer to the true score.

Physical and psychosocial symptom control is an important part of quality care for advanced cancer patients. For this study, only adolescents who score in the 0 = functional to 1 = minimal dysfunction categories will be included in the study. The items used from the EFAT-2 for this study include: communication, mental status, pain, dyspnea, fatigue, motivation, and activities of daily living (ADL). An additional item to measure GI distress will be added to screen out those individuals who have nausea, vomiting or diarrhea that may interfere with functional performance. See appendix for EFAT-2 instrument.

### The Control Preferences Scale (CPS)

The Control Preferences Scale (CPS) developed by Degner and colleagues (1997) will be used to measure the degree of control and adolescent desires in making decisions about current care. The CPS is a valid and reliable scale that measures the degree of control an individual desires when making decisions about medical treatment (Degner, Sloan, & Venkatesh, 1997). This tool evolved from an extensive grounded theory study by Degner and Beaton (1987) describing life and death decision-making and the influence of social context (Degner, Sloan, et al., 1997). Basically, the authors surmise that an individual's preferred role in treatment decision-making can be detected along a continuum that ranges from maintaining total control to relinquishing control to the physician or HCP. The CPS was developed specifically for individuals facing the life-threatening illness of cancer following empirical evidence that individuals who exercise control over decisions about medical treatments have better outcomes (Degner, Sloan, et al., 1997).

The CPS has been tested extensively in large groups of cancer patients nationally and internationally (Davison & Degner, 1998; Degner, Kristjanson, et al., 1997; Degner & Sloan, 1992; Degner, Sloan, et al., 1997; Hack, Degner, Watson, & Sinha, 2006). The model used for scale measurement is the unfolding theory by Coombs, (1976) (Degner, Sloan, et al., 1997). By using a card sorting system, an individual selects his/her decisional preference through successive paired comparisons while thinking about one particular decision of reference. For this study the question to the adolescent will be "Which one of these cards shows your preference in decision-making about your *current* cancer care and treatment?" There are 5 cards A, B, C, D, and E. For this study, a pre-determined fixed order of the cards will be presented to the adolescent: BDCEA. The first two cards will be shown to the adolescent (B and D). Once the adolescent selects his/her preferred card, the next card (C) will be compared to the preferred card. This will continue until all 5 cards are compared. This method has been useful in clinical populations (Degner, Sloan, et al., 1997). Preference orders can be categorized based on the adolescent's most preferred role: active (A, B); collaborative (C); or passive (D, E). If more than one preference is selected, the two most preferred roles can be described as follows: Active-Active (AB, BA); Active-Collaborative (BC); Collaborative-Passive

(CD); or Passive-Passive (DE, or ED) (Degner, Sloan, et al., 1997). See appendix for CPS cards.

Knowing an adolescent's preference for involvement in decision-making may provide insight during analysis of the EOL preparedness process. It is proposed that adolescents who prefer an active or collaborative role in decision-making will display a higher level of Readiness and therefore engage in EOL preparedness.

#### Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) developed by Zimet, Dahlem, Zimet, and Farley (1988) will be used to measure the adolescent's perceived adequacy of support from family, friends and significant other (Zimet, et al., 1990). The MSPSS is a brief 12-item measure that has demonstrated consistent construct validity and internal consistency reliability across multiple diverse samples (Cronbach  $\alpha$  from .84 to .93 for the scale as a whole) (Canty-Mitchell & Zimet, 2000; Dahlem, Zimet, & Walker, 1991; Zimet, et al., 1990). A 7-point Likert-type scale is used for response, ranging from *very strongly disagree* (1) to *very strongly agree* (7). The scale has been used in college students, young adults, pregnant women, and specifically in the adolescent population in both clinical and non-clinical settings (Canty-Mitchell & Zimet, 2000; Dahlem, et al., 1991; Zimet, et al., 1990). In the original study, Zimet *et al.* (1988) confirmed a 3 factor structure (family, friends, and significant other) which was supported in each subsequent study (Canty-Mitchell & Zimet, 2000; Dahlem, et al., 1991; Zimet, et al., 1990). A copy of the MSPSS is included in the appendix.

Family support is of particular interest to the current EOL preparedness case study. However, determining an adolescent's perception of support from friends or a "special person" is equally important. Items in the MSPSS were specifically designed to allow adolescents to interpret the relevance of the sources of social support (Canty-Mitchell & Zimet, 2000). For example, the item "There is a special person who is around when I am in need" could be interpreted by the adolescent as a teacher, counselor, HCP, boyfriend/girlfriend or any number of significant relationships. The importance for this study is establishing whether or not an adolescent perceives support while facing EOL. It is proposed that adolescents with a higher level of perceived social support will display a higher level of Readiness and therefore engage in EOL preparedness. In addition, it is

proposed that adolescents who perceive a high level of family support and open communication within their family will communicate their EOL Personal Plan with their family. Collecting data on perceived social support from the MSPSS will allow the researcher to determine convergence about support with other sources of evidence during analysis.

The Peaceful Acceptance of Illness Subscale (from: Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE) Scale) (Mack, et al., 2008).

The current conceptual model theorizes Readiness as an antecedent to EOL preparedness. Therefore, theoretically the process of Readiness has to occur to at least some degree, before the adolescent will engage in the process of EOL preparedness. Readiness consists of three attributes: awareness, acceptance, and willingness to take action.

The process of readiness will be qualitatively addressed during the semi-structured interview and quantitatively measured by administering a Peaceful Acceptance of Illness Subscale developed by Mack and colleagues (2008) (Mack, et al., 2008) along with a few items that were specifically developed for this study.

Adolescents who are eligible for the study have already acknowledged their understanding or awareness that their cancer is incurable. The degree of awareness will be further explored during the adolescent interviews.

The Peaceful Acceptance of Illness Subscale will be used to measure the adolescent's emotional acceptance of their incurable prognosis. The Peaceful Acceptance of Illness subscale comes from the PEACE Scale which was developed based on interviews with terminally ill patients, clinical observations and review of the literature (Mack, et al., 2008). The initial scale consisted of 38 potential items that were reduced to 12 items with item to total correlations  $\geq 0.30$ . Items focus on the extent of a patient's acceptance of the cancer diagnosis and the sense of inner peace or struggle that an individual with terminal illness may have. The 12 item PEACE scale was administered to 160 patients (20 years or older) with advanced cancer. The overall internal consistency reliability of the scale was adequate (Cronbach  $\alpha = 0.85$ ). A factor analysis determined 2 subscales, the Peaceful Acceptance of Illness subscale (Cronbach  $\alpha = 0.78$ ) and the Struggle with Illness Subscale (Cronbach  $\alpha = 0.81$ ). The Peaceful Acceptance of Illness

Subscale consists of 5 items which measure the emotional acceptance and inner peace an individual is experiencing despite a terminal cancer diagnosis. The 7-item Struggle with Illness Subscale evaluates the emotions of anger, shame, and embarrassment in relationship to one's cancer condition; and the existential struggle of accepting a terminal cancer diagnosis. Total subscale scores were inversely correlated ( $r = -0.54$ ;  $p < 0.0001$ ) (Mack, et al., 2008).

For the current study, only the 5-item Peaceful Acceptance of Illness Subscale will be used to measure acceptance, an attribute of readiness. The subscale is listed below and the PEACE scale in its entirety is included in the appendix.

Peaceful Acceptance of Illness Subscale:

1. To what extent are you able to accept your diagnosis of cancer?
2. To what extent would you say you have a sense of inner peace and harmony?
3. To what extent do you feel that you have made peace with your illness?
4. Do you feel well-loved now?
5. To what extent do you feel a sense of inner calm and tranquility?

Responses are measured by a 4-point Likert-type scale (1 = not at all; 2 = to a slight extent; 3 = to some extent; 4 = to a large extent).

#### Willingness to Take Action

Three questions were developed for this study to assess an adolescent's willingness to take action to prepare for the physical, emotional and/or spiritual aspects of EOL. The following questions address willingness to take action to prepare for EOL:

1. How willing are you to discuss your concerns with a parent or HCP about what will happen as your cancer progresses?
2. How willing are you to talk about your feelings of grief or sadness with a parent or HCP?
3. Do you want to find out more about what will be happening as your cancer progresses?

A 4-point Likert-type scale is used for response (1 = not at all; 2 = to a slight extent; 3 = to some extent; 4 = to a large extent). By collecting information on awareness, acceptance and willingness to take action to prepare for EOL, the researcher will get an overall understanding of the level of Readiness to prepare for EOL.

## QUAL-E

The QUAL-E is an instrument that will be used to measure an adolescent's perceived QOL at EOL. Steinhauser et al. have conducted numerous studies on QOL at EOL (Steinhauser, 2005; Steinhauser, Bosworth, et al., 2002; Steinhauser, et al., 2001; Steinhauser, Christakis, et al., 2000; Steinhauser, et al., 2004; Steinhauser, Clipp, et al., 2006; Steinhauser, Clipp, et al., 2000; Steinhauser, Clipp, & Tulskey, 2002; Steinhauser, Voils, et al., 2006). The QUAL-E was developed based on focus group interviews and a national survey conducted with dying patients, family members and health care professionals to determine what factors are important at the end of life. Psychometric properties of the QUAL-E demonstrate acceptable reliability and validity and consistent performance across diverse demographic samples. Test-retest reliability determined stability over a 1 week period. A copy of the instrument is found in the appendix.

This 25-item measurement scale has 4 domains: *Life Completion* ( $\alpha$  0.80); *Symptoms Impact* ( $\alpha$  0.87); *Relationship with HCP* ( $\alpha$  0.71); and *Preparation for End of Life* ( $\alpha$  0.68). The QUAL-E was developed to measure QOL at EOL in patients with a variety of advanced illness trajectories across multiple care settings (i.e. hospice, palliative care, or inpatient hospital settings), who may or may not define themselves as terminally ill. This instrument will measure the adolescent's subjective experience of factors that are important for a good death. The 4 subscales represented in the QUAL-E are:

1. Life Completion subscale: assesses one's interpersonal contributions to others, the ability to help others or make a difference in life. It also includes the experience of meaning and peace.
2. Symptom Impact subscale: assesses an individual's symptom severity and the level of concern about their identified symptoms. Each individual identifies symptoms that are most problematic for him/her.
3. Relationship with the HCP subscale: assesses how well an individual is known as a person. It includes knowing what to expect and participation in decision-making as well as level of control over EOL decisions

4. Preparation Subscale: assesses an individual's concern about becoming a burden; perception of family preparation for EOL; as well as reflection of life regrets. It taps more into the aspect of resolution or peace about death.

Although the QUAL-E was developed based on studies conducted in the adult population, there are several pediatric studies which validate children, adolescents and their families have similar concerns that contribute to overall quality of life at the end of life (Hendrickson & McCorkle, 2008; Howell & Brazil, 2005). Detailed information from pediatric studies about EOL issues is found in the review of literature in Chapter Two.

#### *Direct Observation*

Direct observation will involve documenting the adolescent's environment and interactions with family members or HCPs at time of qualitative interviews. Direct observation is another source of evidence and will be documented through field notes. Field notes may record physical details of non-verbal communication or details about the social context of observational episodes. Field notes may be briefly jotted down on the spot, but should be expanded upon as soon as possible after the encounter (Munhall, 2007). Yin (2009) points out that since case studies take place in a natural setting opportunities for direct observation are automatically created. Observational evidence becomes an additional source of information providing useful data about the phenomenon of inquiry (R. Yin, 2009). Direct observation will occur with each face to face contact with the adolescent.

#### *Medical Record*

Evidence will be collected through a medical record review. The medical record will contain information about diagnosis; prognosis; physician conversations; plan of treatment; psychosocial issues; demographic information; recent hospitalizations; medications, etc. The medical record is considered a legal document. Data will be used to confirm other sources of information, or to supplement information that may be missing in the current case. Table 8 and Table 9 provide data collection guides that will be used while gathering data from direct observation and the adolescent's medical record.

Table 8: Demographic & Environmental Characteristics Flow Sheet.

<b>Demographic Characteristics</b>	<b>Case # _____ ID # _____</b>
<i>Current Age</i>	
<i>Sex</i>	
<i>Education</i>	Last grade complete in school: Current grade:
<i>Disease Status</i>	
<ul style="list-style-type: none"> <li>• Diagnosis</li> </ul>	Specific type of Cancer: Stage:
<ul style="list-style-type: none"> <li>• Date of diagnosis</li> </ul>	
<ul style="list-style-type: none"> <li>• Age at diagnosis</li> </ul>	
<ul style="list-style-type: none"> <li>• Original Prognosis</li> </ul>	
<ul style="list-style-type: none"> <li>• Current Prognosis</li> </ul>	
<ul style="list-style-type: none"> <li>• Length of Cancer Experience</li> </ul>	(measured from diagnosis to current time point)
<ul style="list-style-type: none"> <li>• Date of Stem Cell Transplant if Applicable</li> </ul>	
<ul style="list-style-type: none"> <li>• Date of Relapse(s) if applicable</li> </ul>	
<ul style="list-style-type: none"> <li>• Date of Remission if applicable</li> </ul>	
<ul style="list-style-type: none"> <li>• Date of documentation of refractory disease if applicable</li> </ul>	
<ul style="list-style-type: none"> <li>• Treatment Regimen</li> </ul>	Copy of Treatment Protocol: Any Change in Protocol:
<ul style="list-style-type: none"> <li>• Approx. date of transition from curative focus to Palliative/EOL Care Focus</li> </ul>	
<i>Race:</i>	
<i>Ethnicity</i>	
<b>Environmental characteristics</b>	
<i>Place of Care</i>	
<ul style="list-style-type: none"> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Describe adolescent environment; if adolescent is home-bound, where does he/she spend most of time (living quarters)
<i>Staff</i>	
<ul style="list-style-type: none"> <li>• Primary MD</li> </ul>	
<ul style="list-style-type: none"> <li>• Primary RNs</li> </ul>	

<ul style="list-style-type: none"> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> If adolescent has any Healthcare provider interactions around the time of the interview (homecare or clinic personnel), they will be described.
<ul style="list-style-type: none"> <li>• Continuity of Staff</li> </ul>	
<ul style="list-style-type: none"> <li>• New Staff</li> </ul>	Date initiated: (i.e. homecare or hospice staff)
<i>Initial EOL Discussion-</i>	Initial date: Individuals present: Person leading discussion: Focus of Conversation:
- Follow-up discussions	Dates: Individuals present: Person leading discussion: Focus of conversation:
- Follow-up discussions	Dates: Individuals present: Person leading discussion: Focus of conversation:
<i>Advance Directives and/or Do Not Resuscitate (DNR)</i>	Date: Person leading discussion:

Table 9: Personal & Family Characteristics Flow Sheet.

<b>Personal Characteristics</b>	Case # _____ ID # _____
<i>Physical Functioning</i>	<b>See EFAT 2 Results</b>
<ul style="list-style-type: none"> <li>• Medical Record documentation <ul style="list-style-type: none"> <li>- Medication used to manage symptoms</li> <li>- Non-pharmacological measures to manage symptoms</li> </ul> </li> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Document facial expressions-smiling versus grimacing etc.
<i>Psychosocial Functioning</i>	<b>See EFAT 2 Results:</b>
<ul style="list-style-type: none"> <li>• Medical Record documentation <ul style="list-style-type: none"> <li>- Medication used to manage symptoms</li> <li>- Non-pharmacological measures to manage symptoms</li> </ul> </li> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Document engagement in conversations, mood, affect, etc.
<i>Decisional Control Preferences</i>	<b>See Control Preferences Scale (CPS) Results:</b>
<b>Family Characteristics</b>	
<i>Family Support</i>	<b>See MSPSS Family subscale:</b>
<ul style="list-style-type: none"> <li>• Medical Record documentation <ul style="list-style-type: none"> <li>- Psychosocial issues that may impact family documented in medical record</li> <li>- Documentation of how issues were addressed per review of medical record</li> </ul> </li> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Describe family interactions; physical or emotional support displayed; amount of time spent together, where adolescent spends most of his/her time in relation to the family etc.
<i>Family Communication</i>	<b>MSPSS item:</b> <i>I can talk about my problems with my family</i>
<ul style="list-style-type: none"> <li>• Medical Record documentation <ul style="list-style-type: none"> <li>- Details in medical record about prognostic and other EOL discussions re: perception of family communication</li> </ul> </li> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Describe family communication; tone of voice when communicating; body language; intimacy of conversation, etc.

<i>Family Cultural Practices</i>	
<ul style="list-style-type: none"> <li>• Medical Record documentation</li> </ul>	
<ul style="list-style-type: none"> <li>- Details in medical record that document cultural practices or beliefs (generally this is only recorded regarding use of blood products)</li> </ul>	
<ul style="list-style-type: none"> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Describe symbols or visible artifacts in living quarters representing cultural beliefs or practices.
<i>Family Spiritual Practices</i>	
<ul style="list-style-type: none"> <li>• Medical Record documentation</li> </ul>	
<ul style="list-style-type: none"> <li>- Details in medical record that document spiritual practices or beliefs- sometimes identified under religious affiliation on chart</li> </ul>	
<ul style="list-style-type: none"> <li>• Direct Observation</li> </ul>	<b>Field Notes:</b> Describe symbols or visible artifacts in living quarters representing spiritual beliefs or practices.

In summary, sources of evidence in this case study will come from multiple sources (qualitative interviews, quantitative measures, information from the adolescent's medical record, physical and/or cultural artifacts, and direct observation). Multiple sources of evidence will collectively provide the data needed for analysis.

#### *Procedure*

Adolescents who meet eligibility criteria will be provided with information about the study along with informed consent if the adolescent is 18 years or older. For adolescents 14 - 17 years old information will be provided along with informed assent and informed consent of one parent. After consent/assent is obtained the adolescent will be enrolled in the study. The current explanatory case study will consist of two adolescent cases. Baseline data will be collected at the time of consent. Multiple measures will be collected at two additional time points. Each case will generate sufficient data to make generalizations to theoretical propositions. Limiting the number of cases is a necessary part of the current design since extensive data collection will be done on each case.

#### *Confidentiality*

No personal identification will be included with the data. A study ID will be assigned to each case. Data in print form will be kept in a locked file, separate from subject names or identifiable information. Electronic data will be secured on a password protected computer system with access limited to study principal investigator and student investigator. The Case Study Database which will include all of the raw data (field notes, transcribed and de-identified interviews, flow sheets, analysis tables, quantitative data, narratives, etc.) will be kept in one location and securely filed to protect participant confidentiality. Reliability of the Case Study is enhanced by having the raw data that leads to the study conclusions readily available (R. Yin, 2009).

#### *Data Collection Procedures*

The following section provides detailed information on data collection procedures. This is particularly important to assure consistency across cases and thereby increase reliability in multiple-case study research (R. Yin, 2009). A well organized process encourages systematic inquiry which is central to case study method (Gangeness & Yurkovich, 2006).

*Baseline Data at Time of Consent*

Data collection will begin after informed consent/assent. The participant ID number will be placed on top of each form. The adolescent will be asked to fill out a self-reported demographic sheet (Table 10); the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, et al., 1990); and a measure of Readiness. Readiness consists of the Peaceful Acceptance of Illness Subscale (Mack, et al., 2008) (5 items) and Willingness to Take Action Questionnaire (3 items). The Control Preferences Scale (CPS) (Degner, Sloan, et al., 1997) will be administered through a card-sorting procedure as outlined in Section Two, to determine adolescent's preferred role in participatory decision-making.

Table 10: Adolescent Self-Reported Demographics.

<b>Baseline Demographics Self-Report</b> Case # _____ ID # _____
Please confirm the following information:
1. Current Age: _____
2. Sex: _____
3. Education: Last grade completed in School _____; Current Grade _____
4. Age at Diagnosis: _____
5. Race: _____
6. Primary Doctor: _____
7. Primary Nurses: _____

After baseline data collection measures are obtained, an interview appointment will be scheduled (Time 1). The interview will occur approximately one week after baseline data is collected and consent is obtained. Prior to Time 1 the researcher will review the adolescent's medical record to increase knowledge on the adolescent's case. This may be helpful during the semi-structured interview. Information from the medical record will provide demographic, environmental, personal and family characteristics which will be added to other sources of data to provide additional evidence to substantiate findings. The Demographic & Environmental Characteristics Flow Sheet and Personal & Family Characteristics Flow sheet will guide the medical records review. See Tables 8 and 9.

#### *Time 1 Data Collection*

Multiple sources of evidence will be collected at baseline and one week later at Time 1. Each time the researcher meets with the adolescent, direct observation will be used to assimilate non-verbal information about the adolescent, his/her environment, and significant relationships. The main source of information at Time 1 will be the qualitative interview.

At Time 1, prior to the interview, physical and psychosocial functioning will be measured by the EFAT 2 (Kaasa & Wessel, 2001). This will assure the adolescent's functioning is not adversely affected by physical or psychosocial symptom distress making it difficult for the adolescent to participate in a research study. The EFAT-2 measures an adolescent's ability to communicate; their mental status; motivation; ADL; pain; dyspnea; and fatigue. GI Distress will also be measured. If any physical or psychosocial symptom described on the EFAT-2 interferes moderately or severely with an adolescent's daily functioning, the adolescent will not be a candidate for continuation in the EOL preparedness multiple-case study. The attending physician will be notified of reported physical and/or psychosocial distress symptoms that are moderate or severe.

Once adequate functional status is determined, a semi-structured interview with the adolescent will be conducted. The interview will address the components within the conceptual model. This includes information on Readiness, EOL preparedness and demographic, environmental, personal and family characteristics. Interviews will be conducted at a place that is convenient and comfortable for the adolescent. This could be

at the adolescent's home or a designated quiet area at the oncology clinic. All interviews will be audio recorded and transcribed verbatim. The text will be de-identified prior to analysis; (specific names of individuals, i.e. family members, physicians, nurses, etc. will be removed and replaced with pseudonyms). At the completion of the interview, as a token of appreciation, the adolescent will be given a \$25 gift card.

A second interview (Time 2) will be scheduled approximately one month after the initial interview. Data from Time 1 for each case will be analyzed prior to Time 2. Analysis between Time 1 and Time 2 will allow the investigator to tailor the structured interview questions prior to the second interview in an attempt to fill knowledge gaps while advancing theoretical understanding of how time influences the EOL preparedness phenomenon.

#### *Time 2 Data Collection*

Time 2 will provide the opportunity to once again, examine multiple sources of evidence to advance theoretical understanding of the EOL preparedness phenomenon, particularly in relationship to time. If EOL preparedness is indeed a dynamic process that evolves over time, theoretically one should see an increase in preparedness as time passes. Specific quantitative measures will be re-examined at Time 2 and include the EFAT 2 (Kaasa & Wessel, 2001) to assess physical and psychosocial functioning; quantitative measures on the process of Readiness will be repeated to see if there is a change over time (including the Peaceful Acceptance of Illness Subscale (Mack, et al., 2008) and willingness to take action items).

Updated information on Personal & Family Characteristics as well as Demographic & Environmental Characteristics will be collected via chart review and direct observation to provide additional evidence to substantiate findings.

A second semi-structured interview with each adolescent will be conducted at Time 2 to address the components within the conceptual model. This includes information on Readiness, EOL preparedness and characteristics that may influence how the adolescent prepares for EOL (Demographic & Environmental Characteristics; and Personal & Family Characteristics). The researcher will specifically assess for changes in Readiness and EOL preparedness over time.

At the end of the interview, information will be collected on the outcomes of the study including communication of personal EOL plan and QOL at EOL. Quality of life will also be measured quantitatively by the QUAL-E (Steinhauser, et al., 2004). At the completion of Time 2, as a token of appreciation, the adolescent will be given a \$25 gift card. Types of measurement used at each time interval are listed in Table 11.

Table 11: Overview of Measures and Time Interval.

	<b>Consent</b>	<b>1 Week Later</b>	<b>1 Month Later</b>
<b>Quantitative Measurement</b>	<b>Baseline Data</b>	<b>Time 1</b>	<b>Time 2</b>
Physical & Psychosocial Functioning (EFAT-2)		X	X
Decisional Control Preferences (CPS)	X		
Social and Family Support (MSPSS)	X		
Assessing Readiness (PEACE)	X		X
Quality of Life (QUAL-E)			X
<b>Qualitative Interview</b>		<b>Time 1</b>	<b>Time 2</b>
Semi-Structured Interview		X	X
<b>Other Sources of Evidence</b>		<b>Time 1</b>	<b>Time 2</b>
Demographic Self-Report	X		
Medical Records Review	X	X	X
Direct Observation/Field Notes	X	X	X

## SECTION THREE: ANALYSIS

### Overview

The following section is devoted to analysis. It includes triangulation of data, content analysis and pattern matching as strategies for understanding the data that is collected. Analysis will begin with a Single Case at Time 1 and progress to the Single Case Report which examines within case changes across time. Once this is done for both Case 1 and Case 2, the two cases will be compared for similarities and differences across cases. The overall goal in analysis of a case study is to establish inferences about the case (Gangeness & Yurkovich, 2006). In the current case study inferences will be made about the EOL preparedness phenomenon in adolescents with incurable cancer.

Organizing the data is an important first step in analysis. Since multiple sources of evidence will be collected, the researcher will need to examine the evidence, categorize and recombine both quantitative and qualitative evidence to address the case study propositions. There are several ways that data can be analyzed in case study research. Unfortunately there are few fixed formulas that can be applied to analysis. Instead, much depends on gathering sufficient evidence from multiple sources and rigorously contemplating how the empirical findings are theoretically linked (R. Yin, 2009). Sufficient presentation of evidence that conceptually links the findings to the theory, while carefully considering alternative interpretations, is the key to successful analysis. Yin (2009) makes the analogy that presenting one's empirical findings from a case study is like telling a story. Every research study has a story to tell. There is a beginning, middle, and an end. However, without a strategy the story will never be crafted. In case study research an analytic strategy helps the researcher to treat evidence fairly, while producing compelling analytic conclusions, and ruling out alternative interpretations (R. Yin, 2009).

Although Yin (2009) sites four general strategies, the most preferred analytic strategy relies on theoretical propositions (R. Yin, 2009). Propositions provide a theoretical orientation to guide the case study analysis. The analysis section of this chapter will describe how the investigator will apply specific analytic techniques while relying on case study propositions to interpret findings for: 1) individual cases, 2) cases across time, and finally 3) for comparison across multiple cases.

### *Triangulation of Data*

First before analytic strategies such as pattern matching can be applied to the data one must corroborate the findings. A major strength of case study data collection is obtaining many different sources of evidence. The purpose of collecting data with multiple sources of evidence is to show the development of converging lines of inquiry. In other words, showing how each source of evidence supports the same fact or event within the case. This is also known as data triangulation. For example, if chart documentation and direct observation support what was discussed in the interview, this increases the reliability of the finding. Data triangulation addresses construct validity by showing how multiple sources of evidence provide multiple measures of the same construct within the theoretical model (R. Yin, 2009).

### *Content Analysis*

Qualitative data will be analyzed before it is added to the triangulation of other data. Content analysis breaks down the data into the categories that make logical sense within the conceptual model. Deductive content analysis is the method that will be used for qualitative analysis in this study. Content analysis has a long history of use not only in nursing research but in other health disciplines such as psychology, sociology, and communication (Elo & Kyngas, 2008). Content analysis is a flexible approach that is content-sensitive, which makes it particularly appealing for the current Case Study design.

There are two primary approaches to content analysis. The first approach is inductive, or as Hsieh and Shannon (2005) has described it, the “conventional” approach. Researchers use this approach to describe a phenomenon when there has not been enough former knowledge about the phenomenon. Sometimes the inductive or conventional approach is used to develop a better understanding of a phenomenon or to define a concept being studied. Words are grouped together to form categories which help to formulate the meaning of a construct or phenomenon (Hsieh & Shannon, 2005).

Deductive content analysis is the second approach to content analysis. When a conceptual model or theory already exists, the researcher may wish to analyze the qualitative interview using a deductive approach (Elo & Kyngas, 2008). Hsieh and Shannon (2005) refer to this as a directed content analysis (Hsieh & Shannon, 2005). In

deductive content analysis, theory directs the approach to interview questions, study design, and analysis. The goal for deductive content analysis is to conceptually extend a theoretical framework, or to validate the existing theory (Elo & Kyngas, 2008; Hsieh & Shannon, 2005).

The structured interview questions for this study follow the constructs within the conceptual model. Thus, each construct provides the initial coding scheme based on theory or prior research. This is displayed in the Table 12. Notice in Table 12 there is an “other” category. Data that are coded as “other” will allow the researcher to examine the data from the interview that could not be coded with the preexisting theoretical codes. The primary investigator and student investigator will determine if the data represents a new category or an additional subcategory of an existing code. An inductive approach may be necessary when new categories are identified.

Table 12: Categorization Framework for Deductive Content Analysis.

Characteristics	Readiness	EOL Preparedness	Communication of Plan	QOL at EOL	Other
Demographic	Awareness	Knowledge about EOL	To Parent(s)	Life Completion	
Environmental	Acceptance	Acknowledgement of Grief & Emotions	To HCP	Symptom Impact	
Personal	Willingness to Take Action	Identification of the Meaning of Death & Spirituality		Relationship with HCP	
Family		Conceptualization of Plan		Preparation	
Other	Other	Other	Other	Other	

### *Trustworthiness*

Deductive Content analysis requires the same accountability as other forms of qualitative research for establishing trustworthiness. In qualitative research the terms credibility and dependability are two words used to describe specific ways that trustworthiness is achieved (Graneheim & Lundman, 2004). These terms are very similar to validity and reliability; terms commonly used in quantitative methods of research.

### *Credibility*

To establish credibility of findings, a researcher should have confidence that the focus of the study matches the data that is collected. The process of analysis should also match the intended focus (Graneheim & Lundman, 2004). For the current study, the interview questions are designed to follow the constructs of the EOL preparedness conceptual model. The deductive approach to content analysis links the data back to the theory. During data collection, probing becomes an invaluable tool for assuring credibility of the data by allowing the participant to clarify the meaning of a response that may be in question (Barriball & While, 1994). Selecting participants who are willing to discuss their experiences of facing EOL also contributes to the credibility of findings.

Similar to other qualitative methods content analysis requires the researcher to be immersed in the data by reading it through several times to become completely familiar with the participant's words and their meanings thus obtaining a sense of the whole (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Sandelowski, 1995).

Selecting relevant data that represents each category is important while analyzing the content of the interview. There may be times when the text is not interpreted the same way by each researcher since interpretation is subjective. Therefore, dialogue between the student investigator and principal investigator (PI) will be ongoing during the analysis process. The intent will be not only to verify the coding of the text, but also to determine whether other researchers and experts would agree with how the data is sorted and labeled (Graneheim & Lundman, 2004). Representative quotes from the transcribed text also help to establish credibility of findings.

### *Dependability*

Another aspect of trustworthiness in qualitative research is dependability (Graneheim & Lundman, 2004). For the current study, dependability will be enhanced by

using the conceptual definitions to code the data to the constructs in the model. The student investigator will begin coding the data with the predetermined categories that are defined through conceptual definitions, or codes. Any data that cannot be coded will be highlighted as “other” and analyzed later (Hsieh & Shannon, 2005). Decisions will then be made as to how data will be coded when it does not fit into a predetermined category. The student investigator and PI will collectively determine if the data represents a new category or a subcategory of an existing code. Theory will be used to guide discussion of findings. Discussion promotes dependability of the newly identified categories (Graneheim & Lundman, 2004).

In summary, content analysis is the method of analysis that will be used to analyze the semi-structured interviews. Data will be coded according to predetermined constructs within the conceptual model and placed into a categorization framework. See Table 12. Procedures are put in place to assure trustworthiness of analysis.

*Single Case Report: (C1) and (C2)*

Interview data will be added to other sources of data for triangulation of results. Each case will be analyzed first individually and then across time. The overall strategy that will be used for this multiple-case study analysis is pattern matching. Propositions will guide the data analysis of single case reports and cross case reports. Each of the constructs of the model will be assessed in light of each proposition after triangulating the evidence.

Certain sources of evidence will be easier to categorize than others. Flow sheets will assist the collection of demographic, environmental, personal, and family characteristics (i.e. Table 8 and Table 9). In addition, results from quantitative measures will be placed with the corresponding construct within the model. Lastly, codes or meaning units derived from content analysis of the semi-structured interviews will be grouped with the corresponding construct within the model. Empty table shells will provide a framework for data analysis as displayed in Table 13. Empty Table shells will also help with construct validity by establishing a chain of evidence that links the source of data to the construct within the conceptual model.

Table 13: Empty Table Shells for Triangulation of Data in Single Case Reports.

Corroboration	Characteristics	Readiness	EOL Preparedness	Plan	QOL at EOL
	Demographic	Awareness	Knowledge about EOL		
Source of data					
Source of data					
Source of data					
	Environmental	Acceptance	Acknowledgement of Grief & Emotions		
Source of data					
Source of data					
Source of data					
	Personal	Willingness to Take Action	Identification of the Meaning of Death & Spirituality		
Source of data					
Source of data					
Source of data					
	Family		Conceptualization of Plan		
Source of data					
Source of data					
Source of data					

### *Propositions for Single Case Report (C1 and C2)*

The next step will be to examine the data collected on the constructs of the conceptual model in light of the theoretical propositions. This will be done through a process known as pattern matching. In the current case study, a specific type of pattern matching called explanation building will be used. The goal during data analysis is to build an explanation about the case (R. Yin, 2009). This is done by stipulating a presumed set of causal links. The links in this study are stipulated by the propositions. Through an iterative process, a gradual building of patterns will emerge to explain how and why constructs within the model are related.

#### **Proposition One:**

Contextual factors (*demographic, environmental, personal and family characteristics*) will be related to Readiness, (*awareness, acceptance, and willingness to take action*); EOL preparedness, (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); and communication of personal plan.

#### **CASE QUESTIONS**

##### *Demographic & Environmental Characteristics*

1. How will initial prognosis relate to Readiness, EOL preparedness, and communication of personal plan?
2. How will refractory disease relate to Readiness, EOL preparedness, and communication of personal plan?
3. How will length of cancer experience relate to Readiness, EOL preparedness, and communication of personal plan?
4. How will treatment regimen relate to Readiness, EOL preparedness, and communication of personal plan?
5. How will length of time since transitioning from curative focus to palliative/EOL care focus relate to Readiness, EOL preparedness, and communication of personal plan?
6. How will other disease status characteristics relate to Readiness, EOL preparedness, and communication of personal plan?

7. How will race and/or ethnicity relate to Readiness, EOL preparedness, and communication of personal plan?
8. How will continuity of staff relate to Readiness, EOL preparedness, and communication of personal plan?
9. How will more education or higher cognitive processing (abstract thinking) relate to Readiness, EOL preparedness, and communication of personal plan?
10. How will living at home with a palliative EOL care focus relate to Readiness, EOL preparedness, and communication of personal plan?
11. How will EOL discussions relate to Readiness, EOL preparedness, and communication of personal plan?

*Personal & Family Characteristics*

12. How will physical functioning relate to Readiness, EOL preparedness, and communication of personal plan?
13. How will psychosocial functioning relate to Readiness, EOL preparedness, and communication of personal plan?
14. How will decisional control preferences relate to Readiness, EOL preparedness, and communication of personal plan?
15. How will family support relate to Readiness, EOL preparedness, and communication of personal plan?
16. How will family communication relate to Readiness, EOL preparedness, and communication of personal plan?
17. How will family cultural practices relate to Readiness, EOL preparedness, and communication of personal plan?
18. How will family spiritual practices relate to Readiness, EOL preparedness, and communication of personal plan?

### **Proposition Two**

Readiness (*awareness, acceptance, and willingness to take action*) precedes EOL preparedness (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*).

#### **CASE QUESTIONS**

1. How are awareness, acceptance and willingness to take action interrelated?
2. Does awareness precede acceptance?
3. Does awareness and acceptance precede willingness to take action?

### **Proposition Three**

EOL preparedness (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) is related to communication of personal plan.

#### **CASE QUESTIONS**

1. How will the process of EOL preparedness relate to the development of a personal plan?
  - a. How will knowledge about EOL relate to the development of a personal plan?
  - b. How will acknowledgement of grief and emotions relate to the development of a personal plan?
  - c. How will identification of the meaning of death and spirituality relate to the development of a personal plan?
  - d. How will conceptualization of a personal plan relate to the development of a personal plan?
2. How will the participation in the process of EOL preparedness relate to communication of personal plan?
  - a. How will knowledge about EOL relate to communication of a personal plan?
  - b. How will acknowledgement of grief and emotions relate to communication of a personal plan?

- c. How will identification of the meaning of death and spirituality relate to communication of a personal plan?
- d. How will conceptualization of a personal plan relate to communication of a personal plan?

**Proposition Four**

End-of-Life preparedness (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) is related to QOL at EOL.

**CASE QUESTIONS**

1. How will knowledge about EOL relate to QOL at EOL?
2. How will acknowledgement of grief and emotions relate to QOL at EOL?
3. How will identification of the meaning of death and spirituality relate to QOL at EOL?
4. How will conceptualization of a personal plan relate to QOL at EOL?

*Writing Single Case Reports*

Single cases (C1 and C2) will be analyzed after data is collected at Time One as described above. A summary report will be written which will show the relationships between the constructs within the model. The propositions will be addressed and the case questions will be answered in the report. Questions that remain unanswered or ambiguous will be highlighted and addressed during the Time 2 data collection and interview.

### *Examining Within Case Changes across Time*

Single cases (C1 and C2) will again be analyzed at Time 2 in the same way they were analyzed at Time 1. However, the researcher will examine how changes in constructs within the conceptual model change across time. A summary report will be written after Time 2 which will include the analysis of individual cases across time. The following proposition will be added to the examination of cases across time.

#### **Proposition Five**

Readiness (*awareness, acceptance, and willingness to take action*); EOL preparedness (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); and communication of personal plan are related to time.

#### **CASE QUESTIONS**

1. How will Readiness change over time?
  - a. How will *awareness* change over time?
  - b. How will *acceptance* change over time?
  - c. How will *willingness to take action* change over time?
2. How will EOL preparedness (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) change over time?
  - a. How will *knowledge about EOL* change over time?
  - b. How will *acknowledgement of grief & emotions* change over time?
  - c. How will *identification of the meaning of death & spirituality* change over time?
  - d. How will *conceptualization of personal plan* change over time?
3. How will communication of personal plan change over time?

### *Cross Case Analyses and Report*

After comparisons are made in each case across time, the final step in analysis will compare within case changes across C1 and C2. This is the main outcome of the study; to look at the relationship of Case 1 to Case 2 over time and to compare what happens. Propositions will guide the data analysis of cross case report again using a pattern matching strategy. Similarities and differences will be examined across cases to determine case conclusions and theoretical implications. Findings will be written in a cross case report and summarized in Chapter 4. The following proposition will guide analyses across cases.

#### **Proposition Six**

The main propositional statement across cases will be: There will be similarities and differences within case changes across C1 and C2.

#### **CASE QUESTIONS**

1. How are Case 1 and Case 2 similar and different at Time 1?
2. How are Case 1 and Case 2 similar and different at Time 2?
3. How are Case 1 and Case 2 similar and different across time?

#### *Reporting Multiple-Case Study Results*

The final step for analysis will be writing the multiple case study results. This will involve synthesizing the findings across cases and across time. Theoretical generalizations regarding EOL preparedness in adolescents with incurable cancer will be drawn. Recommendations about theory modification will also be addressed.

## SECTION FOUR: PROTECTION OF HUMAN SUBJECTS

The final section of the chapter addresses the protection of human subjects. The Health Insurance Portability and Accountability Act (HIPSS), and the Indiana University-Purdue University and Clarian guidelines were followed for this study involving human subjects' research (Olsen, 2003). In addition, since the proposed study involves participants with cancer, the proposal was reviewed by the Scientific Review Committee (SRC) first. Approval from SRC was included with the study submission to IUPUI and Clarian IRB. An example of the informed consent is provided in the appendix.

### *Sample Recruitment*

Recruitment was begun after the study was approved by both SRC and IRB respectively. Participants were recruited respecting HIPAA guidelines. Potential participants were identified by physicians at a pediatric tertiary care center. A referral was made to the researcher who obtained informed consent/assent.

### *Consent/Assent*

Since this research study involves adolescents under the legal age of consent there are unique terms and conditions that are relative to the assent of adolescents and the consent of their parents for participation in research. Broome (1999) describes the developmental considerations for involving children and adolescents in research. These include the need to provide clear descriptions and full disclosure of the research at a developmentally appropriate level (Broome, 1999). During the process of informed consent/assent the adolescent was given detailed information about the study purpose, procedures, risks and benefits of participating in the study. The study was thoroughly explained in a cognitively and developmentally age-appropriate manner.

Participants provided written informed consent if participant age was greater than or equal to 18 years old, and assent for adolescents 14 to 17 years old, with parental consent. The research study does not involve greater than minimal risk to children under the age of 18. Therefore consent by only one parent is adequate. The researcher remained cognizant of the power differential between adolescents and adults (Broome, 1999) and reminded the adolescent of options to withdraw from the study at any time without any questions asked. Confidentiality was maintained and the signed consent/assent forms are stored in a locked cabinet in the School of Nursing.

## CHAPTER 4: RESULTS

### Introduction

This chapter presents the results from the multiple-case study of two cases involving adolescents living with advanced cancer. Multiple sources of data from both qualitative and quantitative sources were collected on the constructs reflected in the conceptual model. Data were collected for each case across 2 times. Data were triangulated to assess the relationships between qualitative and quantitative data. Summaries of each case over time, as well as an overall summary of the association between cases are included in this chapter.

Chapter 4 is divided into three sections. **Section One** presents all of the triangulated data from: 1) Case 1, Time 1 & 2; and 2) Case 2, Time 1 & 2. **Section Two** presents a summary of the analyses for Case 1 at both times and across time; and for Case 2 at both times and across time. **Section Three** describes the cross case analyses of Case 1 and Case 2. Similarities and differences between cases across time are examined. Theoretical generalizations are made with proposed theory modifications.

There are six main propositions, or hypotheses that have guided the data collection and analysis for this study. The propositions are incorporated into the analysis in an effort to explain causal links within the conceptual model that may impact QOL and to expand theoretical understanding of how adolescents living with advanced cancer become ready to address, prepare, and communicate plans for EOL. Propositions 1 through 3 guide the analysis of each case at each time point. Proposition 4 is added to the analyses at Time 2. Proposition 5 guides analysis of the cases across time. And finally, proposition 6 guides analysis of findings across cases. The propositions are repeated here for review.

### *Study Propositions*

- 1. Contextual factors** (*demographic, environmental, personal and family characteristics*) **will be related to Readiness**, (*awareness, acceptance, and willingness to take action*); **EOL preparedness**, (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); **and communication of personal plan.**
- 2. Readiness** (*awareness, acceptance, and willingness to take action*) **precedes EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*).
- 3. EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) **is related to communication of personal plan.**
- 4. EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*) **is related to QOL at EOL.**
- 5. Readiness** (*awareness, acceptance, and willingness to take action*); **EOL preparedness** (*knowledge about EOL, acknowledgement of grief & emotions, identification of the meaning of death & spirituality, and conceptualization of personal plan*); **and communication of personal plan are related to time.**
- 6. There will be similarities and differences within case changes across Case 1 and Case 2.**

## SECTION ONE: PRESENTATION OF DATA

The first section presents all of the data for Case 1 and Case 2. Quantitative and qualitative data are presented for each case for Time 1, then Time 2. Tables are provided to guide the reader with interpretation for each of the constructs in the conceptual model. Tables contain exact data, such as item and mean scores for quantitative measures, information from the medical record review, and exact quotes from the adolescents' interviews. The text in each section summarizes the triangulated data.

Case study method allows researchers to examine a complex phenomenon within a real life context without changing or controlling variables in the study. For the current study, every effort was made to assure positive interactions and support were not disrupted while studying the processes of readiness and EOL preparedness. Contextual factors became part of the study. The context of the current study included demographic, environmental, personal, and family characteristics. In addition, the theoretical constructs are summarized and tables are provided to guide the reader with interpretation of analysis. Qualitative and quantitative data were collected and will be specifically addressed in the analysis section of each case.

### Preparing Data for Triangulation

Qualitative data were collected through semi-structured interviews and analyzed prior to triangulation. Each interview was audio recorded and transcribed verbatim. The transcribed data were coded independently by two researchers using a deductive approach for content analysis as described by Elo and Kyngäs (2008) (Elo & Kyngas, 2008). Content was coded into categories using constructs in the conceptual model. Data that did not fit the conceptual model was coded as "other". Other categories were coded, discussed and agreed upon by two researchers. Content that was coded differently was discussed among the researchers until consensus was reached. The value of dialogue among co-researchers is defended by Graneheim and Lundman (Graneheim & Lundman, 2004). The constructs that were most often coded differently were "knowledge about EOL" and "awareness". Although the "awareness" construct includes a cognitive component (or knowledge) that death is probable, the "knowledge about EOL" construct is an attribute within the EOL preparedness process and specifically addresses education about what to expect physically or emotionally as one is dying. Knowledge about EOL

involves dialogue and may help with pragmatic decisions about advanced directives and preferred location of death. The QSR NVivo 8 software program was used to sort qualitative data into categories, and as a means of tracing codes back to the original text.

Field notes pertaining to each case, and information gathered from the medical record were either hand-written or typed into a Word document. Hand-written notes were scanned into pdf documents. Each case was assigned a case ID, which was placed on all paper documents. Original documents of quantitative data (measures and forms) completed by the adolescents were also scanned into pdf documents and stored in the case study data base on a secure password protected computer. All non-electronic documents containing data for each case are stored in a locked cabinet in the School of Nursing. Any “patient” identifiers have been removed. The names of each adolescent and his/her medical providers or family members have been replaced with pseudonyms. The pseudonym for Case 1 is Cameron. The pseudonym for Case 2 is Jennifer.

Multiple sources of evidence from qualitative and quantitative data were collected and analyzed across time for each case. All electronic data including the recorded and transcribed interviews, qualitative codes in NVivo 8, field notes, information obtained from the medical record reviews, baseline demographics self-report form, quantitative measures pertaining to each adolescent case (including the New Edmonton Functional Assessment Tool, the Multidimensional Scale of Perceived Social Support, the Peaceful Acceptance of Illness Subscale, and the QUAL-E, measuring quality of life in seriously ill patients) are stored in a secure computer database that is password protected. All sources of data for each theoretical construct were grouped together into a table to see where corroboration occurred. Information is presented in table format for each construct at each time point for each Case; and described in the adjacent text. Summaries of the analyses are provided in Section Two.

## Overview of Data Collection at each Time Point

### *Time 1 Data Collection*

Baseline and Time 1 data were collected approximately 1 week apart. This was done to ease the burden of participating in a research study for adolescents with advanced cancer. At baseline, informed consent was obtained and quantitative measures on social support, acceptance of illness and preference for decisional control were collected. A medical record review was done between baseline data collection and the Time 1 interview. At Time 1, functional status was screened prior to a semi-structured interview that lasted approximately 1 hour. Presentation of data at Time 1 includes data collected from baseline, the medical record review after baseline, and data collected at Time 1.

### *Time 2 Data Collection*

Time 2 data were collected approximately 1 month after Time 1. A medical record review was done between Time 1 data collection and Time 2 data collection. Presentation of data from Time 2 includes data collected from the medical record review after Time 1, and the data collected at Time 2. At Time 2, functional status was screened prior to a semi-structured interview that lasted approximately 1 hour. After the interview, quantitative data were collected on acceptance of illness and QOL.

## Overview of Data Presentation

Data are presented for each case at each time point in a similar fashion. Theoretical constructs from the conceptual model provide a framework for the presentation of the data. At Time 1, theoretical constructs include contextual factors, and the processes of readiness and end-of-life preparedness. Contextual factors of the current study include demographic, environmental, personal, and family characteristics. The readiness process includes awareness, acceptance, and willingness to take action or engage in EOL preparedness. And finally, the EOL preparedness process includes knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of a plan

At Time 2, the same theoretical constructs are examined (contextual factors, readiness process, and EOL preparedness process); however, additional data examining QOL and communication of personal plan are collected. A more detailed discussion of

how the data is presented according to each of the theoretical constructs is provided below.

### *Presentation of Data According to Theoretical Constructs*

#### *Context: Demographic Characteristics*

Demographics are one of the contextual factors collected for each case, and include age, sex, education, race, and disease status. Definitions are provided in tables and summarized in the adjacent text at each time point. Current age, age at diagnosis, sex, education, and race were collected from the adolescent using a Baseline Demographics Self-Report Form. This information was confirmed with the medical record review. Disease status was collected on each adolescent and includes information about diagnosis, treatment, response to treatment, length of cancer experience, prognosis, medical tests, and enrollment in Phase 1 clinical trial, if applicable. Quantitative data were obtained from the medical record review and qualitative data from semi-structured interviews.

#### *Context: Environmental Characteristics*

Data collected on environmental characteristics include place of care, focus of care, continuity of staff, and discussions about EOL or incurable prognosis. Qualitative data for environmental characteristics include the semi-structured interview, direct observation, and eligibility criteria, confirmed through contact with attending oncologist and initial contact with adolescent. Quantitative data include information from the medical record review and the baseline demographics self-report form.

#### *Context: Personal Characteristics*

There were four a priori data content areas specified for personal characteristics: decisional control preferences, knowledge preference, physical symptom distress, and psychosocial symptom distress. Another personal characteristic category we interpreted during content analysis of the semi-structured interview was: coping behaviors. This is defined as the adolescent's ways of dealing with the difficult situation of living with advanced cancer. Qualitative data for personal characteristics were derived from the semi-structured interview and direct observation. Quantitative data for this construct were derived from information in the medical record review, the Control Preferences Scale, knowledge preference, and the New Edmonton Functional Assessment Tool (EFAT-2).

### **Decisional Control**

The Control Preferences Scale was used to measure the adolescent's decisional control preference (Degner, Sloan, et al., 1997). Five cards for decisional control were placed in a fixed order presentation (BDCEA). The adolescent was given 2 cards to examine. Both cards had a picture of a doctor and a patient talking. The first card (B), said, "I prefer to make the final selection of my treatment after seriously considering my doctor's opinion". The second card (D), said, "I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion". Each time the adolescent made a selection, another card was provided, to compare to his/her preferred card. This process continues until all 5 cards were examined. According to Degner et al. (1997), a categorical variable can be created based on the person's two most preferred roles: Active-Active (AB, BA), Active-Collaborative (BC), Collaborative-Active (CB), Collaborative-Passive (CD), Passive-Collaborative (DC) and Passive-Passive (DE, ED).

### **Knowledge Preference**

In Degner & Beaton's work on the grounded theory of life-death decision making in 1987 which provided the basis for the control preferences scale, they found that the desire for information is an entirely separate construct from a person's willingness to use information for making choices (Degner, Sloan, et al., 1997). In other words, a person might desire to have as much information as possible, but might prefer to have the physician make the final decisions about care. Knowledge preference for the current study was measured by asking the adolescent to select a preference from five options, ranging from 'I want all possible information' to 'I don't want to know anything'.

### **Physical and Psychosocial Symptom Screening**

Physical and psychosocial symptoms were measured qualitatively by direct observation and the semi-structured interview. Symptoms were measured quantitatively by the medical record review and by questions asked during the symptom distress screening using the New Edmonton Functional Assessment Tool (EFAT-2) (Kaasa & Wessel, 2001). The EFAT-2 globally evaluates physical and psychosocial symptoms that may be interfering with every day function. Physical symptoms that were evaluated include pain, dyspnea, fatigue, mobility, and GI Distress. Impact on daily function is

rated “0”, no impact on function; “1” minimal dysfunction, “2” moderate dysfunction, or “3” severe dysfunction. Scores are determined based on physical assessment and adolescent’s verbal response to questions on each symptom. Communication, mental status, and motivation are also part of the EFAT-2 and were screened in the same way.

#### *Context: Family Characteristics and other Social Support*

There were 3 data content areas specified a priori to measure family characteristics: family and other social support, family communication and family cultural and spiritual practices. Two other categories emerged from the interview that fit within the context of family and social support. The first category is family coping, defined as the adolescent’s perception of how the family is dealing with adolescent’s advanced cancer. The second category addresses things not helpful defined as the adolescent’s perception of words or actions of others that are not beneficial while living with advanced cancer

Qualitative data for family characteristics were derived mainly from the semi-structured interview. Quantitative data were derived from the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, et al., 1990). The MSPSS is a 12 item Likert-type scale that measures perceived social support from 3 main sources: significant other, family and friends. Items are scored from 1 = very strongly disagree to 7 = very strongly agree. Individual items along with the adolescent’s scores are included for each case at Time 1.

#### *The Construct of Readiness*

The theoretical construct of Readiness includes awareness, acceptance, and a willingness to take action to prepare for EOL or engage in discussions about EOL. A summary of the qualitative and quantitative data collected on each of the attributes of readiness are explained in the following paragraphs.

#### *Re-examining the Awareness Construct*

Initially, it was envisioned that the adolescents enrolled in this study along with their physicians would be aware that cure was not possible and death would eventually occur. The initial eligibility criteria were based on the fact that there was an EOL discussion about the incurable prognosis and impending death between the adolescent and his/her physician; and the adolescent could recall and acknowledge that discussion.

However, recruitment was particularly challenging given these criteria. The study was open six months without a single adolescent enrolled. An IRB amendment was filed and approved to change the name of the study, removing “incurable” and “end-of-life” from the study title. The study title is currently “Understanding Quality of Life in Adolescents Living with Advanced Cancer”. In addition, the wording on the consent form was changed from “You are invited to participate in a research study about adolescents living with cancer that *cannot be cured*” to “You are invited to participate in a research study about adolescents living with cancer that *is not* cured. This allows for a certain element of uncertainty. The amendment was approved May 11, 2010 and the first adolescent was approached on June 1<sup>st</sup> and consented June 3<sup>rd</sup>. The second adolescent quickly followed, consenting on July 6, 2010. Due to the change in eligibility criteria, any adolescent can be enrolled that is currently living with advanced cancer that is not cured. Awareness of incurable prognosis does not have to be evident.

Glaser and Strauss in their classic NIH study on awareness of dying conducted in the early 60’s, found cancer patients behave and interact with others based on their awareness context (Glaser & Strauss, 1965). There are four basic awareness contexts. The first is called closed awareness. In this context, the dying individual does not know he/she is dying, although others do, such as healthcare providers and family members. The second context is suspected awareness. In this context, the dying individual suspects he or she is dying and attempts to confirm or refute these suspicions. The third context is mutual pretense. In this context, the dying individual is aware he/she is dying; the healthcare provider or family is also aware, but all agree to act as if the dying individual is going to live. The fourth context is open awareness. Here, the dying individual and others recognize impending death. Individuals operating in the open awareness context, behave accordingly with open communication and behaviors that acknowledge death will eventually occur (Glaser & Strauss, 1965). Glaser and Strauss’ study involved mainly adults and the awareness contexts were sequential. Once individuals progressed to open awareness, they did not revert to other awareness contexts.

In Myra Bluebond-Langner’s work with children and adolescents dying of leukemia, she found that children most often lived in the mutual pretense context. Those who progressed to an open awareness context would often revert back to the mutual

pretense context while dying because of the social cues they received from others (Bluebond-Langner, 1978). Data on awareness were obtained from semi-structured interviews, and coded according to the four awareness contexts of closed, suspected, mutual pretense or open awareness.

#### *Acceptance*

Acceptance was measured qualitatively in the semi-structured interviews and quantitatively using the Peaceful Acceptance of Illness Subscale from the Peace Equanimity and Acceptance in the Cancer Experience (PEACE) Scale (Mack, et al., 2008). The Peaceful Acceptance of Illness Subscale has 5 items that are measured on a scale of 1 to 4 (not at all, to a slight extent, to some extent, to a large extent). Individual item scores and total scores are listed for each case.

#### *Willingness to Take Action*

The third component of the Readiness construct is willingness to take action to prepare for EOL or engage in discussions about EOL. Willingness was measured by 3 items that were asked during the interview. The adolescent was asked the following three questions:

- 1) How willing are you to discuss your concerns, or things you are worried about?
- 2) How willing are you to discuss your feelings, or the things that make you sad or afraid?
- 3) How willing are you to find out more about what will be happening if your cancer progresses?

Items were measured on a scale of 1 to 4 (not at all, to a slight extent, to some extent, to a large extent). For the first 2 items, the adolescent was asked to rate their responses for a family member and a HCP.

### *The Construct of End-of-Life Preparedness*

End-of-life preparedness is defined as a process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end of life consistent with his/her desires. This involves acquiring knowledge about EOL, acknowledging grief and emotions, identifying the meaning of death and spirituality, and conceptualizing an EOL plan. All data for the EOL preparedness construct were obtained from the semi-structured interviews.

#### *Data Collected at Time 2 Only*

Additional data was collected at Time 2 on two constructs: communication of EOL personal plan, and QOL. It is hypothesized that the process of EOL preparedness, will result in communication of the adolescent's EOL personal plan with his/her family and caregivers, and result in a satisfactory quality of life at the end of life.

#### *Communication of Plan*

Communication of an EOL personal plan is defined as the adolescent's written or verbal expression about a conceptualized plan which includes goals/priorities, and EOL preferences. This data was collected during the semi-structured interview.

#### *Quality of Life at the End of Life*

Quality of life at the end of life is defined as the adolescent's subjective estimation of the quality of symptom control, relationships with others, meaningfulness of life, and resolution of impending death. This construct was measured quantitatively by the QUAL-E (Steinhauser, et al., 2004), and qualitatively from content derived from the interview. The QUAL-E is a 25-item Likert-type scale that measures the subjective experience of factors that were found to be important for a good death (Steinhauser, Bosworth, et al., 2002; Steinhauser, Christakis, et al., 2000; Steinhauser, et al., 2004). The QUAL-E has 4 subscales symptom impact, relationship with health care system, preparation, and life completion. In addition there are global items for each of the subscale constructs and an overall global QOL item. The QUAL-E was developed to measure QOL at EOL in patients with a variety of advanced illness trajectories across multiple care settings (i.e. hospice, palliative care, or inpatient hospital settings), who may or may not define themselves as terminally ill. Individual items as well as item and subscale scores are included for each case.

## CASE 1: CAMERON

This section will present the findings from Case 1. The adolescent's pseudonym is Cameron and his physician's pseudonym is Dr. Smith. A medical overview is provided as an introduction to Cameron's case. Triangulated data analyses are reported for each of the main theoretical constructs first for Time 1, then Time 2.

### *Case 1: Cameron's Medical Overview*

Cameron is a 15 year old African-American male who is a freshman in high school at the time of this study. He self identifies his race as black. He considers Dr. Smith, a physician at an outlying hospital to be his primary doctor. Cameron was diagnosed with lung cancer on February 4, 2008 at the age of 13. A lung biopsy confirmed metastatic bilateral carcinoid tumors of the lungs on March 17, 2008. No definitive primary tumor was found and his tumors were unresectable. This type of cancer is very rare in the pediatric population so Dr. Smith consulted with adult carcinoid tumor experts to explore treatment options. Initially, Cameron was treated with Avastin (bevacizumab) and temozolomide for four months. He received Sandstatin (octreotide) briefly, but it was discontinued. Cameron's tumors continued to grow despite treatment. He began treatment with Cisplatin, alternating with Adriamycin (doxorubicin) and VP-16 (etoposide), in the Spring of 2009. His last chemotherapy was given in December of 2009. Cameron's total doxorubicin dose was 175 mg/m<sup>2</sup>. The risk of developing life threatening heart damage such as congestive heart failure, dilated cardiomyopathy or death, dramatically increases when the cumulative total dose of doxorubicin reaches 550 mg/m<sup>2</sup>. An echocardiogram in January of 2010 showed mildly elevated pulmonary artery pressures but normal systolic function, and an ejection fraction of 75%.

In May of 2010, scans revealed the tumors were essentially unchanged. Since Cameron did not respond to any standard treatment, adult tumor experts recommended: 1) IMRT or cyberknife (radiation) as a possible palliative measure, or 2) Everolimus as a possible chemotherapy option, as some safety studies had been conducted. Dr. Smith also explored other Phase 1 clinical trials which were discussed with Cameron and his family. On May 18, 2010, Cameron began the Phase 1 clinical trial ADVL 0911, NTX-010. This trial involved the one time infusion of the Seneca Valley Virus as a possible oncolytic virus (Morton, 2010). Since most people have not contracted the Seneca Valley Virus and

it is excreted through body fluids, namely feces; Cameron had to stay out of school until the virus was cleared. He traveled to clinic weekly, where he was put into contact isolation for his follow-up appointments. His stool samples were checked and labs were drawn weekly, until it was confirmed that the virus cleared on June 15, 2010.

Cameron's scans showed minimal response to the Seneca Valley Virus trial, with no new pulmonary lesions. On June 28, 2010, a discussion about therapeutic options was documented by his physician. Cameron was then started on another Phase 1 study of an oral small molecule inhibitor of gamma-secretase.

Cameron was identified as a possible candidate for the current study by his physician. I was given the contact information and approached Cameron and his grandmother for possible inclusion in the current study on June 1, 2010, during one of his follow-up clinic appointments. His grandmother is his legal guardian. After explaining the purpose of the study, along with the risks and benefits, I encouraged Cameron to think about it and talk it over with his grandmother. I followed up with a phone call 24 hours later and Cameron verbally agreed to participate. Written consent/assent was obtained on June 3<sup>rd</sup> at his home and baseline measures were collected. His first interview (Time 1) was conducted a week later on June 10<sup>th</sup>. The final data collection (Time 2) occurred one month later on July 8, 2010. There was a marked difference in Cameron's fatigue level, and dyspnea between Time 1 and Time 2. After the Seneca Valley virus had cleared at Time 2, Cameron seemed much more alert, able to stay focused and engaged during the interview, and had less shortness of breath.

Other pertinent medical history includes cachexia. Cameron weighs 25.9 kilograms or approximately 57 pounds and is 148 centimeters tall, or just under 5 feet. He had normal growth and development until age 9 when he started losing weight. He was also diagnosed with scoliosis at that time. Despite a gastrostomy tube placement for supplemental feedings, he failed to gain weight. In 2005, at the age of 10, Cameron spent a month in the hospital for failure to thrive, pain disorder (including lower extremity and abdominal pain) and rectoanal sphincter dysfunction. His home situation was complex. The Department of Child Services became involved prior to diagnosis of cancer. Shortly after discharge from hospital in 2005, Cameron was placed in foster care by Child Protective Services for child battery and neglect. In 2006, his grandmother assumed legal

guardianship. In 2007, at the age of 12, prior to Cameron's cancer diagnosis, a Harrington Rod was placed for scoliosis. Subsequent scans of the chest in February 2008 revealed metastatic lung cancer.

*Case 1: Cameron's Baseline and Time 1 Data*

*Summary of Context: Demographic Characteristics*

Demographic characteristics data and definitions for Case 1 Time 1 are provided in Table 14, Context: Demographic Characteristics, and summarized in the following text. Demographic data reported on the Demographics Self-Report Form were confirmed in the medical record review. Cameron self-identifies as a 15 year old black male. He is old enough to understand his disease process, is an exceptional student in school, and interested in art. Cameron has been battling advanced cancer for two years with only slow progression of his disease. Additionally, Cameron has been dealing with chronic illness since age 9, with a complex home situation which led to his grandmother becoming his legal guardian.

Cameron recognizes the seriousness of his disease and describes the impact of living with advanced cancer. Two main themes emerged in Cameron's first interview pertaining to living with advanced cancer: 1) living with advanced cancer impacts normal activities, and 2) living with advanced cancer strengthens an individual's character.

Cameron recognizes that living with advanced cancer is hard and interferes with his ability to do normal activities like playing sports and hanging out with his friends. He feels he has missed out on his childhood because of all the time he has spent in the hospital. Sometimes he also feels socially isolated from his family, because he is "cooped up" in the house, rather than outside with his brothers and sisters.

Cameron acknowledges that living with advanced cancer strengthens his character. He views himself as stronger, more focused, and more appreciative of life, family, friends and school, because of his cancer experience. Cameron recognizes that it is hard making friends when you are sick; so he strives hard to cherish and hold onto the friends that he has. Cameron's cancer experience helps him to have a broader perspective on life. His disease status helps him to see the world in a different way. For example, he values going to school and gaining knowledge through education; and strives to do his very best.

**Case 1 Time 1**

**Table 14: Context Demographic Characteristics.**

<b>Definition</b>	<b>Data</b>
<p><i>Demographics</i></p> <ul style="list-style-type: none"> <li>• <b>Age:</b> Defined as life interval of adolescent</li> <li>• <b>Sex:</b> Defined as the classification of an individual into an exclusive group of male or female based on typical reproductive function</li> <li>• <b>Education:</b> Defined as level of formal schooling an adolescent has received</li> <li>• <b>Race:</b> Defined as adolescent’s perception of belonging to a distinct group of the human population distinguishable from others based on shared biological traits</li> <li>• <b>Disease Status:</b> Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness</li> </ul>	<p>Quantitative Data</p> <p><b>Baseline Demographics Self-Report Form</b></p> <ul style="list-style-type: none"> <li>• Current age: 15 years old</li> <li>• Age at diagnosis: 13 years old</li> <li>• Sex: Male</li> <li>• Education last grade completed: 9<sup>th</sup> Grade</li> <li>• Race: Black</li> </ul>
	<p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <p><i>Age, Sex, Race, Education</i></p> <ul style="list-style-type: none"> <li>• Above information confirmed with medical record</li> <li>• Documented in medical record- “straight A student and an artist”</li> <li>• Religion: Baptist</li> </ul> <p><i>Disease Status</i></p> <ul style="list-style-type: none"> <li>• Diagnosis: Refractory carcinoid tumor of the lungs</li> <li>• Date of Diagnosis: February 4, 2008</li> <li>• Age at diagnosis: 13 years old</li> <li>• Original Prognosis: Unresectable metastatic carcinoid tumor of the lungs, no primary site found</li> <li>• Current Prognosis: Slow progressive disease, not cured by any standard treatment</li> <li>• Length of cancer experience: (Time since diagnosis to entrance in QOL study) 2 years 4 months</li> <li>• Refractory disease since diagnosis</li> <li>• Treatment Regimen: March 2008 – Avastin &amp; temozolomide Spring 2009 – Cisplatin, alternating with doxorubicin &amp; etoposide</li> <li>• Lung Biopsy 3/17/2008</li> <li>• Chemotherapy started 3/17/2008</li> <li>• Date of last chemotherapy treatment: December 2009</li> <li>• Phase 1 clinical trial (Experimental Therapy) <ul style="list-style-type: none"> <li>- <b>ADVLO911</b>, A Phase I Dose Escalation Study of Seneca Valley Virus (NTX·OI0), A Replication-Competent Picornavirus, in Relapsed/Refractory Pediatric Patients with Neuroblastoma, Rhabdomyosarcoma, or Rare Tumors with Neuroendocrine Features (Infusion of Seneca Valley Virus) 5-18-2010</li> </ul> </li> </ul>

Definition	Data
	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><b>Disease Status:</b>  When I first got cancer...I was in the hospital and it was March 17<sup>th</sup> that's the day I had my lung biopsy.</p> <p>LIVING WITH ADVANCED CANCER: AFFECTS NORMALCY</p> <p><i>CB - I'm very interested in knowing what it's like for you being an adolescent or teenager that has cancer that is advanced. So would you please start by telling me what it's like to be a 15 year old guy living with advanced cancer?</i></p> <p>Mmmn, It's hard, er. It's hard cause like I've been sick since I was a little kid. And umm like I really didn't have a childhood cause a lot of stuff, Uh, I was in the hospital a lot. I missed out on a lot of stuff 'cause I was sick. I didn't get to play sports or play with my brothers and stuff. So it's, it's hard but... Yeah it's, it's hard. It is <i>not</i> easy... I mean, I'm, I'm makin' it though, so.</p> <p><i>CB - What are the biggest ways you think it affects you?</i></p> <p>Don't get to hang out and do stuff with my friends and stuff. I'm always cooped up in the house, 'cause I'm not feeling good and nothin', and that hurts me a lot. I'd rather be, I'd rather be out doin' stuff outside with my brothers and sisters.</p> <p>LIVING WITH ADVANCED CANCER: STRENGTHENS CHARACTER</p> <p><i>CB- Do you think the type of cancer or how serious it is, has that helped to prepare you in any way for just dealing with what you have to deal with today?</i></p> <p>Yeah I think it makes me stronger, as a person. And makes me able to deal with a lot more stuff and makes me more appreciative of a lot of stuff; makes me not take stuff for granted. And yeah I think it does help me see the world in a different way. See stuff in a different way and not just be one-minded. I see stuff in different ways, yeah.</p>

Definition	Data
	<p data-bbox="740 235 1435 296"><i>CB-What are the ways that you see the world differently? Can you explain that a little bit better?</i></p> <p data-bbox="834 331 1435 800">Like, with school, most kids they really don't like school, you know? They really don't care for their grades and stuff, but for me I love school and I love bein' in school any chance I get. I was mad when school was cancelled because I only got to go to school like three days a week and when it was cancelled on a day I'm supposed to go, that's just one less day I get to go to school. Most kids would be happy! And I really do care about my grades and when I get bad grades I get mad at myself and try to do better. So I try to motivate myself to study to keep my grades up and stuff, just for me, just because I know that the grades are important.</p> <p data-bbox="740 835 1435 932"><i>CB-What are some of the things you appreciate or you feel like you appreciate that perhaps you wouldn't be so aware of, if you didn't have this serious cancer?</i></p> <p data-bbox="834 968 1435 1064">Life! Family. Like, friends. Like it's hard making friends when you sick so when you do get a good friend you try, you try to hold on to 'em, yeah.</p>

### *Summary of Context: Environmental Characteristics*

Environmental characteristics data and definitions for Case 1 Time 1 are provided in Table 15, Context: Environmental Characteristics on page 149, and summarized in the following text.

#### **Place of Care**

Cameron lives at home but was making trips to the tertiary care outpatient center twice a week for participation in a Phase 1 clinical trial. In addition, his involvement in the Phase 1 clinical trial limited his attendance at school until the virus was cleared.

#### **Focus of Care**

Medical records document Cameron's cancer was unable to be cured by standard therapy. It was also noted that the Phase 1 clinical trial was experimental in nature. Cameron views his cancer as chronic and serious, but at this time point, does not openly acknowledge it is life-threatening. He understands his cancer is unchanged, however, he believes the doctors are trying to figure out how to get rid of it, implying a "curative" intent to treatment.

#### **Continuity of Care**

Cameron identified his primary doctor and nurse on the baseline demographic self-report form. The physician and nurse identified were from the outlying hospital. Cameron's medical record review confirms Dr. Smith (pseudonym) is the primary oncologist. In addition, an attending oncologist and pediatric oncology fellow are identified from the tertiary care center. Cameron mentions Dr. Smith fondly during the interview. Dr. Smith continues to be involved with Cameron's care and provides support within his local community.

#### **Initial and Ongoing End-of-Life Discussions**

Part of the eligibility criteria for enrollment in this study includes acknowledgment by the physician and Cameron that his cancer is not cured. The signed informed consent/assent for the Phase 1 clinical trial describes the treatment as "experimental" since "there is not a standard treatment for your cancer at this point". However, there was no documentation about ongoing discussions regarding incurable prognosis or EOL issues between Cameron and any of his healthcare providers.

In summary, Cameron is living with advanced cancer at home with frequent outpatient visits to a tertiary care center where he is undergoing experimental cancer treatment. Although he recognizes his advanced cancer has not improved, he believes physicians are still attempting to cure or “get rid of” his cancer. Cameron has continuity of care from Dr. Smith even though he is undergoing a Phase 1 clinical trial at the tertiary care center. Cameron did not mention initial or ongoing discussions about his incurable prognosis or EOL issues.

**Case 1 Time 1**

**Table 15: Context Environmental Characteristics.**

<b>Definition</b>	<b>Data</b>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Place of Care:</b> Defined as environment where adolescent is living with advanced and incurable cancer</li> </ul>	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• Interviews were conducted at the adolescent’s home. He lives with his maternal grandmother, maternal great aunt, and siblings. The home is a one story ranch with attached garage, in obvious need of repairs, and located in an impoverished neighborhood. The environment was clean, however, the air smelled of stale cigarette smoke. Plastic frames were used to hang pictures on the wall. There was a large picture of President Obama in the Living Room and some ebony wood sculptures of African-American women. A large table lined one wall with a bright red tablecloth and several wood chairs along three sides. The interview was conducted in a small back room that had one loveseat. A large frame with the hand-written words “My Family” hung on the wall with several small photos of children and grand-children. Another frame contained a newspaper article, yellowed with time, displaying Cameron’s grandmother’s grandfather who lived to be 122 years old. Windows were open to circulate air through the house.</li> </ul> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Living with grandmother and maternal great aunt</li> <li>• May attend school after virus is cleared through documented blood sample and stool sample</li> <li>• Clinic appointments at tertiary care center two times a week for current Phase 1 clinical trial</li> </ul>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care:</b> Defined as adolescent’s perception of specific purpose for care delivery</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>(The Cancer)</i> It’s been the same; it hasn’t changed dramatically or nothin’. It’s still the same size and they stopped it from growing but it’s still there. And they tryin’ to figure out how to get rid of it.</p> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Cancer unable to be cured by standard therapy</li> <li>• Phase 1 clinical trials (Experimental Therapy) <ul style="list-style-type: none"> <li>- Infusion of Seneca Valley Virus 5-18-2010</li> <li>- <b>ADV L0919</b> Phase 1 study of R04929097</li> </ul> </li> </ul>

<b>Definition</b>	<b>Data</b>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Continuity of Staff:</b>            Defined as continuation of familiar nursing and medical staff while transitioning to end of life         </li> </ul>	<p>Quantitative Data</p> <p><b>Baseline Demographics Self-Report Form</b></p> <ul style="list-style-type: none"> <li>Adolescent identified physician and nurse from outlying hospital as primary doctor and nurse</li> </ul>
	<p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>Physician from outlying hospital was identified as the primary oncologist in the medical record.</li> <li>In addition an Attending pediatric oncologist and pediatric oncology fellow from the tertiary care center were identified in the medical record as the primary physicians for the Phase 1 clinical trial.</li> </ul>
	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>I am pretty close with <i>Dr. Smith</i> too.</p> <p>Just being there like the doctors and stuff they be, they there you know</p>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Initial EOL Discussion:</b>            Defined as a conversation between physician and adolescent (and his/her family) about impending death or incurable prognosis.         </li> <li> <b>Ongoing EOL Discussions:</b> Defined as ongoing discussions between physician and adolescent or adolescent and his/her family about death or EOL issues         </li> </ul>	<p>Qualitative Data</p> <p><b>Eligibility Criteria</b></p> <ul style="list-style-type: none"> <li>Cameron verbally acknowledged his cancer is currently not cured, prior to consent</li> <li>Attending Oncologist referred adolescent to current study based on incurable status</li> </ul> <p><b>Interview</b></p> <ul style="list-style-type: none"> <li>No mention of initial or ongoing EOL discussions during the interview</li> </ul>
	<p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>Signed informed consent states the clinical trial is “experimental” and “there is not a standard treatment for your cancer at this point”</li> <li>There was no documentation of ongoing discussion about EOL issues</li> </ul>

### *Summary of Context: Personal Characteristics*

Personal characteristics data and definitions for Case 1 Time 1 are provided in Table 16, Context: Personal Characteristics on page 155, and summarized in the following text.

#### **Decisional Control Preferences**

Preference for decisional control was determined qualitatively by the semi-structured interview. Cameron takes ownership of his body and wants to be actively involved in his treatment. He appreciates knowing the specifics of his cancer treatment. He also appreciates the honest communication of his physicians, even when the news might be difficult to hear. Cameron's preference for decisional control was confirmed by the Control Preferences Scale (Degner, Sloan, et al., 1997). Cameron's top choices were BC, indicating an Active-Collaborative preference for decisional control.

#### **Knowledge Preference**

For knowledge preference, Cameron selected "I want all possible information, good news and bad news". Cameron prefers all information about his condition and also wants to actively collaborate with his physicians about the treatment decisions. Quotes from the semi-structured interview support Cameron's desire to know what to expect because he hates being uninformed. He particularly appreciates how Dr. Smith treats him as a young adult who deserves to know what is happening.

#### **Physical Symptom Distress**

At Time 1, EFAT-2 screening revealed Cameron had minimal dysfunction for pain and fatigue, moderate dysfunction for dyspnea, and no impact on function for GI distress. However, Cameron's symptoms for pain, fatigue, and dyspnea appeared to worsen as the interview progressed. The following paragraphs describe the symptoms in more detail.

##### Pain

During the EFAT-2 screening, Cameron stated his pain is controlled adequately with current medication. The medical record review showed he is on a continuous morphine drip at 4 mg/hr with the option of having 1.5 mg every 10 minutes if needed. Cameron's pump was inside of a backpack with a patient controlled analgesia (PCA) button readily available if he needed it. However, during the interview Cameron had one

episode of acute pain where he had to stop talking and take several deep breaths, but he quickly stated that he was okay. He pressed the PCA button a couple of times during the interview. He also mentioned he gets headaches.

In the medical record review, physician's described Cameron's pain as getting worse over the past several months since chemotherapy stopped; however, the pain in his shoulder has improved with the continuous morphine drip. During the interview, Cameron mentions pain a few times in relation to socializing with others and needing social support. For Cameron, pain interferes with his desire to interact with others. He mentions how some of the volunteers at the hospital would want to come in and talk, but when he was in pain, he sometimes preferred to be left alone. At the same time, Cameron acknowledges the need for social support while coping with pain. He is very thankful for the support of his grandmother.

### Fatigue

Fatigue minimally interferes with daily function according to the EFAT-2 screening. Cameron stated he needed to rest but less than 50% of his day. The medical record review revealed a noticeable decrease in energy over the past few months. During the interview, direct observation was used to measure fatigue qualitatively. Cameron kept his eyes closed for most of the interview. At first, when Cameron was talking with his eyes closed, his voice was also a little shaky. I tried to interpret his actions to determine if he was closing his eyes because of the difficult nature of the discussion, and the fact that I did not know him very well. He spoke slowly at times and his speech was also intermittently garbled. He was thoughtful about his answers, and I tried to give him the pauses that he needed to articulate his thoughts and feelings. Toward the end of the interview, the long pauses also contributed to his dozing off. Cameron denied being too tired and agreed to let me know if he needed to stop to rest. But as time went on, it appeared he required more effort and concentration to articulate his responses, so I decided it would be best to end the interview and gather additional information at the next interview. At the end of the interview, Cameron said his eyes were closed because the light was bothering his head. My overall impression was that he really wanted to stay involved in the study.

### Shortness of Breath

Cameron is not on any oxygen however, during the EFAT-2 screening he had to take 2 breaths while counting slowing to 15. This shows dyspnea is interfering with Cameron's daily function. In the medical record review, his episodes of shortness of breath were documented as being most noticeable during changes in temperature. Qualitatively, direct observation was used during the interview to measure dyspnea. He had occasional nasal flaring that was most noticeable when he talked for prolonged periods of time. At times he would also force air out while talking.

### Cachexia

Cachexia was described in the medical record and through direct observation. Cameron has the elongated face of an adolescent with larger hands and feet in proportion to his body. For baseline measures and informed consent, we sat on wooden chairs at the dining room table. Cameron was uncomfortable due to the wasting of his muscles and bony prominences along his spine. He asked his grandmother to bring him a small pillow which he hung on the back of the chair. As previously mentioned, Cameron weighs only 57 pounds and is 58 inches tall. He has a hypermetabolic state due to the advanced cancer and despite supplemental gastrostomy tube feedings of over 2000 calories per night he barely maintains his weight. He is on Megace to stimulate his appetite which seems to help with his oral intake during the day. Cameron's grandmother is his primary caregiver and helps with medications, doctor visits, and supplemental feedings at night. His Karnofsky score is 60%. The Karnofsky Performance Scale Index classifies patients according to functional impairment. Lower Karnofsky scores indicate worse performance and less chance for survival with most serious illnesses.

### **Psychosocial Symptom Distress**

Psychosocial symptom distress was measured with the EFAT-2 screening motivation. Although Cameron is not able to participate in all activities due to the limitations of his advanced cancer, he was able to participate in activities more than 50% of the time. He is illustrating a book that he has written. His sketches are cartoon characters all done with colored pencils. Cameron is proud of his book and is a very good artist. The psychosocial symptom that came up qualitatively during the interview was fear of the unknown. Not knowing what to expect is frightening for Cameron.

## **Coping Behaviors**

Coping behaviors was not in the original model but emerged as a theme in the qualitative analysis of Cameron's interview. Cameron used coping skills to deal with his pain. Drawing was an effective method of diversion. Secondly, he felt having time alone, without social interaction, was helpful. Having a positive mindset was another helpful way of coping with advanced cancer for Cameron. He credits his grandmother for helping him to focus on positive thoughts. And finally, Cameron found that talking was a helpful way to cope with his condition. Dr. Smith, his grandmother and teachers were the individuals Cameron felt comfortable talking to. Talking provided stress release. Open communication is an important part of social support and is also covered in the next section on family characteristics.

In summary, Cameron desires a participatory role in decisions about his care. He appreciates honest conversations that inform him about his cancer treatment. He prefers to have all information about his condition both good news and bad. Cameron has physical and psychosocial symptoms that interfere with daily living; most notably pain, shortness of breath, fatigue and fear of the unknown. Cameron has found ways to cope with advanced cancer by keeping his mind off of his pain, using diversion, and focusing on the positive. Dr. Smith and Cameron's grandmother play an active role in helping Cameron by keeping him involved in his treatment decisions and listening to him when he needs to talk. The interview for Time 1 was particularly challenging because of the physical symptom distress that Cameron was experiencing as the interview continued. The initial screening showed minimal dysfunction which progressed during the interview, resulting in fatigue. Due to Cameron's advanced cancer, he was having some pain that required intermittent doses of self-administered IV Morphine. As the interview progressed, Cameron had more difficulty staying alert and focused. Initially, I was trying to tease out the effect of discussing an emotionally laden topic with Cameron versus his physical symptom distress. Clearly, he wholeheartedly desired to participate in the interview; however, his physical symptoms interfered with his ability to stay engaged, so we wrapped up our discussion.

Case 1 Time 1

Table 16: Context Personal Characteristics.

Definition	Data
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Decisional Control Preferences:</b> Defined as adolescent's preferred level of involvement in decisions about care and treatment </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>'Cause I like to know what's goin' on with myself yeah, I mean, it's my body and I would like to know. I just don't wanna be a guinea pig who's doin' all these tests and stuff and not know what the test is and what it's going to do to me and stuff. I like to know how the test's gonna affect me and stuff and so yeah, I do like to be involved with my doctors and stuff.</p> <p>Like the doctors and stuff they be, they there you know, they talk to me when I don't understand stuff and they actually keep me involved with my treatment and stuff they don't just keep me in the dark about stuff 'cause they afraid of how I'm gonna react or afraid of like I'm not going to be able to handle it and that helps a lot too.</p> <hr/> <p>Quantitative Data</p> <p><b>Tool- Control Preferences Scale (CPS)</b></p> <p><b>Preference for involvement in decisions: Active-Collaborative Role</b></p> <p>Cameron's top preferences were:</p> <ol style="list-style-type: none"> <li>I prefer to make the final decision about my treatment after seriously considering my doctor's opinion</li> <li>I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</li> </ol>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Knowledge Preference:</b> Defined as adolescent's desire for information related to their disease and prognosis </li> </ul>	<p>Quantitative Data</p> <p><b>Knowledge Preference</b></p> <p><i>5 options given- ranging from "I want all information good and bad" to "I don't want to know anything at all"</i></p> <ul style="list-style-type: none"> <li> <b>Choice:</b> I want all possible information (Good News and Bad News) </li> </ul> <hr/> <p>Qualitative Data</p> <p><b>Interview</b></p> <p>Every time before I start a new treatment or a test I don't know nothing about, they always sit me down and tell me what to expect and what's gonna go on and what they're gonna do and what I'm gonna do and how stuff's gonna go down; and that's a big help for me, you know, just knowin' what's gonna happen and stuff. Cause I hate bein' put in the dark.</p>

Definition	Data
	<p>He (<i>Dr. Smith</i>) didn't look at me as a little kid. He looked at me as a young adult that needs to know what's goin' on with himself so that helps. That helped a lot.</p>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Physical Symptom Distress:</b> Defined as perceived physical symptoms that interfere moderately or severely with daily activities</li> </ul>	<p>Qualitative Data  <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Pain</b> <ul style="list-style-type: none"> <li>- Used Patient Controlled Anesthesia (PCA) button on portable pump during interview</li> <li>- Facial grimacing; took several deep breaths with eyes closed; appeared to be in some sort of acute pain at one point, but stated he was ok</li> </ul> </li> </ul> <p>Qualitative Data  <b>Direct Observation during Interview</b></p> <ul style="list-style-type: none"> <li>• <b>Fatigue</b> <ul style="list-style-type: none"> <li>- At times during interview, Cameron was talking slowly; eyes closed, speech a little garbled</li> <li>- At another point, Cameron closed his eyes and his head tilted down toward chest, there was a long pause and finally I called his name to ask if he was ok.</li> </ul> </li> </ul> <p><i>CB-Are you getting too tired?</i>  Cameron- I'm fine.  <i>CB-You're okay?</i>  Cameron- Yeah.  <i>CB-Alright, you tell me if we need to stop okay?</i>  Cameron- I will.</p> <ul style="list-style-type: none"> <li>- Much effort and concentration toward end of interview to articulate responses; I determined it best to end the interview and gather additional information at the next interview</li> </ul> <p>Qualitative Data  <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Shortness of breath</b> <ul style="list-style-type: none"> <li>- Intermittent shortness of breath while talking with nasal flaring noted.</li> <li>- Talked with eyes closed throughout most of the interview</li> <li>- At times forced air out while talking</li> </ul> </li> </ul> <p>Qualitative Data  <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Cachexia</b> <ul style="list-style-type: none"> <li>- Thin and frail</li> <li>- Face elongated; larger hands and feet</li> </ul> </li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>- Wasting of muscles</li> <li>- Bony prominences caused discomfort while sitting on wooden chair during informed consent process. Cameron asked his grandmother for a small pillow to hang on the back of the chair.</li> </ul> <p>Qualitative Data</p> <p><b>Interview</b></p> <p><b>Pain</b></p> <p>Like it's a big thing like when they sick or at the moment if they're not feeling good it's good to just leave them alone and let them deal with <i>however</i> they deal with their pain. Some people like to be alone and not like talk or like just be left alone, and some people don't get that. That holds a lot for me.</p> <p>REFERENCE TO GRANDMOTHER</p> <p>You, you gonna need somebody there for you...the pain, you-you just gonna, you gonna get negative and the pain gonna get too much and you gonna wanna just quit.</p> <p>I get headaches and stuff and the light is in my eyes and messing me up...</p> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• <b>Pain</b> <ul style="list-style-type: none"> <li>- Described pain as worse over past several months since chemo stopped</li> <li>- Pain in Right shoulder improved with continuous Morphine</li> <li>- No actual chest pain, most likely referred pain from tumor adjacent to pleura</li> <li>- Pain in lower back never resolved but not a problem currently</li> <li>- PCA pain medication: Morphine 1mg/1ml concentration [Basal rate 4 mg per hour; Bolus 1.5 mg every 10 minutes as needed]</li> </ul> </li> <li>• <b>Fatigue</b> <ul style="list-style-type: none"> <li>- Decreased energy over past few months</li> </ul> </li> <li>• <b>Shortness of breath</b> <ul style="list-style-type: none"> <li>- Episodes of shortness of breath, most noticeable in changes of temperature</li> </ul> </li> <li>• <b>Cachexia</b> <ul style="list-style-type: none"> <li>- Weight 25.9 Kilograms or 57 pounds</li> <li>- Height 148 centimeters or 58 inches</li> <li>- Hypermetabolic state</li> </ul> </li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>- Medications: <ul style="list-style-type: none"> <li>▪ Megace 120 mg prn helps increase appetite for oral foods</li> <li>▪ Zofran 8mg prn; Phenergan 12.5 mg prn for nausea</li> </ul> </li> <li>- Supplemental feedings per gastrostomy tube at night: Resource Just For Kids 1.5 (2130 calories per day)</li> <li>• <b>Karnofsky Score = 60%</b></li> <li>- Requires occasional assistance but is able to care for most of his personal needs</li> </ul> <p>Quantitative Data  <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li>• Pain: Minimal dysfunction (pain controlled with current medication)</li> <li>• Dyspnea: Moderate dysfunction (2 breaths while counting to 10, and shortness of breath on exertion or when talking at length; no use of oxygen)</li> <li>• Fatigue: Minimal dysfunction (rests &lt; 50% of day)</li> <li>• GI Distress: No impact on function (Cameron states he is not having any nausea, vomiting, diarrhea or constipation issues)</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Psychosocial Symptom Distress:</b> Defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities</li> </ul>	<p>Qualitative Data  <b>Interview</b>  <i>Fear</i></p> <p>Yeah, that's the scary part for me...Not knowing what's goin' to happen</p> <p>Quantitative Data  <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li>• Motivation: Minimal dysfunction (participates in activities &gt; 50% of the time)</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Coping Behaviors:</b> Defined as ways of dealing with the difficult situation of living with advanced cancer</li> </ul>	<p>Qualitative Data  <b>Interview</b></p> <p>HAVING TIME ALONE</p> <p>Some people like to be alone and not like talk or like just be left alone, and some people don't get that. That holds a lot for me.</p> <p>DRAWING</p> <p>Drawing helps me a lot too. It helps me keep my mind off the pain and stuff. That's why I like to draw, it can keep me busy.</p>

Definition	Data
	<p data-bbox="735 233 959 258">POSITIVE MINDSET</p> <p data-bbox="829 264 1430 730">Another thing is staying positive. Not lettin' people, like if you think you gonna be sick then you gonna be sick but like when the doctors say something like, 'Oh, this chemo is gonna make you feel bad' and stuff like that; it might make you feel bad but don't have that mindset of me getting chemo, I'm supposed to feel bad just because the doctor said this. You wanna stay positive and say, 'Well I might not feel as bad as the doctors think I am'. So I just stay positive. Like if you think you gonna feel sick then you think you gonna feel sick. If think you gonna throw up, then you gonna throw up; so you better not think like that and just, just stay positive.</p> <p data-bbox="829 768 1308 793">...and staying positive...that helps me...</p> <p data-bbox="735 835 971 861">TALKING ABOUT IT</p> <p data-bbox="829 867 1430 1031">If you don't get it off your chest and keep it in your mind, you'll keep getting madder and madder until you do something you'll regret. And so most of the time after you talk to somebody you cool down or you felt better.</p> <p data-bbox="829 1068 1382 1165">And that's what helps me a lot was when my grandma talks to me and keep me positive, and stuff like that.</p> <p data-bbox="829 1203 1430 1499">And the teachers at my school too, they pretty supportive too and I can talk to some of, most of my teachers I can sit down and talk to. And they try to keep me positive...so it's good to be close to some people that you can sit down and just let everything out. And not worry about how they gonna think about you or about what, or about how you gotta say stuff and you're not gonna offend nobody by what you say or how you feel and stuff.</p>

### *Summary of Context: Family and Social Support Characteristics*

Family characteristics data and definitions for Case 1 Time 1 are provided in Table 17, Context: Family Characteristics, and summarized in the following text.

#### **Family and Other Social Support**

Cameron perceives a great deal of social support, particularly from his grandmother and Dr. Smith. Sources of support that emerged during the interview include not only his family and HCPs, but other hospital staff, teachers from his school, and friends within his community. There is some overlap in social support and other contextual factors that have already been discussed, such as continuity of care, decisional control and coping behaviors (talking to others). Social support includes being present through the process of living with advanced cancer. It also includes open communication between the adolescent and his/her primary social support systems. Therefore separating social support from these other constructs was difficult.

#### Family Social Support

The main sources of family support that Cameron mentions during the Time 1 interview are his grandmother and his brother Trent (pseudonym). Cameron only mentioned his mother one time briefly while discussing people who brought him food prior to his cancer diagnosis during a prolonged hospitalization. Cameron describes his grandmother as the one who honestly spoke to him at diagnosis and remains a constant source of support as he lives with advanced cancer. His grandmother keeps him focused and helps him maintain a positive attitude. She coordinates social support from Cameron's school.

Cameron's younger brother Trent shares his cancer journey by going each year to a week-long camp for children and adolescents with cancer. One family member is allowed to accompany the child or adolescent diagnosed with cancer and Cameron chose Trent. Trent and Cameron have developed friendships at camp and look forward to camp each year.

The MSPSS measures Cameron's social support. On the family support subscale the mean score was 6.75 on a scale of 1 to 7. Higher scores indicate more perceived support. Cameron's quantitative score for family support matches his perception of support evident in the Time 1 interview.

### HCP and Hospital Staff Social Support

Cameron perceives social support from both his nurses and doctors. This support is particularly evident to Cameron when his HCPs keep him informed about his disease and what to expect with cancer treatments. For Cameron, being informed facilitates a participatory role in decision-making and helps to foster trust with his primary HCP, Dr. Smith. Cameron feels Dr. Smith's support because he is a constant presence through his cancer journey, and communicates openly with Cameron, respecting his right to know what is happening.

Other hospital personnel who are mentioned as sources of social support include child life, social workers, and hospital volunteers. Cameron formed relationships with staff and volunteers during his prolonged hospitalization. They brought him food from local restaurants since they were aware he really did not like the hospital food.

### Teacher and School Social Support

The teachers from school are another source of social support. They are aware of Cameron's situation and are updated on his condition each year. This allows Cameron to talk to his teachers and receive their support as he lives with advanced cancer.

The MSPSS has a subscale that quantitatively measures social support from a significant other. This can be anyone the adolescent identifies. The mean score for Cameron's significant other subscale was 6.75. This corresponds with Cameron's comments during the interview about social support from his teachers, Dr. Smith, and other HCPs, volunteers, and hospital staff.

### Community and Friend Social Support

Cameron identifies friends within his community and from camp as a source of social support. He recognizes the difficulty of making friends when you're sick, and the value of holding on to the friendships he develops. Although Cameron could not identify one particular friend, he did share there are many friends within his community that offer support. Most of the friends he feels comfortable talking to are adults from school or camp. He talks about their ongoing investment in him, by taking the time to hang out, or go to the movies. They provide the opportunity for Cameron to share his thoughts or feelings on a deeper level. Social support from friends was measured quantitatively with the MSPSS friend subscale. Cameron's mean score for the friend subscale was 6.75.

Overall, Cameron's perceived social support was evenly disbursed across all subscales with a total score of 6.75.

### **Family Communication**

Communication impacts social support. This was evident in HCP communication, as well as communication between Cameron and his grandmother. Cameron acknowledges talking is helpful in processing feelings, such as anger that can build up.

Family communication was measured by the semi-structured interview and by direct observation of verbal and non-verbal cues between Cameron and his grandmother; and quantitatively by examining one item on the MSPSS: "I can talk about my problems with my family". Cameron rated this item a 6 on a scale of 1 to 7. On this item Cameron strongly agrees he is able to talk about problems with his family.

Cameron vividly recalls the date of his lung biopsy in 2008, and the sequence of events that followed after the doctor entered his room. Although Cameron believes his doctor was afraid to share the bad news with him, he is thankful for his grandmother's honesty from the very beginning.

Cameron's relationship with his grandmother was evident while observing not only their interactions, but also their communication in the clinic, and in their home at baseline, and at Time 1. Mutual respect and courtesy were displayed. Cameron's grandmother allowed him to make the final decision about participating in the current study, but once he had decided, she wholeheartedly encouraged him to open up and talk to me. She told him not to be afraid to say whatever he wanted to say. She placed her hand on his shoulder and she had warmth in her eyes and in her smile. Even in that brief encounter, I could sense the comfort and security that Cameron felt.

### **Family Cultural and Spiritual Practices**

Cultural, ethnic, spiritual, or religious practices may influence how an individual or family approaches advanced cancer or faces death. Cultural and spiritual practices were collected qualitatively during the interview and by direct observation of cultural or spiritual artifacts. Cameron acknowledges his spiritual belief in God. He credits his grandma for keeping him in church. Cameron's belief in God and his religious practices of going to church and reading his Bible are a source of strength for him. Additionally, the first time I met Cameron in his home he wore a silver-plated cross around his neck.

## **Family Coping**

Family coping was an “other” category that emerged during the adolescents’ interviews. It is defined as an adolescent’s perception of how family members or social support system are dealing with the adolescent’s advanced cancer. Cameron perceives the important people in his life are handling his advanced cancer very well, and he finds that helpful.

## **Things Not Helpful from Others**

During the interviews, adolescents identified things that were not helpful from others. I have included a category that addresses “things not helpful from others” in this section, because it seemed to be a logical fit. “Things not helpful from others” is defined as words or actions of others that are not beneficial, as perceived by the adolescent living with advanced cancer. One of the things perceived as not beneficial involves a threat to the adolescent’s independence. Cameron had a difficult time articulating this in the first interview, but it becomes clearer at Time 2. Doing something for the adolescent when he or she is capable of doing it for himself/herself is a threat to independence.

In summary, Cameron perceives a great deal of social support from his family, particularly his grandmother, and from others, such as his doctors, nurses, hospital personnel, teachers, and friends within his community. Social support is conveyed to Cameron by “being there”, openly and honestly communicating, allowing Cameron to be actively involved in his cancer treatment and decisions about his care, sharing life experiences, listening when Cameron needs to talk, and respecting the person that he is.

Open communication provides support and facilitates trust. Cameron credits his grandmother for keeping him positive, focused, and in church. His Christian faith provides a source of strength as he lives with advanced cancer. Cameron perceives his social support system is not experiencing distress from his illness and that is helpful. When others try to interfere with his independence it is not helpful. Although there was conceptual overlap across some of the environmental, personal and family characteristics, they are all part of the context. The context includes human relationships and interactions between the adolescent, his/her family, health care system, and extended community.

Case 1 Time 1

Table 17: Context Family and Social Support Characteristics.

Definition	Data
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family and Other Social Support:</b> Defined as adolescent's perception of family and other sources of encouragement, support, and help during difficult times           </li> </ul>	<p><b>Interview</b></p> <p>FAMILY SOCIAL SUPPORT</p> <p>My Grandma. I think she keeps me positive and keep me in church and keepin' my head straight. And other family members, and my friends and like the nurses and stuff, they so nice and supportive. They help me through stuff.</p> <p>Yeah, it's important to have somebody there for you cause I don't think I would be able to make it if I didn't have my grandma. I don't think, if I didn't have nobody there for me, like my grandma, I would've been, I don't know what; I would've did something bad to myself or somethin' ...I, I, You can't make it by yourself. You, you gonna need somebody there for you and if you don't, you gonna end up killin' yourself or something or like you gonna end up tryin' trying to commit suicide or tryin' to hurt yourself or tryin' to do something cause you can't; the pain, you-you just gonna, you gonna get negative and the pain gonna get too much and you gonna wanna just quit. (pause) So I'm, I'm kinda happy and I'm glad that I got my grandma...</p> <p>And I was just lookin' out over the crowd and I started lookin' at my little brother that was sittin' up front.</p> <p>Yeah (<i>Camp</i>), it's for cancer kids and they get to bring one sibling, and one family member really. 'Cause some people bring their cousins and stuff. But my first year, I brought <i>Trent</i> and he fell in love with it. We both truly fell in love with the camp. And we both made friends and stuff. Like I can't not let him go no more, cause now he got friends there too now.</p> <p>HEALTH CARE PROVIDER SOCIAL SUPPORT and like the nurses and stuff, they so nice and supportive</p>

Definition	Data
	<p>HEALTH CARE PROVIDER SOCIAL SUPPORT</p> <p>just being there like the doctors and stuff they be, they there you know</p> <p>they (<i>my doctors</i>) talk to me when I don't understand stuff and they actually keep me involved with my treatment and stuff they don't just keep me in the dark about stuff 'cause they afraid of how I'm gonna react or afraid of like I'm not going to be able to handle it and that helps a lot too.</p> <p>Every time before I start a new treatment or a test I don't know nothing about, they always sit me down and tell me what to expect and what's gonna go on and what they're gonna do and what I'm gonna do and how stuff's gonna go down; and that's a big help for me, you know, just knowin' what's gonna happen and stuff. Cause I hate bein' put in the dark</p> <p><i>CB-Mm-hm. And you feel like Dr. Smith has kind of kept you in the light throughout your whole time that you've had cancer?</i></p> <p>Yeah.</p> <p><i>CB-Good. Does that help you trust him for when you need to talk to him about something?</i></p> <p>Oh yeah. I trust him a lot. I think he is the only, and the first doctor that I can really talk to. And the only and first doctor I really got close to was him... yeah.</p> <p><i>CB- What are the things you think that made it so you that you were able to get close to him? 'Cause sometimes it's hard to get close to our doctors.</i></p> <p>Well he didn't force himself upon me. He was just nice and he was there for me when I needed; and he was just nice from the get go. And he didn't look at me as a little kid. He looked at me as a young adult that needs to know what's goin' on with himself so that helps, that helped a lot.</p> <p>HOSPITAL STAFF SOCIAL SUPPORT</p> <p>Child-life, yeah; and my social worker. And some of the volunteers I really became close with too.</p>

Definition	Data
	<p data-bbox="803 233 1219 260"><b>HOSPITAL STAFF SOCIAL SUPPORT</b></p> <p data-bbox="898 266 1425 894">There was volunteers at the hospital and there was one volunteer named <i>Abby</i> and I became real close with her too. I love cause they know I hate the hospital food. They would always bring me up like KFC or Buffalo Wild Wings is my favorite. Or like Little Italy's or like Pizza Hut for like dinner and lunch and stuff. And some would bring up some breakfast from McDonald's cause they know I hate, I despise the hospital food. It's not all that bad but after a while of eatin' the same stuff over and over you can get tired of it. Like, like one time before they found out what was wrong with me, I was in the hospital for a month straight just so they could keep an eye on me and a month straight of eatin' that food! Every once in a while mama, my mom would bring me up somethin'</p> <p data-bbox="803 936 1289 963"><b>TEACHER AND SCHOOL SOCIAL SUPPORT</b></p> <p data-bbox="898 970 1425 1331">And the teachers at my school too, they pretty supportive too and I can talk to some of, most of my teachers I can sit down and talk to. And they try to keep me positive...so it's good to be close to some people that you can sit down and just let everything out. And not worry about how they gonna think about you or about what, or about how you gotta say stuff and you're not gonna offend nobody by what you say or how you feel and stuff.</p> <p data-bbox="898 1373 1425 1703">Yeah I had different teachers and usually at the beginning of the year my grandma, like the nurses from St Mary's hospital will come in and my grandma meets with them, like they have a big meeting; the nurses from St Mary's hospital, there are two nurses from St Mary's and my grandma and they meet with the counselors at school and my teachers and the principal and they just sit down and talk about what's going on with me</p> <p data-bbox="803 1745 1321 1772"><b>COMMUNITY AND FRIEND SOCIAL SUPPORT</b></p> <p data-bbox="898 1778 1406 1898">Like, friends. Like it's hard making friends when you sick so when you do get a good friend you try, you try to hold on to 'em, yeah.</p>

Definition	Data
	<p><i>CB-Do you have a special friend you could tell me about?</i></p> <p>Not really. I mean, I have a lot of cool, nice friends that are at this camp I go to, it's a cancer camp it's for cancer kids and their siblings and I met a lot of cool, nice kids there but...It just so happen to be all my good friends that I can really talk to, talk to, are adults that I met through, from like school or I met them through camp and stuff. And they come and we hang out and go to the movies and we often talk too. Like I know <i>Mike Salsa</i>, like he owns the <i>Salsa</i> restaurants here in (<i>our city</i>) and I know <i>Jeremy Templeton</i>...he owns a car dealership and ... we became really close.</p> <p>Yeah they (<i>others from the cancer camp</i>) gave us the email and stuff so I keep in touch with them throughout the year. And St Mary's has a Christmas party every year and mostly, the camp is through St Mary's Hospital and mostly all the kids that go to camp usually be at the Christmas party. And sometimes when you go to the fundraisers sometimes some kids be there.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family and Other Social Support:</b> MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (MSPSS) - 12 item scale to measure Social Support</li> </ul>	<p>Quantitative <b>MSPSS</b> <b>Significant Other Subscale</b></p> <ul style="list-style-type: none"> <li>• There is a special person who is around when I am in need- <u>6</u></li> <li>• There is a special person with whom I can share joys and sorrows- <u>7</u></li> <li>• I have a special person who is a real source of comfort to me- <u>7</u></li> <li>• There is a special person in my life who cares about my feelings- <u>7</u></li> </ul> <p><b>Mean Score = 6.75</b></p> <hr/> <p>Quantitative <b>MSPSS</b> <b>Family Subscale</b></p> <ul style="list-style-type: none"> <li>• My family really tries to help me- <u>7</u></li> <li>• I get the emotional help &amp; support I need from my family- <u>7</u></li> <li>• I can talk about my problems with my family- <u>6</u></li> <li>• My family is willing to help me make decisions- <u>7</u></li> </ul> <p><b>Mean Score = 6.75</b></p>

Definition	Data
	<p>Quantitative  <b>MSPSS</b>  <b>Friends Subscale</b></p> <ul style="list-style-type: none"> <li>• My friends really try to help me- <u>7</u></li> <li>• I can count on my friends when things go wrong- <u>6</u></li> <li>• I have friends with whom I can share my joys and sorrows- <u>7</u></li> <li>• I can talk about my problems with my friends- <u>7</u></li> </ul> <p><b>Mean Score = 6.75</b></p> <hr/> <p>Quantitative  <b>MSPSS</b>  <b>Total Social Support Score = 6.75</b></p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Communication:</b>  Defined as the degree of open discussion among family members about difficult topics such as EOL</li> </ul>	<p>Qualitative Data  <b>Interview</b></p> <p>Like when I first got cancer...I was in the hospital and it was March 17<sup>th</sup>, that's the day I had my lung biopsy and he came in the room after the procedure and took my grandma in the hallway and told her. So at first the doctor that did the lung biopsy I think he was kind of scared to tell me but my grandma she came in and told me after a while when she was in the hallway and so it's not like my grandma she didn't keep it from me, and that was a good thing, I think.</p> <p><i>CB- Did you know the doctor was talking to your grandma?</i></p> <p>Yeah, because I was awake when he came in and asked her to step out into the hallway. And then when she came in she was all quiet and stuff and she sat down, and then she told me she had something to tell me and then she just told me. And I just started crying for a second there and then she started talking to me and stuff cause I couldn't figure out 'why me? Why I had to be the one who had cancer?' and stuff and so she told me like, she asked me, 'Why not me? What makes me better than the other kids and stuff?' And just started talkin' to me about some stuff. And that's what helps me a lot was when my grandma talks to me and keep me positive, and stuff like that.</p>

Definition	Data
	<p><i>CB-Who would you say you trust the most to share important things?</i></p> <p>Dr. Smith... Well. See it's hard cause... (pause) I'd say my grandma but I am pretty close with Dr. Smith too.</p> <p><i>CB- You can pick more than one person, that's alright.</i></p> <p>Them two</p> <p><i>CB- I'm curious... if you want to talk to somebody, like let's say you want to talk to your grandmother or you want to talk to Dr. Smith, how do you go about having those conversations?</i></p> <p>Hmmn. Sometimes they can tell somethin's not right. And they'll ask you what's wrong and that's what starts the conversation and sometimes you just go up to 'em and ask if they have time and if they say, 'yeah' you say, you wanna talk to them about some stuff...and if they got time and they say, 'yes' you just go somewhere private and you just start talkin'.</p> <p><i>CB-Do you think talking is good?</i></p> <p>Yes I do. 'Cause if you don't get it off your chest and keep it in your mind, you'll keep getting madder and madder until you do something you'll regret. And so most of the time after you talk to somebody you cool down or you felt better.</p>
	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• Cameron and his grandmother were respectful when communicating to each other. <ul style="list-style-type: none"> <li>- When I was talking to Cameron's grandmother at consent, he said "Excuse me" to interrupt our conversation and ask for a pillow for his back.</li> <li>- Cameron's grandmother maintained eye contact when speaking to Cameron and offered support by placing her hand on his shoulder and smiling.</li> <li>- Cameron's grandmother allowed him to make the decision about participating in the current study, but once the decision was made she wholeheartedly encouraged him to talk openly to me during the interview. She provided a quiet room in the house where Cameron and I could talk.</li> </ul> </li> </ul>

Definition	Data
	Quantitative <b>MSPSS</b> <ul style="list-style-type: none"> <li>I can talk about my problems with my family- <u>6</u></li> </ul>
<i>Family Characteristics</i> <ul style="list-style-type: none"> <li><b>Family Cultural and Spiritual Practices:</b> Defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent's personal and family life</li> </ul>	Qualitative Data <b>Interview</b> My Grandma. I think she keeps me positive and keep me in church and keepin' my head straight.  <i>CB- You know, it takes a really brave person to be able to talk about what you're feeling and what you're thinking and I'm real curious about like what are the things that give you the strength to deal with everybody and everything?</i> I would say God; and reading my Bible and staying in church and staying positive. Yeah that helps me, yeah.
<i>Family Characteristics</i> <ul style="list-style-type: none"> <li><b>Family Coping:</b> Defined as adolescent's perception of how family members or others within social support system are dealing with adolescent's advanced cancer</li> </ul>	<i>CB- If you would, please tell me how do you think the important people in your life are handling your illness?</i> Well umm really good, really, really, really good.  <i>CB- Really good?</i> Yeah...and if they not, they don't let it show in front of me. And that's really good for me.
<i>Family Characteristics</i> <ul style="list-style-type: none"> <li><b>Things Not Helpful from Others:</b> Defined as words or actions of others that are not beneficial, as perceived by the adolescent living with advanced cancer</li> </ul>	Qualitative Data <b>Interview</b> Some people when you're sick and stuff they wanna like... I don't know how to say it, they, they, like they make me, Some people make you feel like when you sick... you can't... uhh, how, how can I say? Hmm. (pause) They keep askin' you if you okay and they keep uh like wantin' to do stuff for you but when you're not feeling good you just want to be left alone and like that's a big thing with me

### *Summary of Construct: Readiness*

Readiness data and definitions for Case 1 Time 1 are provided in Table 18, Readiness, and summarized in the following text.

#### *Awareness*

Cameron has not responded to standard cancer chemotherapy treatments. His last chemotherapy was in December of 2009. Cameron and his grandmother have signed the informed consent/assent for a Phase 1 clinical trial. However, in the informed consent, there are mixed messages. On the consent, it is documented that one of the goals of the Phase 1 study is to determine whether the clinical trial “is a beneficial treatment for your tumor”. The consent blends the experimental nature of the trial with a hope for a cure. For example, the verbiage in the consent says,

The potential benefit of treatment with xxx (*the Phase 1 clinical trial*) is that it may cause your cancer to stop growing or to shrink for a period of time. It may lessen the symptoms, such as pain, that are caused by the cancer. Because there is not much information about xxx (*the Phase 1 clinical trial*) effect on cancers in humans, we do not know if you will benefit from taking part in this study. Information learned from this study may help future patients with cancer.

This information is confounded by the fact that in pediatric oncology nearly every child/adolescent diagnosed with cancer is on some sort of clinical trial. This allows individuals, especially those individuals who are non-medical to ignore the *Phase 1* part of the consent, and focus on the possibility that *this* clinical trial will be the one that works. This appears to be the case for Cameron and is supported in the qualitative data that follows.

Cameron operated in a closed awareness context. When I asked him to describe changes in his cancer over time, his focus is on how the cancer has not changed and the doctors are still trying to figure out how to get rid of it. With further probing he commented on the fact that his cancer is actually getting a little better.

The concerns and worries that Cameron discusses during the Time 1 interview validate futuristic thinking. Although he worries that he will not get better and sees cancer limiting his ability to care for himself, he does not express an awareness of the possibility of death. For example he worries that he will be sick for the rest of his life and

be unable to care of himself when he gets older, because of the cancer. Although the experience of cancer has made Cameron more appreciative of life, family, and friends, he does not give a clear indication of an awareness that will die from his cancer.

#### *Acceptance*

There were no qualitative data that addressed acceptance of an incurable prognosis and impending death. Peaceful acceptance of cancer was measured quantitatively with the Peaceful Acceptance in Illness subscale. Individual item scores related to acceptance along with Cameron's total score are listed in Table 18. Cameron's total subscale score for peaceful acceptance was 16. He responded with a (3) to some extent or (4) to a large extent on four of the five subscale items. For the item "To what extent do you feel you have made peace with your illness?" Cameron responded with a (2) to a slight extent. So although Cameron is able to accept his cancer diagnosis to a large extent, Cameron still has the need for greater acceptance that his cancer may not improve and may quite possibly get worse.

#### *Willingness to Take Action*

Cameron feels most comfortable talking to his grandmother and Dr. Smith. He acknowledges a willingness to talk about his worries and concerns to a large extent with both his grandmother and Dr. Smith. However, in terms of his willingness to talk about his feelings or the things that make him sad or afraid he responds to some extent for both. Cameron's willingness to find out more about what to expect if his cancer progresses was rated a (4), to a large extent. Cameron clearly shows willingness or intent for the acquisition of knowledge about his disease as it progresses. This corresponds to Cameron's knowledge preference that was described earlier, or wanting to know all possible information including good news and bad news.

In summary, awareness, acceptance, and willingness to take action are not a linear process. Cameron is neither aware nor accepting of his incurable prognosis. However, according to the acceptance scale, he fully accepts his cancer diagnosis, feels well loved and claims to have somewhat of an inner peace and tranquility. Cameron is willing to take action by engaging in discussions and finding out more about his disease progression. Cameron shows a great deal of willingness to engage in discussions about his worries or concerns and less willingness to discuss his emotions. Cameron operates in

a closed awareness context, describing his cancer as improving a little. Despite the fact that he is participating in a Phase 1 clinical trial, he perceives the doctors are still trying to figure out a cure for his disease. Although Cameron has accepted his diagnosis of cancer, he continues to struggle with the fact that he may never live in a disease-free state.

**Case 1 Time 1**  
**Table 18: Readiness.**

Definition	Data
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness:</b> Defined as the level of cognitive recognition of an incurable prognosis</li> <li>- <b>Closed awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in closed awareness, the adolescent does not recognize impending death</li> </ul>	<p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Signed informed consent for Phase 1 clinical trial</li> </ul> <p>Qualitative Data  <b>Interview</b>            CLOSED AWARENESS</p> <p><i>CB- Can you tell me a little bit about when you were first diagnosed with cancer? And how serious was your cancer then and whether or not the seriousness of your cancer, has that changed over time?</i></p> <p style="padding-left: 40px;">It's been the same uhhh it hasn't changed dramatically or nothin'. It's still the same size and they stopped it from growing but it's still there. And they tryin' to figure out how to get rid of it.</p> <p><i>CB- Alright. So can you tell me how you came to realize how your cancer was becoming, do you think it's becoming more serious than it was at first or... do you think it's about the same?</i></p> <p style="padding-left: 40px;">Mmm I think I'm; actually think it's getting better.</p> <p><i>CB- You think it's getting better?</i></p> <p style="padding-left: 40px;">Just a little, it got better just a tiny bit.</p> <p><i>CB- Okay.</i></p> <p style="padding-left: 40px;">But it's still better so.</p> <p><i>CB- What are your greatest worries or your concerns, things that you're worried about?</i></p> <p style="padding-left: 40px;">That I'll be sick for the rest of my life, and uhh, not bein' able to take care of myself like I would like to. Like uhh, I wanna have a family and have kids, and get out and mow the grass on Sundays and stuff like that. I guess my biggest worry is not being able to basically take care of myself when I get older...because of the cancer.</p> <p><i>CB- Do you think the type of cancer or how serious it is, has that helped to prepare you in any way for, you know, just dealing with what you have to deal with today?</i></p> <p style="padding-left: 40px;">Yeah I think it makes me stronger, as a person. And makes me able to deal with a lot more</p>

Definition	Data
	<p>stuff and makes me more appreciative of a lot of stuff. Makes me not take stuff for granted. And uhh yeah I think it does help me see, see the world in a different way. See stuff in a different way and not just be one-minded. I see stuff in different ways, yeah.</p> <p><i>CB- What are some of the things you appreciate or you feel like you appreciate umm that perhaps you wouldn't be so aware of, you know if you didn't have this serious cancer?</i></p> <p>Life! Family. Like, friends. Like it's hard making friends when you sick so when you do get a good friend you try, you try to hold on to 'em, yeah.</p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Acceptance:</b> Defined as the level of emotional acquiescence of an incurable prognosis <ul style="list-style-type: none"> <li>- <b>PEACE- Peaceful Acceptance of Illness Subscale</b></li> </ul> </li> </ul>	<p>Quantitative Data</p> <p><b>PEACE- Peaceful Acceptance of Illness Subscale</b> (1= not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>4</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>2</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = 16</b></p> <p>Qualitative Data</p> <p><b>Interview</b></p> <ul style="list-style-type: none"> <li>• <i>There were no qualitative data at Time 1 to support acceptance of incurable prognosis</i></li> </ul>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness to Take Action:</b> Defined as level of intent or desire to take action to prepare for EOL, or engage in EOL discussions</li> </ul>	<p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to discuss concerns</b></p> <p><i>CB- How willing are you to discuss your concerns or things that you're worried about with Dr. Smith? Would you say not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To a large extent = <b>4</b></p> <p><i>CB- Okay. And how about the same thing, the same question for your grandmother?</i></p> <p>To a large extent = <b>4</b></p>

Definition	Data
	<p>Quantitative Data (verbally collected during interview)  <b>Willingness to discuss feelings</b></p> <p><i>CB- Okay and then the second one is how willing are you to talk about your feelings? So those would be the things that make you sad, or afraid; how willing are you to talk about that with Dr. Smith? Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To, to some extent I think = <u>3</u></p> <p><i>CB- How about talking about your feelings and these would be the things that make you sad or afraid so how you're feeling, not just what you're worried about but deeper like how that's making you feel with your grandmother? Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To some extent = <u>3</u></p>
	<p>Quantitative Data (verbally collected during interview)  <b>Willingness to find out more as cancer progresses</b></p> <p><i>CB- And the last question is do you want to find out more about what will be happening if your cancer progresses? Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To a large extent, yeah = <u>4</u></p>

### *Summary of Construct: End-of-Life Preparedness*

End-of-life preparedness data and definitions for Case 1 Time 1 are provided in Table 19, End-of-Life Preparedness, and summarized in the following text.

#### *Knowledge about End-of-Life*

Cameron's knowledge concerns are related to his cancer, more specifically the treatment and the impact on his future. He does not identify knowledge concerns about EOL, although he hints about death when he says he doesn't know when it's going to be over, but quickly follows with a comment about his future. For example, when I asked about his biggest problems, he focused on the disease process and not the dying process. His concerns involve not knowing how much longer he will be able to take chemotherapy and how that is going to impact his future.

#### *Acknowledgement of Grief and Emotions*

Although Cameron hinted about his fear of death, he did not openly acknowledge grief and emotions about EOL. I probed by repeating his key words of "not knowing". He admitted that was the scary part, not knowing. Once he admitted to his fear, I probed deeper into his fear, "So would you say those are your biggest fears? Just the not knowing?" Cameron initially disagrees then after some thought he concedes. At this time point the biggest fear he will openly admit is the unknown. This discussion led to us talking about his worry or concern that he will be sick for the rest of his life. He did not want to go deeper into a level of discussion that involved a fear of death.

#### *Identification of the Meaning of Death and Spirituality*

Cameron was able find meaning in why he was diagnosed with cancer; however, he did not address the meaning of death and spirituality. Cameron's cancer is rare in the pediatric population. He justifies his cancer diagnosis and treatment as a means of helping other children in the future. Cameron is not ready to talk about the possibility that he is dying; therefore, he did not discuss the meaning of death or any of his spiritual beliefs related to death and dying.

### *Conceptualization of an End-of-Life Plan*

Cameron has long-term goals and his plan is futuristic. He wants to become a pediatric hematologist. For example, I asked if he had thought about things he wanted to accomplish in the weeks or months ahead. His response includes graduating from high school, going to college and contributing to society with a meaningful profession. Cameron has not started to conceptualize an EOL plan. Memory making, legacy, or setting priorities for immediate future are not on his mind. Again this concurs with the fact that he does not openly acknowledge the fact that he is dying.

In summary, at Time 1 interview Cameron spent very little time discussing any of the attributes of EOL preparedness. He hinted about his fear of death but further probing led him to focus his attention on the uncertainty of his cancer diagnosis and its impact on his future. His goals or things he wants to accomplish reinforce his futuristic thinking. The idea of making memories with his family, leaving a legacy, or setting priorities for the immediate future appears foreign to Cameron.

**Case 1 Time 1**

**Table 19: End-of-Life Preparedness.**

<b>Definition</b>	<b>Data</b>
<p><i>EOL Preparedness</i></p> <p><b>End-of-Life Preparedness:</b> Defined as process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end-of-life consistent with his/her desires. Attributes include: knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan</p> <ul style="list-style-type: none"> <li>• <b>Knowledge about EOL</b> Defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue and may help with pragmatic decisions about advance directives and preferred location of death.</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- What do you feel are the biggest problems that are affecting you right now?</i></p> <p>Cancer. Not knowing how much longer I will take the cancer, I mean how much longer I will take the chemo they gonna give me. And not knowing when it's going to be over and what it's going to do to me in the future.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Acknowledgement of Grief &amp; Emotions:</b> Defined as recognition of grief, loss, or anticipated separation of death; and the accompanying emotions that loss, separation, or death bring</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- So a lot of those unknowns? Those don't know what's gonna happen kind of things?</i></p> <p>Yeah, that's the scary part for me.</p> <p><i>CB- Mm-hm. (pause) So would you say those are your biggest fears? Just the not knowing?</i></p> <p>Huhn- uh... (pause)... I would say... well yeah, I would say yeah, yeah that would probably be the yeah... the biggest, yeah. Not knowing what's goin' to happen.</p> <p><i>CB- What are your greatest worries or your concerns, things that you're worried about?</i></p> <p>That I'll be sick for the rest of my life, and uhh, not bein' able to take care of myself like I would like to. Like uhh, I wanna have a family and have kids. And get out and mow the grass on Sundays. And stuff like that. I guess my biggest worry is not being able to basically take care of myself when I get older... because of the cancer.</p>

<b>Definition</b>	<b>Data</b>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Identification of the Meaning of Death and Spirituality:</b> Defined as the adolescent's discovery of the significance of death and any spiritual beliefs related to death</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>Well I think I got cancer because God wants me to be able to help other kids that might get this cancer in the future 'cause I am the first ever to get this cancer and stuff. I think... I will be able to help other kids so the doctors know how to treat them and they won't have to go through the stuff that I'm goin' through right now for the longest period of time that I'm doing chemo and stuff... They can find out how I got it</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Conceptualization of an EOL Plan:</b> Defined as the development of a plan which includes adolescent's goals, priorities and EOL preferences</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB-Okay. Have you thought about things that you want to accomplish in the weeks or the months ahead?</i></p> <p>Things that I want to accomplish; I want to graduate from high school and go to college and make something of myself. Just because I'm sick doesn't mean I want to live off the government and stuff I wanna make something of myself, do something for myself.</p> <p><i>CB-Have you thought about what you want to study?</i></p> <p>A hematologist, he studies the blood and stuff. That's what I want to do. A pediatric doctor- works on helping kids.</p> <p><i>CB-Have you thought about things that you might want to do with the important people in your life?</i></p> <p>Like</p> <p><i>CB-In the next few months or years or in the future are there any things that you feel like you really want to do, or memories you want to make, or places you want to go?</i></p> <p>Uhhhhh...can't think of nothing else really. No, so, I don't think so.</p> <p><i>CB-Okay... the important people in your life, is there information that you hope they know about you or when they think, 'Oh Cameron, I hope they remember this about me'. Do you ever think about that?</i></p> <p>No, huhn-uh, not really.</p>

### *Case 1: Cameron's Time 2 Data*

#### *Summary of Context: Demographic and Environmental Characteristics*

Demographic and environmental characteristics data for Case 1 Time 2 are provided in Table 20, Context: Demographic and Environmental Characteristics, and summarized in the following text. The only demographic data that changed for Case 1 Time 2 was disease status. Cameron showed no response to the Seneca Valley Virus Phase 1 clinical trial **ADVL0911**. A CT scan revealed he had no new pulmonary lesions. Documentation in the medical record on 6/15/10 confirms the Seneca Valley virus has cleared from Cameron's system. A clinic note on 6/28/10 documents a "long discussion" between Cameron and his physician about his tumor and therapeutic options; however, there were no details of the discussion recorded. Additionally, consent/assent to a new Phase 1 clinical trial, (**ADVL0919** Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia) was present in the medical record.

At Time 2, Cameron reiterates that living with advanced cancer has affected his ability to lead a normal life. He feels he has missed out on a normal childhood because he was sick or because others were worried something might happen. Their overprotection limits his opportunities to participate in activities that he enjoys.

The interview for Time 2 was conducted at Cameron's house. It was a particularly hot day. The house did not have air conditioning, only fans to circulate the air. Cameron preferred to sit on the floor because it was cooler. We sat together and talked. The house smelled of stale cigarette smoke and there was a noticeable pile of beer cans on the driveway in front of the house. Cameron is on summer break from school so he spends his days at home. He recently spent a week at a camp for children and adolescents diagnosed with cancer and their siblings. Cameron continues to be closely monitored at the tertiary care center and with his local oncologist because he is in a Phase 1 clinical trial.

Although Cameron had a long discussion with his doctor about his tumor and therapeutic options, the specific details were not described in his medical chart. Cameron verbalizes some apprehension about the changes in his medication, i.e. clinical trial. However, he perceives the Phase 1 clinical trial as a limited opportunity to treat his

disease, with other options available if this does not work. According to his explanation, he had three options. He selected the Phase 1 clinical trial because it was open for recruitment. This window of opportunity would close, once a specified number of subjects are enrolled. In Cameron's mind, the other options would always be there.

The verbiage on this informed consent is similar to the last Phase 1 clinical trial. There are mixed messages that range from "We do not know if this will work in humans" to "It may cause your cancer to stop growing" or "lessen the symptoms such as pain".

Continuity of staff was evident at Time 2 with Cameron's physician Dr. Smith. He is seeing Cameron frequently for medical monitoring and follow-up EKG's that are a required part of the clinical trial. Cameron acknowledges an ongoing relationship with Dr. Smith throughout all of his cancer treatment, including the Phase 1 clinical trial. There is a disconnect in continuity of nursing staff for Cameron as he participates in the Phase 1 clinical trial. I explored how much Cameron stayed in contact with his primary nurse identified on his Baseline Demographics Self-Report form. Cameron regrets that outside of the hospital he has little contact with nurses he has formed relationships with.

In summary, at Time 2 Cameron continues to live at home with his grandmother making frequent visits to the tertiary care center. He has finished one Phase 1 clinical trial and has started a second Phase 1 clinical trial. Scans reveal his cancer has not changed. Living with advanced cancer continues to affect the normalcy of Cameron's life. He feels he has missed out on a lot of things because of his cancer. Although Cameron recognizes the uncertainty of changes in his medical treatment, he still perceives his cancer is treatable, with other options available if this Phase 1 clinical trial does not work. Continuity of staff is evident with his physician, but not his nurses. There was documentation in the medical record of a "long discussion" about his tumor and treatment options with his oncologist at the tertiary care center. Specific details about the discussion were not given.

**Case 1 Time 2**

**Table 20: Context Demographic and Environmental Characteristics.**

Definition	Data
<p><b>DEMOGRAPHIC SECTION</b>  <i>Demographics</i></p> <ul style="list-style-type: none"> <li>• <b>Disease Status:</b> Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness</li> </ul>	<p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• 6/15/10 Clinic Note               <ul style="list-style-type: none"> <li>- Seneca Valley Virus had cleared</li> <li>- CT scan showed no new pulmonary lesions</li> </ul> </li> <li>• 6/28/10 Phase 1 clinical trial (Experimental Therapy)               <ul style="list-style-type: none"> <li>- <b>ADV0919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia</li> </ul> </li> </ul> <p>Qualitative Data  <b>Interview: Disease Status</b>            LIVING WITH ADVANCED CANCER: AFFECTS NORMALCY            You really don't have a childhood or like havin' fun and spendin' the night somewhere or havin' sleepovers and stuff cause you gotta be worried about taking your medicine and you not feeling good or stuff like that. Um I missed out on a lot, I missed out on a lot of stuff cause I was sick or 'cause they was scared something was gonna happen to me just because I was sick.</p>
<p><b>ENVIRONMENTAL SECTION</b>  <i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Place of Care:</b> Defined as environment where adolescent is living with advanced and incurable cancer</li> </ul>	<p>Qualitative Data  <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• Interviews were conducted at the adolescent's home. Empty beer cans were piled in a heap near the garage door.</li> <li>• It was a very hot day. The windows were open and fans were blowing to circulate air throughout the house. Stale cigarette smoke filled the air. Cameron's brother answered the door and told me I could "go on back" Time 2 interview was conducted in the same back room with one loveseat. Cameron was kneeling on the floor picking up papers and throwing them in the trash. He said he was just trying to pick up a little. He asked if it was hot outside and remarked about how hot it was in the house. He said it was cooler on the floor. There was an old metal fan blowing air from the hallway into the room. I asked if he wanted to just sit on the floor for the interview and he said, "Yes, if you don't mind". So we sat together on the floor and talked.</li> </ul> <p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Ongoing Clinic appointments at tertiary care center for current Phase 1 clinical trial</li> </ul>

<b>Definition</b>	<b>Data</b>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care:</b> Defined as adolescent's perception of specific purpose for care delivery</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>There's a lot happening. Like a lot of my medicine has changed and stuff.</p> <p>Oh, I just started a new medicine and uh it's supposed to affect my heart rate so like I've been doing a lot of EKG's...But like that's all that's really changed, I started taking new medicine and all these side effects...</p> <p>I had like three different choices and the reason I picked this one was because uh the other two would always be open to me but this was like a Trial One test and um like once they get the subjects they close it for a while and like people can't like just get the medicine. So the study was open and I got it with five pills in it. So if this doesn't work out I can always take the other two options.</p> <hr/> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• X-ray of growth plate, "will start new protocol"</li> <li>• Signed informed consent for Phase 1 clinical trial</li> </ul>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff:</b> Defined as continuation of familiar nursing and medical staff while transitioning to end of life</li> </ul>	<p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Clinic notes were from pediatric oncologist at tertiary care center</li> </ul> <hr/> <p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- And how often do you get to see him, Cameron?</i></p> <p>Like now, I'm seeing him [Dr. Smith] a lot 'cause of my medicine. But it just depends on what medicine I'm on and how much he really needs to see me. He tries to see me at least once a month.</p> <p><i>CB- Do you have much contact with them [your primary nurses] now?</i></p> <p>No. Outside the hospital, no. I probably do wish I could, but I really don't.</p>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Ongoing EOL Discussions:</b> Defined as ongoing discussions between physician and adolescent or adolescent and his/her family about death or EOL issues</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <ul style="list-style-type: none"> <li>• There were no comments in the interview about initial or ongoing EOL discussions</li> </ul> <hr/> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• 6/28/10 Clinic Note <ul style="list-style-type: none"> <li>- "Long discussion" with MD regarding tumor and therapeutic options (no details of discussion documented)</li> </ul> </li> </ul>

*Summary of Context: Personal Characteristics*

Personal characteristics data for Case 1 Time 2 are provided in Table 21, Context: Personal Characteristics, and summarized in the following text. At Time 2, Cameron takes more of an active role in collaborating with his physicians about treatment decisions. He describes how his physician gave him all of the treatment options, and how Dr. Smith gave additional input. But ultimately Cameron decided which option he preferred.

Physical symptoms that were apparent at Time 2 include pain, fatigue, shortness of breath and cachexia. The EFAT-2 reveals minimal dysfunction for pain, dyspnea, fatigue and motivation with no impact on GI symptoms.

Cameron continues to have pain that is controlled with the use of a patient controlled analgesia (PCA) of continuous and intermittent IV morphine. The dosage remains the same. Cameron had one mild episode of observable pain during the interview which required the use of his PCA button to administer an intermittent dose of morphine.

Cameron appears more alert and less tired during the Time 2 interview. However, his medical record revealed fatigue and weakness on the 6/28/10 clinic note. Cameron kept his eyes open during the entire interview and he experienced no slurring of speech.

Cameron did not appear as short of breath at Time 2; however, he did have intermittent dyspnea with nasal flaring that was more noticeable when he spoke for prolonged periods of time. He was able to count to 15 without taking a breath and currently he does not have oxygen available. His oxygen saturations when checked at the tertiary care center are in the 90's, at rest. His home environment may be affecting his dyspnea, since his house does not have air conditioning and the outside temperature is in the mid 90's. The house smells of stale smoke, which most likely indicates individuals do smoke in the house. Cameron verbally acknowledges he has difficulty breathing at times and commented that he could not breathe if the fan is directly on him. Cameron's cachexia is unchanged and his Karnofsky score remains at 60%.

There are potential side effects that may occur while participating in the Phase 1 clinical trial. Frequent EKG's are being done to assess the effect of the Phase 1 Clinical drug R04929097 on the heart. Cameron is very aware that the Phase 1 clinical trial may affect his heart.

Psychosocial symptoms identified include worry. Close monitoring of the heart with frequent EKG's may be contributing to his worry. In the medical record for the 6/15/10 clinic appointment, grandma states Cameron "is worried".

The EFAT-2 screening shows only minimal dysfunction for motivation. Cameron continues to be motivated in activities that interest him, and reports participating in activities more than 50 % of the time (i.e. drawing, reading and playing games on the computer).

Coping behaviors at Time 2 include talking to others, particularly positive people, letting go of things that can't be controlled and exercising independence. Cameron feels better about himself when he does what he is able to do.

In summary, at Time 2 Cameron takes an active role in making decisions about his treatments, after seriously considering the opinions of his doctors. Pain, fatigue, and shortness of breath continue to be prominent symptoms. However, during this interview Cameron was more alert, kept his eyes open, and did not experience slurring of his speech. Although he continues to have dyspnea, it was better than at Time 1. Potential heart-related side effects from the current Phase 1 clinical trial and changes in his treatment regimen are worrisome to Cameron. He remains motivated and participates in sedentary activities such as drawing, reading, and playing games on the computer more than 50% of the time. Coping behaviors include talking with others, particularly individuals who are positive, letting go of things out of his control, and exercising his independence by trying to do as much as he can for himself.

**Case 1 Time 2**

**Table 21: Context Personal Characteristics.**

Definition	Data
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Decisional Control Preferences:</b> Defined as adolescent’s preferred level of involvement in decisions about care and treatment </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- I did see that the doctor talked to you about what was going on and kind of explained some different options and stuff but it didn’t say that much about what he said so can you tell me a little bit about that?</i></p> <p>He explained the different choices I had, the medicines I can take like there’s another medicine that is IV and I would’ve had to take pills too and it’s a Trial One experimental drug and there is a different pill that my doctor here in (<i>my city</i>) had came up with. He told me the side effects of the medication and which one I should do, or which one is safer for me to take and stuff.</p> <p><i>CB- Okay, and that’s the one you’re doing now?</i></p> <p>Um no. They had three different medicines. They had two pills and one IV and I picked the one pill. I had like three different choices and the reason I picked this one was because uh the other two would always be open to me; but this was like a Trial One test and um like once they get the subjects they close it for a while and like people can’t like just get the medicine. So the study was open and I got it with five pills in it. So if this doesn’t work out I can always take the other two options.</p> <p>And if somebody would’ve come and taken this before me than I would have to wait a long time before I would be able to take it again.</p>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Knowledge Preference:</b> Defined as adolescent’s desire for information related to their disease and prognosis </li> </ul>	<ul style="list-style-type: none"> <li>No new information on knowledge preference at Time 2</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Physical Symptom Distress:</b> Defined as perceived physical symptoms that interfere moderately or severely with daily activities </li> </ul>	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li> <b>Pain</b> <ul style="list-style-type: none"> <li>Used Patient Controlled Anesthesia (PCA) button on portable pump during interview</li> <li>One mild episode of pain was observed, where Cameron stopped and closed his eyes briefly breathing slowly and evenly for about 10 seconds then opened his eyes and started talking again.</li> </ul> </li> </ul>

Definition	Data
	<p>Qualitative Data</p> <p><b>Direct Observation during Interview</b></p> <ul style="list-style-type: none"> <li>• <b>Fatigue</b> <ul style="list-style-type: none"> <li>- Talked with eyes open during the interview</li> <li>- Cameron remained alert during the interview</li> <li>- There was no slurring of speech, no nodding of head, etc.</li> </ul> </li> </ul> <p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Shortness of breath</b> <ul style="list-style-type: none"> <li>- Intermittent shortness of breath while talking with nasal flaring noted; more prominent when talking for longer periods of time</li> <li>- House without air conditioning (outside temperature mid 90's)</li> <li>- House has odor of stale cigarette smoke</li> </ul> </li> </ul> <p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Cachexia</b> <ul style="list-style-type: none"> <li>- Unchanged</li> </ul> </li> </ul>
	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><b>Shortness of Breath</b></p> <p><i>CB- Okay. And as far as shortness of breath, do you feel like you're having a hard time breathing at all?</i></p> <p>Back then, yes. But not right now, no. {Cameron starts fanning himself with a fold out paper fan}</p> <p>Can you scoot that fan over a little bit?</p> <p><i>CB- I can. (Fan is moved in front of Cameron)</i></p> <p>Not directly on me 'cause I can't breathe.</p> <p>Qualitative Data</p> <p><b>Interview</b></p> <p><b>Potential Symptoms or side effects from clinical trial</b></p> <p>Oh, I just started a new medicine and uh it's supposed to affect my heart rate so like I've been doin' a lot of EKG's. I have to take a EKG before I take the medicine, four hours after I take the medicine and then 24 hours after I take the medicine.</p> <p>Yeah so uh I think they said only with day one and day seven and then like certain days I have to keep doin' the EKG's and they keep up with my heart rate. But like that's all that's really changed, I started taking new medicine and all these side effects and like I guess it's supposed to affect my</p>

Definition	Data
	<p data-bbox="837 235 1422 327">growth too. And for some reason they took x-rays of my knees and I guess it's supposed to be like a growth study or something.</p> <p data-bbox="740 331 951 363">Quantitative Data</p> <p data-bbox="740 367 1040 399"><b>Medical Record Review</b></p> <ul data-bbox="789 403 1422 1247" style="list-style-type: none"> <li data-bbox="789 403 1422 632"> <p data-bbox="837 403 899 434"><b>Pain</b></p> <p data-bbox="837 438 1073 470">6/28/10 Clinic Note</p> <ul data-bbox="837 474 1422 632" style="list-style-type: none"> <li data-bbox="837 474 1247 506">- "Pain relieved with Morphine"</li> <li data-bbox="837 510 1422 632">- Medication same: PCA pain medication: Morphine 1mg/1ml concentration [Basal rate 4 mg per hour with Bolus 1.5 mg every 10 minutes as needed]</li> </ul> </li> <li data-bbox="789 636 1073 737"> <p data-bbox="837 636 935 667"><b>Fatigue</b></p> <p data-bbox="837 672 1073 703">6/28/10 Clinic Note</p> <ul data-bbox="837 707 1154 739" style="list-style-type: none"> <li data-bbox="837 707 1154 739">- Fatigue and weakness"</li> </ul> </li> <li data-bbox="789 743 1325 806"> <p data-bbox="837 743 1081 774"><b>Shortness of breath</b></p> <ul data-bbox="837 779 1325 810" style="list-style-type: none"> <li data-bbox="837 779 1325 810">- Oxygen saturations in the 90's at rest</li> </ul> </li> <li data-bbox="789 814 1422 1108"> <p data-bbox="837 814 954 846"><b>Cachexia</b></p> <p data-bbox="837 850 1073 882">6/28/10 Clinic Note</p> <ul data-bbox="837 886 1422 1108" style="list-style-type: none"> <li data-bbox="837 886 997 917">- Anorexia</li> <li data-bbox="837 921 1422 984">- Weight increased one kilogram to 25.9 Kg or approximately 57 pounds</li> <li data-bbox="837 989 1175 1020">- Medications: unchanged</li> <li data-bbox="837 1024 1422 1108">- Supplemental feedings per gastrostomy tube at night: Resource Just For Kids 1.5 (2130 calories per day)</li> </ul> </li> <li data-bbox="789 1113 1422 1247"> <p data-bbox="837 1113 1227 1144"><b>Karnofsky Score = 60% (same)</b></p> <ul data-bbox="837 1148 1422 1247" style="list-style-type: none"> <li data-bbox="837 1148 1422 1247">- 6/28/10 Clinic Note- requires occasional assistance but is able to care for most of his personal needs</li> </ul> </li> </ul> <p data-bbox="740 1283 951 1314">Quantitative Data</p> <p data-bbox="740 1318 1377 1381"><b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul data-bbox="789 1386 1422 1759" style="list-style-type: none"> <li data-bbox="789 1386 1422 1449">• Pain: Minimal dysfunction (pain controlled with current medication)</li> <li data-bbox="789 1453 1422 1587">• Dyspnea: Minimal dysfunction (Counted to 15 quickly without taking a breath), shortness of breath on exertion or when talking at length; no use of oxygen)</li> <li data-bbox="789 1591 1422 1654">• Fatigue: Minimal dysfunction (rests &lt; 50% of day)</li> <li data-bbox="789 1659 1422 1759">• GI Distress: Functional (Cameron states he is not having any nausea, vomiting, diarrhea or constipation issues)</li> </ul>

<b>Definition</b>	<b>Data</b>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Psychosocial Symptom Distress:</b> Defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities </li> </ul>	<p>Qualitative Data  <b>Interview</b>  <b>Motivation</b>  <i>CB- And motivation. Can you tell me some of the things you've been doing in the past couple of days?</i>  Um drawing and reading a book and playing on the computer.</p> <hr/> <p>Quantitative Data  <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li> Motivation: Minimal dysfunction (participates in activities &gt; 50% of the time) </li> </ul> <hr/> <p>Qualitative Data  <b>Interview</b>  <b>Worry</b>  I need to call him 'cause there's a lot happening. Like a lot of my medicine has changed and stuff. And he's real religious and we got to talking. There's been a lot of changes in my life since I talked to him last and so I need to call him and catch him up</p> <hr/> <p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li> 6/15/10 Clinic Note- Grandma states Cameron is "worried" </li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Coping Behaviors:</b> Defined as ways of dealing with the difficult situation of living with advanced cancer </li> </ul>	<p>Qualitative Data  <b>Interview</b>  TALKING ABOUT IT  <i>CB- When you have worries and fears that come into your mind, what do you find helpful Cameron to deal with that?</i>  Talk about it.</p> <p>It doesn't really help to keep stuff in. When you think about it, then sometimes you're really scared of nothing and you don't really know that it's nothing until you talk to somebody about it.</p> <p>Yeah that really would be helpful to have somebody, it is always helpful to tell somebody your plans and like let them help you and stuff, and yeah it really helps to have somebody with you to help you along the way. It's always helpful to have help, so. You definitely gotta have positive people though. Don't tell somebody that you know gonna be like, 'you can't do this because you are sick. You can't do it because of this or that. You definitely don't wanna tell people that you know gonna put you down.</p>

Definition	Data
	<p data-bbox="740 235 1260 260">LETTING GO OF WHAT YOU CAN'T CONTROL</p> <p data-bbox="837 264 1422 394">I get upset and then I get angry but there's nothin' I can really do about it though. I try not to get myself all worked up about it. I'll be mad for a while but then I just forget about it.</p> <p data-bbox="740 432 1049 457">EXERCISE INDEPENDENCE</p> <p data-bbox="837 462 1422 653">Yeah. I'm a lot, my grandma says I'm a lot, I'm independent too much and I try to do a lot of stuff by myself and like uh I just try to like make myself feel like I can do like stuff that every kid can do. Even if it's something little, it still makes me feel better about myself.</p>

*Summary of Context: Family and Social Support Characteristics*

Family characteristics data for Case 1 Time 2 are provided in Table 22, Context: Family Characteristics, and summarized in the following text. At Time 2, Cameron perceives ongoing social support from multiple sources, including his family, HCPs, and friends within the community.

Community and friend support were evident in Cameron's stories about camp. Cameron and his brother Trent spent the week at a camp for children and adolescents with cancer, and their siblings. One of the highlights of the week was when Jim Salsa, prepared Buffalo wings for the older kids at camp, and they all just hung out like normal teenagers. Cameron mentioned Jim Salsa at Time 1, and also his "friend" who owns the car dealership. This friend is helping him publish his book.

Cameron perceives support from his doctors as they keep him informed about his treatment options and explain which treatment would be best for him. He acknowledges a strong relationship with Dr. Smith and feels he can approach him to discuss meaningful issues. Dr. Smith was the only medical or nursing staff that Cameron feels connected to during the current Phase 1 clinical trial. This may partially be due to the fact that his relationships were primarily with his local oncologist, Dr. Smith, and local hospital; and he has not had sufficient time to develop trusting relationships with the staff at the tertiary care center.

Cameron perceives less support from nursing staff outside of the hospital setting. He mentions that in the hospital most of the nurses know him, and some nurses know him better than others. Cameron is aware that other children/adolescents with cancer maintain relationships with nursing staff, but he does not. Cameron acknowledges this would probably be beneficial.

For Cameron, having someone to talk to is also very important. Open communication is based on trust which allows Cameron to share with comfort and ease. Cameron feels most connected to his grandma as a source of support while he is living with the uncertainty of advanced cancer. Open family communication has allowed Cameron to share some of his worries and fears with his grandmother. Her reassurance reminds Cameron he is never alone, which is an important element of social support.

At Time 2, family communication was also observed between Cameron and his younger brother Trent. Cameron communicated with Trent in the same polite way that was witnessed between Cameron and his grandmother at Time 1. Cameron felt comfortable asking for Trent's assistance, to make him a sandwich, during the interview, and to bring him his book at the end of the interview. Cameron was also eager to include Trent in the conversation once our "interview" was over. He and Trent shared stories about all the fun they had at camp, especially in the air-conditioned Oklahoma Dorm.

Family cultural and spiritual practices were evident when Cameron discussed his faith in God and when he commented about needing to talk to his camp counselor. The commonality of their religious beliefs provides an additional level of support

One thing that is not helpful to Cameron is when other people make decisions for him that limits his ability to live a "normal" life. Cameron is living with advanced cancer and is aware of the limitations of his condition. He knows when he is well enough to do something. However, Cameron's appearance (small stature and cachexia) logically contribute to the apprehensions of others. Regardless, Cameron feels a sense of injustice when others show discrimination because he has advanced cancer.

In summary, at Time 2 Cameron perceives ongoing social support from his family and others, including his doctors, friends in his community, and his camp counselor. Cameron reiterates the close relationship he has with his grandmother and is thankful for her reassurance as he faces an uncertain future. Cameron's close relationship with his brother Trent was evident in their social interactions and communication with one another. For Cameron, open communication is a significant part of social support which requires a certain element of trust. Cameron acknowledges shared religious beliefs provide an additional element of support for him. Although Cameron is aware of the limitations of his disease, he does not find it helpful when others deny him the opportunities to participate in social activities.

**Case 1 Time 2**

**Table 22: Context Family and Social Support Characteristics.**

<b>Definition</b>	<b>Data</b>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family and Other Social Support:</b> Defined as adolescent’s perception of family and other sources of encouragement, support, and help during difficult times </li> </ul>	<p><b>Interview</b></p> <p>COMMUNITY AND FRIEND SOCIAL SUPPORT</p> <p><i>CB- So the things that you did at camp, can you tell me what you liked the most?</i></p> <p>Probably the fireworks, and the cooking class I took, and the beach party.</p> <p>Yeah we had a party and after the party the little kids had to leave the party at 10, no at 9 but we left at 10 and we went back to the Oklahoma Dorm, and uhh...Jim Salsa he owns all the Salsa restaurants here in our city, him and his head chef made Buffalo hot wild wings and uh, after the party we went back to the cabin and ate Buffalo Wild Wings and we just like played around and stuff and some people didn’t go to bed until like 3 o’clock.</p> <p>Yeah I got one of my counselor’s phone numbers but one of them is from the U.K. so I didn’t really get to get his number cause that’s loooooong distance. But he said he’d be here until August when we go back to school. But my other counselor I got his number.</p> <p>I need, I need to call him ‘cause there’s a lot happening. Like a lot of my medicine has changed and stuff. And he’s real religious and we got to talking There’s been a lot of changes in my life since I talked to him last and so I need to call him and catch him up.</p> <p>I’ve been meaning to call people but then I just, I don’t know why I don’t, I just don’t.</p> <p><i>CB- Yeah, so you’re working with a friend to get it published?</i></p> <p>Yeah he knows a publisher. And uh, he said he’d help me get it published...He’s been so busy lately though. He owns a car dealership and has like five different shops and his son golfs and golf is like part of his life, his son’s life. And uh they travel a lot. And so he’s been traveling a lot of places and stuff.</p>

Definition	Data
	<p><i>CB- So have you been able to tell him you're finished with it yet?</i>  Yeah I told him and he said he's free next week, actually tomorrow he should be coming back.</p> <p>HCP SOCIAL SUPPORT  <i>CB- I did see that the doctor talked to you about what was going on...can you tell me a little bit about that?</i>  He explained the um different choices I had um the medicines I can take like there's another medicine that is IV and I would've had to take pills too and it's a trial one experimental drug and there is a different pill that uh my doctor here in [names city] had came up with. He told me the side effects of the medication and which one I should do, or which one is safer for me to take and stuff.</p> <p><i>CB- Have you been able to talk to Dr. Smith about any of the things that you really want to accomplish?</i>  If I really wanted to, I know I could 'cause me and Dr. Smith, yeah we have a solid relationship but we never really talk about it but I feel like if I wanted to I could go to him and talk to him about some of this stuff.</p> <p>Yeah I really like him (Dr. Smith) he's really nice</p> <p>LACK OF CONTINUITY IN NURSING CARE  <i>CB- I'm curious about the nurse that you said was your primary nurse. Are you able to talk to her?</i>  Well at St Mary's Hospital you really don't have a primary nurse but I'm close to all the nurses so some of them I feel I can really talk to and others I feel like I can't. Cause like I've got relationships with mostly all the nurses that uh at St Mary's. They all really do take care of me, so they all know like my uh how to take care of me and stuff so like there are nurses that know me better than other nurses because they had me more and so like I think I'm closest with them and probably would be able to maybe talk to them about some stuff better.</p>

Definition	Data
	<p><i>CB- Okay, how about at (the Tertiary care center) with the study that you're going through? Do you have any contact with any nursing staff or people that are kind of following you through the study?</i></p> <p>Personally, no I don't myself but I know some kids do like to keep in touch with the nurses and stuff. It's just not something that I do but it would probably be nice and I know some kids that does do that.</p> <p><i>CB- Uh-huh. When you're going down to (the Tertiary care center) for your visits for this new study, is there anybody that you know you have the opportunity to kind of connect with during the study or are you just kind of in and out?</i></p> <p>At this point, no, mostly just in and out.</p> <p><i>CB- Okay. And then hospital-wise, is there anybody that you know in the hospital that you feel connected to as you're going through this next clinical trial?</i></p> <p>My doctor. That's probably all.</p> <p><i>CB- Okay, so your doctor at (the Tertiary care center)? Your doctor here (at St Mary's)?</i></p> <p>Yeah Dr. Smith</p> <p>FAMILY SOCIAL SUPPORT</p> <p><i>CB- So during this time right now in your life, who is the person that is probably the one you can connect with or are able to connect with...</i></p> <p>At the hospital or just like anybody?</p> <p><i>CB- Yeah, anybody.</i></p> <p>My grandma maybe.</p> <p>...it really helps to have somebody with you to help you along the way. It's always helpful to have help, so. You definitely gotta have positive people though. Don't tell somebody that you know gonna be like, 'you can't do this because you are sick; you can't do it because of this or that. You definitely don't wanna tell people that you know gonna put you down.</p> <p><i>CB- What other things can you think of that I haven't asked you that you really think we need to know about adolescents that are going through advanced cancer?</i></p> <p>(Long pause) Well uh, I have to think about that one...Really you should just let them know that they are not alone and uh that they can talk to you and not force them to talk to you, let them come to you like on their own.</p>

Definition	Data
	<p><i>CB- Do you think there would be a way for us to be available to adolescents like you...a way... to communicate...by phone, or in person, or by the internet. Would one way be easier than another?</i></p> <p>You could like give them your number and your email address and then just let them know that you're there any time they need to talk to you so that will make them feel comfortable talking to you.</p> <p><i>CB- Okay. Are there certain people do you think that would be better for them to connect with...Like I'm thinking would it, would it be somebody like me, that you don't know very well or would it be somebody that would be like your doctor or your primary nurse or...</i></p> <p>Yeah somebody that you're close with and somebody that you feel comfortable talking to and somebody that they feel like ain't gonna go and tell everybody and anybody about what they talked about. Somebody you can share your feelings with, without having to worry about everybody finding out about it. So yeah somebody that they're close with, not just a stranger to them.</p> <p><i>CB- Right. So there definitely has to be that level of trust where you can open up and share on a deep level with that person.</i></p> <p>Yeah. Like if you not comfortable talking to them you won't get out what you really need and want to say 'cause you scared about what they gonna say and what they gonna think and stuff.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family Communication:</b>            Defined as the degree of open discussion among family members about difficult topics such as EOL         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>It is always helpful to tell somebody your plans and like let them help you and stuff...</p> <p><i>CB- Have you been able to talk about any of that (your fears and worries) with, with your grandma or with Dr. Smith?</i></p> <p>With my grandma yeah.</p> <p><i>CB- Are there things that are helpful when you do talk about it or are there ways that we could help you or somebody like you that was going through all of those worries of not knowing?</i></p> <p>Just try to assure them that everything's going to be okay. And uh that you're there for them. Keep reminding them that other people have made it with the same thing they going through probably, and that they're not alone. (Long pause)</p>

Definition	Data
	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>I did not have the opportunity to observe communication between Cameron and his grandmother at Time 2. She was in her bedroom with the door open. Her room was directly across the hall from the room where Cameron and I talked. It was very warm in the house and fans created a “white noise” that made it nearly impossible to hear what was happening from room to room. Cameron’s brother answered the door and said I could go on back to talk to Cameron.</li> <li>Positive communication between Cameron and his 13 year old brother Trent were observed at Time 2. During the interview Cameron called out politely for Trent and asked “Will you come here please?” He then proceeded to ask if Trent would make him a bologna sandwich because he was hungry. Trent brought back the sandwich wrapped in a white paper napkin. He smiled and then left. At the end of the interview Cameron asked Trent to bring him his book, so that he could show it to me. When Trent returned, Cameron included him in our conversation by saying “She wants to know how you liked camp?” The two of them smiled and joked about all the fun they had, especially staying in the air conditioned Oklahoma Dorm.</li> </ul>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Family Cultural and Spiritual Practices:</b> Defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent’s personal and family life</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>I need, I need to call him ‘cause there’s a lot happening. Like a lot of my medicine has changed and stuff. And he’s real religious and we got to talking. There’s been a lot of changes in my life since I talked to him last and so I need to call him and catch him up.</p> <p>Yeah and he’s really religious and stuff and I do believe in God and stuff, and I feel more open to talking to him.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Family Coping:</b> Defined as adolescent’s perception of how family members or others within social support system are dealing with adolescent’s advanced cancer</li> </ul>	<ul style="list-style-type: none"> <li>No new information on family coping at Time 2</li> </ul>

<b>Definition</b>	<b>Data</b>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Things Not Helpful from Others:</b> Defined as words or actions of others that are not beneficial, as perceived by the adolescent living with advanced cancer</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- Along with that you mentioned that sometimes people made decisions for you that maybe you would've been able to do...but they were afraid it might hurt you if you did do it. So can you help us understand some of the things that maybe you would've been able to do if we would've given you a chance?</i></p> <p>Like um. For example, for example uh I had signed up for uh being the wrestling manager at my school and I signed up before the other managers that was there and my coach wouldn't let me go on any away games cause he was scared that if something happened to me while we was away, he wouldn't know what to do. And um that kind of wasn't fair 'cause sometimes I felt good and I was, I was doin' good and had my medicine and stuff, I always took my medicine and stuff so like nothing would've happened to me. And he let the other kids go, the other managers go and I didn't get to go, like to any of the away games. Stuff like that.</p> <p>Yeah. And like they don't give me chances to like to show them that I can do it and stuff like that.</p>

### *Summary of Construct: Readiness*

Readiness data for Case 1 Time 2 are provided in Table 23, Readiness on page 202, and summarized in the following text. Cameron appears to understand the experimental nature of the Phase 1 clinical trial. Qualitative data show a change in Cameron's awareness context.

#### *Awareness*

Data at Time 2 show Cameron operating in a closed awareness context at one point and a suspected awareness context at another point. His plans focused on the distant future of going to college and becoming a pediatric hematologist. Although he had worries about how his cancer might limit his ability to care for himself, he did not acknowledge worry about how cancer might limit the length of his life. At Time 2 Cameron continues to focus on college but within a context filled with more uncertainty. He sees the certainty of finishing college but the timeframe is less certain.

During the Time 2 interview, Cameron also moves to a suspected awareness context. In suspected awareness the adolescent suspects he or she is dying and attempts to confirm or refute these suspicions. As Cameron describes the difficulty of not knowing what his future holds. He acknowledges the possibility that he might die. In the context of suspected awareness he gives a list of things he is unsure of, including whether or not the chemotherapy is going to work, if he is going to make it to college, or even if he will wake up in the morning. Cameron's thinking has shifted here to focus on the possibility that his time is limited.

#### *Acceptance*

Acceptance was measured using the Peaceful Acceptance of Illness Subscale from the Peace Equanimity and Acceptance in the Cancer Experience (PEACE) Scale (Mack, et al., 2008). Individual items along with Cameron's scores are listed in Table 23. Cameron's total subscale score for peaceful acceptance at Time 2 increased to 17. Interestingly the only response that changed was the item "To what extent do you feel you have made peace with your illness?" Cameron responded with a (3) to some extent. There were no qualitative data to support an emotional acceptance of incurable prognosis and impending death, so it is difficult to know why this change occurred. Cameron reported sharing some of his worries and fears of "not knowing" with his grandmother,

and was able to talk openly with one of his counselors at camp who has similar religious beliefs. However, Cameron also openly acknowledges his struggle with the uncertainty of his condition and admits that a lot of things have changed.

#### *Willingness to Take Action*

The last component of the Readiness construct is willingness to take action to prepare for EOL or engage in discussions about EOL. Willingness at Time 2 was measured by the same three items that were asked during the interview at Time 1. Individual items along with Cameron's scores are listed in Table 23. Cameron continues to be very willing to take action to prepare for EOL. His willingness to talk about his feelings or the things that make him sad or afraid increased for Time 2.

In summary, at Time 2, Cameron seems more aware of the fact that his clinical trial is experimental, that it is a "Trial One" study and that his future is less certain. He is becoming aware, or at least suspecting that his prognosis is incurable. His level of emotional acceptance of his prognosis seems to have increased slightly. However, he struggles with not knowing what his future holds. Most notably Cameron is very willing to take action by engaging in discussions about his concerns (on a cognitive level), and his feelings (on an emotional level). He is also very willing to find out more about his disease progression. It appears Cameron's willingness precedes his awareness and acceptance of his incurable prognosis.

**Case 1 Time 2**

**Table 23: Readiness.**

<b>Definition</b>	<b>Data</b>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness:</b> Defined as the level of cognitive recognition of an incurable prognosis               <ul style="list-style-type: none"> <li>- <b>Closed awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in closed awareness, the adolescent does not recognize impending death</li> <li>- <b>Suspected awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in suspected awareness the adolescent suspects he or she is dying and attempts to confirm or refute these suspicions</li> </ul> </li> </ul>	<p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Signed informed consent for Phase 1 clinical trial</li> </ul> <hr/> <p>Qualitative Data  <b>Interview</b>  <b>CLOSED AWARENESS</b>            I really don't think it would be helpful to plan out your future. It'd be helpful to have an outline of what you want to do...like wanting to finish college but don't make it like so like you want to... finish in a certain time... because you know you're gonna finish but you can't be specific...</p> <hr/> <p>Qualitative Data  <b>Interview</b>  <b>SUSPECTED AWARENESS</b>            I need, I need to call him 'cause there's a lot happening. Like a lot of my medicine has changed and stuff. And he's real religious and we got to talking There's been a lot of changes in my life since I talked to him last and so I need to call him and catch him up.</p> <p>And it's a Trial One experimental drug</p> <p>Not knowing</p> <ul style="list-style-type: none"> <li>- if the chemo's going to work.</li> <li>- if I'm going to make it to college.</li> <li>- if I'm gonna be able to do this in the morning</li> <li>- if I'm gonna wake up, at all really. (Long pause) It's difficult not knowing.</li> </ul>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Acceptance:</b> Defined as the level of emotional acquiescence of an incurable prognosis</li> </ul>	<p>Quantitative Data  <b>PEACE- Peaceful Acceptance of Illness Subscale</b> (1= not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>4</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>3</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = 17</b></p>

	<p>Qualitative Data <b>Interview</b></p> <ul style="list-style-type: none"> <li>• <i>There were no qualitative data at Time 2 to support acceptance of incurable prognosis</i></li> </ul>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness to Take Action:</b> Defined as level of intent or desire to take action to prepare for EOL</li> </ul>	<p>Quantitative Data (verbally collected during interview) <b>Willingness to discuss concerns</b> (1 = not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• How willing are you to discuss your concerns or things that you're worried about with your grandmother and Dr. Smith?</li> </ul> <p>- To a large extent = <b>4</b> for both</p>
	<p>Quantitative Data (verbally collected during interview) <b>Willingness to discuss feelings</b> (1 = not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• How willing are you to talk about your feelings, those are the things that make you sad or afraid, with your grandmother and with Dr. Smith?</li> </ul> <p>- To a large extent = <b>4</b> for both</p>
	<p>Quantitative Data (verbally collected during interview) <b>Willingness to find out more as cancer progresses</b> (1 = not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• Do you want to find out more about what will be happening if your cancer progresses?</li> </ul> <p>- Yes. To a large extent = <b>4</b></p>

### *Summary of Construct: End-of-Life Preparedness*

EOL preparedness data for Case 1 Time 2 are provided in Table 24, EOL Preparedness on page 206, and summarized in the following text. All data for the EOL preparedness construct were obtained from the semi-structured interview.

#### *Knowledge about EOL*

At Time 2, there were no qualitative data to indicate discussions about dying have occurred. However, Cameron was able to dialogue about a hypothetical situation involving an adolescent's discussion of advance directives. Cameron believes such discussions would be beneficial, given his current condition. He would prefer to have conversations now, because there is so much he cannot control about his situation.

Sometimes talking about things in the third person, or using a hypothetical situation puts a distance on topics that can be emotionally charged. Cameron's response gives insight to the level of uncertainty that he is experiencing, and his need to have some sort of decisional control in the event that his disease progresses.

#### *Acknowledgement of Grief and Emotions*

Death and the anticipation of dying bring a gamut of emotions that signify loss and separation. Acknowledgement of grief and emotions is defined as recognition of grief, loss, or anticipated separation of death, and the accompanying emotions that loss, separation, or death bring. Although Cameron hinted about his fear of death in his first interview, at Time 2 he is able to articulate the multiple losses that he is facing. There is the loss of a cure, the loss of his strength, the loss of his dreams, and the ultimate loss of his life. At Time 2, Cameron describes being able to talk about this with his grandmother.

Acknowledging grief and emotions gives the dying individual the opportunity to validate the multiple losses that death can bring. When these emotions are shared within the context of the adolescent's social support system, it also provides the opportunity for others to provide comfort and reassurance to face the uncertainty of the future together.

#### *Identification of the Meaning of Death and Spirituality*

Although Cameron acknowledges his belief in God, he does not discuss how his spiritual beliefs relate to death or an after-life. This may be due to the fact that he has not yet begun to process the reality of his own death. Therefore, he does not have a need to talk about what death means.

### *Conceptualization of an End-of-Life Plan*

The final attribute in EOL preparedness is conceptualization of an EOL plan. Cameron has not discussed any EOL preferences. Cameron was willing to give input about his perspective on developing a plan. In Cameron's opinion, a plan is too concrete. Due to the uncertainty of Cameron's disease, he feels having an outline may be beneficial, but a plan was too specific. Cameron's list of reasons why a plan was not realistic includes the unpredictability of cancer, disappointments that occur if a plan cannot be fulfilled, and setbacks that occur from day to day. Examples of barriers that interfere with accomplishing one's goals include chemotherapy, unanticipated hospitalization, doctor appointments and simply not feeling good enough. Cameron lives with a determination and tenacity to achieve his goals, despite his diagnosis of advanced cancer.

In summary, at Time 2, Cameron continues to spend very little time discussing any of the attributes of EOL preparedness. He was open to discussing hypothetical situations about EOL preferences, and was able to describe some of his deepest fears including his fear of death. Although Cameron's goals are futuristic, he shows less certainty about the time frame in which they will be achieved. Cameron prefers an outline over a plan for his goals and priorities in life.

**Case 1 Time 2**

**Table 24: End-of-Life Preparedness.**

Definition	Data
<p><i>EOL Preparedness</i>  <b>End-of-Life Preparedness:</b> Defined as process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end-of-life consistent with his/her desires. Attributes include: knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan</p> <ul style="list-style-type: none"> <li> <b>Knowledge about EOL:</b> Defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue and may help with pragmatic decisions about advance directives and preferred location of death.         </li> </ul>	<p>Qualitative Data  <b>Interview</b></p> <ul style="list-style-type: none"> <li> <i>There were no qualitative data at Time 2 pertaining to Knowledge about EOL</i> </li> </ul> <p>HYPOTHETICAL SITUATION  <i>CB- Taking our outline a step further, sometimes we have a hard time when adolescents are real sick, with just saying okay, what if this happens then what do you want or who do you want to make the decisions. Do you think that would be a good thing to talk about with adolescents or no?</i></p> <p>It probably would be, yeah. Just so you know like if something happens you've planned for it. So yeah if somethin' happens bad you're not left out there alone.</p> <p><i>CB- Right. I think, I think one of the things that we struggle with is knowing when should we talk about those things? 'Cause I mean we don't want anything bad to happen but what if something bad does happen? So can you give us any help in knowing when we should have those kinds of conversations?</i></p> <p>Can you say that again?</p> <p><i>CB- If something bad does happen, then like you said, it would be nice to have a plan. So when do you think, when would be a good time to have those conversations and talk about that? Like would it be good, like you're still uh you're doing things to try to treat your cancer so is it good to have those conversations now, or a few months from now, or a year from now?</i></p> <p>Now. It'd be helpful now.</p> <p><i>CB- It'd be helpful now?</i></p> <p>Yeah cause a lot can change. Uh it would be helpful when uh you're at the point in somebody's life where they can't control a lot of stuff and um they have no, no, no real say in how things are gonna go that would probably be the best time. And like say you're doin' chemo, that'd be a good time 'cause you can't control the outcome of the chemo and stuff. Yeah like when you doin' something that you know you have to</p>

Definition	Data
	<p>do but you can't control the outcome of it that would be a real good time to sit down and plan like plan your future.</p> <p><i>CB- Okay. And talk about some of those what if this happens then you would want that to happen, that sort of thing?</i></p> <p>Yeah.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Acknowledgement of Grief &amp; Emotions:</b> Defined as recognition of grief, loss, or anticipated separation of death; and the accompanying emotions that loss, separation, or death bring</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB-Last time we talked also a little bit about fears and worries and you told me it was hard not knowing what's going to happen and I was wondering if you would feel comfortable telling me a little bit more about that.</i></p> <p>Not knowing how long my chemo's gonna take. Not knowing if the chemo's goin to work. Not knowing how I'm gonna feel. Like not knowing how strong I'm gonna be when I wake up in the morning or how I'm gonna feel. Not, not knowing if I'm goin' to make it to college. Stuff like, just not knowing a lot. Not knowing if I'm gonna be able to do this in the morning. Not knowing if I'll feel strong, like when I'm on chemo, not knowing if I'm gonna wake up, at all really. (Long pause) It's difficult not knowing.</p> <p><i>CB-Mm-hm. Have you been able to talk about any of that with, with your grandma or with Dr. Smith?</i></p> <p>With my grandma yeah.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Identification of the Meaning of Death and Spirituality:</b> Defined as the adolescent's discovery of the significance of death and any spiritual beliefs related to death</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <ul style="list-style-type: none"> <li>• <i>There were no qualitative data at Time 2 pertaining to Identification of the Meaning of Death and Spirituality</i></li> </ul>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Conceptualization of an EOL Plan:</b> Defined as the development of a plan which includes adolescent's goals, priorities and EOL preferences</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- Last time we talked a little bit about things you want to accomplish in the months or weeks or years ahead and I'm curious to know if you think writing down or making a plan, if that would be beneficial in any way for somebody with advanced cancer like you or any other young people?</i></p> <p>I don't think so 'cause like when you sick everything doesn't go the way you plan so you have to just go along with the flow. And it might take you a little bit longer than what you'd</p>

Definition	Data
	<p>planned to do something, like ‘cause um your chemo and stuff. But if you just keep with it you can get it done. But it probably wouldn’t help a lot to plan because things never go as you plan when you sick, like everything is not perfect. To where if you were healthy you gonna be able to plan like to do somethin’ on a certain day and not have to worry about if you have to go to the hospital or have a doctor’s appointment or uh if you’re gonna be feeling good enough to do it. So yeah I really don’t think it would be helpful to plan out your future. It’d be helpful to have an outline of what you want to do, but don’t be specific of every little thing. Because then you’re gonna be expecting to do it and you don’t want to be disappointed. But like you could have a long one, a long one of like wanting to finish college but don’t make it like so like you want to go to a certain college or finish in a certain time uh like do it in a certain amount of time or like finish so like fast or so high in your class or whatever. Because you know you’re gonna finish but you can’t be specific of where or how and how you’re gonna get it done. It’d probably be good to have an outline a long one of how you’re gonna live your life. But just don’t plan it specifically of how you’re gonna do stuff.</p> <p><i>CB- Hey did you get your book published? Or finished?</i></p> <p>I got it finished yeah.</p> <p>Yeah he (<i>my friend</i>) knows a publisher. And uh, he said he’d help me get it published.</p>

### *Summary of Construct: Outcomes*

Data collected on the outcomes of communication and quality of life for Case 1, are provided in Table 25 on page 213, and summarized in the following text.

#### *Communication of End-of-Life Personal Plan*

Cameron has not developed an EOL plan so therefore there was no communication of that plan. As mentioned in the previous section, Cameron preferred the idea of an outline over a plan for a number of reasons. Mainly, an outline is less constraining, yet still gives some direction or structure. Cameron felt sharing his “hypothetical” outline with a family member or his doctor would be beneficial. Cameron has not shared his priorities or short term goals with Dr. Smith. However, Cameron did emphasize he has a good relationship with his doctor and would feel comfortable talking about it, if he really wanted to. At this point, Cameron is not really operating within the construct of EOL preparedness. He has not developed an EOL plan, or outline; and therefore does not feel the need to have discussions like this with his physician.

#### *Quality of Life at the End of Life*

##### **Symptom Impact**

The symptom impact items assess an individual’s symptom severity, and the level of concern about identified symptoms. The QUAL-E allows each individual to identify symptoms that are most problematic for him/her. The three symptoms that have bothered Cameron the most over the past month are shortness of breath, pain, and nausea. The symptom that bothered him the most in the past week was pain. Cameron describes his pain severity as moderate, and the frequency as very often. It interferes quite a bit with his ability to enjoy life. He worries moderately to quite a bit about pain occurring in the future. Cameron’s subscale score for symptom impact was 9 (range 4 - 20). The mean score for the symptom impact subscale was 2.25, with “1” representing lowest QOL and “5” representing highest QOL. Cameron strongly feels his physical symptoms impact his overall quality of life. Cameron’s symptom impact subscale score is consistent with data collected in the chart and during the semi-structured interviews; and verifies the impact of physical symptoms on Cameron’s overall quality of life.

### **Relationship with Health Care System**

Items in this subscale assess how well an individual is known as a person, knowledge on what to expect, participation in decision-making, and level of control over EOL decisions. Cameron's subscale score for this section was 25 (range 5 - 25). Cameron's mean score for this subscale was "5", with "1" representing lowest QOL and "5" representing highest QOL.

Cameron's subscale score for this section is fairly consistent with qualitative data reported in the semi-structured interview. He feels being an active participant in his health care is very important to his overall quality of life. A good example is described in the personal characteristics section regarding decisional control. Cameron's doctor gave all the therapeutic options as well as medical opinion about what would be best for Cameron. Then after carefully weighing all the options, Cameron made the final decision. Cameron also gave several examples throughout his case study of how his HCPs had honest discussions, and explained what to expect from a new treatment. Cameron feels like Dr. Smith really cares about him as a person. Cameron feels in general he knows what to expect (item 9) about the course of his illness; yet his interview at Time 2 revealed a great deal of uncertainty and fear of the unknown. Item 9 may be capturing his cognitive knowledge about his disease, but not his emotional ability to process and accept his incurable condition.

### **Preparation**

Items on the preparation subscale assess an individual's concern about becoming a burden to others, perception of family preparation for EOL, as well as reflection of life regrets. It taps more into the aspect of resolution or peace about death. Cameron feels concerns about the future are slightly important to his overall quality of life. Perhaps this is because he currently envisions his life in the distant future. Cameron is not worried about his family's ability to cope with the future, and only slightly worried that he will become a burden to his family. However, thoughts of dying frighten him to a moderate degree. Cameron's preparation subscale score was relatively high, 20 (range 5 - 25). The mean score for the preparation subscale was 4, with "1" representing lowest QOL and "5" representing highest QOL.

## **Life Completion**

Life completion items assess one's interpersonal contributions to others and the ability to make a difference in life. It also includes meaning in life and spirituality. Steihauser and colleagues (2000) found that one of the attributes of a good death is "being at peace" (Steihauser, Christakis, et al., 2000). For some, this meant being at peace with God, for others it had no religious or theological connotation. It was simply an inner sense of tranquility, a spiritual peace. For Cameron, he feels a great deal of peace and despite his illness, has a strong sense of meaning in his life. His spiritual beliefs reported during the semi-structured interviews are consistent with his item scores here. Cameron's subscale score for life completion was 34 (range 7 - 35). The mean score for the Life Completion subscale was 4.85, with "1" representing lowest QOL and "5" representing highest QOL. Other items on the life completion subscale, such as "There is someone in my life with whom I can share my deepest thoughts" and "I feel at peace" are very similar to Cameron's quantitative reports of perceived social support and peaceful acceptance of illness.

There are two ways quantitatively to evaluate Cameron's overall quality of life, the total scale score, and a single item, number 26, measuring a global QOL score. Cameron's total scale score was 88 (range 21 - 105). The total QOL score divided by the number of items equates to a mean score of 4.19. This is fairly high, which is not surprising given Cameron's subscale scores. However, Cameron rates his overall QOL to only be "fair". This may have to do with the weight that Cameron places on symptom impact, namely his pain, to his overall QOL. Alternatively, this could be due to the fact that the QUAL-E is not measuring everything that affects Cameron's perceived overall QOL. Cameron is experiencing a great deal of pain, which is interfering with his daily living and ability to enjoy life. Cameron is worried quite a bit about his pain occurring in the future. Cameron's mean subscale score for symptom impact was only 2.25. Cameron's pain may be significantly affecting his overall perception of quality of life.

Cameron struggled with the meaning of quality of life. In hindsight, perhaps I should have asked him how living with advanced cancer specifically affected his physical, emotional, social, and spiritual areas of his life. Instead, I encouraged him to use his own interpretation to describe his current QOL. Cameron's complete response is

listed in Table 25. It is very similar to his discussion about living with advanced cancer at Time 1. Basically, Cameron compares his QOL with someone who is healthy. He emphasizes the limitations of being sick; and the added responsibility for taking medication. Living with advanced cancer affects Cameron's quality of life because it interferes with the freedom of being a young person, and having fun. He feels he has grown up too quickly, and in a sense has missed out on a lot of his childhood; not only because he was sick but because others perceived he was not well enough to participate.

#### *Examining Risks and Benefits*

At the end of the Time 2 interview, I asked about the risks and benefits of participating in the study. Cameron's responses are included in Table 25. He did not feel there were topics too difficult to discuss. He also describes it was beneficial to talk about and process his thoughts and feelings.

In summary, outcomes for EOL preparedness include communication of a personal EOL plan, and QOL at EOL. There were very little data collected on the attributes of EOL preparedness to indicate Cameron is preparing for EOL, although he is beginning to acknowledge more uncertainty and fear about the possibility of an incurable prognosis. Attributes within the EOL preparedness construct cannot be linked to overall quality of life because there were very little data to support Cameron's participation in the EOL preparedness construct. However, Cameron's quality of life was fairly good. In Cameron's Case, data support contextual factors, such as his relationship with the health care team, social support, and spiritual beliefs positively influenced Cameron's overall QOL. Cameron has not developed an EOL plan or outline. Therefore, he has not communicated his plan to a family member or a HCP. Cameron's QUAL-E score for the total scale was relatively high. However, he rates his overall QOL as fair. Physical symptoms negatively impacted his overall QOL.

Case 1 Time 2

Table 25: Outcomes: Communication and Quality of Life.

Definition	Data
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li> <b>Communication of End-of-Life Personal Plan:</b> Defined as adolescent's written or verbal expression about conceptualized plan which includes goals, priorities and EOL preferences         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- When you're thinking about that outline then, do you think it would be good to be able to share that outline with somebody in your family, or with your doctor? I mean would that be beneficial for people to know what you want to do so we can kind of help facilitate or help uh...</i></p> <p>Yeah that really would be helpful to have somebody, it is always helpful to tell somebody your plans and like let them help you and stuff</p> <p><i>CB- Right. Have you been able to talk to Dr. Smith about any of the things that you really want to accomplish? Maybe even short term things you want to do in this next year, has that been a possibility?</i></p> <p>If I really wanted to, I know I could cause me and Dr. Smith, yeah we have a solid relationship but we never really talk about it but I feel like if I wanted to I could go to him and talk to him about some of this stuff.</p>
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li> <b>Quality of Life at the End of Life:</b> Defined as adolescent's subjective estimation of the quality of symptom control, relationships with others, the meaningfulness of life and resolution of impending death         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- So I was wondering if you would describe the quality of your life right now.</i></p> <p>What do you mean by quality of life?</p> <p><i>CB- Can you tell me what you think when you think of quality of life? Because that's the thing, so many people think of different things and I'm really interested in what you think.</i></p> <p>Like the way, the way I live my life and stuff? Uh well it's a lot different between being sick and being healthy. Because you can do a lot more when you're healthy. Uh I do think that the quality of life is different when you're sick. Uh you have more responsibilities. Uh you can't just forget to take your medicine because then it's like, yeah you definitely have more responsibilities. And you're not as free or open to do more different stuff umm like other kids are. Uh, it's a lot harder and you definitely have to grow up a lot faster than like some people probably want to. Uh it's a lot less fun. You really don't have a choice. You really don't have a childhood, or like havin' fun and spendin' the night</p>

Definition	Data
<div data-bbox="295 569 636 762" style="border: 1px solid black; padding: 5px; margin: 10px auto; width: fit-content;"> <p>SYMPTOM IMPACT SUBSCALE</p> <p>MEAN SCORE = 2.25</p> </div>	<p>somewhere, or havin' sleepovers and stuff 'cause you gotta be worried about taking your medicine and uh you not feeling good or stuff like that. Um I missed out on a lot. I missed out on a lot of stuff 'cause I was sick or 'cause they was scared something was gonna happen to me just because I was sick. They really didn't want to give me a chance. Yeah it's kind of, it's a lot different. That's what I think, it's a lot, it's a lot different. (Long pause). I think that's all. That's all I think.</p> <p>Quantitative <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>SYMPTOM IMPACT SUBSCALE</b></p> <p><i>Top 3 symptoms identified for the past month = <u>shortness of breath, pain, and nausea</u></i></p> <p><i>Symptom most problematic in past week = <u>pain</u></i></p> <p>(1 = rarely, 2 = a few times, 3 = fairly often, 4 = very often, 5 = most of the time)</p> <p>1. During the last week, how often have you experienced pain? <u>4</u></p> <p>(1 = very mild, 2 = mild, 3 = moderate, 4 = severe, 5 = very severe)</p> <p>2. During the last week, on average, how severe has pain been? <u>3</u></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <p>3. During the last week, how much has pain interfered with your ability to enjoy your life? <u>4</u></p> <p>4. How worried are you about pain occurring in the future? <u>3 to 4</u></p> <p><b>Items 1 - 4 reverse coded; min 4 maximum 20</b> <b>Reverse coded score = 9</b></p> <p>Item not included in subscale: (1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <p>5. <b>In general, how important are your PHYSICAL SYMPTOMS OR PROBLEMS to your overall quality of life? <u>4</u></b></p>

Definition	Data
<div data-bbox="289 247 638 478" style="border: 1px solid black; padding: 5px;"> <p>RELATIONSHIP WITH HEALTH CARE SYSTEM SUBSCALE</p> <p>MEAN SCORE = 5</p> </div>	<p>Quantitative  <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>RELATIONSHIP WITH HEALTH CARE SYSTEM SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <ol style="list-style-type: none"> <li>6. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions. <u>5</u></li> <li>7. I participate as much as I want in the decisions about my care. <u>5</u></li> <li>8. Beyond my illness, my doctor has a sense of who I am as a person <u>5</u></li> <li>9. In general, I know what to expect about the course of my illness. <u>5</u></li> <li>10. As my illness progresses, I know where to go to get answers to my questions. <u>5</u></li> </ol> <p><b>Items 6 - 10; minimum 5, maximum 25</b>  <b>Score = <u>25</u></b></p> <p>Item not included in subscale:</p> <ol style="list-style-type: none"> <li>11. <b>In general, how important is feeling like an ACTIVE PARTICIPANT in your HEALTH CARE to your overall quality of life?</b> <u>5</u></li> </ol>
<div data-bbox="289 1150 638 1291" style="border: 1px solid black; padding: 5px;"> <p>PREPARATION SUBSCALE</p> <p>MEAN SCORE = 4</p> </div>	<p>Quantitative  <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>PREPARATION SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <ol style="list-style-type: none"> <li>12. I worry that my family is not prepared to cope with the future. <u>1</u></li> <li>13. I have regrets about the way I have lived my life. <u>2</u></li> <li>14. At times I worry that I <u>will be</u> a burden to my family. <u>2</u></li> <li>15. Thoughts of dying frighten me. <u>3</u></li> <li>16. I worry about the financial strain caused by my illness. <u>2</u></li> </ol> <p><b>Items 12 - 16 reverse coded; minimum 5, maximum 25</b>  <b>Reverse coded score = <u>20</u></b></p> <p>Item not included in subscale:</p> <ol style="list-style-type: none"> <li>17. <b>In general, how important are CONCERNS ABOUT THE FUTURE to your overall quality of life?</b> <u>2</u></li> </ol>

Definition	Data
<div style="border: 1px solid black; padding: 5px; margin: 5px;"> <p>LIFE COMPLETION SUBSCALE</p> <p>MEAN SCORE = 4.85</p> </div>	<p>Quantitative <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>LIFE COMPLETION SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <p>18. I have been able to say important things to those close to me. <u>5</u></p> <p>19. I make a positive difference in the lives of others. <u>5</u></p> <p>20. I have been able to help others through time together, gifts, or wisdom. <u>5</u></p> <p>21. I have been able to share important things with my family. <u>5</u></p> <p>22. Despite my illness, I have a sense of meaning in my life. <u>5</u></p> <p>23. I feel at peace. <u>4</u></p> <p>24. There is someone in my life with whom I can share my deepest thoughts. <u>5</u></p> <p><b>Items 18 - 24; minimum 7, maximum 35</b> <b>Score = <u>34</u></b></p> <p>Item not included in subscale:</p> <p>25. <b>In general, how important is the feeling that your LIFE IS COMPLETE to your overall quality of life?</b> <u>4</u></p>
	<p>Quantitative <b>QUAL-E</b> <b>TOTAL SCORE</b></p> <p><b>21 items that make up each of the subscales; minimum 21, maximum 105</b></p> <p><b>Cameron's Total Score = <u>88</u></b></p> <p><b>TOTAL SCALE MEAN SCORE = 4.19</b></p>
	<p>Quantitative <b>QUAL-E</b> GLOBAL QOL measured as single item # 26; minimum 1, maximum 5</p> <p>(Very Poor = 1, Poor = 2, Fair = 3, Good = 4, Excellent = 5)</p> <p>26. How would you rate your OVERALL QUALITY OF LIFE? <u>3 Fair</u></p>

<b>Definition</b>	<b>Data</b>
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li>• <b>Evaluation of the Study</b> Potential risk</li> </ul>	<p>Qualitative Data <b>Interview</b> EVALUATE POTENTIAL RISK</p> <p><i>CB- The last thing I want to ask you... is there anything that I said that made you feel too uncomfortable that maybe I shouldn't ask or...</i></p> <p>Not to me, no.</p>
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li>• <b>Evaluation of the Study</b> Potential benefit</li> </ul>	<p>Qualitative Data <b>Interview</b> EVALUATE POTENTIAL BENEFIT</p> <p><i>CB- Okay, were there any things that you think...like talking to me, was that helpful in any way?</i></p> <p>Stuff about how I really felt</p> <p>And um about like how people make decisions for me and they really don't give me a chance I didn't really think about that a lot until you asked me so that was good, that was good for me. That's about all I can think of right now.</p>

## CASE 2: JENNIFER

This section will present the findings from Case 2. The adolescent's pseudonym is Jennifer. She identified two oncologists who are primarily responsible for her care. Their pseudonyms are Dr. Jones and Dr. Johnson. A medical overview is provided as an introduction to Jennifer's case. Data were triangulated to assess the relationship between qualitative and quantitative data for each of the main theoretical constructs for Time 1, Time 2.

### Case 2: Medical Overview

Jennifer is a 20 year old African American female who has already completed high school at the time of this study. She is currently living with her mother and sister. Jennifer and her mother were living out of state. Jennifer began having some pain in her legs. Her mother took her to doctors in that area, but no definitive diagnosis could be found. Meanwhile, Jennifer's mother moved to the state where this study is being conducted, and was living with her boyfriend and his family. She began working at a local long-term care facility. Some of Jennifer's mother's co-workers recommended Jennifer be seen at the pediatric tertiary care center, since her condition was not improving. It was not specified in the medical record where Jennifer was living during this time.

Jennifer presented to the tertiary care center with a large mass in her left thigh (15 cm x 17.8 cm), and she was no longer able to walk. She lost 40 pounds in six months and was severely malnourished, with her weight (42.2 Kg), in less than the third percentile for her height. She was in pain, had tachycardia, dyspnea, and an elevated blood pressure. Jennifer was diagnosed with a Malignant Peripheral Nerve Sheath Tumor (MPNST) on February 23, 2010. A biopsy on March 1, 2010 revealed the peripheral nerve sheath tumor was a spindle cell sarcoma, with a particularly poor prognosis.

Approximately 50% of the individuals who have MPNSTs also have a condition known as neurofibromatosis type 1 (NF1), or von Recklinghausen's disease (Widemann, 2006). Although Jennifer had café au lait spots, and her initial CT scan showed multiple lesions in her neck, chest, abdomen, and lower extremities that were consistent with benign neurofibromas; Jennifer was never formally diagnosed with NF1. The only curative treatment for MPNST is surgery. Jennifer's left thigh tumor was too large to

resect at diagnosis. Additionally, she had a small lesion in her right anterior thigh, a small lesion in her right popliteal fossa (2 cm), and multiple avid masses/lesions in her chest and lower extremities that were consistent with malignant transformation of peripheral nerve sheath tumors. On March 7, 2010, she was started on a Phase II clinical trial of chemotherapy in sporadic and neurofibromatosis Type 1 associated high grade malignant peripheral nerve sheath tumors - NIH 06-C-0043. She had 2 cycles (at intervals of 21 days) of ifosfamide and doxorubicin, and 2 cycles (at intervals of 21 days) of ifosfamide and etoposide. The hope was that the tumors would shrink particularly in the left thigh, and surgery could be performed after initial chemotherapy. A Port-o-cath, central venous device and gastrostomy tube were placed on March 4, 2010.

Jennifer's mother established in-state residency; and Jennifer and her sister moved from out of state to their current address. There was a short interval of time when Jennifer did not have a place to stay, so she moved in with her grandmother.

During the three months that Jennifer was treated, she experienced ifosfamide toxicity, continued to lose weight, had an increase in her pain, shortness of breath, and nausea and vomiting. After 4 cycles of chemotherapy, her tumors showed no response. A CT scan detected multiple pleural based pulmonary masses along with a new mass in the right axilla. Chemotherapy was stopped at the end of May, 2010. Jennifer has had refractory disease since diagnosis. Her disease has continued to progress. On June 10<sup>th</sup>, Jennifer was started on a Fentanyl patch and oral morphine for increased pain. On June 15<sup>th</sup>, Dr. Jones discussed disease progression with Jennifer and her mother, who both decided on comfort measures only. A referral to hospice was made. On June 16<sup>th</sup>, a visit to the home was made to begin the process of enrollment in hospice. Jennifer and her mother changed their minds and returned to the clinic to discuss a Phase 1 clinical trial.

Dr. Jones was primarily involved in Jennifer's care during the 4 cycles of chemotherapy and through her referral to hospice. However, Dr. Johnson became more involved in Jennifer's care when she opted to return to the oncology clinic for ongoing visits to manage pain and discuss the Phase 1 clinical trial. Jennifer was experiencing a great deal of pain. Necessary changes were made in her medications to control her pain and to allow her to be eligible for the Phase 1 clinical trial, **ADV0919** Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with

recurrent or progressive tumors, or leukemia. On this particular trial, administration of Fentanyl is contraindicated. On June 22<sup>nd</sup>, Jennifer consented to the Phase 1 clinical trial and she was actually started on the trial July 20<sup>th</sup>.

Dr. Johnson also discussed Jennifer's eligibility for the current QOL study with me. Since Jennifer recently turned 20 years old, she was not eligible for recruitment into the QOL study, (age eligibility 14 - 19). I discussed this with my committee who suggested sending in another amendment to IRB to extend the upper age to 21 years. The IRB amendment was quickly approved (submitted on June 21<sup>st</sup> and approved on June 24<sup>th</sup>).

Dr. Johnson discussed the QOL study at Jennifer's next clinic appointment and received permission to give me her contact information. I contacted Jennifer by phone to explain the purpose of the study, and to inform her of the potential risks and benefits. I arranged to meet in person with her a few days later on July 6, 2010 at the clinic. Informed consent was obtained and baseline measures were collected in a quiet location at the tertiary care center. Her first interview (Time 1) was conducted a week later on July 12<sup>th</sup>. The final data collection (Time 2) occurred three weeks later on August, 4, 2010. The time from Jennifer's initial cancer diagnosis to enrollment in the current QOL study was only 4 months and 6 days.

## Case 2: Baseline and Time 1 Data

### *Summary of Context: Demographic Characteristics*

Demographic characteristics data and definitions for Case 2 Time 1 are provided in Table 26, Context: Demographic Characteristics, page 222, and summarized in the following text.

Demographic details about Jennifer's cancer are described in the *Case Two Medical Overview*. She identifies herself as a 20 year old African-American female. Jennifer comprehends her disease process. Her cancer was advanced at diagnosis and rapidly progressed. She did not respond to the Phase II clinical trial of chemotherapy. During the Time 1 interview, Jennifer was asked to describe what it is like to be living with advanced cancer. Her response is recorded in Table 26. Mainly for Jennifer, living with advanced cancer is difficult because of the physical and emotional impact of her disease. She acknowledges her cancer has affected her ability to do normal daily activities, and is stressful because of the emotional impact on her family. Despite the emotional stress and physical limitations, Jennifer has a certain resignation. Even though she does not like the limitations of her disease, she realizes she still has value as a unique individual and member of her family. She recognizes it does not change who she is as a person.

**Case 2 Time 1**

**Table 26: Context: Demographic Characteristics.**

Definition	Data
<p><i>Demographics</i></p> <ul style="list-style-type: none"> <li>• <b>Age:</b> Defined as life interval of adolescent</li> <li>• <b>Sex:</b> Defined as the classification of an individual into an exclusive group of male or female based on typical reproductive function</li> <li>• <b>Education:</b> Defined as level of formal schooling an adolescent has received</li> <li>• <b>Race:</b> Defined as adolescent’s perception of belonging to a distinct group of the human population distinguishable from others based on shared biological traits</li> <li>• <b>Disease Status:</b> Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness</li> </ul>	<p>Quantitative Data</p> <p><b>Baseline Demographics Self-Report Form</b></p> <ul style="list-style-type: none"> <li>• Current age: 20 years old</li> <li>• Age at diagnosis: 19 years old</li> <li>• Sex: Female</li> <li>• Education last grade completed: 12<sup>th</sup> Grade</li> <li>• Race: African-American</li> </ul> <hr/> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <p><i>Age, Sex, Education, and Race</i></p> <ul style="list-style-type: none"> <li>• Above information confirmed with medical record</li> </ul> <p><i>Disease Status</i></p> <ul style="list-style-type: none"> <li>• Diagnosis: Malignant Peripheral Nerve Sheath Tumor (MPNST)</li> <li>• Age at diagnosis: 19 years old</li> <li>• Date of Diagnosis: February 23, 2010</li> <li>• Lost 40 pounds in 6 months and cannot walk</li> <li>• Biopsy 3-1-10 showed peripheral nerve sheath tumor, spindle cell sarcoma</li> <li>• Port-o-cath central venous device and gastrostomy tube placed on 3-4-10</li> <li>• Original Prognosis: MPNST             <ul style="list-style-type: none"> <li>- CT scan showed large posterior left thigh mass 15 cm x 17.8 cm; right anterior thigh small lesion, right popliteal fossa 2 cm lesion; multiple avid masses/lesions in chest and lower extremities consistent with malignant transformation of peripheral nerve sheath tumors; low density lesions in neck chest abdomen and lower extremities consistent with benign neurofibromas</li> <li>- Positive café au lait spots, but no formal diagnosis of neurofibromatosis</li> </ul> </li> <li>• Current Prognosis: Progressive disease, not cured by any standard treatment</li> <li>• Length of cancer experience (Time since diagnosis to entrance in QOL study): <b>4 months 6 days</b></li> <li>• Refractory disease since diagnosis</li> <li>• Chemotherapy started March 7, 2010</li> <li>• Date of last chemotherapy treatment: Chemo stopped after Cycle 4 (end of May 2010)</li> <li>• Phase 1 clinical trial (Experimental Therapy) <b>ADVL0919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia – started July 20, 2010</li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>• Treatment Regimen: Phase II Trial of chemotherapy in sporadic and neurofibromatosis Type 1 associated high grade malignant peripheral nerve sheath tumors - NIH 06-C-0043 <ul style="list-style-type: none"> <li>- 2 cycles (at intervals of 21 days) of ifosfamide and doxorubicin <ul style="list-style-type: none"> <li>➤ Cycle 1 started on March 7, 2010</li> <li>➤ Cycle 2 started on March 29, 2010</li> </ul> </li> <li>- 2 cycles (at intervals of 21 days) of ifosfamide and etoposide <ul style="list-style-type: none"> <li>➤ Cycle 3 started on April 19, 2010</li> <li>➤ Cycle 4 started on May 10, 2010</li> </ul> </li> <li>- Patients with radiographic evidence of progressive disease after 4 cycles of chemotherapy = removed from study <ul style="list-style-type: none"> <li>➤ CT scan after cycle 4 showed large mass- right axilla and multiple pleural-based pulmonary masses that were unchanged from prior exam</li> </ul> </li> </ul> </li> <li>• Clinic notes related to treatment <ul style="list-style-type: none"> <li>- Clinic Note on 4-12-2010 <ul style="list-style-type: none"> <li>➤ Ifosfamide induced toxicity required methylene blue with last 2 of 5 doses</li> <li>➤ Weight loss, question compliance with feedings</li> </ul> </li> <li>- Clinic note on 5-20-10 <ul style="list-style-type: none"> <li>➤ Weak; not tolerating feedings; chronic emesis; severe side and stomach pain; shortness of breath</li> </ul> </li> <li>- Clinic Note on 6-10-10 <ul style="list-style-type: none"> <li>➤ Increased pain started on Fentanyl patch 175mcg and oral morphine sulfate immediate release (MSIR) 15-30 mg every 2hours as needed</li> </ul> </li> <li>- Clinic Note on 6-15-10 <ul style="list-style-type: none"> <li>➤ Doctor discussed disease progression with patient and mom</li> <li>➤ Patient and mom decided on comfort measures only</li> </ul> </li> <li>- Clinic Note on June 16, 2010 <ul style="list-style-type: none"> <li>➤ Hospice referral</li> <li>➤ Hospice visit to home to begin process of enrollment</li> </ul> </li> <li>- Clinic Note on June 22, 2010 <ul style="list-style-type: none"> <li>➤ Consented to Phase 1 clinical trial, not enrolled in hospice while on Phase 1 clinical trial</li> </ul> </li> </ul> </li> </ul>

<b>Definition</b>	<b>Data</b>
<p>(Cont.)</p> <ul style="list-style-type: none"> <li> <b>Disease Status:</b> Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><b>LIVING WITH ADVANCED CANCER</b></p> <p><i>CB - So would you please start by telling me what it's like to be 20 years old as a young woman living with advanced cancer?</i></p> <p>Umm. It's kind of norm -difficult, basically but yeah I can still live my normal life, you know, and still try to have fun and you know be happy with my family and everything but I mean it's difficult knowing that you're sick and seeing that, you know, family members upset and depressed that you going through it. And the looks on their faces and knowing that they're depressed depresses me out. And um it's a lot of stress because you know you're in and out of the hospital and you're sick a lot. And you can't really do a lot of things you want to do, I can't really do a lot of things I want to do. But um I still wanna try, I mean it's kind of hard 'cause I still can't do day to day activities. And so it's very difficult, but yet kind of, you know, can cope with it 'cause I can still be me. But it's very stressful.</p> <p><i>CB- It sounds like you've kind of adjusted to what you're new normal is in living with advanced disease. Did it take you a while to adjust to that?</i></p> <p>Yeah. It took me a while to um get used to, you know, having to do these things or knowing that I'm not going to be able to do certain things again. It took a while, but I mean once I was able to do it and got used to it, I mean I was okay with it. I mean I still don't like it just 'cause I can't help out and everything but I'm okay with it.</p>

### *Summary of Context: Environmental Characteristics*

Environmental characteristics data and definitions for Case 2 Time 1 are provided in Table 27, Context: Environmental Characteristics, page 228, and summarized in the following text.

#### **Place of Care**

Place of care was determined by direct observation of Jennifer at the tertiary care center, outpatient clinic, and in her home when Time 1 interview was conducted. In the medical record review, it was noted that Jennifer was making frequent trips to the tertiary care center, outpatient clinic for issues related to pain control and possible participation in a Phase 1 clinical trial.

#### **Focus of Care**

Focus of care was determined by the semi-structured interview and by the medical record review. In the medical record, there was documentation that Jennifer's cancer did not respond to the chemotherapy regimen, and a prognostic discussion occurred. Initially, Jennifer and her mother opted for comfort measures only. After the initial hospice visit to the home, Jennifer and her mother decided to pursue the option of a Phase 1 clinical trial. Although Jennifer had signed the informed consent for the Phase 1 clinical trial prior to the Time 1 interview, she had not started the clinical trial. Palliative care measures are documented in the chart. Jennifer was started on a Fentanyl patch and oral morphine for increased pain. These medications were started prior to the prognostic discussion as palliative care measures to treat adverse symptoms are routine practice in pediatric oncology. Additionally, as Jennifer continued to experience pain, adjustments were made in her pain medication to control her pain prior to enrollment in the Phase 1 clinical trial. Although Jennifer signed consent for the Phase 1 clinical trial on June 22<sup>nd</sup>, she did not actually start the clinical trial until July 20<sup>th</sup>. This allowed time for the doctors to change her pain medication prior to enrollment in the Phase 1 clinical trial. One of the necessary changes involved taking Jennifer off the Fentanyl patch. This was contraindicated for enrollment in the Phase 1 clinical trial. Jennifer was put on a high dose of sustained release morphine, with immediate release morphine available every 2 hours.

During the interview, Jennifer acknowledges the importance of hanging onto hope that something might work. But she also realistically recognizes the clinical trial might

not work. She seems to understand the uncertainty of an experimental drug. Jennifer acknowledges the focus of her care is not curative. This acknowledgement is accompanied by fear.

### **Continuity of Care**

Continuity of staff, as well as initial and ongoing discussions about incurable prognosis or EOL issues were assessed quantitatively and qualitatively. Jennifer identified her primary doctor and nurse on the baseline demographic self-report form. The physician identified as her primary doctor was a pediatric oncology fellow, who is currently managing her care and work up to enter the Phase 1 clinical trial. The nurse she identified works on the inpatient oncology floor at the tertiary care center. Jennifer spent quite a bit of time in the hospital during her chemotherapy treatments, due to complications. During the interview, Jennifer also mentions this same nurse, pseudonym Adeline, and a patient care assistant, pseudonym Zoe, from the inpatient oncology floor as her 2 primary nurses who she feels comfortable talking to. Jennifer does not identify a current outpatient nurse who is providing follow-up care. During the interview, Jennifer identifies a female doctor as the primary physician she feels comfortable talking to. She struggles to remember her primary physician's name. This may just be a lapse in memory or may be due to the fact that she is transitioning to another primary doctor, who will be following her in the clinic.

One of the disadvantages of receiving care at a tertiary care center is there are many physicians and nurses that provide care. It is a teaching hospital, so there are attending physicians, fellows, residents and medical interns. Sometimes there is a change in physician for a Phase 1 clinical trial. There are inpatient nurses, outpatient nurses, and separate nurses and research staff for Phase 1 clinical trials. There are clinical nurse specialists who address educational needs in the inpatient environment; and pediatric nurse practitioners who have prescriptive authority and see patients in both the inpatient and outpatient setting. The need for continuity of care across inpatient and outpatient settings was evident in Jennifer's case, particularly among the nursing discipline.

### **Initial and Ongoing End-of-Life Discussions**

Part of the eligibility criteria for enrollment in the current QOL study includes acknowledgment by the physician and Jennifer that her cancer is not cured. Jennifer acknowledged this during our first phone contact, and it was acknowledged on the informed consent at baseline. In addition, the signed informed consent/assent for the Phase 1 clinical trial describes “there is not a standard treatment for your cancer at this point”. Dr. Johnson acknowledged Jennifer’s incurable prognosis at the time of referral to the Phase 1 clinical trial and to the current QOL study. There was also documentation in the medical record of Dr. Jones discussing incurable prognosis with Jennifer and her mother.

In summary, Jennifer is living at home with advanced cancer that is currently not cured. She lives with her mother and sister. She is making frequent outpatient visits to a tertiary care center for pain management and a medical work-up to participate in a Phase 1 clinical trial. Jennifer understands the focus of her care is not curative; and recognizes the experimental nature of the Phase 1 clinical trial. She also acknowledges it is helpful to have hope that something might work. Although Jennifer has consented to the Phase 1 clinical trial, she has not yet started the experimental drug. Initially, she consented to hospice, but changed her mind and wants to participate in the Phase 1 clinical trial. Hospice was discontinued since both services cannot be provided simultaneously in this state.

Jennifer lacks continuity of care particularly from the nursing discipline while transitioning from curative therapy. Jennifer identifies two primary physicians. Dr. Jones, provided care during chemotherapy treatment, documented a prognostic discussion about incurable prognosis, and provided the initial referral to a home hospice agency. Dr. Johnson is currently making adjustments in her pain medication to better manage her pain before enrolling in the clinical trial.

Jennifer had an initial prognostic discussion indicating disease progression and incurable prognosis. However, there is no mention or documentation of ongoing discussions about incurable prognosis or EOL with the exception of a signed informed consent for Phase 1 clinical trial.

**Case 2 Time 1**

**Table 27: Context Environmental Characteristics.**

Definition	Data
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Place of Care:</b> Defined as environment where adolescent is living with advanced and incurable cancer</li> </ul>	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• Interviews were conducted at Jennifer’s home. She lives with mother and sister Her home is located in along a busy street in an impoverished neighborhood. There was an alley that ran behind the house, and I was instructed to park in the grass. The back door entered into a small kitchen which led to the Living Room. The environment was clean with very few furnishings. Interviews were conducted in the Living Room with a large L-shaped couch, Love seat and flat screen TV. The room was decorated with a couple of pictures, an old computer, and a large black vase on a coffee table. There was a window air-conditioner.</li> </ul> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Living with mother and sister</li> <li>• Clinic appointments at tertiary care center two times a week for pain control and work up for Phase 1 clinical trial</li> </ul>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care:</b> Defined as adolescent’s perception of specific purpose for care delivery</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>It frightens me knowing that it’s steadily just going to get worse, instead of, you know, slowing down, or being cured.</p> <p>Uhh I guess them tellin’ me like the treatment and complications about the treatment and medications that they wanted me to do and try, that might help me or might not help me. I guess that helped me a little bit knowing that there is hope that something might work. Yeah that helped me out a little bit by saying yeah, there is hope that I can get better</p> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Increased pain on 6-10-10, started on Fentanyl patch and oral morphine</li> <li>• Initially Hospice Referral was made on June 16<sup>th</sup> after prognostic discussion, then Jennifer changed her mind and wanted to enroll in the Phase 1 clinical trial</li> <li>• Returned to clinic for increased pain <ul style="list-style-type: none"> <li>- Fentanyl patch discontinued</li> <li>- Morphine sustained release 160 mg twice a day started, with immediate release 30 mg tablets available every 2 hours if needed</li> </ul> </li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>Medical work-up for Phase 1 clinical trial (Experimental Therapy) <ul style="list-style-type: none"> <li><b>ADVLO919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia (Consent signed 6-22-10; began trial on 7-20-10)</li> </ul> </li> </ul>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Continuity of Staff:</b> Defined as continuation of familiar nursing and medical staff while transitioning to end of life</li> </ul>	<p>Quantitative Data <b>Baseline Demographics Self-Report Form</b></p> <ul style="list-style-type: none"> <li>Adolescent identified Dr. Johnson as primary doctor and Adeline as her primary nurse. Adeline works inpatient on the hematology-oncology floor at the tertiary care center</li> </ul> <hr/> <p>Quantitative Data <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>Dr. Jones is an attending pediatric oncologist who has provided ongoing care during active treatment and through initial EOL discussion.</li> <li>In addition a pediatric oncology fellow, Dr. Johnson is following Jennifer from the tertiary care center as an outpatient</li> </ul> <hr/> <p>Qualitative Data <b>Interview</b></p> <p><i>CB- Okay and how about with um, can you think of like a physician or one of the healthcare providers that you're close to that you feel like that that's the person you usually discuss things, how willing are you to discuss your concerns with them?</i></p> <p>You mean like a doctor or a nurse or?</p> <p>Well I'm close with a couple of the nurses, Adeline and Zoe</p> <p><i>CB- Okay. And do you have a physician that you're close with?</i></p> <p>Umm. Doctor, I'm trying to think of her name.</p> <p><i>CB- Is it Dr. Jones? Sara?</i></p> <p>Yeah, Dr. Jones, Sara Jones. Thank you. I mean it was on the tip of my tongue.</p>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Initial EOL Discussion:</b> Defined as a conversation between physician and adolescent (and his/her family) about impending death or incurable prognosis</li> </ul>	<p>Qualitative Data <b>Eligibility Criteria</b></p> <ul style="list-style-type: none"> <li>Jennifer verbally acknowledged her cancer is currently not cured, prior to consent in QOL study</li> <li>Oncologist referred adolescent to current study based on incurable status</li> </ul>

Definition	Data
	Quantitative Data <b>Medical Record Review</b> <ul style="list-style-type: none"> <li>• Documentation of initial EOL discussion with Dr. Jones on June 15, 2010</li> <li>• Documentation that Jennifer and her mother opted for comfort care on June 15<sup>th</sup></li> <li>• Documentation of Hospice Referral (June 16<sup>th</sup>)</li> <li>• Signed informed consent for Phase 1 clinical trial (June 22<sup>nd</sup>) Verbiage on consent states: the clinical trial is “experimental” and “there is not a standard treatment for your cancer at this point”</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Ongoing EOL Discussions:</b> Defined as ongoing discussions between physician and adolescent or adolescent and his/her family about death or EOL issues</li> </ul>	<b>Medical Record Review</b> <ul style="list-style-type: none"> <li>• <i>There were no other discussions documented in the medical record about incurable prognosis</i></li> </ul>

### *Summary of Context: Personal Characteristics*

Personal characteristics data and definitions for Case 2 Time 1 are provided in Table 28, Context: Personal Characteristics, and summarized in the following text.

#### **Decisional Control Preferences**

Preference for decisional control was determined qualitatively by the semi-structured interview, and quantitatively by the Control Preferences Scale (Degner, Sloan, et al., 1997). Jennifer's top selection was C, "I prefer that my doctor and I share responsibility for deciding which treatment is best for me". Her second preference was D. "I prefer my doctor makes the final decision about which treatment will be used, but seriously considers my opinion". Jennifer's preference for decisional control is a collaborative-passive role. A collaborative-passive role allows Jennifer and her doctor to share the responsibility for treatment decisions. However, Jennifer prefers that her doctor make the final decision after her opinion is seriously considered. She desires knowledge about her disease and disease progression with adequate time to think about decisions; and does not necessarily want to be the one making the final decisions. Having adequate time to think about decisions is important to Jennifer. She prefers to find out information now, as her disease progresses, rather than later. She appreciates the honest communication of her physicians, even when difficult news needs to be communicated.

#### **Knowledge Preference**

Jennifer's knowledge preference was determined quantitatively by having her select from five options ranging from all possible information to no information at all. Jennifer prefers to know all possible information about her condition including both good news and bad news.

#### **Physical Symptom Distress**

Physical symptom distress was measured qualitatively by direct observation and by comments in the interview. It was measured quantitatively by the medical record review and by questions asked during the symptom distress screening using the New Edmonton Functional Assessment Tool (EFAT-2) (Kaasa & Wessel, 2001). At Time 1, Jennifer's EFAT-2 assessment revealed minimal dysfunction for dyspnea, fatigue, and activities of daily living (ADL), with no impact on function for pain and GI distress. However, further inquiry during the interview revealed break-through pain is still an

issue for Jennifer. The physical symptoms that were screened are described in the following text.

### Pain

During the EFAT-2 screening, Jennifer stated her pain is controlled well enough with the medication that she is prescribed, indicating no impact on function. According to the medical record review Jennifer is taking 160 mg sustained-release oral morphine twice a day, with short-acting morphine, (immediate-release) available every 2 hours if needed. She was taken off the Fentanyl patch because it was not effective in controlling her pain.

During the interview, Jennifer said her pain interferes with her mobility because it hurts to move. She continues to experience break-through pain. However, the changes in her pain medications seem to reduce or alleviate the pain.

### Fatigue

Quantitatively fatigue was measured with the EFAT-2 and the medical record review. For the EFAT-2 screening, Jennifer stated she needed to rest less than 50% of her day, which is coded as minimal dysfunction. Qualitatively, Jennifer describes the link between her fatigue and lack of sleep. Jennifer had chronic emesis in May during her chemotherapy treatments which interrupted her sleep. This ultimately affected her energy level and fatigue.

### Shortness of Breath

Dyspnea was measured quantitatively with the EFAT-2 and the medical record review. Jennifer has metastatic tumors in her lungs. During the EFAT-2 screening she showed minimal dysfunction for dyspnea. She had to take 1 breath while counting slowing to 15. However, she is not on any oxygen. In the medical record review, episodes of shortness of breath were documented. Qualitatively during the interview, Jennifer describes she becomes short of breath with upon exertion.

### Mobility

Jennifer is bothered by her immobility. Due to nerve compression and the size of her primary left thigh tumor, Jennifer has lost the ability to bear weight on her left leg. Her left foot droops and turns inward. Mobility was captured under ADL on the EFAT-2. Jennifer is able to move independently with the use of a walker, so her mobility score

showed minimal dysfunction. More importantly, Jennifer links her decrease in mobility to a compromise in her safety. Concerns about her safety, with further probing, revealed a connection to death-related fears. This is described further in the psychosocial symptom distress section below.

### Cachexia

Cachexia was described quantitatively in the medical record and qualitatively through direct observation. Jennifer has wasting of her muscles and pronounced bony prominences. She weighs 92 pounds and is in the third percentile for her height. She is in a hypermetabolic state due to her advanced cancer and despite supplemental gastrostomy tube feedings, she continues to lose weight.

### GI Distress

GI distress was measured quantitatively with the EFAT-2 and the medical record review. Jennifer denies having nausea, vomiting, diarrhea, or GI distress during the EFAT-2 screening, so there was no impact on function. In the medical record review, there was record of Jennifer not tolerating her gastrostomy tube feedings and episodes of chronic emesis in May. This may be due to the chemotherapy regimen at the time. She has oral Zofran available every 8 hours as needed.

## **Psychosocial Symptom Distress**

### Motivation

Psychosocial symptom distress was measured quantitatively with the EFAT-2 screening motivation. Although Jennifer is not able to participate in all activities due to the limitations of her advanced cancer, she did state she was able to participate in activities approximately 50% of the time. Jennifer showed minimal dysfunction on the EFAT-2 for motivation. Since Jennifer's symptoms are better controlled, she is now better able to participate in the activities she enjoys.

### *Fear*

Like Cameron, Jennifer describes fear while living with advanced cancer. Jennifer's fears pertain to the progression of her disease, knowing that she will continue to decline, rather than get better. There is also fear of the unknown related to not knowing the time frame until death, and how a rapid decline will affect her ability to continue living life as she knows it now.

Jennifer's fears related to her immobility seem to affect her on a subconscious level. With further probing, Jennifer describes having dreams about not being able to get out of her wheelchair or being stuck in a burning building. Literature from psychologists working with dying adolescents, have described how some adolescents express their death-related fears through recurrent dreams about sinking in the sand, being lost in a familiar city, taking a trip in a black limousine, or being stuck in a shrinking shower (Tadmor, et al., 2003). Jennifer's dreams may be linked to her fear of dying.

### **Coping Behaviors**

Coping behaviors were not in the original model but emerged as a theme in the qualitative analysis of Jennifer's interview. Jennifer used coping skills to promote patience, to release negative emotions, and to help her remain calm. She finds relief in writing poetry to release her emotions, reading a good book, or doing quiet activities that foster patience. And finally, Jennifer found that talking was a helpful way to cope with her condition. She found value in talking to her social workers and psychologists. Talking relieved the weight and stress of living with advanced cancer.

In summary, Jennifer prefers a collaborative role in treatment decisions, but is willing to have her doctor make the final decision after seriously considering her opinion. She appreciates honest conversations that inform her about her cancer treatment. She prefers to have all information both good news and bad news about her condition. Jennifer has physical and psychosocial symptoms that interfere with daily living, most notably immobility, fatigue, pain, and fears about dying. Jennifer has found ways to cope with advanced cancer by doing activities that reduce her anxiety, relieve stress, and release negative emotions. Coping behaviors that are effective for Jennifer include writing poetry, reading books, participating in quiet activities, such as arts and crafts, and talking to others about her thoughts and feelings.

**Case 2 Time 1**

**Table 28: Context Personal Characteristics.**

<b>Definition</b>	<b>Data</b>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Decisional Control Preferences:</b> Defined as adolescent's preferred level of involvement in decisions about care and treatment         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- Do you want to find out more about what will be happening if your cancer progresses?</i></p> <p>Um... yeah I would like to find out what would happen. I mean I'd rather know what would happen now than finding out when it's too late.</p> <p><i>CB- Okay. So you would like to know information um so that you can kind of make decisions ahead of time? Is that what you're saying? Or think about them?</i></p> <p>Yeah, I'd like to think about them.</p> <hr/> <p>Quantitative Data</p> <p><b>Tool- Control Preferences Scale (CPS)</b></p> <p><b>Preference for involvement in decisions:</b></p> <ul style="list-style-type: none"> <li> <b>Collaborative-Passive Role</b>            Jennifer's top preferences were:           <ul style="list-style-type: none"> <li>- I prefer that my doctor and I share responsibility for deciding which treatment is best for me.</li> <li>- I prefer my doctor makes the final decision about which treatment will be used, but seriously considers my opinion</li> </ul> </li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Knowledge Preference:</b> Defined as adolescent's desire for information related to their disease and prognosis         </li> </ul>	<p>Quantitative Data</p> <p><b>Knowledge Preference</b></p> <p><i>5 options given- ranging from "I want all information good and bad" to "I don't want to know anything at all"</i></p> <ul style="list-style-type: none"> <li> <b>Choice:</b> I want all possible information (Good News and Bad News)         </li> </ul> <hr/> <p>Qualitative Data</p> <p><b>Interview</b></p> <p>They just tell me straight out the truth.</p> <p><i>CB- Okay. And you appreciate that? Knowing...</i></p> <p>Yeah I appreciate them telling me exactly what I need to know. Like the truth, instead of, you know, trying to make things better.</p>

Definition	Data
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Physical Symptom</b>  <b>Distress:</b> Defined as perceived physical symptoms that interfere moderately or severely with daily activities </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>PAIN</p> <p>Um basically the pain. Because my back be hurtin' a lot also. The doctor says it's because of the tumor in the leg and one in the chest wall. Also with the back pain I have, it's hard for me you know, to move to do certain things. Because it hurts too bad for me to move. Um like, when I like sit up, it hurts. And when I try to lay down, I put a whole bunch of pillows behind me or like even when I try to stand up my back hurts, because I'm movin' and so it hurts.</p> <p>The pain medicine they had me on at first wasn't helping. I was in a lot of pain all the time nonstop. So they took me off of the Fentanlyl patches and off my morphine pill and so now I have 160 mg instead of just the 15. But that helps me...and I can take one and the pain that I am in, will just ease up. I can be like in a whole lot of pain and after I take those my pain, you know, let's say it's like a 10 and it drops down to maybe a 2 or a 3. Or I'm at a 5 or a 6 and it drops to more like a zero. So I figure those pills help me with the constant pain, better. But I still do be in pain at times.</p> <p>Qualitative Data</p> <p><b>Interview</b></p> <p>FATIGUE</p> <p>But um it is kind of hard to have energy because I really wasn't sleeping from me being sick and the chemo and medicine I wasn't sleeping a lot so I was, I'm always tired and I just want to lay down and sleep.</p> <p>Qualitative Data</p> <p><b>Interview</b></p> <p>SHORTNESS OF BREATH</p> <p>And it's hard cause I get light-headed and shortness of breath when I try to move around a lot or stand too long.</p> <p><i>CB- Okay, generally speaking, do you have shortness of breath during the day?</i></p> <p>Um yeah, like when I try to get up and move around.</p> <p><i>CB- Okay. And um, does it interfere with the things that you want to do sometimes or most of the time?</i></p> <p>Sometimes. I mean when I was able to walk, I couldn't do like certain activities like sports and everything like that because of my breathlessness.</p>

Definition	Data
	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>MOBILITY But I mean, it's still hard that I can't do those activities, because I'm in a wheelchair and I can't really walk on one leg.</p> <p>And like when I do have energy and I feel hyper I want to do something my mom is like, 'No, sit down and relax' -cause she doesn't want me falling and hurting myself because I mean, I'm like weaker than I was and so I can't really move as good as I was.</p> <p><i>CB- What do you feel are the biggest problems affecting you right now?</i></p> <p>Um the biggest problems affecting me right now would probably have to be my leg, not being able to walk. Because I mean, if there's an emergency or if I need to get out of the house quick, or there's something wrong, I'm not going to be able to do it quickly or you know, move fast enough...that's a problem. That messes with my safety. Not being able to do things. You know, that puts me in danger because I can't.</p>
	<p>Qualitative Data</p> <p><b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• <b>Cachexia</b> <ul style="list-style-type: none"> <li>- Thin and frail</li> <li>- Wasting of muscles</li> </ul> </li> <li>• <b>Mobility</b> <ul style="list-style-type: none"> <li>- Observed Jennifer move from couch to a corner table using walker; does not weight bear on left leg</li> </ul> </li> </ul>
	<p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• <b>Pain</b> <ul style="list-style-type: none"> <li>- Morphine sustained-release 160 mg tablets twice daily.</li> <li>- Morphine 15 mg immediate-release tablets every 2 hours as needed</li> </ul> </li> </ul> <p>Quantitative Data</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• <b>Shortness of breath</b> <ul style="list-style-type: none"> <li>- Shortness of breath documented on 5-20-10 clinic note</li> </ul> </li> <li>• <b>Cachexia</b> <ul style="list-style-type: none"> <li>- Weight 42.2 Kilograms or 92 pounds</li> <li>- Less than third percentile for height</li> </ul> </li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>- Malnutrition</li> <li>- Hypermetabolic state, due to malignancy</li> <li>- Supplemental feedings per gastrostomy tube</li> <li>• <b>GI Distress</b> <ul style="list-style-type: none"> <li>- Not tolerating feedings, chronic emesis with stomach and side pain documented on 5-20-10 clinic note</li> <li>- Medications: oral Zofran 8mg every 8 hours as needed</li> </ul> </li> </ul> <p>Quantitative Data  <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li>• <b>Pain:</b> Minimal dysfunction (pain controlled with current medication)</li> <li>• <b>Dyspnea:</b> Minimal dysfunction (1 breath while counting to 15; no use of oxygen)</li> <li>• <b>Fatigue:</b> Minimal dysfunction (rests &lt; 50% of day)</li> <li>• <b>GI Distress:</b> Functional (Jennifer states she is not having any nausea, vomiting, diarrhea or constipation issues)</li> <li>• <b>Mobility (activities of daily living):</b> Minimal dysfunction (walker used to move around inside house), unable to bear weight on left leg</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Psychosocial Symptom Distress:</b> Defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities</li> </ul>	<p>Qualitative Data</p> <p><b>Interview- MOTIVATION</b>  But I think I'm startin' to get back up to it because I love reading my novels, and writing my poetry and coloring and stuff, so I think I'm starting to get back up to it.</p> <p><b>Interview- FEAR</b>  It frightens me knowing that it's steadily just going to get worse, instead of, you know, slowing down, or being cured. And it scares me that it is only going to get worse and knowing that the doctors are saying, 'Oh we don't know how much time you have left' that scares me. I mean yeah I might live for years on, but I mean, just the fact of knowing that scares me, because of how fast it's spreading. Who knows, it could be months from now! And so that scares me also.</p> <p><b>Interview- FEAR</b>  <i>CB- Going back to the safety thing, getting out of places quickly, is that something that is on your mind a lot?</i>  Yeah. I'm not saying that anything's going to happen to the house. In case we were somewhere else or 'cause like anything could happen. We could be out at the restaurant or at a bank or something and somebody can come up and try to</p>

Definition	Data
	<p>rob or something can happen and I can't run or I can't make it...</p> <p>So that scares me. Because you could be walking down the street and somebody come up, and I can't run.</p> <p><i>CB- Mm-hm. Do you ever have, do you ever have dreams that you can't get out of a place? Or does it bother you on that level? Like where you dream about it?</i></p> <p>I mean, there have been dreams that I've had with me being stuck in my wheelchair; and being in a situation that I needed to get out and I couldn't get out of the chair. So yeah, I mean I had a dream where like I can't remember where we were but we were out somewhere and the building was like caught on fire and I couldn't get out to get out like fast enough because I'm in the chair and I'm rolling and I'm scared of elevators. And I can't get on the elevator and I can't get out the stairs and so, yeah I have had them.</p> <p>Quantitative Data  <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li>• Motivation: Minimal dysfunction (participates in activities 50% of the time)</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Coping Behaviors:</b> Defined as ways of dealing with the difficult situation of living with advanced cancer</li> </ul>	<p>Qualitative Data  <b>Interview</b>  WRITING POETRY</p> <p>Yeah, I love writing poetry. So I mean I write poetry about everyday things, like my life or other people's life or situations that people go through. I write when I'm upset or anything like that. I write. And I keep writing until I feel better.</p> <p>I have three journals of them and I'm working on getting them published</p> <p>Qualitative Data  <b>Interview</b>  READING</p> <p>But I also read novels. I love to read. You should see like when I was at my old house there was this closet with big double doors, I had one of those and along that whole shelf, it was filled with books. In two rows, stacked back to back it was filled with books. I had over a hundred, over a hundred something books, maybe two-three hundred books and I still have most of them. I just got to get a shelf to put 'em on.</p> <p>Yeah. Reading calms me down, I mean, especially</p>

Definition	Data
	<p>a good book. I mean I love novels like fiction or sometimes even a non-fiction book, as long as it's like romance or a horror novel or just drama. I would love it.</p> <p>ARTS AND ACTIVITIES THAT FOSTER PATIENCE</p> <p>Certain little arts and crafts activities, like coloring I have coloring books I color in, you know cause like patience kind of, patience things. I'm not really a patient person but with me coloring and being able to take the time to make the picture look good uses patience and it takes a lot to make me calm down. And I like jewelry. I got a little jewelry kit so I make bracelets and necklaces and you know just little everyday arts and activities. And I've got to get me some more activities.</p> <p>And then this, I have like a little paint app on my phone. And I can show you something...these I made...This one's called Paint Joy.</p> <p>I got like Solitary, and then this game is- it takes patience, it's like a matching game, you take all the blocks off and match them up so it takes patience and memory. So you know, little patience and memory games or art forms are what I like to do. Arts and activities, I like to do all that. Or paint too.</p> <p>TALKING ABOUT IT</p> <p>Yeah. It's a good thing and it should be encouraged for people to talk to their social workers and psychologists. Because I mean you're- with all that's going on you get so stressed out and it feels like everything's piling on. And when you talk and you're relieving some of that stress and there feels like a weight's being lifted off your shoulders and everything. 'Cause you're getting it off your chest and everything and then you know how you feel; instead of keeping it bottled up and piling up and being stressed out even more to the point where you just break down you know. By talkin' to them you're relieving it and it helps you out more. Um so you don't get too stressed out. So you help yourself feel better by talking.</p>

### *Summary of Context: Family and Social Support Characteristics*

Family characteristics data and definitions for Case 2 Time 1 are provided in Table 29, Context: Family Characteristics, page 244, and summarized in the following text

#### **Family Social Support**

Jennifer has a complex home situation. Initially, she lived out of state, but moved here, after her mother established residency. Her mother was working locally but living with her boyfriend and his family. Due to Jennifer's advanced disease, she required a caregiver after discharge so she moved in with her grandmother, out of state, until local residency could be established. Currently Jennifer lives with her mom and her sister.

Jennifer perceives a great deal of support from her family and medical staff; and less support from her friends. This is evidenced in the medical record review, the Multidimensional Scale of Perceived Social Support (MSPSS), and during the Time 1 interview. The main sources of family support that Jennifer mentions during the Time 1 interview are her mother and sister. Jennifer's sister is 2 years younger than her and recently moved here to live with Jennifer and her mother. Jennifer is thankful for support from her mom and sister who include her in activities and help her feel normal. Jennifer feels a close bond with her sister and believes her illness has brought them even closer. She feels her sister would do anything for her.

#### **Family Communication**

Although Jennifer is able to talk to her family, sometimes she is hesitant to discuss her feelings with them, or to broach topics related to death and dying. Jennifer was able to talk to her mother once about the fact that she wishes to be cremated rather than buried. But she realizes death is a difficult topic. Jennifer picks up verbal and non-verbal cues that help her to realize her family's anxiety or distress about her incurable prognosis. She is particularly aware of the look on her sister's face. Jennifer recognizes her family's inability to provide psychological and social support to her, if they are too sad. On the MSPSS family support subscale, the mean score was 6.5 on a scale of 1 to 7. Higher scores indicate more perceived support. Jennifer's quantitative score for family support matches her perception of support evident in the Time 1 interview.

### **Other Social Support**

Jennifer perceives ongoing support from the doctors, nurses, and other hospital staff, such as social workers and psychologists. She appreciates the honesty of her HCPs when she has questions; and senses their support if she needs to discuss anything. Social workers and hospital psychologists were also mentioned as sources of social support. Jennifer describes the ease of talking to a trained professional because they sit, and listen, ask questions, and help with processing thoughts and feelings

Unlike Cameron in Case 1, Jennifer has already graduated from high school. She did not mention social support from teachers or other individuals in her community. The mean score for the MSPSS subscale for significant other support was equivalent to the family support subscale at 6.5. It is possible this subscale score represents the support provided by the doctors, nurses, or other hospital staff.

The only mention of friends during the Time 1 interview occurred when Jennifer described her junior and senior proms. She showed me pictures and referred to the events as some of her favorite memories. The same young man was in both pictures. She says they are still friends. The medical record review describes how she misses her friends and perceives less friend support. Living in a new state has separated her from friends as well. The mean score for the MSPSS subscale for friends was only 3.75. This correlates with her perception of less support from friends. Jennifer's total social support scale on the MSPSS was 5.58, but likely due to her decreased perception of friend support.

### **Family Cultural and Spiritual Practices**

Jennifer acknowledges a belief in God, participates in prayer, and associates with the Christian faith. She said there are people praying for her and telling her God is going to heal her. However, she does not find any of these practices helpful when it comes to coping with her advanced cancer.

### **Family Coping**

Family coping was a category that emerged during the adolescents' interviews while coding content analysis. Jennifer perceives her illness is upsetting to her family members; and this in turn, causes additional distress.

### **Things Not Helpful from Others**

Another category that emerged during content analysis coding of the adolescent interviews described things that were not helpful while living with advanced cancer. For Jennifer, she did not want to talk about her cancer with people that she didn't know, such as friends of her grandmother; and she did not want to be constantly reminded of her illness and its limitations. Jennifer reminds us that dying individuals are still living and do not want to be defined by their illness.

In summary, Jennifer has recently moved to a new community where she lives with her mom and sister. Jennifer perceives a great deal of social support from her mother and sister who help her feel normal and include her in activities. Although she has openly discussed death with her mother, she realizes it is a topic that many people do not want to talk about. She has identified non-verbal cues that constrain discussion about her advanced disease, or death and dying. Jennifer perceives a negative impact on support when her family is too distressed.

Jennifer perceives a great deal of support from her doctors, nurses, and social workers. She also acknowledges support from hospital psychologist as she processes her emotions. Jennifer perceives less support from her friends, but is living in a new community where distance interferes with her ability to be around them.

Jennifer proclaims a Christian faith and belief in God. However, she does not find her spiritual beliefs or practices helpful in coping with advanced cancer. She did not acknowledge any cultural practices.

Jennifer perceives her family is sad or depressed about her condition and that causes additional distress for her. Additionally, she does not like to be reminded of her illness and its limitations, and prefers not to talk about her illness with people that she does not know, such as friends or acquaintances of her grandmother.

**Case 2 Time 1**

**Table 29: Context Family and Social Support Characteristics.**

Definition	Data
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family and Other Social Support:</b> Defined as adolescent’s perception of family and other sources of encouragement, support, and help during difficult times</li> </ul>	<p>Quantitative</p> <p><b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• During initial hospitalization               <ul style="list-style-type: none"> <li>- Perceives less friend support</li> <li>- Annoyed with grandmother who said pain was all in her head, ‘making it up’</li> <li>- Views mom as supportive during difficult times</li> <li>- Mood- engages easily in conversations but appears sad</li> <li>- Mom establishing residency in this area, currently lives with boyfriend and his family locally; no other local residence for Jennifer</li> <li>- Discharge arrangements to live out of state with grandmother who is ‘strict and judgmental’</li> <li>- Complains of being lonely during hospitalization and misses friends</li> </ul> </li> <li>• Currently               <ul style="list-style-type: none"> <li>- Lives with mom and sister</li> </ul> </li> </ul> <p>Qualitative</p> <p><b>Interview</b></p> <p>FAMILY SOCIAL SUPPORT</p> <p>Um, well I have my family to like support me like talk with me and to help me out with things that I need helped out with. So them just supporting me and being there when I need to talk, it helps me out. Especially the nurses and the doctors, if I need to talk or have questions I can go to them.</p> <p>I have the family support I need and everything to make me still feel like I’m normal; and not leave me out of certain activities.</p> <p>But I love my sister. She’s like...I don’t know, I can’t really explain it. How can I say? She’s supportive. ‘Cause I mean she’ll help you out and you know, she’ll do anything for you. And we would be like protective of each other when we were in school. And if I got into a fight or something, or someone tried to fight me, she’d come up to me, to my back and say ‘why you trying to fight my sister?’ ‘You back down!’</p>

Definition	Data
	<p data-bbox="802 235 1101 260">FAMILY SOCIAL SUPPORT</p> <p data-bbox="802 264 1403 327"><i>CB- Okay. And have you always been close or has this illness sort of brought you even closer?</i></p> <p data-bbox="899 331 1409 630">I mean there was times when we were real younger when we didn't get along. We always fought. But then as we got older we were...real close. But you know with me being sick, yeah, it's gotten us even closer. When she found out I was sick, she took it kind of hard. But yeah, it brought us even closer. I think it scares her you know and everything.</p> <p data-bbox="802 667 1302 693">HEALTH CARE PROVIDER SOCIAL SUPPORT</p> <p data-bbox="899 697 1409 861">So them just supporting me and being there when I need to talk, it helps me out. Especially the nurses and the doctors, if I need to talk or have questions I can go to them.</p> <p data-bbox="802 865 1403 966"><i>CB- Okay. And you feel like they'll answer the questions that you have? And are they upfront with you do you feel?</i></p> <p data-bbox="899 970 1435 1163">Yeah. I think they're really upfront. I mean if I ask a question they don't beat around the bush or try to give me an answer that they think I might want to hear or what they think would be best, they just tell me straight out the truth.</p> <p data-bbox="802 1201 1205 1226">HOSPITAL STAFF SOCIAL SUPPORT</p> <p data-bbox="802 1230 1409 1365"><i>CB- Are there social workers or psychologists or anybody else that's part of the healthcare team that you think is- or could be particularly helpful to someone like you?</i></p> <p data-bbox="899 1369 1425 1869">Yeah there's um I think the social workers, I mean, they're a good, a good help when it comes to talkin' about certain things. And psychologists, I didn't really talk to, I talked with them a couple times. But I mean, they're good at helping you too when it comes to, you know you being upset and depressed and you needing someone to talk to and understanding what you're feeling. I mean, it's easy to talk to them because they listen, they sit there and they listen to you and they will ask you questions. And so yeah, I think they're very helpful when it comes to talking to you. It makes you feel better.</p>

Definition	Data
	<p>FRIEND SOCIAL SUPPORT</p> <p>Yeah I mean, we were friends in this one and then we started dating and like this prom was in April of '07 and we started dating in June of '07 so we were still dating in this one but then we broke up but we are still friends so. I talk to him; I get to talk to him. I think he still likes me. Cause I mean how he acts and how his sister says how much he say he worries. His sister says he worries about me. She says 'I think he still likes you Jennifer'. Which is okay, I guess.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family and Other Social Support:</b>            MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (MSPSS)           <ul style="list-style-type: none"> <li>- 12 item scale to measure Social Support</li> </ul> </li> </ul>	<p>Quantitative</p> <p><b>MSPSS</b></p> <p><b>Significant Other Subscale</b></p> <ul style="list-style-type: none"> <li>• There is a special person who is around when I am in need- <u>6</u></li> <li>• There is a special person with whom I can share joys and sorrows- <u>7</u></li> <li>• I have a special person who is a real source of comfort to me- <u>7</u></li> <li>• There is a special person in my life who cares about my feelings- <u>6</u></li> </ul> <p><b>Mean Score = 6.5</b></p> <hr/> <p>Quantitative</p> <p><b>MSPSS</b></p> <p><b>Family Subscale</b></p> <ul style="list-style-type: none"> <li>• My family really tries to help me- <u>7</u></li> <li>• I get the emotional help &amp; support I need from my family- <u>6</u></li> <li>• I can talk about my problems with my family- <u>7</u></li> <li>• My family is willing to help me make decisions- <u>6</u></li> </ul> <p><b>Mean Score = 6.5</b></p> <hr/> <p>Quantitative</p> <p><b>MSPSS</b></p> <p><b>Friends Subscale</b></p> <ul style="list-style-type: none"> <li>• My friends really try to help me- <u>3</u></li> <li>• I can count on my friends when things go wrong- <u>4</u></li> <li>• I have friends with whom I can share my joys and sorrows- <u>4</u></li> <li>• I can talk about my problems with my friends- <u>4</u></li> </ul> <p><b>Mean Score = 3.75</b></p> <hr/> <p>Quantitative <b>MSPSS</b></p> <p><b>Total Social Support Score = 5.58</b></p>

<b>Definition</b>	<b>Data</b>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family Communication:</b>            Defined as the degree of open discussion among family members about difficult topics such as EOL         </li> </ul>	<p><b>Qualitative Data</b> <b>Interview</b></p> <p>Well I have my family to like support me like talk with me...and being there when I need to talk, it helps me out.</p> <p>Sometimes I don't like talking about my feelings with them because I could tell it makes, you know, it gets them all worked up or depressed and they don't like seeing me depressed. Or sometimes they don't, you know, they don't really want to talk about it 'cause they don't know what to say and it's hard for them. So with them being hard for them to talk about it, it be hard for me to talk about it 'cause I wouldn't have the help because it would be too sad for them.</p> <p><i>CB- Have you, have you been able to talk to them about, about um how much you're going to miss them and how much perhaps they're going to miss you?</i></p> <p>Umm, not really. Because I mean that's a hard subject to talk about; and no one wants to talk about death or anything, so it's kind of a hard subject to talk about.</p> <p>I mean I told my mom once, like if I, when I told her I didn't want to be buried I said if I chose I would be cremated.</p> <p>But she (<i>my sister</i>) doesn't like talking about it or showing it. I think she is trying to stay strong and everything for me. 'Cause I can tell without her even saying it.</p> <p>I think she (<i>my sister</i>) try to act like her normal self you know, like she was before I got sick you know. But I can usually see it in her face at times. If I'm sick or I need help, or just the look in her face, I can tell it bothers her.</p>
	<p><b>Qualitative Data</b> <b>Direct Observation</b></p> <p>At baseline data collection and Time 1 Interview, I was able to observe communication and interaction between Jennifer and her mother. At baseline, they spoke openly about her incurable prognosis and how Jennifer may or may not be eligible for the Phase 1</p>

Definition	Data
	<p>clinical trial. They talked about Jennifer's sister, who is a talented artist and has designed some tattoos as a tribute to Jennifer. Jennifer and her mother told me about a trip they are planning to Disney World in the near future.</p> <p>At Time 1, Jennifer's mother and sister were both in the living room with Jennifer. Jennifer's sister was typing at the computer, but did not say anything. Her mother said they would both leave so that Jennifer and I could have some privacy to talk.</p> <p>Quantitative <b>MSPSS</b></p> <ul style="list-style-type: none"> <li>I can talk about my problems with my family- <u>7</u></li> </ul>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Family Cultural and Spiritual Practices:</b> Defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent's personal and family life</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p><i>CB- Are there any cultural traditions or spiritual beliefs or anything that you know kind of help you deal with your advanced disease?</i></p> <p>For me, not really. But to other people it may be. I, I am a Christian. I do believe that there is a God and everything like that, but I wouldn't say you know it helps me cope with me being sick or anything like that. I mean yes there's family members that's praying for me and churches are praying and saying God can heal, can cure me and God's gonna do this for me, and I have faith and I mean I pray myself. But I wouldn't say, like that helped me deal with being sick or help me feel any better. You never know, for some people it might help for them; but for me- not really.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li><b>Family Coping:</b> Defined as adolescent's perception of how family members or others within social support system are dealing with adolescent's advanced cancer</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p>But I mean it's difficult knowing that you're sick and seeing that, you know, family members upset and depressed that you going through it. And the looks on their faces and knowing that they're depressed depresses me out.</p>

<b>Definition</b>	<b>Data</b>
<p data-bbox="282 233 558 260"><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li data-bbox="334 266 760 464"> <p data-bbox="334 266 760 464">• <b>Things Not Helpful from Others:</b> Defined as words or actions of others that are not beneficial, as perceived by the adolescent living with advanced cancer</p> </li> </ul>	<p data-bbox="802 233 1000 260"><b>Qualitative Data</b></p> <p data-bbox="802 266 927 294"><b>Interview</b></p> <p data-bbox="899 300 1430 764">           Uh being reminded that I'm sick doesn't really help me. I know I'm sick and people you know are reminding me...um, being reminded that I'm sick, and people are you know talking about it over and over like 'You're sick and you need to do this and you can't do that'. My grandma and family does, certain family members do that, 'You're sick'. Yes, I know I'm sick. I don't like being reminded I'm sick because it makes me feel even more worse knowing that I'm sick and that's all they want to talk about. And so being constantly reminded of it doesn't really help.         </p> <p data-bbox="899 804 1430 1367">           Mmm, a lot of people coming up to me wanting to talk about it basically, like people I don't know that might know somebody in the family or, and I don't know them and they come up and talk about it, 'How are you feeling today? Are you okay today? Are you hungry? Are you eating?' doesn't really help, it just stresses me out because I hear that so much already and then from people I don't know, it makes it even more stressful...they like may know my grandparents, or...but they don't know me. I have people that go to church with my grandma or they go to my grandma's shop to get their hair done and my grandma tells them about me or gives them my number and then they call me and start talking to me about it.         </p>

### *Summary of Construct: Readiness*

Readiness data and definitions for Case 2 Time 1 are provided in Table 30, Readiness page 253, and summarized in the following text.

#### *Awareness*

Jennifer is aware of her incurable prognosis. As previously mentioned, she had a discussion with her physician about her disease progression and therapeutic options. Jennifer initially opted for comfort measures only, but now is interested in trying a Phase 1 clinical trial.

Jennifer explains how she became aware that her cancer was getting worse in two ways. First, she realized her disease was progressing by the physical changes she was experiencing. When she was first diagnosed with cancer, she was able to walk. As her disease progressed, it affected the strength and mobility of her leg until eventually she could no longer walk. Secondly, her doctors kept her informed of her disease progression. Initially, she understood her cancer was confined to the tissue and nerves of her left leg, and as the cancer progressed, she was told it spread to her bone, chest walls, and under her right arm. Despite a cognitive awareness of her disease progression and incurable prognosis, Jennifer did not always operate in an open awareness context. During the Time 1 Interview, Jennifer vacillated between an open awareness context and a mutual pretense awareness context. This was not sequential. She moved back and forth between the two contexts. I followed her lead as we discussed her hopes and fears.

Initially, Jennifer openly acknowledged her incurable prognosis and steady progression of her disease. There were other times when Jennifer needed to be away from the constant awareness of death. She needed to hope and believe that her life was going to be normal. I felt like I needed to allow her to be there too. In the mutual pretense awareness context, she discussed going to college and starting her own business. Toward the end of the interview, Jennifer once again talks about the inevitability of her disease progression. She recognizes the importance of living today and doing what she is able to do for as long as possible.

### *Acceptance*

Acceptance was measured quantitatively with the Peaceful Acceptance of Illness Subscale from the Peace Equanimity and Acceptance in the Cancer Experience (PEACE) Scale (Mack, et al., 2008). Jennifer's total subscale score for peaceful acceptance was 17. This is comparable to the higher Peaceful Acceptance scores in adults living with advanced cancer (Mack, et al., 2008). The Peaceful Acceptance of Illness Subscale has 5 items that are measured on a scale of 1 to 4 (not at all, to a slight extent, to some extent, to a large extent). Individual items along with Jennifer's scores are listed in Table 30. She responded with a (3) to some extent or (4) to a large extent on all five subscale items.

During the interview, Jennifer's acceptance of her cancer diagnosis and its limitations seemed to vary. For example, at one point she demonstrated a certain resignation that although she still doesn't like it, she is okay with knowing she will not be able to do certain things again. At another point in the interview, she was not willing to accept her limitations and set a personal goal to get her leg to work again so that she can walk. Although quantitatively Jennifer's Peaceful Acceptance of Illness subscale score is relatively high, qualitatively she vacillates back and forth in her degree of acceptance. However, there are several times where Jennifer acknowledges a struggle to accept her terminal condition. She finds it particularly difficult to think about leaving her family behind.

### *Willingness to Take Action*

The third component of the Readiness construct is willingness to take action to prepare for EOL or engage in discussions about EOL. Items were measured on a scale of 1 to 4 (not at all, to a slight extent, to some extent, to a large extent). Jennifer's responses are included in Table 30. For example, although Jennifer was willing to talk about her worries and concerns to a large extent with both her family and HCPs, she was not as willing to discuss her feelings, or things that make her sad or afraid. As previously mentioned under family communication, Jennifer picks up social cues that help her to realize her family or HCPs do not want to talk about emotionally charged topics. This quote is repeated in Table 30.

Jennifer's willingness to find out more about what to expect if her cancer progresses was rated a (4), to a large extent. As previously mentioned in the personal

characteristics section, Jennifer's knowledge preference was to know all possible information good and bad news. Here Jennifer clearly shows willingness or intent to acquire knowledge about her disease as it progresses, and would prefer to have that information now.

In summary, at Jennifer's Time 1 interview, awareness, acceptance, and willingness to take action are not a linear process. Jennifer demonstrates a great deal of willingness to take action by engaging in discussions about her worries, and finding out more about her disease progression. However, Jennifer shows less willingness to discuss her emotions based on social cues she picks up from her family or HCPs.

Awareness and acceptance are not static traits. Although Jennifer has been informed about her disease progression and incurable prognosis, she does not always operate in an open awareness context. She fluctuates between open awareness and mutual pretense awareness contexts. In the same way, Jennifer does not always accept the limitations of her disease or her terminal prognosis. She is particularly struggling with the emotional separation from her family that is an inevitable part of death. There were times during the interview when Jennifer wanted to talk openly about the fact that she is dying, but there were other times when she needed to still imagine a future with a college degree and a career of her own. The key was allowing Jennifer to lead the two of us back and forth as she processed the reality of her situation.



Definition	Data
<p>- <b>Open awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in open awareness, the dying individual and others recognize impending death, and openly acknowledge death will eventually occur. Their behavior and communication support an open awareness context.</p>	<p>know, to deal with it and say, ‘Okay, I can do this and I can beat it’ because I understand what’s going on.</p> <p>MUTUAL PRETENSE AWARENESS Yeah. My goals um I wanted to go to college on campus but I couldn’t because my leg had gotten bad. But I mean I’m still, you know, planning on going online. But my goals are to: go to college, get my degree and you know at least try to start my own business or get a good career, you know, in what I want to do.</p> <p>OPEN AWARENESS It frightens me knowing that it’s steadily just going to get worse, instead of, you know, slowing down, or being cured. And it scares me that it is only going to get worse and knowing that the doctors are saying, ‘Oh we don’t know how much time you have left’ that scares me. I mean yeah I might live for years on, but I mean, just the fact of knowing that scares me, because of how fast it’s spreading. Who knows, it could be months from now! And so that scares me also.</p> <p>Because you know I want to do things that I can do now and want to do ‘em. And that way when the time comes and I am sick and can’t do it, at least I did it this “so and so”. And I had fun and I did it this many times and it wasn’t scheduled. So I just want to go out there and live.</p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Acceptance:</b> Defined as the level of emotional acquiescence of an incurable prognosis</li> <li>- <b>PEACE- Peaceful Acceptance of Illness Subscale</b></li> </ul>	<p>Quantitative Data</p> <p><b>PEACE- Peaceful Acceptance of Illness Subscale</b> (1 = not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b><u>4</u></b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b><u>3</u></b></li> <li>• To what extent do you feel that you have made peace with your illness? <b><u>3</u></b></li> <li>• Do you feel well-loved now? <b><u>4</u></b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b><u>3</u></b></li> </ul> <p><b>Total Subscale Score = 17</b></p>

Definition	Data
	<p><b>Qualitative Data</b></p> <p><b>Interview</b></p> <p>Yeah. It took me a while to um get used to, you know, having to do these things or knowing that I'm not going to be able to do certain things again. It took a while... I mean I still don't like it just 'cause I can't help out and everything but I'm okay with it.</p> <p>...if I die it was time for me to go...</p> <p><b>STRUGGLE TO ACCEPT</b></p> <p>And another thing that I want to accomplish is me being able to use this leg again... Yeah I can't really walk or use that foot and this is all I can do to it (rotates and flexes foot minimally). But my plan is to get it to stretch out again. I hate having it bent up. And try to get that foot moving so I can walk again.</p> <p>I couldn't, I can't, I couldn't bear leaving my mom and my sister behind. I wouldn't know, I wouldn't figure how they would feel. I wouldn't know what they will go through and do, you know, after something like that.</p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness to Take Action:</b> Defined as level of intent or desire to take action to prepare for EOL, or engage in EOL discussions</li> </ul>	<p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to discuss concerns</b></p> <p><i>CB- How willing are you to discuss your concerns or things that you're worried about with one of your family members? Would you say not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To a large extent = <b>4</b></p> <p><i>CB- Okay. And how about the same thing, the same question for Dr. Jones and the 2 nurses you feel close to, Adeline and Zoe?</i></p> <p>To a large extent = <b>4</b></p>

Definition	Data
	<p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to discuss feelings</b></p> <p><i>CB- Okay. And the second question is just a little bit different, but it also asks about your willingness to talk but this one is about your feelings or the things that make you sad or afraid. How willing are you to talk about that with your family members? And the second part is with the nurses and doctor that you've identified. Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To some extent for both = <u>3</u></p> <p>Because um sometimes I don't like talking about my feelings with them because I could tell it makes , you know, it gets them all worked up or depressed and they don't like seeing me depressed. Or sometimes they don't, you know, they don't really want to talk about it 'cause they don't know what to say and it's hard for them. So with them being hard for them to talk about it, it be hard for me to talk about it 'cause I wouldn't have the help because it would be too sad for them.</p>
	<p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to find out more as cancer progresses</b></p> <p><i>CB- Okay. So uh the third question then is, do you want to find out more about what will be happening if your cancer progresses?</i></p> <p>Um... yeah I would like to find out what would happen. I mean I'd rather know what would happen now than finding out when it's too late.</p> <p><i>CB- Okay. So you would like to know information um so that you can kind of make decisions ahead of time? Is that what you're saying? Or think about them?</i></p> <p>Yeah, I'd like to think about them.</p> <p><i>CB- Okay, so would you say you would like that to a slight extent, to some extent or to a large extent?</i></p> <p>Um to a large extent = <u>4</u></p>

### *Summary of Construct: End-of-Life Preparedness*

End-of-life preparedness data and definitions for Case 2 Time 1 are provided in Table 31, EOL Preparedness, page 260, and summarized in the following text. All data for the EOL preparedness construct were obtained qualitatively from the semi-structured interview. In Jennifer's Time 1 interview, there were several examples that showed she was processing her grief and emotions, as well as her existential thoughts about her own existence after death. For the most part, EOL preparedness was not packaged into neat little boxes that followed each attribute. Rather, it spilled out into many areas, which are demonstrated in the examples in Table 31. Communication was a driving force that facilitated EOL preparedness. In the same way, when communication was blocked or missing, EOL preparedness was also blocked or missing.

#### *Knowledge about End-of-Life*

Knowledge about EOL is defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue and may help with pragmatic decisions about advance directives and preferred location of death. At Time 1, EOL discussions about knowledge on what to expect physically and emotionally were missing. These are difficult topics for HCPs to talk about, and it is not always known, if, or when, the adolescent wants to have such conversations about what to expect with death and dying. However, Jennifer clearly indicated her willingness to find out more about what would be happening as her disease progresses. Just asking that one question about willingness prompted Jennifer to elaborate on the topic and say she wanted the information now, before it was too late, so that she would have adequate time to process the information. Unfortunately Jennifer is left with the uncertainty of not knowing what she can expect, and what her choices are. This results in fear of the unknown. Examples of Jennifer's fear were given in previous sections when she described not knowing how long it will be, or how it will physically affect her as the cancer rapidly spreads. Her fear is manifested in daily thoughts of being unable to escape a harmful situation because she is in a wheelchair; and her dreams of being unable to escape from a burning building.

### *Acknowledgement of Grief and Emotions*

Acknowledgement of grief and emotions is defined as recognition of grief, loss, or anticipated separation of death; and the accompanying emotions that loss, separation, or death bring. Jennifer is grieving multiple losses. She is grieving her life will be shorter than it should be, because she is young and her “fun” years have just begun. She is grieving the loss of her mobility and her ability to do every day normal activities. She is grieving her inability to work and contribute to the financial stress her family is experiencing. But most of all she is grieving the loss and separation from her family. She is concerned about their well-being after she is gone. See Table 31.

Although Jennifer talks very openly with me, she expresses hesitation in openly discussing her grief and emotions with her mom and her sister. Death is a difficult topic to talk about; particularly when it involves someone you know or care about deeply. Death can bring powerful emotions to the surface, and sometimes those emotions become barriers or road blocks to open communication. Jennifer has identified the social cues (verbal and non-verbal) that inhibit discussions about grief and emotions.

Jennifer acknowledges she will miss her family and she knows they will miss her, but she is not really comfortable talking about that with them. Jennifer shared her hopes with me that her family will continue to live and be happy after she is gone.

### *Identification of the Meaning of Death and Spirituality*

Another attribute of EOL preparedness involves identification of the meaning of death and spirituality. This is defined as the adolescent’s discovery of the significance of death and any spiritual beliefs related to death. My discussion with Jennifer about grief and emotions also captured her spiritual beliefs about life after death. She believes she will always be with her family in spirit. Jennifer did not share any comments about the meaning of death, other than knowing if she dies it was her time to go.

### *Conceptualization of an End-of-Life Plan*

The final attribute in EOL preparedness is conceptualization of an EOL Plan. This is defined as the development of a plan which includes the adolescent’s goals, priorities and EOL preferences. At Time 1, Jennifer identifies her primary goals as going to college, and starting a career, and re-gaining the use of her leg. She has not put a lot of thought into immediate goals or setting priorities. She did not really like the idea of

developing a plan or outline to share with her family or healthcare provider. She mainly wants to focus on living today and doing things she is able to do each day. For Jennifer a plan seems too specific. Whereas, living with advanced cancer has multiple variables that could interfere with moving the plan into action. See Jennifer's quotes on conceptualization of EOL plan, in Table 31. Jennifer is looking forward to going on a trip to Florida with her family. In addition, she wants to make memories together with her family, doing simple things like having a barbeque, or doing something fun together.

In summary, at Time 1, Jennifer was able to discuss her grief and emotions, and her thoughts about life after death. She could at least think about what memories she wanted to make in the near future, with her family. She had a difficult time conceptualizing a plan that would list her priorities, because she identified too many variables that could interfere with her ability to carry out a plan. Jennifer's goals were futuristic, and somewhat unrealistic. However, they provided a necessary buffer to the reality of her impending death.

**Case 2 Time 1**

**Table 31: End-of-Life Preparedness.**

<b>Definition</b>	<b>Data</b>
<p><i>EOL Preparedness</i></p> <p><b>End-of-Life Preparedness:</b> Defined as process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end-of-life consistent with his/her desires. Attributes include: knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan</p> <ul style="list-style-type: none"> <li>• <b>Knowledge about EOL</b> Defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue and may help with pragmatic decisions about advance directives and preferred location of death.</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>There were no examples given pertaining to Knowledge about EOL.</i></p> <p>LACK OF KNOWLEDGE ABOUT EOL</p> <p>Um... yeah I would like to find out what would happen. I mean I'd rather know what would happen now than finding out when it's too late.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Acknowledgement of Grief &amp; Emotions:</b> Defined as recognition of grief, loss, or anticipated separation of death; and the accompanying emotions that loss, separation, or death bring</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>GRIEVING A SHORTENED LIFE</p> <p>And knowing that the doctors are saying, 'Oh we don't know how much time you have left' that scares me.</p> <p>I mean, my life, you know I'm just twenty so I'm like halfway there or not even half. But I'm not, how can I say this? My fun years and you know young years isn't over yet.</p> <p>GRIEVING LOSS OF MOBILITY</p> <p>I can't really do a lot of things I want to do.</p> <p>I still can't do day to day activities.</p> <p>But I mean, it's still hard that I can't do those activities, because I'm in a wheelchair and I can't really walk on one leg.</p> <p>GRIEVING LOSS OF CONTRIBUTION TO FAMILY</p> <p>I mean I want to be able to say, 'Ok I went to work today. I got this bill for you Mom! Don't worry about it'</p>

Definition	Data
	<p data-bbox="1003 226 1438 296">-but I can't do it... And I <i>hate</i> that I can't do that.</p> <p data-bbox="906 331 1360 359">GRIEVING SEPARATION FROM FAMILY</p> <p data-bbox="1003 363 1360 432">Yeah. And leaving my family behind.</p> <p data-bbox="1003 468 1438 695">I couldn't, I can't, I couldn't bear leaving my mom and my sister behind. I wouldn't know, I wouldn't figure how they would feel. I wouldn't know what they will go through and do, you know, after something like that.</p> <p data-bbox="906 730 1422 863"><i>CB- Mm-hm. Have you, have you been able to talk to them about, about how much you're going to miss them and how much perhaps they're going to miss you?</i></p> <p data-bbox="1003 898 1422 1367">Umm, not really. Because I mean that's a hard subject to talk about; and no one wants to talk about death or anything, so it's kind of a hard subject to talk about. But I know that they'll miss me a lot and I know they'll know I'll miss them too. But, I mean, when that time do come I don't want them to be, you know, sad and you know, just depressed and give up on life. I want them, you know, to still live their life and be happy and everything.</p> <p data-bbox="906 1402 1422 1465"><i>CB- Mm-hm, mm-hm. Do you think saying that to them might be helpful?</i></p> <p data-bbox="1003 1501 1438 1892">Um. It might. I mean I told my mom once, like if I; when I told her I didn't want to be buried I said if I chose I would be cremated. That way, like she can have my ashes with her, sitting somewhere. And so I mean, that way she'll feel like I'm still there with her. I might not be there physically and verbally, but spiritly and that way, I'll still be there for her. Uh you know, that way she can have me close to her</p>

Definition	Data
	<p>and everything. And then she heard about somethin' on the internet or something; like they take somebody's ashes and they put 'em like in a diamond or somethin' like that and they can have it like in a necklace or a ring. I told her well she can do that like in a necklace, and you know always have me close with her. And she could have it in the shape of a heart. So I would be like near her heart. I told her that and it made her smile a little so. It made her laugh, we were joking around at the time. But, I mean I could tell she liked it.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Identification of the Meaning of Death and Spirituality:</b> Defined as the adolescent's discovery of the significance of death and any spiritual beliefs related to death</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p>Because if it were, I mean, if I die it was time for me to go; and know that I'm still with them in spirit and everything. So I'm always going to be with them.</p> <p>I would be cremated. That way, like she can have my ashes with her, sitting somewhere. And so I mean, that way she'll feel like I'm still there with her. I might not be there physically and verbally, but spiritually and that way, I'll still be there for her. Uh you know, that way she can have me close to her and everything.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Conceptualization of an EOL Plan:</b> Defined as the development of a plan which includes adolescent's goals, priorities and EOL preferences</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p><i>CB- Tell me about some of those things that you hope you can accomplish in the time that you have left. Do you ever think about the goals and things you want to do?</i></p> <p>Yeah. My goals um I wanted to go to college on campus but I couldn't because my leg had gotten bad. But I mean I'm still, you know, planning on going online. But my goals are to: go to college, get my degree and you know at least try to start my own business or get a good career, you know, in what I want to</p>

Definition	Data
	<p>do. And another thing that I want to accomplish is me being able to use this leg again.</p> <p>Yeah I can't really walk or use that foot and this is all I can do to it (rotates and flexes foot minimally). But my plan is to get it to stretch out again. I hate having it bent up. And try to get that foot moving so I can walk again.</p> <p>So that's what my main goals are: school and for me to try to walk again.</p> <p><i>CB- Um we talked a little bit about some of the things that you want to do or accomplish in the months ahead, or year ahead. Have you thought about developing a personal plan or outline that perhaps you can share with your family or healthcare provider that's closest to you; so they kind of know some of the things that you want to do?</i></p> <p>No I haven't really thought about it. Mostly, the main thing that I want to do is go to Florida, which we are. But other than that I mean I just really like for, you know today just going out and living it, and trying to have fun. Not planning things, just going out and say 'Okay let's do this today or let's do this, <i>this day.</i>'</p> <p>Yeah. And, 'Let's go out and do this on this weekend'. So you know I mean when, we haven't been really planning anything or don't want it to be planned. You know 'cause me planning things and say 'yeah let's do this!' Because we don't know when I'm going to; it's just too difficult to say 'Okay I'm goin' to plan this so we can do this' because I'm not gonna be able to do it on this time or I might not be able to do it then. Because you know I want to do things that I can do now and want to do 'em. And that way</p>

Definition	Data
	<p data-bbox="1003 233 1430 426">when the time comes and I am sick and can't do it, at least I did it this "so and so". And I had fun and I did it this many times and it wasn't scheduled. So I just want to go out there and live.</p> <p data-bbox="906 468 1430 630"><i>CB- Okay, how about like memories? Have you thought about like memories you want to make with your family or things that you want to do so that you can have some things to remember together?</i></p> <p data-bbox="1003 667 1430 1163">Um. You know, vacations and trips and stuff. Like on the 31<sup>st</sup> we're going to Florida so that's a memory that I want them to remember and me to remember perfectly. You know, like all the fun that we're goin' to have and everything like that. 'Cause we're gonna take tons of pictures and stuff like that. Family reunions and barbeques, you know just spendin' time with the family; is mostly the memories that I want for them to, everybody to remember. All the good times and stuff like that.</p>

### *Case 2 Time 2 Data Analysis*

Triangulated data analyses from Case 2 Time 2 are presented in this section. Data for Case 2 Time 2 were collected three weeks from Time 1. Findings are presented in the same way as Time 1. Tables are provided for each of the main constructs, with a summary of the data presented in the text. Constructs included in this analysis section are contextual factors (demographic, environmental, personal and family characteristics), readiness (awareness, acceptance and willingness to take action or engage in EOL preparedness), EOL preparedness (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of a plan), communication of personal EOL plan, and quality of life at the end of life.

#### *Summary of Context: Demographic and Environmental Characteristics*

Demographic and Environmental Characteristics data and definitions for Case 2 Time 2 are provided in Table 32, Context: Demographic and Environmental Characteristics page 267, and summarized in the following text. The only demographic data that changed for Case 2 at Time 2 pertained to disease status. A week after Time 1, Jennifer started on the Phase 1 clinical trial, **ADVL0919** Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia. A week after the trial started, Jennifer was seen in the clinic and had a wound consult for multiple subcutaneous lesions on her buttocks and thighs. In addition there are soft tissue lesions in her spine, surrounding each nerve root, beginning at L5. At Time 2, Jennifer expresses a concern about her progressive weakness and fears her disease is getting worse.

Jennifer continues to live at home with her mom and sister. She is seen on an outpatient basis at the tertiary care center. The study drug that she is on requires frequent monitoring by EKGs and blood work. Jennifer understands the focus of her care is experimental, and states, she will know by September if the study drug is working or not. If it is not working she will be taken off the Phase 1 clinical trial. If it is working, she will remain on it. I asked her if she thought about what if it doesn't work. After some hesitation, she describes she will simply continue to live.

Jennifer is continuing to see Dr. Johnson at least once a week. This is providing continuity of care as she is facing her advanced and incurable prognosis. She does not see Dr. Jones very much anymore. She believes her doctors are doing everything they can and she appreciates that. Jennifer did not identify any nursing personnel at Time 2. However, she does have a private aide which is discussed more under the personal characteristics section. In addition, services were coordinated at the outpatient tertiary care center for a wound consult and social work consult. Although there were no discussions about EOL documented by the physician, Jennifer saw one of the social workers at the clinic and briefly discussed some of the things she wants to do before she dies. She also shared her grief about how her life will end sooner than she would like.

In summary, at Time 2, Jennifer continues to live at home with her mom and sister making frequent visits to the tertiary care center. She is benefitting from the full services available at the tertiary care center, including wound and social work consults. She has the continuity of one primary physician, Dr. Johnson, but does not mention any ongoing nursing support. She has started a Phase 1 clinical trial which requires frequent monitoring. Jennifer realizes the study drug is experimental and will be offered for a limited time. She will be taken off the study drug in September, if she is showing no response. At this point, Jennifer's disease is continuing to progress with new lesions in her spine and subcutaneous tissue of her buttocks and thighs. Jennifer acknowledges physical cues, namely weakness, that contributes to her cognitive awareness that her disease may be getting worse. Although there are no EOL discussions documented in the medical record from a physician standpoint, there was documentation of an EOL discussion with the social worker. Additionally, Jennifer has been talking to her mother more about her fears related to EOL. These discussions are included in the family characteristics section that follows.

**Case 2 Time 2**

**Table 32: Context Demographic and Environmental Characteristics.**

<b>Definition</b>	<b>Data</b>
<p><b>DEMOGRAPHIC SECTION</b> <i>Demographics</i></p> <ul style="list-style-type: none"> <li>• <b>Disease Status:</b> Defined as a description of adolescent cancer experience specifically related to the diagnosis and prognosis as well as the trajectory of the illness</li> </ul>	<p>Quantitative Data <b>Medical Record Review</b> Started on Phase 1 clinical trial (Experimental Therapy) July 20, 2010</p> <ul style="list-style-type: none"> <li>- <b>ADV L0919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia</li> </ul> <p>7/27/10 Clinic Note</p> <ul style="list-style-type: none"> <li>- Day 8 of 1<sup>st</sup> cycle of Phase 1 ADV L0919</li> <li>- Wound consult</li> <li>- Subcutaneous lesions on buttocks, thighs</li> <li>- Soft tissue lesions surrounding each nerve root beginning at L5</li> <li>- Multiple plexiform neurofibromas in pelvis and lower extremities</li> </ul> <hr/> <p>Qualitative Data <b>Interview: Disease Status</b> I feel weaker. I mean I may not feel a lot weaker but I can tell the difference.  ...and I'm afraid that I'm getting worse</p>
<p><b>ENVIRONMENTAL SECTION</b> <i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Place of Care:</b> Defined as environment where adolescent is living with advanced and incurable cancer</li> </ul>	<p>Qualitative Data <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li>• Interview conducted at adolescent's home. <i>No new information</i></li> </ul> <hr/> <p>Quantitative Data <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Ongoing Clinic appointments at tertiary care center for current Phase 1 clinical trial. Seen in clinic twice weekly</li> </ul>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care:</b> Defined as adolescent's perception of specific purpose for care delivery</li> </ul>	<p>Qualitative Data <b>Interview</b> Besides the experimental drug they got me on, no nothing really has changed. <i>CB- Okay, how's it going with the experimental drug?</i>  We don't know yet. They've been having me get blood work and EKGs done like twice a week.</p>

Definition	Data
	<p>And I go get scans done on the 17<sup>th</sup> and then we find out if the drug is working after two months...September I should find out.</p> <p>And if it isn't working, they'll take me off it. But if it is working I guess they're gonna keep me on.</p> <p><i>CB- Okay. Have you thought about what if it doesn't work at all? Or?</i> I'll probably just have to just live life until whatever happens.</p>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff:</b> Defined as continuation of familiar nursing and medical staff while transitioning to end of life</li> </ul>	<p>Quantitative Data <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Primary oncologist is now Dr. Johnson</li> </ul> <p>Qualitative Data <b>Interview</b></p> <p>I think the doctors are trying their hardest and they're doing everything that they can and I appreciate that. 'Cause they haven't given up on me yet so I appreciate that.</p> <p><i>CB- Okay. And you see Dr. Johnson, that's who you see the most right now?</i> Yes.</p> <p><i>CB- How about Dr. Jones? Do you see her very much?</i> Sometimes...but Dr. Johnson, I see him mostly.</p> <p><i>CB- Okay, about how often are you seeing him?</i> Um I'm going in the doctor's office about twice a week so I think I'm seeing him once a week out of the two times I go.</p> <p><i>No mention of ongoing nursing support</i></p>
<p><i>Environmental Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Ongoing EOL Discussions:</b> Defined as ongoing discussions between physician and adolescent or adolescent and his/her family about death or EOL issues</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p><i>Discussions with family documented under family communication section</i></p> <p>Quantitative Data <b>Medical Record Review</b> Clinic Note on 7-22-10 Social Work note</p> <ul style="list-style-type: none"> <li>- Talked briefly about things she wants to do before "it's too late"</li> <li>- Tearful when talking about the fact that her life will end sooner than she wants it to.</li> </ul>

### *Summary of Context: Personal Characteristics*

Personal characteristics data and definitions for Case 2 Time 2 are provided in Table 33, Context: Personal Characteristics, page 272, and summarized in the following text. At Time 2, Jennifer discusses her preferences for involvement in treatment decisions and knowledge about her disease progression. Jennifer stands firm in her belief that adolescents have the right to know what is happening as their cancer progresses, and when their cancer can no longer be cured. She recognizes adolescents may not always know what to do, but should at least be given the information and the options that are available. Jennifer also acknowledges her desire to include her mother in discussions and decisions about her care, particularly as her disease progresses. Jennifer realizes her legal age as an adult, but expresses the need to have someone “older and wiser” looking out for her interests, given the situation at hand. Jennifer’s comments reinforce her desire for a collaborative role in decisions about her care.

One interesting shift at Time 2 was Jennifer’s preference for knowledge as her disease progresses. Although I did not ask Jennifer her knowledge preference with the 5 choices given at Time 1 (“*I want all information good and bad*” to “*I don’t want to know anything at all*”), I did measure willingness to obtain knowledge as her disease progresses. This is part of the readiness construct. Jennifer expresses a desire to know about her disease and even the progression of her disease; however, she is experiencing a great deal of fear. If the study drug does not work, she said she is too afraid to find out what is going to happen. It appears she wants some information but not all information. This brings up an important question. Is there a limited window of time when discussions about what to expect and knowledge about EOL is less threatening? Does it help to find out this information ahead of time, so that advanced care planning is already taken care of? If so, would that alleviate some of the fear of the unknown? These are questions that have not been answered in this study.

Jennifer continues to have physical symptoms that, according to the EFAT-2, minimally interfere with her daily activities. There were no changes in her medications to treat her physical symptoms. Her symptoms include, pain, dyspnea, fatigue, GI distress and mobility issues. In addition, she is bothered at Time 2 by an increase in weakness. Jennifer’s weakness fluctuates from day to day. Although she might have a bad day, and

then a good day; the next time she experiences a bad day, she detects a change for the worse. Her weakness is steadily progressing. Jennifer continues to have cachexia. Although she is not having trouble with her heart, she is being closely monitored with EKGs because of the potential adverse effect of the study drug on her heart.

At Time 2, Jennifer's most notable symptoms are related to her psychosocial symptom distress. She has a great deal of fear, and is struggling mentally and emotionally with acceptance of her terminal prognosis. She is unable to control the decline in her condition. She does not understand why this is happening to her, or what she can do to make it better, or if there is anything else she can try. Jennifer's fears include the fear of the certainty of death, and the uncertainty that accompanies the process of dying. Jennifer's fears also include leaving her mom and sister behind, and no longer being there to support them. She fears not having enough time to do the things she wants to do before she dies. Lastly, she recognizes her fear is sometimes manifested in dreams, and states her bad dreams started after she found out she was getting worse.

According to the EFAT-2, Jennifer is experiencing moderate dysfunction for motivation. She participates in activities that she enjoys less than 50% of the day. She engages in some activities easier than others, such as reading rather than writing; however, she claims her motivation is starting to increase.

At Time 2, Jennifer uses active coping behaviors to deal with her advanced disease. She tries to focus on the positive, and what she is able to do. For example, she recently went on a trip to Disney World with her family, rather than dwell on all the things she could not do, she thought about how she was able to spend time with her family, and travel to a place she had never been before. Likewise she focuses on the goals that she is still able to accomplish, rather than the ones that seem out of reach.

Another coping behavior Jennifer uses is identifying with other individuals who are coping with similar or challenging situations. This helps her to realize that she too can get through the situation at hand. Examples include other children diagnosed with cancer and her uncle who is paralyzed.

Jennifer continues to benefit from engaging in activities she enjoys, such as reading, coloring, or writing poetry. She thinks of them as hobbies. They act as a form of distraction to keep her mind from dwelling on her situation; so they give her a mental reprieve.

Lastly, Jennifer actively chooses to fight back, even though she is cognitively aware her disease is advancing. She exercises a determination to fight not only for herself, but for her mom and her sister. She is not willing to give up, and pushes herself to do as much as she can to stay strong physically and mentally.

In summary, at Time 2, Jennifer continues to prefer a collaborative role in decisions about her medical care. She maintains her stance that adolescents deserve to have all information about their disease progression, incurable prognosis, and treatment options. However, she is hesitant to gain more information about her own disease progression. Jennifer acknowledges decisions may become more difficult as her cancer continues to advance; and therefore, communicates a desire to involve her mother in a collaborative role to provide additional support in decision-making.

Jennifer's physical symptoms are relatively the same, except for her progressive weakness. Jennifer is experiencing a great deal of psychosocial distress, namely fear related to death and dying. Her fears seem to interfere with her daily living, and are also manifested subconsciously in her dreams. At Time 2, Jennifer shares several more ways she actively copes with her condition, including focusing on the positives, doing what she can, and fighting back despite her worsening condition.

**Case 2 Time 2**

**Table 33: Context Personal Characteristics.**

Definition	Data
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Decisional Control Preferences:</b> Defined as adolescent's preferred level of involvement in decisions about care and treatment         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- Do you think it would be important for us as HCPs to try um to get some conversations going so that we could find out what that adolescent or young adult would like to do in the event that their cancer is not cured?</i></p> <p>I think conversations with us or with anyone who's going through it would you know help them out with what they need, what they want to do with it, if it can't be cured and it might be kind of hard to figure out what they want to do but they at least need to know what's going on and know that they have options.</p> <p><i>CB-Mm-hm. When would be a good time for um those sorts of conversations to be initiated?</i></p> <p>I'd say when it's very important to be talked about it. Like when that time comes and it needs to be talked about, is when they should talk about it...So I think that a conversation should become, you know when it needs to come around.</p> <p>I'd say the conversation would probably be good to start, you know as it progresses like they can start sayin' 'Okay this is what's going on with you' and then while they keep a track, keep an eye on it as it progresses further on 'til they know what they need to do know what's going on and you know give the options to the person. So I'd have to say as it progresses.</p> <p>PARENTAL INVOLVEMENT IN DECISIONS</p> <p>I know I'm an adult and everything and my decisions is the ones that they're going to go by; but sometimes you know, I might not know the right decision to make and I might need my mom's help on choosing what's right and what they think I should do...So I can see you know, what she thinks might help and get her opinions and what she think I should do; and then me, myself, my opinions on what I should do; and you know work it out together to come to a decision on what to do.</p> <p>I'm just you know still basically a teenager, and I don't know a lot you know, of what's going on. And my mom you know, she's older than me so she probably knows people who went through it or seen or learned something about it. So she</p>

Definition	Data
	<p>probably knows what's going on or what to do, better than I can. So yeah, I'd have to say as time goes by, yeah that would be a good thing. <i>(Pause)</i> 'Cause she's more older and more wise than me.</p>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Knowledge Preference:</b>            Defined as adolescent's desire for information related to their disease and prognosis         </li> </ul>	<p>Qualitative Data  <b>Interview</b>            I think conversations with us... would help...out ...if it can't be cured ...but they at least need to know what's going on and know that they have options.</p> <p><i>CB- How willing are you to find out more information about what will be happening if your cancer progresses?</i>            To a slight extent. Because I mean as it progresses and if the drug isn't working I mean, I'd be too afraid to know what's going to happen. So I mean I want to know what's going to happen but I'm also afraid of what's going to happen. So I'd have to say to a slight extent.</p>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Physical Symptom Distress:</b> Defined as perceived physical symptoms that interfere moderately or severely with daily activities         </li> </ul>	<p>Qualitative Data  <b>Direct Observation</b></p> <ul style="list-style-type: none"> <li> <b>Cachexia</b>            - Unchanged         </li> </ul> <p>Qualitative Data  <b>Interview</b></p> <p>PAIN            Um sometimes. Like I have back pain and stuff. But the pain pills I'm on mostly work so I don't hurt a lot.</p> <p>FATIGUE            Um I started off doing more but I'm starting to cut back down so I mean I might take me a small nap during the day but then I'm up for a while and go back to sleep later on that night.</p> <p>WEAKNESS            I feel weaker. I mean I may not feel a lot weaker but I can tell the difference. So when I move around like that I may be moving real well on one day and then the next day I... don't feel like moving</p> <p>Yeah it fluctuates. Yeah like one day I feel good and then the next day I'm bad and then the day after that I'm good again... 'Cause like the days that I am weak you can tell I'm weaker more than I was the last time I was weak.</p>

Definition	Data
	<p><b>WEAKNESS (Cont.)</b> So like if I'm moving good one day and then I get a little weak the next day and like I'm moving but I'm hardly moving and then the next day I'm good and then when I get weak again...</p> <p>POTENTIAL SYMPTOMS OR SIDE EFFECTS FROM CLINICAL TRIAL Yeah and they're also giving me EKG's to make sure the medicine isn't messing with my heart. And so far it hasn't been affecting my heart so.</p> <p>Quantitative Data <b>Medical Record Review</b> 7/27/10 Clinic Note</p> <ul style="list-style-type: none"> <li>- Day 8 of 1<sup>st</sup> cycle of Phase 1 ADVL0919</li> <li>- EKG pre-dose, 4 hour post dose, and 24 hour post dose</li> <li>- Wound consult</li> <li>- Subcutaneous lesions on buttocks, thighs</li> <li>- Soft tissue lesions surrounding each nerve root beginning at L5</li> <li>- Multiple plexiform neurofibromas in pelvis and lower extremities</li> </ul> <p>Quantitative Data <b>Tool: Edmonton Functional Assessment Tool- revised (EFAT-2)</b></p> <ul style="list-style-type: none"> <li>• <b>Pain:</b> Minimal dysfunction (pain controlled with current medication)</li> <li>• <b>Dyspnea:</b> Minimal dysfunction (Counted to 15 taking 1 breath); no use of oxygen)</li> <li>• <b>Fatigue:</b> Minimal dysfunction (rests approximately 50% of day)</li> <li>• <b>GI Distress:</b> Minimal dysfunction (Jennifer states she is recently having trouble with nausea but no vomiting)</li> <li>• <b>Mobility (activities of daily living):</b> Minimal dysfunction (walker used to move around inside house, unable to bear weight on left leg)</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Psychosocial Symptom Distress:</b> Defined as perceived psychosocial symptoms that interfere moderately or severely with daily activities</li> </ul>	<p>Qualitative Data <b>Interview</b> EMOTIONAL DISTRESS Um I would have to say I don't know because it's hard emotionally and mentally because I feel bad that I have to you know, have help doing all of this and I can't do it on my own and I feel, I feel kind of jealous of people sometimes because they can get up and walk and get on the rides and have fun and go bike riding and I can't. I can't dance anymore. So I mean I feel bad about it sometimes</p>

Definition	Data
	<p>EMOTIONAL DISTRESS (<b>Cont.</b>)  Umm things that are heavy on my mind right now are stuff like why this has to happen to me, and what can I do to make it better, and is there anything else we can do or try, and um you know I don't want to get sicker, I don't want this happening, I want to be around for a long time,</p> <p>FEAR OF DEATH  I mean, I'm scared, I don't want my life to end, you know even though the doctors say they don't know when it's going to happen it's still a scary fact that you know you actually know it's going to happen so I'd have to say those are the things mostly on my mind.</p> <p>and that I'm scared of what's going to happen and I don't want it to happen and I'm really scared about it</p> <p>I was afraid of what was going to happen. And I'm afraid <i>of what's</i> happening</p> <p>FEAR OF LEAVING FAMILY BEHIND  So to me, that's what scares me the most, leaving my family behind, (<i>pause</i>), especially my mom and my little sister.</p> <p>Yeah I'd have to say my mom and my sister's, you know, always been there for me all these years and when I want to be there for them I can't be and that's really scary.</p> <p>FEAR THAT TIME IS RUNNING OUT  So much that you want to do and that you're afraid that you might not be able to do</p> <p>and you're afraid 'cause you don't want to miss out on those things</p> <p>I'm afraid of what's happening and I'm afraid that I can't do anything and I'm afraid that I'm getting worse</p> <p>SUBCONSCIOUS FEARS  They're more like me just waking up like I jump up and everything yeah but not waking up screaming.</p> <p>I'd say mostly that those dreams started after I found out that I had gotten worse is when some of those dreams started happening. But I mean I haven't had one in the last few weeks so maybe I'm okay.</p>

Definition	Data
	<p><b>MOTIVATION</b> I'd probably have to say around maybe less than 50 percent of the day. I mean I do most of my reading, since I got my new book I started reading. I haven't written anything yet but I mean I still got some ideas of what I want to write, I just can't put it together yet... but I'm starting to get motivated to do it.</p> <p>Quantitative Data <b>Tool:</b> <i>Edmonton Functional Assessment Tool- revised (EFAT-2)</i></p> <ul style="list-style-type: none"> <li>• Motivation: Moderate dysfunction</li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Coping Behaviors:</b> Defined as ways of dealing with the difficult situation of living with advanced cancer</li> </ul>	<p>Qualitative Data <b>Interview</b></p> <p><b>FOCUSING ON THE POSITIVES</b> There's things that I didn't get to do; but I still be able to have fun. Like, I mean, when we went to Florida I didn't get to get on any of the rides but I mean I was with my mom and my sister so that was fun. And we were somewhere that we've never been before.</p> <p><b>DOING WHAT YOU CAN</b> And the things that you know you want to do and you <i>can</i> do...you gotta try to shoot for it and ...when you go to do it, do it as much as you can and try to have as much fun as you can.</p> <p>I think just doing as much as you can like trying to get up and get out of the house with my mom and sister as much as I can or walk around as much as I can or color or just anything to move around.</p> <p><b>IDENTIFYING WITH OTHERS</b> I gotta think there's people out there worse than me and I'm doing as good and I can. And as long as I don't give up and still try to live my life and have as much fun as I can then I should be okay.</p> <p>I have a cousin who can't move nothing but like his neck and he's still living and it has to be hard on him but he doesn't show it, he shows that he's smiling and laughing all the time and it's hard on him and it's hard me and he's worse than me, so I gotta think, I mean he's still happy and going through what he's going through so what I'm going through isn't as bad so I can still be happy.</p> <p>Cause I know that um there's other people with the same kind of cancer as me at the hospital too. I met a little girl with hers under her arm...</p>

Definition	Data
	<p data-bbox="740 235 846 260">HOBBIES</p> <p data-bbox="837 264 1422 464">Um I'd have to say maybe some hobbies. Something that they love to do and so they can do that and keep them happy and keep their mind off what's going on so they won't stress themselves out. So...hobbies, you know just something they love to do, love to have around.</p> <p data-bbox="837 499 1430 594">I think it helps I mean, because if I'm reading my books or writing a poem then I don't think about it and so I have to say that helps mentally</p> <p data-bbox="740 636 927 661">FIGHTING BACK</p> <p data-bbox="837 665 1422 831">I look at myself, I'm a fighter, I don't give up easily. I may say I want to give up and say I'm going to give up but I don't. I push myself to do my hardest. And I've always pushed myself to do my hardest, even when it came to school.</p> <p data-bbox="837 867 1430 1033">I'd have to say I guess that's what I'm doing now is pushing myself to show my body that I can fight it and even though I know I'm getting sicker, that I can try to make myself feel stronger; and not give up! And still live my life.</p> <p data-bbox="837 1068 1341 1136">I know I'm going through a hard time but I haven't given up yet.</p> <p data-bbox="837 1171 1422 1304">And I know it's hard but I have to keep trying and have to stay strong for me, my mom, my sister and I can't give up yet. (Pause) ...Well I won't give up.</p>

*Summary of Context: Family and Social Support Characteristics*

Family characteristics data and definitions for Case 2 Time 2 are provided in Table 34, Context: Family Characteristics, page 280, and summarized in the following text. There were no new data on family cultural and spiritual practices, or family coping. At Time 2, Jennifer perceives ongoing social support mainly from her family and HCPs. She feels support from her doctors because they are trying to do everything they can, and are not giving up on her. This statement is troublesome, because Phase 1 clinical trials are not intended to cure. However, Jennifer seems to perceive this as an attempt from her doctors to do everything. She senses their personal investment in her because of this treatment.

At Time 2, I was also able to follow up on Jennifer's comment from Time 1. She perceives that at times, talking about death or EOL issues is too stressful for her doctors, or nurses, or family members. Jennifer was able to replicate non-verbal cues, including body posture, location of hands, and the looks on their faces. Jennifer gives us great insight into social cues that might constrain communication about EOL.

Jennifer's disease is very advanced. Her mother and her sister both work outside of the home. Arrangements have been made for Jennifer to receive additional support at home for help with meal preparation and activities of daily living. Jennifer says her home health aide provides not only physical support, but also emotional support when she needs to talk to someone.

Jennifer acknowledges social support from her family and friends, but primarily acknowledges that support comes from her mom and sister. Jennifer is thankful for their support as she faces the uncertainty of her advanced disease. Their support helps her feel less alone; and she views her life as "good" because they are a part of it.

Open family communication has allowed Jennifer to share some of her worries and fears with her mother and sister. She said she talks to them about her fear that her cancer is progressing. Jennifer's sister becomes sad during their conversations, and communicates her feelings non-verbally. Jennifer says her sister's eyes tell it all. This in turn, prompts Jennifer to change the topic of conversation, or to lighten the mood.

In contrast, Jennifer describes a recent conversation with her mom while they were in Florida. Jennifer saw everyone having fun and doing things that she can no longer do; and this was hard. Jennifer's mom was able to provide reassurance as Jennifer spoke about her fears and concerns. Jennifer's mom reminded her that together they were going to do as much as possible for as long as possible.

In summary, at Time 2, Jennifer acknowledges social support from her doctors, home health aide, sister, and mom. Her main sources of support are her mom and sister. Jennifer communicates openly with them about her fears related to disease progression and her incurable prognosis. Jennifer acknowledges her sister has more difficulty in talking about the fact that she may not be cured. Regardless, Jennifer is thankful for the support her mom and sister provide as she faces the uncertainties ahead.

Jennifer continues to be aware of the verbal and non-verbal cues from family members and HCPs that interfere with communication about death and dying. Emotions are sometimes demonstrated through body language, the tone of voice, or facial expression. Talking about death can bring about powerful emotions that are linked to pain and suffering related to personal experiences with death. The art of EOL communication involves recognizing and acknowledging emotions in order to be fully present with individuals who are facing death.

Case 2 Time 2

Table 34: Context Family and Social Support Characteristics.

Definition	Data
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <b>Family and Other Social Support:</b> Defined as adolescent's perception of family and other sources of encouragement, support, and help during difficult times         </li> </ul>	<p><b>Interview</b> HEALTH CARE PROVIDER SOCIAL SUPPORT</p> <p>I think the doctors are trying their hardest and they're doing everything that they can and I appreciate that. 'Cause they haven't given up on me yet so I appreciate that.</p> <p>Yeah I have a couple of nurses that say that I inspired them too because they said with what I'm going through and like how bad it is they said they would've gave up and they wouldn't deal with it and they see that I'm still trying and I haven't given up yet so they say that I inspire them.</p> <p>I mean I have doctors and nurses that I trust really good</p> <p><i>CB- Last time we talked about conversations with the nurses or doctors and you mentioned that no one really wants to talk about death because it kind of stresses people out...and you said that sometimes stresses you out. So I was wondering if you could tell me about some of those ways that you knew you were stressing people out. Some of the cues, the things that helped you realize 'wow this was just way too difficult for my doctor or my nurse for me to be saying this'.</i></p> <p>Um facial expressions you know just certain phrases or certain things that they say but mostly I would have to say the facial expressions.</p> <p><i>CB- Okay and what way was their facial expression?</i> You know like um like (<i>she places both hands on either side of her head, placing the palms against her temples</i>) 'oh no I can't deal with this' or (<i>grabs the middle of her forehead and furrows her brow, then lets her head fall downward</i>) 'this is too much'; those kind of, type of things. Or like you can see the sadness in their face. That's how you can, I could tell it's too much for someone to hear or it's too hard or depressing I could tell by their facial expressions.</p>

Definition	Data
	<p><i>CB-Do you have anybody that comes into the house or do you have any healthcare people that can come in to help?</i></p> <p>Yeah. I have a private aide.</p> <p><i>CB-Okay. And is that helpful to have somebody like that that's helping you physically?</i></p> <p>Yeah it's helpful. Cause like when I need help to get up or anything she's right there to help me and even if I need someone to talk to and I don't have my mom or my sister near me she'll talk with me if I need it, so she's also supportive.</p> <p>FAMILY SOCIAL SUPPORT</p> <p><i>CB- So who are those people that are your support system in your life right now?</i></p> <p>I would have to say my mom, my sister, my mom's, some of my mom's friends, my sister's friends, you know, I have a couple of my friends that are really supportive too. And my grandma is supportive. She worries a lot but she's supportive. But mostly the people I go to talk to is my mom and my sister.</p> <p>That's the reason she (<i>my sister</i>), you know, that's why she came back up here was to be around me as much as she can and to help me as much as she can cause she doesn't want me suffering and all that.</p> <p>...if I break down crying and everything I have my family there to help me feel better.</p> <p>And I have my family here so I have to say my life is pretty good 'cause I'm not going through it myself.</p> <p>... if I was going through this by myself I don't know if could handle it and I probably would just give up all together and it wouldn't be good on me. So I'd have to say my life is pretty good 'cause I have you know family to go through this with me. Even though I don't want them to have to go through this with me but I have them and their support, so.</p> <p>Yeah I'd have to say my mom and my sister's, you know, always been there for me all these years</p>

Definition	Data
	<p><b>FAMILY SOCIAL SUPPORT (Cont.)</b></p> <p>Yeah I remember once I think my mom was at work and I was at my grandma house and I woke up screaming. My uncle...and then my grandma... rushed to see what's wrong with me ...and they were like 'Are you okay?' and I said I had a bad dream. It was so horrible I can't believe the dream was so bad that I woke up screaming and I knew right then and there that they would be there for me when I needed them because they came downstairs running too and they didn't leave out of the room until I fell back asleep.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li> <p><b>Family Communication:</b> Defined as the degree of open discussion among family members about difficult topics such as EOL</p> </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>Like my sister she doesn't, when she talks she doesn't show or say or explain how she feels. I could tell how she feels in her eyes, her eyes tell it all. I can tell when my sister is upset or when she is sad or angry by just how her eyes look. When I was talking to her yesterday about how I was feeling on the way home and everything before we left and I could see the look in her eyes and it was sad. She was sad so I tried you know, to do some laughing to get her to lighten back up.</p> <p>I was talking, I explained about how I wasn't feeling so good and I was feeling kind of weak and she (<i>my sister</i>) doesn't like me feeling sick or weak because she knows I'm already feeling bad and she doesn't want me to feel worse</p> <p><i>CB- Can you tell me about a time when you talked to someone about being afraid of the fact that your cancer might not be cured and can you tell me kind of how that conversation went?</i></p> <p>I talk to my mom and my sister about that all the time um I would say I was probably having a hard time doing something or maybe standing up to try and walk; and I'd sit back down and start crying...</p> <p>And I think the last conversation I had about that, was just a couple days ago while we were out of town. Because I seen all the people having fun and I couldn't get up and have fun so I was talking to my mom about it. About how I'm afraid of what's happening and I'm afraid that I can't do anything and I'm afraid that I'm</p>

Definition	Data
	<p>getting worse (<i>pause</i>) so yeah. I'd have to say that's the last time, how it started off.</p> <p><i>CB-How did your mom respond to that?</i></p> <p>Mmmn, um, she responded you know being supportive saying that yeah you know that's not all a kid can do but um (<i>pause</i>) we gonna try to get you to do as much things as you can do and get you to have fun like while you can; and you know she was being supportive (<i>pause</i>) and trying to make me feel better, trying to do things to make me laugh.</p> <p><i>CB- Who is the person that you feel most comfortable with, in talking about your hopes, your fears, and your worries?</i></p> <p>Again, I'd probably have to say my family... There are you know doctors and nurses and other people that I would talk about it with. But when it comes to like deep down into it, I'd have to say my family.</p>
<p><i>Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Cultural and Spiritual Practices:</b> Defined as any social, ethnic, spiritual or religious practice that holds an important place in the adolescent's personal and family life</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>No new information on family cultural and spiritual practices at Time 2</i></p>

### *Summary of Construct: Readiness*

Readiness data and definitions for Case 2 Time 2 are provided in Table 35, Readiness, page 291, and summarized in the following text.

#### *Awareness*

At Time 2, Jennifer is aware of her incurable prognosis, but during the interview she chooses to interact in both an open awareness context and mutual pretense context. She has been taking a Phase 1 study drug for 2 weeks now. She is hoping that it will work, but is somewhat skeptical because of the physical changes in her condition, namely the weakness. During the interview, Jennifer went in and out of open awareness, and in and out of her struggle to accept that her life will soon end.

There are many factors that determine how long an individual will live with metastatic disease, including the type of cancer, the organs that are affected, co-morbid conditions, age, nutritional status, and the will to live, etc. So it is not known how long the dying process will last. The uncertainty of not knowing is particularly troublesome for Jennifer. There are things she wants to do, and things she can no longer do. Uncertainty adds to her fear of dying before she is able to achieve her priorities in life, which in turn, contributes to her struggle of acceptance.

Examples of mutual pretense and open awareness contexts are represented in Table 35. In the mutual pretense awareness context, Jennifer plans on saving money for a trip to Jamaica next year, and hopes that she will make it to her 40<sup>th</sup> birthday. In the open awareness context, she openly admits knowing that she is going to die, and she doesn't want her life to end.

#### *Acceptance*

Acceptance was measured using the Peaceful Acceptance of Illness Subscale from the Peace Equanimity and Acceptance in the Cancer Experience (PEACE) Scale (Mack, et al., 2008). Individual items along with Jennifer's score for Time 2 are listed in Table 35. Jennifer's total subscale score for peaceful acceptance at Time 2 remained at 17. There were changes in her responses to some of the individual items. The response to her 'inner peace and harmony' did not change. The response to 'feeling well loved now' did not change. The response to her 'inner calm and tranquility did not change. The 2 items that changed were: "To what extent are you able to accept your diagnosis of cancer?" It

went from a “4” down to a “3”. And “To what extent do you feel you have made peace with your illness?” went from a “3” to a “4”. These items may be a reflection of the fluid nature of Jennifer’s acceptance with her incurable cancer.

Most examples of Jennifer’s acceptance from the qualitative content of Time 2 interview involve a struggle with acceptance. However, there are 2 examples that show she accepts her fate, without going against it. In both examples, Jennifer focuses on living life in the presence of knowing her life will end. Her acceptance involves the choice to continue to live and do what she is able to do, without all the added struggle and turmoil.

During the interview, Jennifer moved in and out of her struggle to accept that fact that she is dying, much like she moved in and out of an open awareness context. There are several themes attached to Jennifer’s struggle to accept. One of her main struggles involves the inevitable separation from her family. She is worried about what will happen to them after she is gone. She struggles with not being around to share in life accomplishments, or provide support when times get rough.

Another theme in Jennifer’s struggle for acceptance involves accepting her unfulfilled dreams. There are things she wants to do, and knows she will be unable to do. She wants to go to college and walk across the stage at graduation. The reality of her disease forces her to readjust her goals. She is exploring the possibility of going to school on-line. There may come a time when she will have to readjust that goal as well. So wanting something, then realizing it cannot happen involves a struggle, then an acceptance, then a readjustment to continue. Jennifer’s acceptance is captured at different points of the struggle-acceptance continuum.

The last struggle with acceptance for Jennifer involves comprehending why this is happening to her. There is not an explanation for why any of this has to happen. It goes against all logic. Why one person and not another? Why good people and not bad? Why a young person who is just starting out in life, rather than someone who has lived a long and meaningful life? We will never have the answers and no words will ever be good enough to convince someone to accept this fate. Acceptance is a process of letting go of all preconceived notions that living a good life results in good things. There is no logic. There is no reason. The only thing we have to offer is our presence and support, so that dying will not occur alone.

### *Willingness to Take Action*

The last component of the Readiness construct is willingness to take action to prepare for EOL or engage in discussions about EOL. Willingness at Time 2 was measured by the same three items that were asked during the interview at Time 1. Jennifer's willingness changed in the 4 weeks from baseline data collection to Time 2. Her willingness to discuss her concerns, as well as her willingness to discuss her feelings did not change. However, her willingness to find out more as her disease progresses did change. Four weeks prior, Jennifer wanted to find out more about her disease progression "to a large extent". At Time 2, Jennifer is hesitant to find out more about her disease progression. Her willingness in this category changed from a "4" to a "2". This was discussed in the personal characteristics section of Time 2, so it will not be elaborated here. But fear seems to be interfering with her willingness to find out more about her disease progression at this time point.

In summary, awareness, acceptance, and willingness to take action are not a linear process. The individual attributes are not static. At Time 2, Jennifer shows us how willingness can change over time, particularly in her willingness to find out more information about disease progression. Jennifer moves in and out of open awareness and mutual pretense awareness contexts. She also moves in and out of acceptance and the struggle to accept impending death. The reasons for her struggle to accept that her life will end are varied, and involve cognitive, emotional, and spiritual processes. Cognitive processes involve readjusting priorities to align with hopes and dreams. Emotional processes involve grieving the loss of so many things, but particularly the separation from her family. Spiritual processes involve finding meaning in life and death. Jennifer is involved in an existential struggle to understand why this is happening to her. She is processing things cognitively, emotionally and spiritually. At Time 2, there are incremental changes, but largely, the struggle continues.

**Case 2 Time 2**  
**Table 35: Readiness.**

<b>Definition</b>	<b>Data</b>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness:</b> Defined as the level of cognitive recognition of an incurable prognosis               <ul style="list-style-type: none"> <li>- <b>Mutual pretense awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in this context the dying individual is aware he/she is dying; the healthcare provider or family is also aware, but all agree to act as if the dying individual is going to live</li> <li>- <b>Open awareness context:</b> defined as the context within which the adolescent interacts with others about impending death; in open awareness, the dying individual and others recognize impending death, and openly acknowledge death will eventually occur. Their behavior and communication support an open awareness context.</li> </ul> </li> </ul>	<p>Quantitative Data  <b>Medical Record Review</b></p> <ul style="list-style-type: none"> <li>• Discussion with Social worker on 7-22-10 about things she wants to do before she dies; and how her life will be ending sooner than she wants it to.</li> </ul> <p>Qualitative Data  <b>Interview</b>            MUTUAL PRETENSE AWARENESS            I want to travel more. I've been to Florida, I want to go to other places. Especially like to maybe Jamaica or like my friend's sister said she goes to Jamaica every year so next year I would- I get to go with her...I just have to save up my money for a plane ticket and I can go with her.             Yeah. I'm just hoping that I be able to make it to my 40<sup>th</sup> birthday.</p> <p>Qualitative Data  <b>Interview</b>            OPEN AWARENESS            I'm scared, I don't want my life to end, you know even though the doctors say they don't know when it's going to happen it's still a scary fact that you know you actually know it's going to happen             I don't want to get sicker, I don't want this happening, I want to be around for a long time, I mean, I'm scared, I don't want my life to end,             I'm afraid of what's happening and I'm afraid that I can't do anything and I'm afraid that I'm getting worse</p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Acceptance:</b> Defined as the level of emotional acquiescence of an incurable prognosis               <ul style="list-style-type: none"> <li>- <b>PEACE- Peaceful Acceptance of Illness Subscale</b></li> </ul> </li> </ul>	<p>Quantitative Data  <b>PEACE- Peaceful Acceptance of Illness Subscale</b>            (1 = not at all, 2 = to a slight extent, 3 = to some extent, 4 = to a large extent)</p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>3</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>4</b></li> <li>• Do you feel well-loved now? <b>4</b></li> </ul>

Definition	Data
	<ul style="list-style-type: none"> <li>• To what extent do you feel a sense of inner calm and tranquility? <u>3</u></li> </ul> <p><b>Total Subscale Score = 17</b></p> <p>Qualitative Data</p> <p><b>Interview</b></p> <p>ACCEPTANCE</p> <p>I'll probably just have to just live life until whatever happens.</p> <p>...and even though I know I'm getting sicker, that I can try to make myself feel stronger; and not give up! And still live my life.</p> <p>STRUGGLE TO ACCEPT SEPARATION FROM FAMILY</p> <p>So to me, that's what scares me the most, leaving my family behind, (<i>pause</i>), especially my mom and my little sister...I would hate to see what would happen to her or my mother if something happened to me.</p> <p>And I know it's hard but I have to keep trying and have to stay strong for me, my mom, my sister and I can't give up yet. (<i>Pause</i>) ...Well I won't give up.</p> <p>...knowing that they'll be okay isn't enough 'cause you can't see if they'll be okay 'cause you won't be here.</p> <p>...and when I want to be there for them I can't be and that's really scary. I want to be there for when my sister, you know goes off, 'cause she's really good at drawing, I want to be there for her when she goes off to college and get that degree or get that good business that she wanted. I want to be there for my mom when she you know decides to do whatever she wants to do and open up her own business or something I want to be able to be there and see all that.</p> <p>STRUGGLE TO ACCEPT UNFULFILLED DREAMS</p> <p>'Man I can't do this! I have to miss out on it 'cause this is happening to me'. And so you have to deal with you know missing out on things, and not being able to do things. it's hard cause you know there's things you got to miss out on... There's so much I want to do and there's so much I know I can't do but there's so much stuff I still want to try.</p>

Definition	Data
	<p>STRUGGLE TO UNDERSTAND WHY</p> <p>I mean I don't think anyone deserves to go through this. I mean I know there's bad people out there...but still I don't think anyone deserve to go through being sick and knowing that they're getting worse or that they're going to die...I don't think anyone deserves that. Even if they are criminals or how bad they are they still don't deserve it. Everybody...deserve to be healthy and live their life ...</p> <p>'cause if you are a good person you're thinking to yourself, 'What could I do for this to happen to me? I didn't do anything to no one. I'm always a good person and I never did anything illegal, never caused trouble so I have no idea why this is happening to me!' Stuff like that goes through your head.</p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li> <b>Willingness to Take Action:</b>            Defined as level of intent or desire to take action to prepare for EOL, or engage in EOL discussions         </li> </ul>	<p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to discuss concerns</b></p> <p><i>CB- How willing are you to discuss your concerns or things that you're worried about with one of your family members? Would you say not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To a large extent = <u>4</u></p> <p><i>CB- How willing are you to discuss your concerns or things you're worried about with one of your primary nurses that you have contact with or Dr. Johnson or Dr. Jones?</i></p> <p>To a large extent = <u>4</u></p> <p>I mean I have doctors and nurses that I trust really good, so to a large extent I'll talk to them about it.</p> <hr/> <p>Quantitative Data (verbally collected during interview)</p> <p><b>Willingness to discuss feelings</b></p> <p><i>CB- And then the second question is: how willing are you to talk about your feelings and those are the things that, um you're talking about that make you sad or afraid? Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p>To some extent for both = <u>3</u></p> <p>And I'd have to say just because I don't want to put a lot on anybody because I mean I'm already putting a lot on myself and with me depressed I don't want them being depressed either. And 'cause if they, if I have to stay strong then I'm gonna need them to be strong too.</p>

Definition	Data
	<p data-bbox="773 235 1435 296"><i>CB- Okay and that goes for your family and/or your doctors or nurses?</i></p> <p data-bbox="870 302 1122 331">Yeah, for everybody.</p> <hr/> <p data-bbox="773 359 1422 388">Quantitative Data (verbally collected during interview)</p> <p data-bbox="773 394 1393 424"><b>Willingness to find out more as cancer progresses</b></p> <p data-bbox="773 451 1435 615"><i>CB- And then the last question, it talks about your willingness to find out more information. So how willing are you to find out more information about what will be happening if your cancer progresses? Not at all, to a slight extent, to some extent, or to a large extent?</i></p> <p data-bbox="870 621 1122 651">To a slight extent = <u>2</u></p> <p data-bbox="870 678 1435 871">Because I mean as it progresses and if the drug isn't working I mean, I'd be too afraid to know what's going to happen. So I mean I want to know what's going to happen but I'm also afraid of what's going to happen. So I'd have to say to a slight extent.</p>

### *Summary of Construct: End-of-Life Preparedness*

End-of-Life preparedness data and definitions for Case 2 Time 2 are provided in Table 36, EOL Preparedness, page 294, and summarized in the following text. All data for the EOL preparedness construct were obtained from the semi-structured interview.

#### *Knowledge about End-of-Life*

Knowledge about EOL is defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue, and may help with pragmatic decisions about advance directives and preferred location of death. At Time 2, there were no qualitative or quantitative data to indicate discussions about the process of dying, EOL preferences, or advance directives have occurred. However, as previously described in the personal characteristics section of Time 2, Jennifer describes her thoughts about involving adolescents in discussions about advance directives or treatment options at EOL. She believes adolescents have a right to know everything that is happening. Discussions should be ongoing as the disease progresses, so the adolescent has adequate time to think about and process the information. Although Jennifer is of legal age to be treated as an adult, she prefers to involve her mother in discussions about her disease progression and prognosis, at this time point. A segment of the discussion regarding decisional control is repeated in Table 36 under knowledge about EOL.

#### *Acknowledgement of Grief and Emotions*

At Time 2, Jennifer spent a great deal of time discussing her grief and emotions, particularly her fears about death and dying. This has been covered thoroughly in Jennifer's Time 2 discussion about psychosocial symptom distress, and in the readiness section when addressing acceptance. It will be briefly discussed here. Quotes that were previously discussed in the other sections are repeated, if applicable, in Table 36 under acknowledgement of grief and emotions.

Generally speaking, Jennifer expressed her emotions (i.e. fear about death and dying), and her grief related to her multiple losses. Jennifer is grieving the loss of things that have already occurred, and that are yet to come. Jennifer grieves for her unfulfilled dreams, her loss of mobility, loss of independence, reduced lifespan, and separation from her family. Death will also rob Jennifer of the opportunity to participate in the future celebrations and accomplishments of her family. Acknowledging grief and emotions

gives the dying individual the opportunity to validate the multiple losses that accompany death. When emotions are shared within the context of the adolescent's social support system, it also provides the opportunity for others to offer comfort and reassurance in the face of uncertainty.

#### *Identification of the Meaning of Death and Spirituality*

Identification of the meaning of death and spirituality is the third attribute of EOL preparedness. It is defined as the adolescent's discovery of the significance of death and any spiritual beliefs related to death. The existential struggle that Jennifer is experiencing was evident at Time 2. Jennifer acknowledges a belief in God at Time 1. She claims however, that her spiritual beliefs and practices do not provide additional comfort as she confronts death. At Time 2, Jennifer discusses her spiritual beliefs related to death or an after-life. For example, she believes family members who have died are "looking down and watching over her", and acknowledges the possibility that they are reincarnated and present in a different form, so they are able to watch over her in her present life. When Jennifer prays at night, she says she talks to her grandparents or uncle letting them know she will see them one day. Still, Jennifer struggles on an existential level to find meaning in her abbreviated life and impending death. Her struggle during the interview of Time 2 was painfully filled with unanswered questions.

#### *Conceptualization of an End-of-Life Plan*

The final attribute in EOL preparedness is conceptualization of an EOL Plan. This is defined as the development of a plan which includes the adolescent's goals, priorities, and EOL preferences. Although Jennifer did not discuss anything about her EOL preferences, she has been thinking about prioritizing what she wants to accomplish before she dies. At Time 1, Jennifer did not like the thought of a plan because of the restrictions it imposes; however, she did identify some priorities. At Time 2, Jennifer describes how she is readjusting her goals. For example, she wants to attend college, so she is adjusting her goal to attend online rather than on campus. Jennifer wants to publish some of her poems, and to put together a memory book of her recent Florida trip. Jennifer is interested in traveling more with her mom and her sister, but also wants to simply celebrate moments together as a family. Jennifer is planning a birthday celebration for her sister, who is turning 18 in a couple of days. She is coordinating the surprise with her

mother. Jennifer is also looking ahead toward her 21<sup>st</sup> birthday. She wants to spend it at home with her family and the friends she hasn't seen for awhile. Lastly, Jennifer has been doing exercises to stretch out her leg more, and has been doing as much as she can to maintain her strength.

In summary, the Time 2 interview contains multiple examples within the EOL preparedness construct. Jennifer spent a great deal of time discussing issues within the attributes of acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan. Although she is struggling on an emotional and existential level to accept her destiny, she is clearly willing to discuss the pain, the grief, and the powerful emotions that she is experiencing.

Ironically, Jennifer did not recollect any discussions pertaining to issues within the knowledge about EOL component. On the contrary, this appears to be somewhat of a mystery to her, and is possibly contributing to her fear of the unknown.

Knowledge about EOL is an important area of discussion for individuals facing the uncertainties of advanced and incurable cancer. Discussions that address knowledge about EOL provide information about what to expect physically or emotionally as one is dying; and help to elicit the adolescent's EOL preferences.

When given hypothetical scenarios about discussions with HCPs involving EOL preferences or advance directives, Jennifer clearly agrees adolescents deserve to have information. She feels discussions about disease progression and options should happen sequentially as the disease progresses, and that including a parent in the discussions might be helpful. Jennifer's willingness to obtain new knowledge as her disease progresses has decreased since Time 1, and she correlates this to her fear. She says that although she wants to know, she is too afraid to know.

It is not known whether Jennifer's fear and uncertainty would be less if knowledge discussions would have occurred, and EOL preferences and advance directives were in place. We only know that at Time 1, Jennifer was very willing to have discussions about what would be happening if her disease progresses. At Time 2, she is only slightly willing to have those same discussions.

**Case 2 Time 2**

**Table 36: End-of-Life Preparedness.**

<b>Definition</b>	<b>Data</b>
<p><i>EOL Preparedness</i></p> <p><b>End-of-Life Preparedness:</b> Defined as process whereby an adolescent becomes cognitively and emotionally equipped to complete the tasks necessary for end-of-life consistent with his/her desires. Attributes include: knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan</p> <ul style="list-style-type: none"> <li> <p><b>Knowledge about EOL</b> Defined as information about what to expect physically or emotionally as one is dying. Knowledge about EOL involves dialogue and may help with pragmatic decisions about advance directives and preferred location of death.</p> </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b> <i>There were no examples given pertaining to Knowledge about EOL.</i></p> <p><b>Personal Characteristics Table: Decisional Control Section</b> <i>CB- Do you think it would be important for us as HCPs to try to get some conversations going so that we could find out what that adolescent or young adult would like to do in the event that their cancer is not cured?</i> I think conversations with us or with anyone who’s going through it would you know help them out with what they need, what they want to do with it, if it can’t be cured and it might be kind of hard to figure out what they want to do but they at least need to know what’s going on and know that they have options.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li> <p><b>Acknowledgement of Grief &amp; Emotions:</b> Defined as recognition of grief, loss, or anticipated separation of death; and the accompanying emotions that loss, separation, or death bring</p> </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b> GRIEVING UNFULFILLED DREAMS I know that I wanted to go to college on campus and I know I can’t do that now</p> <p>And so I’m going to miss the walking across the stage for college graduation (pause) and so it’s hard cause you know there’s things you got to miss out on and you’re afraid ‘cause you don’t want to miss out on those things and you know the, ‘Man I can’t do this! I have to miss out on it ‘cause this is happening to me’. And so you have to deal with you know missing out on things, and not being able to do things.</p> <p>And the things that you know you want to do and you <i>can</i> do...you gotta try to shoot for it and when you can’t, when you go to do it, do it as much as you can and try to have as much fun as you can. ‘Cause those are some scary thoughts and you want to try to keep those off your mind by having as much fun as you can and doing and shooting for your goals.</p> <p>Cause, I mean I wanted to be, I used to when I</p>

Definition	Data
	<p>was able to do everything I wanted to model and do all that</p> <p>GRIEVING LOSS OF MOBILITY  And I feel, I feel kind of jealous of people sometimes because they can get up and walk and get on the rides and have fun and go bike riding and I can't. I can't dance anymore. So I mean I feel bad about it sometimes</p> <p>...and then me being able to say that I was afraid of what was going to happen. And I'm afraid <i>of what's</i> happening. And I think the last conversation I had about that, was just a couple days ago while we were out of town. Because I seen all the people having fun and I couldn't get up and have fun so I was talking to my mom about it. About how I'm afraid of what's happening and I'm afraid that I can't do anything and I'm afraid that I'm getting worse  <i>(pause)</i></p> <p>GRIEVING LOSS OF INDEPENDENCE  it's hard emotionally and mentally because I feel bad that I have to you know, have help doing all of this and I can't do it on my own</p> <p>GRIEVING A SHORTENED LIFE  I don't want this happening, I want to be around for a long time, I mean, I'm scared, I don't want my life to end</p> <p>GRIEVING LOSS OF PARTICIPATION IN FAMILY UNIT  ...and when I want to be there for them I can't be and that's really scary. I want to be there for when my sister 'cause she's really good at drawing, I want to be there for her when she goes off to college and get that degree or get that good business that she wanted. I want to be there for my mom when she you know decides to do whatever she wants to do and open up her own business or something I want to be able to be there and see all that.</p> <p>GRIEVING SEPARATION FROM FAMILY  <i>CB- Let's go back to some of those fears that you talked about if you feel comfortable enough and explore that a little bit further. What do you think would be the thing that would scare someone the most about death?</i>  Um for me I'd have to say the most thing about death that scares me would probably have to be</p>

Definition	Data
	<p>leaving your family behind. Because you know how hard it is to lose family members that you love and that you're close to and you don't want to put people through that with you. Especially your parents or your siblings or grandparents that would probably be the most scariest thing to think about how they would feel or what would happen to them or what they would do if they lost you. So to me, that's what scares me the most, leaving my family behind, (<i>pause</i>), especially my mom and my little sister. 'Cause my sister came back up here just to be with me and I would hate to see what would happen to her or my mother if something happened to me.</p> <p>You know it would be hard on them because you're not around no more and especially on my mom, I know it would be hard for her to lose one of her daughters and my sister, her oldest sister, it would have to be hard.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li> <b>Identification of the Meaning of Death and Spirituality:</b>            Defined as the adolescent's discovery of the significance of death and any spiritual beliefs related to death         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>Yeah there's family members that I've lost that I think about all the time or I know that they're watching down on me and everything but I still think about 'em and sometimes dream about 'em and you know. Knowing that if they were still here, you know that they'll be there for me when I need it and stuff like that.</p> <p>Yeah I believe that I'll see them one day again. Sometimes when I pray at night I tell, you know grandparents and my uncle died when I was little that 'I'll see you again'; and it might not be any time soon but I'll see them again. I always say that I'll see them again. And you never know, they could be back down here reborn or something to be around and keep an eye on you and keep you out of trouble.</p> <p>Cause I think something like that for my uncle. I think he's around here somewhere watching down on me and his daughter and my sister.</p> <p>...because knowing that they'll be okay isn't enough 'cause you can't see if they'll be okay 'cause you won't be here.</p>

Definition	Data
	<p><i>CB- Do you have any...Are there any thoughts that actually help you figure that out, or help you find meaning, or make sense?</i></p> <p>No, there's nothing I can think of.</p> <p><i>CB- Yeah. (Pause) 'Cause it's one of those things that totally doesn't make sense does it?</i></p> <p>Nope. I mean I don't think anyone deserves to go through this. I mean I know there's bad people out there but still I don't think anyone deserve to go through being sick and knowing that they're getting worse or that they're going to die, I don't think anyone deserves that. Even if they are criminals or how bad they are they still don't deserve it. Everybody should have you know, deserve to be healthy and live their life and you know turn, have a chance to turn, if they are horrible people, turn it around. (Pause) I can't think of anything.</p> <p><i>CB- Mm-hm. And somebody like you who is not a horrible person it's really even twice as hard probably to figure out why. It just doesn't make sense.</i></p> <p>No it doesn't. 'Cause if you think, 'cause if you are a good person you're thinking to yourself, 'What could I do for this to happen to me? I didn't do anything to no one. I'm always a good person and I never did anything illegal, never caused trouble so I have no idea why this is happening to me!' Stuff like that goes through your head.</p>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Conceptualization of an EOL Plan:</b> Defined as the development of a plan which includes adolescent's goals, priorities and EOL preferences</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>There's so much I want to do and there's so much I know I can't do but there's so much stuff I still want to try.</p> <p><i>Mm-hm. Have you made like a list of your priorities? The things that you'd like to accomplish?</i></p> <p>Yeah. I mean I know I want to still try to go to school. I mean I know I won't be able to go on campus but I still want to try to go to school. Um I'm working on trying to retype my whole journal of my poetry because I want to get that published. And (pause) I want to travel more.</p>

Definition	Data
	<p data-bbox="773 235 1013 264"><i>Priorities continued</i></p> <p data-bbox="870 268 1422 462">I have this scrapbook that the hospital gave me for my birthday. We got some of my birthday stuff in it, we got to finish putting that in there. We have to fit all the Florida stuff in there. We are gonna make it nice and I'll have to show it to you when we finish it.</p> <p data-bbox="870 491 1351 588">Yeah we're gonna take another girls trip soon... We got to. My mom's birthday is coming up... in November.</p> <p data-bbox="870 617 1422 777">And then maybe something for my birthday. But I don't know. Probably for my birthday I wouldn't mind just being home with all my friends and family, the people I haven't seen in a while.</p> <p data-bbox="870 806 1432 1171">Umm let's see. Well I'm getting ready to have a surprise, I'm trying to surprise my sister for her birthday ...and I wanted to get her a cake and stuff to put in the house and so when she comes home from work and there's a big cake and balloons ready for her.... Yeah. And I'm like 'Ma- we have to do this while she's at work' ...so when she comes home we'll have the cake right there and have her favorite foods. I can't get up and cook it myself but I can at least try to help.</p> <p data-bbox="870 1201 1422 1365">And um what else? I think I'm starting to be able to stretch my leg out a little more, see? I've been trying... I mean it hurts when you get to a certain point, but I'm like 'Okay Jennifer, you can do it!</p> <p data-bbox="870 1394 1409 1423">I got one of my goals down! That was Florida</p> <p data-bbox="870 1453 1396 1512">My next goals are me trying to get at least to school online and getting my book done.</p> <p data-bbox="870 1541 1416 1600">Yeah I can't wait. I want to get it published so bad</p>

### *Summary of Construct: Outcomes*

Outcome data for Case 2 Time 2 are provided in Table 37, Outcomes, page 303, and summarized in the following text. The outcomes examined at Time 2 include communication of EOL personal plan, and QOL at EOL.

#### *Communication of End-of-Life Personal Plan*

As mentioned in the previous section, Jennifer has been thinking about her priorities and the things she would like to accomplish in the near future, and has communicated her priorities with her mother since Time 1. However, Jennifer gives no indication that further discussions about her EOL preferences have occurred.

#### *Quality of Life at the End of Life*

During Jennifer's interviews, she identifies the need for a good support system. Having cancer is hard, and it takes an emotional toll on the individual. Friends and family provide encouragement for Jennifer as she lives with advanced cancer, and this contributes to a better quality of life.

Jennifer also recognizes that doing as much as she can physically, contributes to her quality of life. Jennifer is aware of her physical limitations, and the weakness that is accompanying her disease progression. Jennifer realizes when she pushes herself physically she also benefits mentally to not give up. Moving around, getting out of the house with her mom and her sister, or even a quiet activity like coloring, contribute to Jennifer's QOL.

The last qualitative theme pertaining to QOL that was evident during the interview involves trying to find meaning in her life. There were several times during the interview when Jennifer reflected on things she wanted to do, or ways she could still make a contribution to others. She was able to identify some of her positive characteristics that encourage others. She is a very determined individual, and her fighting spirit has been an inspiration to others. Reflecting upon these things brought a bit of comfort.

Quality of life was measured quantitatively using the QUAL-E. Individual items as well as item and subscale scores are included in Table 37 and are summarized in the text that follows.

### **Symptom Impact**

On the QUAL-E, quality of life is measured on a 5 point Likert-type scale, with “1” representing lower QOL and “5” representing higher QOL. The four subscales are summarized in the following section. The mean score for the symptom impact subscale was 3.25. Jennifer’s most problematic symptom was weakness. She identified the severity as moderate, occurring a few times in the past week. Weakness interferes a little with Jennifer’s ability to enjoy life; but she is worried quite a bit that weakness will occur in the future. This is consistent with content reported during her interviews. Jennifer rates the importance of physical symptoms to her overall QOL a “5”, meaning it is of utmost importance to her QOL.

### **Relationship with Health Care System**

The mean score for the relationship with health care system subscale was 4.4. Jennifer acknowledges a sense of control about her treatment decisions, knows where to go to get answers to her questions as her disease progresses, and feels she participates as much as she wants in decisions about her care. Jennifer is fairly confident her doctor knows her as an individual, beyond the scope of her cancer. The item that Jennifer rated lowest in this section of the QUAL-E involved having a general knowledge about what to expect in the course of her illness. This was supported qualitatively during the interview when Jennifer described the uncertainty of her disease progression, and her fears related to not knowing what to expect with the dying process. Jennifer believes feeling like an active participant in her health care is very important to her overall QOL.

### **Preparation**

The mean score for the preparation subscale was 3. Although Jennifer has no regrets about the way she has lived her life, she is moderately worried about the financial strain caused by her illness, and the burden she will be to her family. She has a great deal of worry that her family is not prepared to cope with the future. This is consistent with what was discussed at length during the interview. Additionally, Jennifer acknowledges that thoughts of dying frighten her quite a bit, which is also consistent with what she acknowledged at length during the interview. Concerns about the future are fairly important to Jennifer’s overall QOL.

### **Life Completion Subscale**

The mean score for the life completion subscale was 3.71. Jennifer completely believes that despite her illness she has a sense of meaning in her life, and there is someone she can share her deepest thoughts with. Jennifer recognizes she makes a positive difference in the lives of others and has been able to share important things with her family quite a bit. However, Jennifer feels she has not always been able to say important things to those who are close to her. Jennifer describes this qualitatively during both Time 1 and Time 2. She is able to articulate the social cues that constrain communication. The last two items in this subscale address feeling at peace, and being able to help others through time, gifts, or wisdom. Jennifer rated each of these items a “3” which correlates with her struggle to feel like she is making a contribution to others; and her existential struggle evident in her Time 2 interview. Feeling that life is complete is only moderately important to Jennifer’s overall QOL.

The total mean score for Jennifer’s QOL was 3.6 and she rates her overall QOL as good. Items that contributed to a higher perception of QOL pertained to social support, health care relationship, sharing important things with her family, and living without regret. Items that contributed to a lower perception of QOL for Jennifer include not being able to say important things to those who are close to her, fear related to thoughts of dying, worry about how her family is going to cope with the future, and worry about the future impact of weakness. The individual QUAL-E items were supported in the Time 1 and Time 2 interviews.

#### *Examining Risks and Benefits*

At the end of the Time 2 interview, I asked about the risks and benefits of participating in the study. Jennifer’s responses are included in Table 37. There was not anything too difficult to discuss during either interview, according to Jennifer. She said it was helpful to talk about her feelings, and she felt a little better and more relaxed after talking with me.

In summary, Jennifer’s conceptualized plan involves priorities or things she wants to accomplish in the near future. She has communicated this segment of an EOL personal plan with her mother. Unfortunately, it appears that Jennifer has not had conversations that address her EOL preferences or advance directives. Therefore she has not

communicated this with her mother. Jennifer acknowledges her desire to have her mother involved in discussions about her disease progression, and treatment or prognostic-related options.

The QUAL-E similarly describes the factors that were identified during the interviews to promote a better QOL for Jennifer, namely her relationship with her HCPs, involvement in decisions, family support and shared memories with her family. The factors on the QUAL-E that interfere with QOL were also similar to the content analyzed during the interviews. Factors that have a negative impact on Jennifer's QOL include fear about dying, weakness, concerns about the well-being of her family after she dies, and being unable to say important things to those who are close to her. Analysis of Jennifer's case shows contextual factors that affect QOL in addition to the attributes within the EOL preparedness construct. This is further described in the case summaries.

Case 2 Time 2

Table 37: Outcomes: Communication and Quality of Life.

Definition	Data
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li> <b>Communication of EOL Personal Plan:</b>            Defined as adolescent’s written or verbal expression about conceptualized plan which includes goals, priorities and EOL preferences         </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p><i>CB- I’d like to know- if we could change that word “plan” to setting priorities...it sounds like you have set some priorities. Have you had a chance to communicate those priorities with your mom or with or sister or with people who are close to you? Or your healthcare provider?</i></p> <p>Yeah I talked to my mom about my priorities, about the stuff that I want to get done with my life yeah.</p> <p><i>CB- Okay, so did you have that conversation with her since the last time we met or did you have that conversation before that?</i>            Since the last time we met.</p> <p><i>CB -So we’re trying to find out how important it is to have somebody like you communicate things to your mom or to your healthcare provider about what your wishes or desires are if your cancer progresses.</i></p> <p>Umm I would say to some extent.            Yeah I mean, I know I’m an adult and everything and my decisions is the ones that they’re going to go by; but sometimes you know, I might not know the right decision to make and I might need my mom’s help on choosing what’s right and what they think I should do</p> <p>Yeah. So I can see you know, what she thinks might help and get her opinions and what she think I should do; and then me, myself, my opinions on what I should do; and you know work it out together to come to a decision on what to do.</p> <p><i>Do you think that will help (pause) the way that you’re living out the rest of your life?</i></p> <p>Um (pause). Yeah I think it will help ’cause I’m just you know still basically a teenager, and I don’t know a lot you know, of what’s going on. And my mom you know, she’s older than me so she probably knows people who went through it or seen or learned something about it. So she probably knows what’s going on or what to do, better than I can. So yeah, I’d have to say as time goes by, yeah that would be a good thing. (Pause) ‘Cause she’s more older and more wise... than me.</p>

Definition	Data
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li> <b>Quality of Life at the End of Life:</b> Defined as adolescent's subjective estimation of the quality of symptom control, relationships with others, the meaningfulness of life and resolution of impending death </li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>RELATIONSHIPS WITH OTHERS</p> <p><i>CB- Okay, so quality of life means different things to different people and I'm interested in knowing what things that you think are important for a young person with advanced cancer to have in order to have a good quality of life.</i></p> <p>Um I'd probably have to say a good support group. You know, family and friends that support them. I mean cause cancer, having cancer it gets kind of hard on you and you get really depressed and scared a lot and having a support group for someone to be there with you and just talk with you when you need it can really help. They'll help bring you up when you need it so you don't give up so easily.</p> <p>PHYSICAL QUALITY OF LIFE</p> <p><i>CB-What sorts or things are important for say your physical quality of life?</i></p> <p>Um, physical I have to say just trying to do as much as I can. I mean I know I can't do much since I'm in a walker and a wheelchair but physically just trying to do as much as you can so you can show your body that you can still do things and so you just don't lay there and give up and then your body gets weaker and worse by the minute.</p> <p>I think just doing as much as you can like trying to get up and get out of the house with my mom and sister as much as I can or walk around as much as I can or color or just anything to move around.</p> <p>LOOKING FOR MEANING IN HER LIFE</p> <p>Yeah. <i>(Pause)</i> I wanted to be able to make a lot so I could give back a lot cause I already told my mom, cause there was this one time I used to play the lotto with my mom I had started when I was working and I was 18 I used to buy the scratch-off tickets and I'm like, 'Okay, if I win this certain amount of money that they're giving away, then I'm donating this all to the hospital' cause there's so many things I've seen on T.V. and so many kids suffering from certain things and... I love kids and I don't like seeing kids suffer so I wanted to donate you know money to a certain hospital or organizations for cures and stuff.</p> <p>There's still you know things that I can get online, I guess and do like support things and pen-pals and I can talk to kids with certain types of cancer and the nerve disorder that I have and try to get them support. I had</p>

Definition	Data
<div data-bbox="289 730 641 898" style="border: 1px solid black; padding: 5px; margin: 10px auto; width: fit-content;"> <p style="text-align: center;">SYMPTOM IMPACT SUBSCALE</p> <p style="text-align: center;">MEAN SCORE = 3.25</p> </div>	<p>pen-pals that gave me support when I was younger so I can try to do the same thing.</p> <p>Yeah people tell me I inspire them a lot and I don't know how! I'm just being me, I'm just being myself. Me being myself, part of me you know, I look at myself, I'm a fighter, I don't give up easily. I may say I want to give up and say I'm going to give up but I don't. I push myself to do my hardest. And I've always pushed myself to do my hardest, even when it came to school. My grades might have not always been good in certain classes but they were good and as good as I could get them, especially my math grades. <i>(Smiling)</i> I love math.</p> <p>Quantitative <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>SYMPTOM IMPACT SUBSCALE</b></p> <p><i>Top 3 symptoms identified for the past month = <u>weakness</u>, <u>tired</u>, and <u>nausea</u></i></p> <p><i>Symptom most problematic in past week = <u>weakness</u></i></p> <p>(1 = rarely, 2 = a few times, 3 = fairly often, 4 = very often, 5 = most of the time)</p> <ol style="list-style-type: none"> <li>1. During the last week, how often have you experienced weakness? <b><u>2</u></b></li> </ol> <p>(1= very mild, 2 = mild, 3 = moderate, 4 = severe, 5 = very severe)</p> <ol style="list-style-type: none"> <li>2. During the last week, on average, how severe has weakness been? <b><u>3</u></b></li> </ol> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <ol style="list-style-type: none"> <li>3. During the last week, how much has weakness interfered with your ability to enjoy your life? <b><u>2</u></b></li> <li>4. How worried are you about weakness occurring in the future? <b><u>4</u></b></li> </ol> <p><b>Items 1 - 4 reverse coded; min 4 maximum 20</b> <b>Reverse coded score = <u>13</u></b></p> <p>Item not included in subscale:</p> <ol style="list-style-type: none"> <li>5. <b>In general, how important are your PHYSICAL SYMPTOMS OR PROBLEMS to your overall quality of life? <u>5</u></b></li> </ol>

Definition	Data
<div data-bbox="284 306 646 512" style="border: 1px solid black; padding: 5px;"> <p>RELATIONSHIP WITH HEALTH CARE SYSTEM SUBSCALE</p> <p>MEAN SCORE = 4.4</p> </div>	<p>Quantitative  <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>RELATIONSHIP WITH HEALTH CARE SYSTEM SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <ol style="list-style-type: none"> <li>6. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions. <u>5</u></li> <li>7. I participate as much as I want in the decisions about my care. <u>5</u></li> <li>8. Beyond my illness, my doctor has a sense of who I am as a person <u>4</u></li> <li>9. In general, I know what to expect about the course of my illness. <u>3</u></li> <li>10. As my illness progresses, I know where to go to get answers to my questions. <u>5</u></li> </ol> <p><b>Items 6 - 10; minimum 5, maximum 25</b>  <b>Score = <u>22</u></b></p> <p>Item not included in subscale:  <b>11. In general, how important is feeling like an ACTIVE PARTICIPANT in your HEALTH CARE to your overall quality of life? <u>5</u></b></p>
<div data-bbox="284 1178 646 1320" style="border: 1px solid black; padding: 5px;"> <p>PREPARATION SUBSCALE</p> <p>MEAN SCORE = 3</p> </div>	<p>Quantitative  <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>PREPARATION SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <ol style="list-style-type: none"> <li>12. I worry that my family is not prepared to cope with the future. <u>4</u></li> <li>13. I have regrets about the way I have lived my life. <u>1</u></li> <li>14. At times I worry that I <u>will be</u> a burden to my family. <u>3</u></li> <li>15. Thoughts of dying frighten me. <u>4</u></li> <li>16. I worry about the financial strain caused by my illness. <u>3</u></li> </ol> <p><b>Items 12 - 16 reverse coded; minimum 5, maximum 25</b>  <b>Reverse coded score = <u>15</u></b></p> <p>Item not included in subscale:  <b>17. In general, how important are CONCERNS ABOUT THE FUTURE to your overall quality of life? <u>4</u></b></p>

Definition	Data
<div style="border: 1px solid black; padding: 5px; margin: 5px;"> <p>LIFE COMPLETION SUBSCALE</p> <p>MEAN SCORE = 3.71</p> </div>	<p>Quantitative <b>QUAL-E-</b> Higher scores = better perceived quality of life</p> <p><b>LIFE COMPLETION SUBSCALE</b></p> <p>(1 = not at all, 2 = a little bit, 3 = a moderate amount, 4 = quite a bit, 5 = completely)</p> <p>18. I have been able to say important things to those close to me. <u>2</u></p> <p>19. I make a positive difference in the lives of others. <b>4</b></p> <p>20. I have been able to help others through time together, gifts, or wisdom. <u>3</u></p> <p>21. I have been able to share important things with my family. <b>4</b></p> <p>22. Despite my illness, I have a sense of meaning in my life. <u>5</u></p> <p>23. I feel at peace. <u>3</u></p> <p>24. There is someone in my life with whom I can share my deepest thoughts. <u>5</u></p> <p><b>Items 18 - 24; minimum 7, maximum 35</b> <b>Score = <u>26</u></b></p> <p>Item not included in subscale:</p> <p><b>25. In general, how important is the feeling that your LIFE IS COMPLETE to your overall quality of life?</b> <u>3</u></p>
	<p>Quantitative <b>QUAL-E</b> <b>TOTAL SCORE</b></p> <p><b>21 items that make up each of the subscales; minimum 21, maximum 105</b></p> <p><b>Jennifer's Total Score = 76</b></p> <p><b>TOTAL QOL MEAN SCORE = 3.6</b></p>
	<p>Quantitative <b>QUAL-E</b></p> <p>GLOBAL QOL measured as single item minimum 1, maximum 5</p> <p>(Very Poor = 1, Poor = 2, Fair = 3, Good = 4, Excellent = 5)</p> <p>26. How would you rate your OVERALL QUALITY OF LIFE? <b>4 Good</b></p>

<b>Definition</b>	<b>Data</b>
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li>• <b>Evaluation of the Study</b> Potential risk</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>EVALUATE POTENTIAL RISK</p> <p><i>CB- Okay. And do you think anything that I asked you -and ybe totally honest with me- but anything that I asked you, did it make you feel uncomfortable at the last session, or this session?</i></p> <p>Nope.</p>
<p><i>Outcomes</i></p> <ul style="list-style-type: none"> <li>• <b>Evaluation of the Study</b> Potential benefit</li> </ul>	<p>Qualitative Data</p> <p><b>Interview</b></p> <p>EVALUATE POTENTIAL BENEFIT</p> <p><i>CB- Is there anything that you can identify that was particularly helpful that we could kind of repeat in the future with other people?</i></p> <p>Um I would have to say mostly talking about you know my feelings and you know how I feel was helpful. Because there's certain things that you know, you want to talk about with people and you can't talk about it with- because you don't know if they want to talk about it. But if someone is asking you those certain questions about those certain feelings...you know they can handle talking to you about it so. I'd just say talking to me about my feelings were helpful because I felt a little better, a little you know relieved or relaxed after talking about it.</p>

## SECTION TWO: SUMMARY OF ANALYSES

The following section will describe summaries of the analyses for Case 1 and Case 2 at each time point and across time. The Case Study Propositions were used to guide analysis. They are listed at the beginning of Chapter 4 and are not repeated here. Through an iterative process of pattern matching, a gradual building of patterns emerged to explain how and why constructs within the model were related. Systematic scrutiny of the analyses illuminated consistencies and discrepancies between the observations and the proposed theoretical model.

### CASE ONE ANALYSES

#### SUMMARY OF CASE 1 TIME 1

Propositions 1 through 3 were used to guide the analysis of Case 1 at Time 1. First, summaries of readiness, EOL preparedness and communication of personal plan are made for Case 1, Time 1. Then, conclusions are drawn about propositions 1 through 3.

##### *Summary of Cameron's Readiness at Time 1*

At Time 1, Cameron operates in a closed awareness context. He does not acknowledge his incurable prognosis and still believes the doctors are trying to cure his disease. Cameron does not acknowledge an acceptance of his incurable condition; however, he acknowledges acceptance of his cancer diagnosis. Cameron is very willing to take action to prepare for EOL by engaging in discussions with his grandmother, or HCP about his concerns and about information related to disease progression. He is somewhat willing to engage in discussions about his feelings with his grandmother, or primary physician.

##### *Summary of Cameron's End-of-Life Preparedness at Time 1*

At time 1, Cameron had very little discussion within the construct of EOL preparedness. He described a lack of knowledge about what his cancer was going to do to him in the future. He acknowledged fear related to the uncertainty of cancer treatment and subsequent impact on his future. He identified spiritual meaning in his cancer experience, but there was no reference to the meaning of death and spirituality. And lastly, he has not conceptualized an EOL plan. His goals are directed toward the distant future.

### *Summary of Cameron's Communication of Personal Plan*

At Time 1, Cameron has not conceptualized a personal plan. Therefore, he has not communicated a personal plan to his grandmother or primary physician.

#### **Proposition One**

The context of the current study was measured by demographic, environmental, personal and family characteristics, also known as contextual factors. Proposition one examines data from contextual factors in relation to three constructs: readiness, EOL preparedness, and communication of personal plan.

Contextual factors that appear to influence readiness, EOL preparedness and communication of plan include length of cancer experience, slow progression of disease, enrollment in Phase 1 clinical trial, and lack of prognostic discussions about incurable condition. It has been 2 years and 4 months since Cameron's cancer diagnosis, and his disease has progressed minimally. Time may have allowed Cameron to slowly adjust to his advanced disease and associated symptoms. The Phase 1 clinical trial may be considered yet another way to attempt to treat his advanced cancer. There was no clear documentation of a prognostic EOL discussion, or transition from curative to palliative/EOL care, which may allow Cameron to maintain the belief that his cancer could still be possibly cured.

#### **Proposition Two**

Proposition two examines whether readiness precedes EOL preparedness. It appears at this time point, that readiness, particularly the attribute of awareness precedes EOL preparedness. Since Cameron did not openly acknowledge an awareness of his incurable condition, he spent little time discussing any of the attributes of EOL preparedness. Analysis of Time 1 data show readiness is not a linear process. For example, awareness does not precede acceptance, and willingness to take action. On the contrary, Cameron expresses a willingness to find out more information if his cancer progresses, and a willingness to engage in discussions, despite his level of awareness. Cameron expresses little, if any emotional acceptance of his incurable prognosis; however, he accepts his cancer diagnosis, as noted on the Peaceful Acceptance of Illness subscale.

**Proposition Three**

Proposition three examines EOL preparedness in relation to communication of a personal plan. At Time 1, it appears that Cameron's lack of awareness and lack of acceptance of his incurable prognosis are interfering with his ability to engage in the EOL preparedness process. Since Cameron spent very little time discussing anything within the EOL preparedness construct, there was no communication of an EOL personal plan. Cameron's goals include the distant future, such as going to college, becoming a pediatric hematologist, and raising a family.

## SUMMARY OF CASE 1 TIME 2

Additional information was gathered on the QOL construct at Time 2. Proposition four was added to the analysis summary of Time 2. The processes of readiness, EOL preparedness and communication of personal plan are summarized first so that conclusions could be made about propositions 1 through 4.

### *Summary of Cameron's Readiness at Time 2*

At Time 2, Cameron fluctuates between a closed awareness context (does not recognize impending death), and a suspected awareness context (suspects he may be dying or cancer is incurable). He expresses an understanding of the experimental nature of the Phase 1 clinical trial. His acceptance has increased, based on the peaceful acceptance of illness subscale score at Time 2. The increase is related to the item, making peace with his illness. Cameron's willingness to take action also increased at Time 2. The increase is related to Cameron's willingness to engage in discussions about his feelings with his grandmother or primary physician. He continues to be very willing to engage in discussions about his concerns and to obtain information related to his disease progression.

### *Summary of Cameron's End-of-Life Preparedness at Time 2*

At Time 2, Cameron is a little more comfortable having discussions within the construct of EOL preparedness. For the attribute of knowledge about EOL, Cameron was able to discuss a hypothetical situation about EOL preferences and decisions. He felt discussions about EOL preferences and advance directives would be advantageous in his current situation. For the attribute of acknowledgement of grief and emotions, Cameron was comfortable exploring his fear of the unknown on a deeper level. He acknowledged his fear related to the unknown outcome of his cancer treatment, and the anticipatory grief related to the multiple losses he is experiencing, including the potential loss of his strength, his future dreams, and life itself. At Time 2, Cameron did not discuss anything pertaining to the attribute identification of the meaning of death and spirituality. And lastly, for the attribute conceptualization of an EOL plan, Cameron did not think it was necessary to make a plan about things he wanted to accomplish in the future. A plan was too concrete and could possibly lead to disappointment. Cameron would prefer an outline over a plan, to allow for the flexibility and adjustments that are a necessary part of

advanced cancer. Cameron has not conceptualized a personal plan. He continues to have a distant goal of attending college.

#### *Summary of Cameron's Communication of Personal Plan*

At Time 2, Cameron has not conceptualized a personal plan. Therefore he has not communicated a personal plan to his grandmother, or primary physician.

#### **Proposition One**

At Time 2, most of the contextual factors in Cameron's case remain the same. The contextual factors that have changed, and therefore, may be related to his increase in awareness, acceptance, and willingness to take action include a lengthy discussion with his physician, a perceived change in his focus of care, and an increase in his psychosocial symptom distress.

Cameron's tumors did not respond to the infusion of the Seneca Valley Virus. He was started on a new Phase 1 clinical trial. Prior to the trial, he had a long discussion with his physician about his tumor and therapeutic options, which may be helping him to adjust to the possibility of an incurable prognosis. At Time 2, Cameron did not appear as confident that the focus of his care was curative. Cameron was more aware of the "experimental" nature of the Phase 1 clinical trial. In addition, participation in the Phase 1 clinical trial required close monitoring of his heart with EKGs which added to the uncertainty of the cancer treatment. Cameron continues to have fear related to the uncertainty of his cancer treatment and prognosis. An added psychosocial symptom of worry appeared at Time 2. This was documented in the medical record and noted in the interview. His worry appears to be related to the changes in his treatment.

#### **Proposition Two**

It appears readiness, particularly the attribute of awareness, precedes EOL preparedness. Analyses of Time 2 data regarding readiness are consistent with Time 1. Data show readiness is not a linear process, i.e. awareness does not precede acceptance, and willingness to take action. Cameron's increase in readiness is related to an increase in discussing some of attributes within the construct of EOL preparedness. Cameron does not openly acknowledge an awareness of his incurable condition, although he intermittently shares his suspicions about dying. The changes in Cameron's awareness have helped him to address some of the issues in EOL preparedness. At Time 2, Cameron

was able to address some of his grief and emotions, and to hypothetically discuss knowledge about EOL, and planning for EOL preferences. When it comes to setting goals and priorities, Cameron prefers an outline over a plan. Cameron did not spend any time addressing the meaning of death and spirituality.

### **Proposition Three**

At Time 2, Cameron has not formally conceptualized a personal plan; therefore, there was no communication of an EOL personal plan. Cameron does not see a need to communicate his priorities with his doctor; however, he feels his relationship with his doctor is conducive for communicating his EOL preferences and priorities if he desires.

### **Proposition Four**

Proposition four examines how EOL preparedness is related to QOL at EOL. For Cameron, the lack of EOL preparedness does not seem to have affected his QOL at EOL. Although Cameron did not spend much time discussing the attributes of EOL preparedness, his overall QOL mean score was (4.19), on a scale of 1 to 5; and he rated his global QOL fair (3). Cameron has several contextual factors that contribute to a positive QOL. The greatest factor negatively influencing his QOL is related to his pain.

#### Symptom Impact Subscale

There were several data from contextual factors that correlated with the QUAL-E subscales. For example, Cameron was experiencing a great deal of pain. His symptom impact subscale was low (2.25). Pain seems to have a negative impact on his QOL. He experiences pain often, it interferes with his ability to enjoy life and he is worried about pain occurring in the future.

#### Relationship with Health Care System Subscale

A contextual factor that was positively correlated with Cameron's QOL is his relationship and involvement with his HCPs. Cameron has a great relationship with his primary physician. His mean score for relationship with the health care system subscale was high (5). This matches what he reported in both Time 1 and Time 2 interviews about being an active participant in treatment-related decisions, having a sense of control about his treatment decisions, and a sense that his physician knows and respects him as a person. Cameron also feels informed about the course of his illness, and knows where to go to get answers to his questions as his disease progresses.

### Preparation Subscale

Personal and family characteristics are linked to QOL. Cameron's grandmother helps Cameron to focus on the positive. The mean score for Cameron's preparation subscale was (4). This also correlates to what Cameron described in Time 1 and Time 2, regarding little worry about how his family is dealing with his illness. Cameron perceives his family is emotionally handling his illness very well, and he finds this helpful. However, there is an item in this subscale that addresses thoughts of dying. During the interviews, Cameron discusses some of his fear, but not in great length. For the item, thoughts of dying frighten me, Cameron rated it a moderate amount, (3). It appears Cameron would benefit from finding a way to process some of his fear about death, whether that be from talking more about it, or expressing it through his gift of art.

### Life Completion Subscale

Cameron uses many coping behaviors to deal with the difficult situation of living with advanced cancer. He talks openly and honestly with his grandmother about his struggles. He independently does as much as possible for himself. He finds meaning in his relationships with others. He finds meaning in his artwork and writing; and meaning in his faith in God. He has an incredibly strong social support system. The mean score for Cameron's life completion subscale was (4.85). The item scores correlate with his strong social support system, having his grandma to share his deepest thoughts with, feeling at peace, and having a sense of meaning in his life, despite his illness.

In summary for Case 1, QOL is related to data from many of the contextual factors that were collected in the case, rather than the attributes within EOL preparedness. Data most significantly related to a decrease in QOL include pain, and thoughts related to fear of dying. Data that most significantly promote a positive QOL involve a relationship with his health care system, and finding ways to make life meaningful. Cameron accomplishes this through family and other relationships, through his spiritual beliefs, independently doing as much as possible, and expressing himself through his art and writing.

## SUMMARY OF CASE 1 ACROSS TIME 1 AND TIME 2

Changes across Time 1 and Time 2 were examined to determine whether readiness, EOL preparedness, and communication of a personal EOL plan were related to time. The study was designed to allow approximately one month between the Time 1 and Time 2 interviews. In this section, the summary of within case changes across Time 1 and Time 2 is presented. Results are summarized in the text. A table summarizing data is included in the appendix. Proposition five was used to guide the analysis across time.

### **Proposition five**

#### *Readiness across Time*

Cameron showed some changes in readiness (awareness, acceptance and willingness to take action) across Time 1 and Time 2. Each of the attributes increased across time. Cameron moved from a closed awareness context at Time 1, to a fluctuation between closed awareness context and suspected awareness context at Time 2. Cameron's acceptance score increased from (16) at Time 1 to (17) at Time 2, although there is still room for improvement in acceptance on the Peaceful Acceptance of Illness subscale. Cameron's change in acceptance is related to the item 'making peace with his illness'. Cameron's willingness to take action changed across time. At Time 2, his willingness to engage in discussions about his feelings increased.

Changes in the readiness construct may be related to the long discussion Cameron had with his physician about his tumor and therapeutic options, and the discussion he had with his grandmother sharing his fears and worries. Additionally, time may have allowed Cameron to process these things, resulting in an increase in awareness, acceptance, and willingness to take action.

#### *End-of-Life Preparedness across Time*

Cameron showed a slight change in some aspects of EOL preparedness (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of personal plan), across time. He spoke briefly about his fears related to the uncertainty of his future, but had not given any thought to conceptualization of an EOL Plan. At Time 2, he was more comfortable exploring his fears on a deeper level, and discussing hypothetical situations about EOL preferences and conceptualizing a personal plan.

### *Communication of Personal Plan across Time*

Since Cameron has not developed a personal plan, there was no communication of that plan across time.

### *Contextual Factors across Time*

There were demographic, environmental, and personal characteristics that remained constant across time and characteristics that changed across Time 1 and Time 2. A summary of the constructs that were measured within the conceptual model across time are available in a Table in the appendix (Table 38, Comparison of Changes in Case 1 across Time).

Since Cameron's symptom distress decreased across time, it is most likely related to the Seneca Valley Virus, which was active in his system at Baseline and Time 1 data collection points. At Time 1, Cameron appeared to have more problems symptomatically particularly related to shortness of breath, fatigue, and pain. Prior to Time 2, the virus had cleared from Cameron's system. Although Cameron continued to experience symptoms related to pain, shortness of breath, and fatigue, he was much more alert at Time 2, had less nasal flaring, and no slurring of speech.

Changes were also seen in discussions with physicians. At Time 1, there was no documentation in the medical record of an initial discussion about Cameron's incurable prognosis. Also, there were no ongoing EOL discussions noted. At Time 2, there was documentation of a long discussion with the doctor about Cameron's tumor and therapeutic options. Most likely the information discussed emphasized Cameron's metastatic lung disease that has not responded to any treatment thus far; however, details of the discussion were not recorded in the medical record. Cameron appears less certain of a curable outcome.

Cameron continues to experience an incredible amount of social support from family, especially his grandmother, his physicians, particularly Dr. Smith, and from friends within his community. One thing that is plainly missing is ongoing continuity of nursing care. During this very uncertain time, he is without the continuity of nurses, who could provide an additional level of support to address his complex psychosocial needs.

## CASE 2 ANALYSES

### SUMMARY OF CASE 2 TIME 1

Propositions 1 through 3 were used to guide the analysis of Case 2 at Time 1. Readiness, EOL preparedness and communication of personal plan are summarized first so that conclusions could be made about propositions 1 through 3.

#### *Summary of Jennifer's Readiness at Time 1*

At Time 1, Jennifer operates in and out of two awareness contexts: open awareness and mutual pretense awareness. There were times she openly acknowledged her incurable prognosis; and there were times when she needed to imagine a distant future, without cancer in it. In the context of open awareness, Jennifer would sometimes share her fears related to death and dying. At other times, she was able to focus on living, despite the fact that eventually she is going to die. In the context of mutual pretense awareness, Jennifer spoke of her distant future and desire to get a college degree and start a career of her own. At Time 1, Jennifer was also able to articulate how she developed an awareness that her cancer was getting worse in two ways. First, awareness developed because of the physical changes she experienced. Jennifer knew her cancer was getting worse because eventually she could no longer use her left leg. Secondly, awareness developed because of conversations with her doctors. They honestly shared information about her disease progression, explaining the cancer spread to other parts of her body, and eventually they explained her cancer could not be cured.

Jennifer vacillates between accepting and struggling to accept her incurable prognosis. During the interview when she is accepting her prognosis, she expresses somewhat of a resignation. However, when she is struggling to accept her prognosis, she talks unrealistically about being able to walk again. During times of struggle, she also expresses emotional turmoil about her separation from her family when she dies. Jennifer's Peaceful Acceptance of Illness Subscale is 17.

Jennifer is very willing to take action to prepare for EOL by engaging in discussions with her family, or HCP about her concerns and about information related to disease progression. She is somewhat willing to engage in discussions about her feelings with her family, or HCP.

### *Summary of Jennifer's End-of-Life Preparedness at Time 1*

At Time 1, Jennifer engaged in discussions within the construct of EOL preparedness. Mainly, Jennifer spent time discussing her grief and emotions. Specific information pertaining to each of the attributes of EOL preparedness is described in the following paragraphs.

#### Knowledge about End-of-Life

There were no comments during the Time 1 interview describing knowledge about what to expect physically or emotionally as one is dying. Jennifer knows she is going to die, however, she does not know how long the process of dying will be, or what to expect as she is dying. On the contrary, Jennifer describes a lack of knowledge about EOL, and expresses a desire to find out more about her disease progression. At Time 1, she prefers to have the information now, before it is too late.

#### Acknowledgement of Grief and Emotions

Jennifer spoke openly about her grief and emotions within the construct of EOL preparedness. She expressed grief pertaining to multiple losses. She grieves her shortened life, her loss of mobility, her inability to work and contribute financially to her family, and she grieves over the pain of being separated from her family. She has not been able to express this deep sadness to her family; however, she was able to talk to her mom about cremation and keeping her ashes after death.

#### Identification of the Meaning of Death and Spirituality

Jennifer spoke a little about the meaning of death and spirituality. She believes if she dies, it is her time to go. But she also believes that her spirit will live on with her family, although she will not be able to talk to them, or be physically present.

#### Conceptualization of End-of-Life Plan

Jennifer has not conceptualized an EOL plan. Jennifer's goals are futuristic, and somewhat unrealistic, given her cancer progression. Her goals include going to college, getting her degree, and trying to start a business or career. She also wants to work on increasing strength and mobility in her leg so that she can walk again. Jennifer has not thought about developing a personal plan to share with her family or doctors. She is hesitant to plan too far ahead, because she doesn't know how she will be feeling, or if she will be able to accomplish her plan in the future. Jennifer wants to make memories in the

immediate future with her family. They have planned a family trip to Florida. But mostly she wants to make memories by doing simple things like barbeques or spending time together as a family. She wants to live as much as she can from day to day.

#### *Summary of Jennifer's Communication of Personal Plan*

At Time 1, Jennifer has not really conceptualized a personal plan. However, she did talk to her mother about her wishes to be cremated, rather than buried.

#### **Proposition One**

The contextual factors that have influenced awareness and acceptance that Jennifer is going to die include physical deterioration in her left leg, despite active treatment with chemotherapy; and honest discussions with her physicians about disease progression and incurable prognosis. The documented EOL discussion explained options, such as comfort measures only or Phase 1 clinical trials when available. This type of discussion explains the reality of Jennifer's situation. It provides the opportunity for her to process reality on a cognitive and emotional level.

At times, Jennifer struggles to accept her prognosis. This may be due to the rapid progression of her disease. The time from diagnosis to initial EOL discussion was only 4 months. This is a very short time to psychologically and emotionally adjust to her terminal condition.

Rapid disease progression, in light of awareness about her incurable condition, may also contribute to Jennifer's willingness to take action. Jennifer has an urgency to find out more about what will be happening as her disease continues to progress.

Although Jennifer has great support from her family and HCPs, she expresses less willingness to talk with them about emotions, or the things that make her sad and afraid. She has identified verbal and non-verbal cues from family members and HCPs that interfere with discussions about death. Jennifer believes it is hard for people, including family and HCPs, to talk about death. This in turn, inhibits discussions about EOL preparedness with her family or HCPs.

Jennifer's physical and psychosocial symptoms are related to EOL preparedness. She has ongoing physical symptoms that have increased in severity as her disease has progressed. Jennifer is also experiencing a great deal of fear related to death and dying, which prompted discussions at Time 1, acknowledging her grief and emotions.

In summary, at Time 1, Jennifer has not conceptualized an EOL personal plan however, she has communicated with her mother about her desire to be cremated rather than buried. The contextual factors that appear to influence the processes of readiness at Time 1 include rapid advancement of her cancer with physical deterioration of her left leg and honest discussions with her physicians, including an initial EOL discussion about her incurable prognosis. The psychosocial symptom of fear influenced discussions about grief and emotions within the construct of EOL preparedness.

### **Proposition Two**

Proposition two examines whether readiness precedes EOL preparedness. At Time 1, all of the attributes of readiness are present (awareness, acceptance, and willingness to take action). It is difficult to know how awareness, acceptance and willingness to take action are interrelated in Jennifer's case. It is not known if awareness precedes acceptance. However, Jennifer appears to struggle more with accepting her incurable prognosis, than in the cognitive awareness of her incurable prognosis. It appears that readiness precedes EOL preparedness. All attributes of readiness are present at Time 1, and Jennifer is participating in some aspects of EOL preparedness, although Jennifer has not actively conceptualized or processed information within all of the attributes of EOL preparedness.

### **Proposition Three**

Proposition three examines how EOL preparedness is related to communication of a personal plan. Jennifer lacks knowledge about EOL, and death and dying, although she has knowledge of her terminal condition. She has not yet fully conceptualized a personal plan containing her EOL preferences and priorities. Therefore, communication about a personal EOL plan has not occurred.

## SUMMARY OF CASE 2 TIME 2

Additional information was gathered on the QOL construct at Time 2. Proposition four was added to the analysis summary of Time 2. The processes of readiness, EOL preparedness and communication of personal plan are summarized first so that conclusions could be made about propositions 1 through 4.

### *Summary of Jennifer's Readiness at Time 2*

At Time 2, Jennifer continues to operate in and out of the same two awareness contexts: open awareness and mutual pretense awareness. She continues to have moments of accepting her prognosis and moments of struggle. Jennifer's Peaceful Acceptance of Illness Subscale remains at 17. There is a change in Jennifer's willingness to take action at Time 2. Her willingness to find out more about her disease progression has significantly decreased. Her willingness to engage in discussions remains the same. She continues to be more cautious about sharing her feelings than her concerns with her family, or HCP.

### *Summary of Jennifer's End-of-Life Preparedness at Time 2*

At Time 2, Jennifer spends more time discussing within the construct of EOL preparedness. Specific information pertaining to each of the attributes of EOL preparedness is described in the following paragraphs.

#### Knowledge about End-of-Life

There were no comments during the Time 2 interview describing knowledge about what to expect physically or emotionally as one is dying. However, Jennifer acknowledges that conversations about EOL preferences or advance directives would be helpful for adolescents living with incurable cancer.

#### Acknowledgement of Grief and Emotions

Jennifer acknowledges in greater depth her grief and emotions. She acknowledges her sadness associated with the loss of her dreams about her future. There are times she comes full circle, to a point of saying, 'I wanted to do X; I can't do X; but I can do Y; so I am going to do Y with determination and enjoyment'.

Jennifer shares different levels of emotions, from frustration to anger, and from disappointment to jealousy. She continues to process her fear of death and grieve the painful separation from her family.

### Identification of the Meaning of Death and Spirituality

At Time 2, Jennifer struggles at an existential level to understand why she is going to die at such a young age. She can't make sense of it all. Jennifer also shares her spiritual beliefs about an afterlife.

### Conceptualization of End-of-Life Plan

At Time 2, Jennifer has made a list of her priorities. She is focusing on things in the immediate future, such as planning birthday celebrations, making a scrap book of her memories from her Florida trip, applying to college online, and trying to get her poetry published. She is also still trying to work on stretching her leg, and feels she is making some improvements.

### *Summary of Jennifer's Communication of Personal Plan*

At Time 2, Jennifer has conceptualized a list of priorities. It appears she has not conceptualized her EOL preferences and advance directives. Jennifer has been able to talk to her mom about her priorities and what she wants to accomplish in her life.

### **Proposition One**

Proposition one examines the contextual factors that are related to readiness, EOL preparedness and communication of plan. At Time 2, most of the contextual factors in Jennifer's case remained the same. The contextual factors that may be related to her changes in readiness, EOL preparedness and communication of plan, include an increase in disease progression, an increase in the physical symptom weakness, and an increase in psychosocial symptoms related to death and dying. As Jennifer becomes more aware of the physical and emotional changes accompanying the dying process, she also is mentally adjusting to the time she has left. These changes are helping her to re-prioritize her goals, to communicate with her mom about her priorities, and discuss more deeply about her grief and emotions, which are evident at Time 2. Social constraint continues to interfere with Jennifer's communication about her grief and emotions related to death and dying with her family and HCP.

### **Proposition Two**

Proposition two addresses whether readiness precedes EOL preparedness. At Time 2, it still appears that awareness precedes EOL preparedness. However, lack of knowledge about EOL, an attribute of EOL preparedness impacts willingness, an

attribute of readiness. This is particularly evident in Jennifer's willingness to find out more about what will be happening as her disease progresses. At Time 2, she is less willing to find out more about disease progression because of her fear of the unknown, and the increased realization that she is dying.

### **Proposition Three**

Proposition three examines how EOL preparedness is related to communication of a personal plan. At Time 2, Jennifer's lack of knowledge about EOL has interfered with her conceptualization of her EOL preferences. Jennifer's acknowledgement of her grief and emotions are helping her to process the limited time in which she has to accomplish her goals; and this is helping her to re-prioritize her life and identify the things she wants to do and accomplish in the time that she has left. At Time 2, Jennifer has not only developed a plan, albeit limited, but she also has been able to discuss her plan with her mother.

### **Proposition Four**

Proposition four examines how EOL preparedness is related to QOL at EOL. In Case 2, it appears that EOL preparedness is related to QOL; however, it is not the only construct affecting QOL at EOL. There are contextual factors that also influence QOL. Quality of life was quantitatively measured by the QUAL-E. Jennifer's overall QOL mean score was (3.6), on a scale of 1 to 5; and she rated her global QOL good (4). Factors on the QUAL-E that contribute to a positive QOL include participation in decisions about her care, and feeling she has control over her treatment decisions, despite a lack of control over her illness. HCP and family support also positively influence Jennifer's QOL. Factors negatively influencing QOL include physical and psychosocial symptom distress, namely weakness, fear related to death and dying, and worry about her family.

#### Symptom Impact Subscale

Jennifer's most problematic physical symptom is weakness. During the past week, her weakness has been moderately severe and she is worried quite a bit about weakness occurring in the future. Weakness is a physical reminder that Jennifer's condition is worsening.

### Relationship with Health Care System Subscale

A contextual feature that was positively correlated with Jennifer's QOL is her relationship and involvement with her HCPs. Jennifer's mean score for relationship with the health care system subscale was 4.4. This scale captures the positive impact of being an active participant in decision-making, having a sense of control in decisions about her care, and a sense that her physician knows and respects her as a person. There is an item on this scale that pertains to Jennifer's knowledge about EOL. The item, 'In general I know what to expect about the course of my illness' correlates with Jennifer's lack of knowledge about EOL. However, there is another item that identifies Jennifer knows where to go to get the answers to her questions as her disease progresses.

### Preparation Subscale

Jennifer's psychosocial symptoms include fear of death and dying, and worry about her family. These symptoms are captured in the preparation subscale. Thoughts of dying frighten Jennifer. She also worries quite a bit about how her family will cope with the future. She worries moderately about the financial strain caused by her illness, and the burden she may cause for her family in the future.

### Life Completion Subscale

The life completion subscale also captures some of the turmoil Jennifer is experiencing as she faces death, namely her struggle to find peace, and her struggle to share her grief and emotions with her family. Jennifer's attempt to find meaning in her life, despite her illness, are also captured in this subscale.

In summary, for Case 2, QOL is related to data from many of the contextual factors that were collected in the case, as well as the attributes within EOL preparedness. Data most significantly related to a decrease in QOL include physical and psychosocial distress; particularly weakness and death-related fears, including turmoil over separation from her family. Data that most significantly promote a positive QOL involve a relationship with her health care system, and relationship with her family including making memories and family support.

## SUMMARY OF CASE 2 ACROSS TIME 1 AND TIME 2

Changes across Time 1 and Time 2 were examined to determine whether readiness, EOL preparedness, and communication of a personal EOL plan were related to time. Results are summarized in the text. A summary of the constructs that were measured within the conceptual model across time are available in a table in the appendix, (Table 39, Comparison of Changes in Case 2 across Time). Proposition five was used to guide the analysis across time.

### **Proposition five**

#### *Readiness across Time*

Changes in readiness were seen across time. Jennifer has a heightened awareness that time is running out. She continues to experience a great struggle to accept her terminal prognosis. Across time, she shows a decreased willingness to engage in discussions about what to expect as she is dying.

Jennifer continued to fluctuate between the two awareness contexts of open awareness and mutual pretense awareness. Jennifer has an increased awareness of disease progression at Time 2 compared to Time 1. Jennifer's acceptance remained the same across time according to the Peaceful Acceptance of Illness subscale. Jennifer's acceptance score was (17) at Time 1 and 2. However, there were changes in item scores within the Peaceful Acceptance of Illness subscale. Comparing the interviews across time, Jennifer shows incremental changes in acceptance, resulting in re-examination of priorities. However, she continues to vacillate between accepting and struggling to accept her terminal prognosis. Jennifer's willingness to take action changed across time. As Jennifer advances toward death, she is less willing to find out more about what will be happening in relation to her disease progression.

#### *End-of-Life Preparedness across Time*

Jennifer showed changes in some aspects of EOL preparedness (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of personal plan), across time. Jennifer continues to lack knowledge about what to expect as she is dying. She acknowledges significant grief and other emotions, particularly death-related fears at both Time 1 and Time 2. She identifies spiritual beliefs related to death and dying. Her meaning of death includes

physical separation from her mom and her sister, but not a separation in spirit. She acknowledged more of her existential struggle to find meaning in her untimely death across time. And lastly, Jennifer was able to conceptualize and re-prioritize her immediate future. Aside from her desire to be cremated rather than buried, Jennifer lacks conceptualization of EOL preferences across time.

#### *Communication of Personal Plan across Time*

Jennifer has conceptualized her immediate priorities across time, she has also been able to communicate what she wants to accomplish in the time she has left. Communication of her personal plan, regarding EOL priorities occurred with her mother.

#### *Contextual Factors across Time*

There were demographic, environmental, and personal characteristics that remained constant across time and characteristics that changed across Time 1 and Time 2 for Case 2. Jennifer's physical symptom distress increased across time. Mainly Jennifer noticed a progressive increase in weakness, which in turn led to more worry about her cancer progression. This led to an increase in death-related fear and emotional turmoil about separating from her family.

Jennifer continues to experience an incredible amount of social support from her family, especially her mom and her sister, and from her health care team. Jennifer continues to identify social cues which constrain discussions about the emotional aspects of death and dying.

### SECTION THREE: CROSS CASE SUMMARY

The following section will summarize within case changes across Time 1 and Time 2. Case 1 will be compared to Case 2 at Time 1; then at Time 2; then across time. **Proposition six**, which proposes there will be similarities and differences within Case 1 and Case 2 across time, will be used to guide the analysis of section three.

#### SUMMARY OF CASE 1 AND CASE 2 AT TIME 1

##### *Similarities between Case 1 and Case 2 at Time 1*

There were several similarities between Case 1 and Case 2 at Time 1. In both cases, adolescents were initially diagnosed with advanced cancer and had a current prognosis of incurable cancer with refractory disease. Both have an interest in Phase 1 clinical trials, and had signed an informed consent. Both perceive living with advanced cancer is difficult, but were able to adjust fairly well. Both adolescents are living at home, while making frequent visits to the outpatient Tertiary Care Center. In both cases, the adolescents preferred a collaborative role in treatment decisions, although Case 1 preferred an active-collaborative role and Case 2 preferred a collaborative-passive role. In both cases at Time 1, the adolescents' knowledge preference included all possible information both good and bad news.

In both cases at Time 1, adolescents were experiencing symptom distress, such as pain, shortness of breath, fatigue and cachexia. In both cases, adolescents developed coping behaviors which included talking about their problems. In both cases, there was positive social support from at least 2 family members and several members of the health care team.

At Time 1, willingness to take action was the same for Case 1 and Case 2. Both adolescents were more willing to discuss their concerns, and less willing to discuss their emotions. In both cases, adolescents expressed a desire to find out more as their disease progresses. Both adolescents lacked knowledge about EOL, and had not conceptualized an EOL personal plan.

### *Differences between Case 1 and Case 2 at Time 1*

There were also several differences between Case 1 and Case 2 at Time 1. The main difference was in their awareness context. Case 1 stayed in a closed awareness context at Time 1, whereas Case 2 fluctuated between an open awareness context and a mutual pretense awareness context. Peaceful acceptance of illness differed slightly at Time 1. Case 1 had a slightly lower score than Case 2, (16 versus 17) respectively. There were differences pertaining to involvement in discussions about EOL preparedness. In Case 1, little time was spent discussing EOL preparedness, aside from briefly mentioning fear of the unknown. In Case 2, the adolescent spent a great deal of time acknowledging grief and emotions related to death and dying, and identified some spiritual beliefs related to death and dying.

There were several differences in the context of Case 1 and Case 2 at Time 1. In Case 1, the adolescent had a slow progressive disease. He was diagnosed over 2 years ago. In Case 2, the adolescent was diagnosed 4 months prior to the determination of an incurable prognosis. Her disease progressed very rapidly. The perceived focus of care was different for Case 1 and Case 2. In Case 1, the adolescent perceived the focus of care to be curative in nature. In Case 2, the adolescent “hoped” for a cure, but realized a cure would most likely not happen. An initial EOL discussion was documented for Case 2, whereas no initial EOL discussion was documented in the medical chart for Case 1. There were differences in perceived social support. In case 2, the adolescent perceived less friend support, which lowered the overall MSPSS score. Perceived family coping was also a concern for Case 2. And lastly, in Case 2, the adolescent denied benefit from cultural or spiritual practices.

## SUMMARY OF CASE 1 AND CASE 2 AT TIME 2

### *Similarities between Case 1 and Case 2 at Time 2*

At Time 2, both adolescent cases were enrolled in the same Phase 1 clinical trial, ADVL091, which requires frequent monitoring of the heart via EKGs. Both were aware of the experimental nature of the Phase 1 clinical trial. In both cases adolescents lived at home, making frequent visits to the tertiary care center. In both cases at Time 2, there was documentation about discussions with a member of the health care team, related to therapeutic treatment options and advanced or incurable cancer. Both were experiencing physical symptoms, such as pain, fatigue and shortness of breath; and psychosocial symptoms related to fear of death and worry. PEACE subscale is the same for both adolescents at Time 2. Both perceive continued social support from their physicians and health care team, with less continuity of care from nursing in the outpatient setting. Both cases have a lack of knowledge about what to expect at EOL. Both cases perceive a plan is too concrete or rigid, and might lead to disappointment if the plan could not be fulfilled. In both cases there were contextual factors that were linked to QOL.

### *Differences between Case 1 and Case 2 at Time 2*

The awareness contexts continue to differ between Case 1 and Case 2. Case 1 is operating in a closed awareness and suspected awareness context. Case 2 is operating in an open awareness and mutual pretense awareness context. Willingness to take action increased for Case 1, and decreased for Case 2 at Time 2. Differences also exist within the EOL preparedness construct. Both acknowledge a fear of death; however, Case 2 more openly acknowledges grief and emotions related to death and dying, and identifies the meaning of death and spirituality. Case 2 has conceptualized a list of immediate priorities and has communicated priorities with a family member. Case 2 continues to focus on the distant future, but with less certainty. Cancer progression differed between cases at Time 2. Case 2 experienced an increase in weakness at Time 2 and rapid progression of disease, with new tumors visible on the CT scan. Case 1 has had minimal change in cancer progression.

## SUMMARY OF CASE 1 AND CASE 2 ACROSS TIME

A summary of Case 1 and Case 2 across time led to the final analysis for this section. There were both similarities and differences between cases across time. In both cases, discussions within the EOL preparedness construct increased across time, particularly within the attribute of acknowledgement of grief and emotions. Conceptualization on an EOL plan was related to awareness of death across time; and a lack of knowledge about EOL across time. Conceptualization of EOL priorities occurred across time in the case that involved an open awareness context. In both cases there was a lack of knowledge about EOL. Likewise, EOL preferences were not conceptualized for either case across time. In both cases adolescents perceived discussions about EOL preferences and advance directives would be beneficial for determining options ahead of time.

Readiness (awareness, acceptance and willingness to take action to prepare for EOL) is a fluid process. Changes in the readiness process occurred across Time 1 and Time 2 for both cases. However, it was not always a forward movement. For example, in Case 2, the attribute of willingness to take action decreased across time, specifically related to obtaining information about disease progression. In Case 1, awareness, acceptance and willingness to take action all increased across time.

Awareness precedes EOL preparedness in both cases across time. As awareness about EOL increased, discussions about EOL preparedness also increased. For example, in the closed awareness context, little discussion about EOL preparedness occurred.

In both cases, social support from family and members of the health care team remained constant across time, which positively influenced quality of life. Social constraint was evident across time for Case 2, which influenced willingness to discuss emotions with family and HCPs.

In summary, analyses across time for Case 1 and 2 reveal consistencies and discrepancies between case observations and the proposed theoretical model. Theory modification and implications for clinical practice will be discussed in Chapter 5.

## CHAPTER 5: DISCUSSION

This chapter is divided into three sections. Section One discusses primary findings for this multiple-case study, in relation to the seven overarching research questions presented in Chapter 3. Section Two describes the theoretical implications; including a review of the original conceptual model and consistencies and discrepancies between the original model and data. Concepts that emerged during data collection and analysis will be discussed, along with proposed changes to the conceptual model when considering new data. Section Three describes limitations of this study with recommendations for future research, and provides a brief summary of the dissertation results.

### SECTION ONE: DISCUSSION OF OVERARCHING RESEARCH QUESTIONS

This study sought to answer seven overarching research questions, listed in Chapter 3. Each research question will be briefly discussed. Section Two will include a more thorough discussion of the theoretical implications that were found from this multiple case study.

#### **Research Question One**

Research question one relates to how an adolescent with incurable cancer becomes ready to engage in EOL preparedness. To answer this question we looked at three things. We examined the contextual factors (demographic, environmental, personal, and family characteristics), to see their influence on the readiness process (awareness, acceptance and willingness to take action to prepare for EOL). We examined how the dimensions of readiness (awareness, acceptance, and willingness to take action) were interrelated, and finally, we examined the influence of time on the readiness process (awareness, acceptance and willingness to take action).

It is not fully understood how readiness (awareness, acceptance and willingness to take action) occurs in adolescents with incurable cancer. However, in this study, certain contextual factors (demographic, environmental, personal and family characteristics) influenced awareness. For instance, Jennifer acknowledged her awareness changed when her disease continued to progress and she could no longer walk, despite the fact that she was still receiving chemotherapy. Her awareness was also influenced by the honest discussions with her physicians about her incurable prognosis. Cameron on the other hand, understood his cancer was not curable, but he also perceived his doctors were

attempting to find a cure, even though he was on a Phase 1 clinical trial. Although Cameron recalled honest conversations with his physicians, there were no discussions regarding incurable prognosis until after Time 1. For Cameron, there were differences in awareness between Time 1 and Time 2. For example, after Time 1 Cameron had a long discussion with his physician about his tumor and therapeutic options. He perceived more uncertainty related to cure, and understood the experimental nature of his second Phase 1 clinical trial. This resulted in a change in his awareness context. At Time 1, Cameron operated in a closed awareness context, without awareness of his terminal condition. At Time 2, Cameron was partially aware, or beginning to suspect that his cancer will not be cured; and he might eventually die.

Findings in our study pertaining to awareness are similar to findings in the pediatric EOL literature. Prognostic discussions accounted for parental awareness of incurable prognosis 50% of the time in Wolfe and colleagues (2000) study (J. Wolfe, Klar, et al., 2000). Parents of dying children also described becoming aware of impending death prior to communication with the physician from recognizing physical condition or appearance, or from a direct comment from their child (Hinds & Drew, 2005; Monterosso & Kristjanson, 2008; J. Wolfe, Klar, et al., 2000). Furthermore, in our study we found as curative intent decreases or becomes less certain; the level of awareness regarding incurable prognosis increases. However, awareness is a dynamic process. This was particularly noticeable in Jennifer's Case. Although she was fully aware that eventually she was going to die from her cancer (open awareness context); there was a back and forth movement between an open awareness context and mutual pretense awareness context (where she acted as if she were not going to die). In the mutual pretense awareness context, Jennifer would discuss things like graduating from college and starting a career, or going to Jamaica next year on vacation. Fluctuation in awareness occurred within each interview and across time, in Jennifer's Case.

Acceptance and willingness to take action were present at Time 1 for both cases. Both constructs were measured quantitatively. An item on the acceptance measure describes acceptance of cancer diagnosis. An item on the willingness measure describes willingness to find out more information as cancer progresses. Therefore, a logical deduction is that a diagnosis of advanced cancer influences both constructs.

Similar to awareness, the constructs of acceptance and willingness to take action occur on a continuum. Although it is more difficult to tease out the contextual factors that influence acceptance and willingness to take action, there were clearly changes that occurred across time.

Time influenced acceptance. For example, Cameron's Peaceful Acceptance of Illness scores increased across time. Jennifer's Peaceful Acceptance of Illness scores remained the same across time. However, variations on the scores of individual items occurred across time, showing the dynamic nature of the construct. Additionally, small increments of change were noticed in Jennifer's interviews across time. For instance, at Time 1, Jennifer discussed 2 primary goals: to try to walk again, and to go to college. At Time 2, Jennifer acknowledged she was working on strengthening her leg, but realized she will never walk across the stage at graduation, or be mobile enough to attend classes on campus. Jennifer goes back and forth in her acceptance and struggle to accept her incurable prognosis. She acknowledges things she wants to do, and things she can no longer do. Slowly we see an adaptation of her goals which are directly related to increments of change in her acceptance. Jennifer never fully accepts her incurable prognosis. This is particularly evident in her struggle to accept the emotional separation from her family at death.

Time also influenced willingness to take action. For Cameron, willingness to take action increased pertaining to his willingness to discuss his emotions. At Time 1, he rated the item a (3 = to some extent) and it increased to a (4 = to a large extent), at Time 2. For Jennifer, willingness to take action decreased pertaining to her willingness to find out more information about disease progression. At Time 1, she rated the item a (4 = to a large extent) and it decreased to a (2 = to a slight extent), at Time 2. The decrease in willingness was related to Jennifer's perception that time is running out. For example at Time 2, Jennifer's overall condition rapidly declined. Her tumors spread and she acknowledged a progressive weakness and expressed fear related to progression of her disease. Furthermore, Jennifer qualifies her numeric rating of willingness with these words, "...as it progresses if the drug isn't working I mean, I'd be too afraid to know what's going to happen. So I mean, I want to know what's going to happen but I'm also afraid of what's going to happen. So I'd have to say to a slight extent". For Jennifer,

contextual factors related to disease progression, physical and psychosocial symptoms, plus time affect willingness to take action.

The dimensions of readiness (awareness, acceptance, and willingness to take action to take action to prepare for EOL) do not appear to be interrelated. Some degree of willingness to take action and acceptance were present at baseline for both Cases, regardless of awareness context. For example, both adolescents equally struggled with accepting the incurable nature of their disease. Open awareness did not lead to an acceptance that life *will* end. In the same way, operating in a closed awareness context did not remove the emotional struggle that life *might* end. Fears about death and dying were present in both cases and acknowledged on the QOL scale (QUAL-E) as well as during the interviews.

### **Research Question Two**

Research question two relates to how an adolescent's readiness (awareness, acceptance and willingness to take action) influences the process of EOL preparedness. To answer this question, we examined awareness, acceptance, and willingness to take action in relation to the attributes within the EOL preparedness construct (knowledge about EOL, acknowledgment of grief and emotions, identification of the meaning of death and spirituality and conceptualization of a personal EOL plan).

Awareness influenced discussions about EOL preparedness, specifically related to grief and emotions or discussions about the meaning of death and spirituality. For example, Cameron, who operated in a closed awareness context at Time 1, felt his greatest problems were related to not knowing how his cancer was going to affect his future. His fears were related to the uncertainty of his cancer on the distant future. His goals were futuristic, such as graduating from high school, going to college, becoming a pediatrician, and raising a family. At Time 2, when he demonstrated some awareness of his incurable prognosis, he was able to describe how his fears are related to his fear of dying. Jennifer was fully aware of her incurable prognosis and spent much time discussing her grief and emotions and the existential struggle to find meaning in her incurable prognosis. Emotional acceptance of incurable prognosis, and the back and forth struggle that occurred became part of EOL preparedness. This was more clearly demonstrated in Jennifer's Case as she particularly struggled to accept the fact that death

meant being separated from her family, particularly her mom and sister. As she anticipated their grief, she was concerned about how life would be for them after she is gone; and this was tied into her acceptance. Open awareness and acceptance helped Jennifer to conceptualize immediate priorities, and across time she was able to communicate her EOL priorities with her mother.

Willingness to take action was present in both cases at the onset of the Study. It measures cognitive intent to engage in discussions regarding knowledge about EOL, and emotional intent to engage in discussions about feelings. The latter connects to the attributes of acknowledgment of grief and emotions and identification of the meaning of death and spirituality. Although Cameron was willing to engage in discussions on a cognitive and emotional level, he spent very little time discussing his grief and emotions or the meaning of death. It appears that level of awareness more clearly indicates the level of emotional discussions that occur within the EOL preparedness construct.

### **Research Question Three**

Research question three relates to how adolescents with incurable cancer prepare for EOL. To answer this question, we examined how the attributes of EOL preparedness (knowledge about EOL, acknowledgment of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of EOL plan) were interrelated. We explored how time influences EOL preparedness, and how demographic, environmental, personal, and family characteristics influence EOL preparedness

In this study, we found that knowledge about EOL was missing, and directly related to discussions with HCPs. For example, Jennifer wanted to know what was going to happen now, before it is too late, in order to think about and process the information. Cameron also lacked knowledge about EOL but clearly described his desire for information in order to have a plan in place, in case something bad happens. The preference for information in both Cameron's and Jennifer's Case was consistent with information preferences reported in adolescents with cancer. Adolescents preferred having information about disease, treatment, and prognosis, and desired a participatory role in decisions about their care (Dunsmore & Quine, 1996; Palmer, et al., 2007; Young, et al., 2003).

Likewise, Cameron, who did not openly acknowledge an awareness or acceptance of his incurable cancer, felt advance care planning discussions should occur anytime an adolescent is getting chemotherapy, because there is a lot of uncertainty related to the outcome. Ongoing discussions between the HCP and adolescent would promote EOL knowledge; and facilitate conceptualization of EOL preferences.

It is not known from this study, if knowledge about EOL would lead to more preparation within the attributes of acknowledgment of grief and emotions, and identification of the meaning of death and spirituality. Lack of knowledge about EOL did not inhibit Jennifer from discussing her grief and emotions. Furthermore, the attributes of acknowledgment of grief and emotions, and identification of the meaning of death and spirituality appear related to emotional acceptance of incurable cancer. It appears both attributes are related to acceptance. In addition, when Jennifer was describing her existential struggle to find meaning in her abbreviated life, it was highly connected to her grief and emotions, so there is probably some conceptual overlap. Conceptualization of EOL priorities/goals appeared separately. As Jennifer struggled to accept her incurable prognosis, she was able to conceptualize her EOL priorities.

For Jennifer, the ability to conceptualize EOL priorities was particularly evident across time. One of her initial goals was to graduate from college and start a career. When asked about planning for immediate goals at Time 1, she had not really thought about it, but wanted to make memories by spending time with her family. By Time 2, Jennifer has had time to think about her priorities/goals. She articulates how there is so much she wants to do, and so much she cannot do; but there is also so much she still wants to try. She more clearly identifies her immediate priorities of publishing her poems, putting together a memory book of a recent trip to Florida, and planning a birthday surprise for her sister in the coming week. Overall, discussions within the EOL preparedness construct increased over time.

In addition to time, there are contextual factors (demographic, environmental, personal and family characteristics) that may account for the increase in Jennifer's EOL preparedness. These include an increase in disease progression evident on CT scans, an increase in weakness, fear, and worry related to disease progression, and ongoing discussions with members of the health care team between Time 1 and Time 2. In

Cameron's Case, contextual factors such as a long prognostic discussion with physician, and a greater understanding of his experimental treatment influenced his awareness, which ultimately influenced his EOL preparedness.

#### **Research Question Four**

Research question four describes how the process of EOL preparedness relates to the adolescent's communication of a personal plan to the adolescent's family member(s) and/or HCP. In our study, we found the EOL plan to have two segments. The first part relates to EOL preferences or advance care planning. The second segment relates to determining EOL priorities, such as goals to accomplish in the near future, or memory-making activities with friends and family.

In our study, regardless of awareness or acceptance of incurable prognosis, adolescents desired to have information about EOL so that EOL preferences could be conceptualized and decisions could be made. Conceptualizing EOL priorities, or goals to accomplish before death, were directly related to acceptance within the EOL preparedness construct.

Jennifer was lacking in knowledge about EOL, so her preferences were not fully communicated. However, she was able to conceptualize what she wanted to accomplish before death and to communicate her priorities with her mother.

Cameron, on the other hand, expressed a desire to engage in discussions about EOL knowledge in order to conceptualize EOL preferences. He did not express a need to conceptualize or communicate immediate EOL priorities or goals. Cameron's lack of awareness is linked to futuristic or distant goals.

Adolescents preferred to have information about their disease progression and knowledge about EOL, but their knowledge and information needs were incongruent with their actual knowledge about EOL. Both adolescents however, felt information about their cancer was disclosed honestly, even when their prognosis was not good. In other studies, adolescents have described frustration with how information was disclosed during treatment. Some felt information was not fully disclosed or disclosed to their parents rather than directly to them (Palmer, et al., 2007; Young, et al., 2003).

### **Research Question Five**

Research question five relates to how contextual factors (demographic, environmental, personal, and family characteristics influence communication of one's personal EOL plan to parent(s) and/or healthcare provider. In this study, we found that social constraint interfered with communication about death. This was more clearly manifested in Jennifer's case. She perceived family members and HCPs did not want to talk about death as evidenced by their facial expressions, or body language. Jennifer described how her sister was particularly averse to discussions related to her disease progression, or possible death. Jennifer in turn, would use humor to lighten the mood or to change the topic. In the same way, Jennifer's mother would listen to her concerns but if Jennifer became too sad, she would lighten the mood by trying to make her laugh. Several studies in the pediatric EOL literature have identified that talking about death with children or adolescents is undoubtedly difficult and triggers strong emotions which may interfere with EOL communication (Bagatell, et al., 2002; Fryer-Edwards, et al., 2006; Khaneja & Milrod, 1998; Serwint, et al., 2002). Pediatric oncology professionals have reported feeling unprepared to handle their own emotions (Newborg, 2008), and many health care professionals report feeling inadequately trained to communicate about EOL (Meraviglia, et al., 2003; Schwartz, et al., 2003).

Although Jennifer acknowledged verbal and non-verbal cues related to social constraint, she still managed to communicate both her preference to be cremated and her EOL priorities with her mother. Jennifer perceived a great deal of support from her family, which was evidenced by the MSPSS and information provided in her interviews.

Our study shows adolescents are experiencing significant psychosocial needs related to pain and symptom management, and the ability to talk freely about their feelings and death-related fears. This is similar to what Jones (2006) found regarding psychosocial needs of adolescents and their families at EOL (Jones, 2006). Providing social support helps to counteract the constraint that is clearly evident at EOL.

### **Research Question Six**

Research question six relates to how an adolescent's QOL at EOL is influenced by communication of a personal EOL plan. We were unable to determine from this study how quality of life at the end of life is influenced by communication of a personal EOL plan. Since data were collected across two time points, this study provided a limited understanding of how QOL at EOL is affected by communication of EOL preferences and priorities. Cameron and Jennifer both described a desire to conceptualize a plan for their EOL preferences. A personal EOL plan was not fully conceptualized, in either Jennifer or Cameron's case, to include EOL preferences (advance directives, etc.) and priorities for immediate future. Therefore, it is not known how communicating such a plan would influence QOL at EOL. However, EOL studies show that when patients communicate their preferences with their physician, they are more likely to experience EOL care that is consistent with their preferences (Gomes & Higginson, 2006; Mack, Weeks, Wright, Block, & Prigerson, 2010). Advance care planning and consideration for EOL preferences and priorities is supported as an important component of palliative EOL care in adolescents and young adults (Freyer, et al., 2006; Hartman, 2004; Himmelstein, 2006; Hinds, et al., 2001; Wiener, et al., 2008).

### **Research Question Seven**

Research question seven relates to how an adolescent's QOL is influenced by EOL preparedness. To answer this question we examined each of the constructs of EOL preparedness in relation to QOL as measured by the QUAL-E. Cameron spent limited time in discussions within the construct of EOL preparedness; however, his QOL score was fairly good. Jennifer on the other hand spent more time discussing her struggle of accepting her incurable prognosis. Her QOL was not as good. Upon further examination, it became clear that several factors both within the EOL preparedness construct and within contextual factors influence QOL. This study was not an intervention study, so any preparedness that occurred, was part of the natural environment. However, both adolescents described a benefit from sharing their feelings as a participant in the study. Clearly EOL preparedness involves having discussions with the adolescent about their worries, concerns and plan for the future. In addition, our study showed demographic factors, such as rapid disease progression, and environmental factors, such as EOL

discussions can influence QOL. Rapid disease progression had a negative effect on Jennifer's QOL by eliciting death-related fears and worries, without sufficient time to process these concerns. This was similar to findings in qualitative work conducted by Andershed and Ternstedt who found a very rapid illness trajectory interfered with feeling prepared for death from caregivers confronting EOL (Andershed & Ternstedt, 2001). Similarly physical and psychosocial symptom distress can interfere with QOL (Palmer, et al., 2007; Penson, et al., 2005; Steinhauser, Clipp, et al., 2000; Theunissen, et al., 2007). In our study, both Jennifer and Cameron were lacking knowledge about EOL which could contribute to higher levels of uncertainty and psychosocial symptom distress. In Jennifer's case, conceptualization of a personal EOL plan was partially completed, as priorities were aligned and discussed with a family member. Since this study provides a limited view, over 1 month in the entire EOL process, and since EOL preparedness was not fully addressed, it is difficult to determine how much QOL at EOL is affected by EOL preparedness. In addition, we were unable to determine whether Jennifer's emotional and existential struggle will eventually resolve. Regardless, the worry about family and death-related fears were evident on the QOL measure for both adolescent. There are several contextual factors (demographic, environmental, personal and family/social support characteristics) that are linked to QOL in this study. These findings were presented in Chapter 4 and are summarized in the following section.

## SECTION TWO: THEORETICAL IMPLICATIONS

In this section the original conceptualization of the theory will be reviewed. Consistencies and discrepancies between the original conceptual model and the data will be summarized. Next, concepts that emerged during data collection and analysis will be presented. Finally, changes to the original conceptual model when considering new data will be proposed along with a revised conceptual model.

### *Original Conceptual Model*

In the original conceptual model, readiness (awareness, acceptance and willingness to take action to prepare for EOL) influences the process of EOL preparedness (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of and EOL plan). Originally, it was proposed that adolescents who engage in the EOL preparedness process will be able to communicate their personal EOL plan to a family member and/or HCP so that preferences for EOL care, and priorities will be achieved. This in turn would influence QOL at EOL. In the original model, demographic, environmental, personal and family characteristics, also known as contextual factors, were proposed to influence the readiness process, EOL preparedness process, and communication of a personal EOL plan. Time was proposed to influence readiness, EOL preparedness, and communication of personal EOL plan. A bidirectional arrow between EOL preparedness and communication of a personal EOL plan indicates that as death approaches, the personal EOL plan may need to be adapted, and once again communicated to a family member and/or HCP so that preferences for EOL care and priorities will be achieved.

### *Consistencies between Theory and Data*

In the current study, there were consistencies and discrepancies between the proposed theory and the data, as well as new concepts that emerged during data analyses. First, there were consistencies in the influence of contextual factors (demographic, environmental, personal and family characteristics) on the attribute of awareness (part of the readiness process in the original model). Contextual factors, such as rapid disease progression, changes in physical or psychosocial symptoms, and prognostic discussions influenced the awareness context.

In this study, time also influenced awareness, acceptance, and willingness to take action. There were changes in each construct that were measured across time. There were some changes in EOL preparedness across time, indicating time may influence this process as well.

Data in this study revealed awareness preceded EOL preparedness. Indeed, the level of awareness was directly related to the level of involvement within the EOL preparedness construct.

Willingness to take action by discussing thoughts, feelings, and information about disease progression influenced EOL preparedness, and conceptualization of EOL preferences. Willingness to take action was influenced by contextual factors, such as disease progression.

The original attributes of EOL preparedness were (knowledge about EOL, acknowledgement of grief and emotions, identification of the meaning of death and spirituality, and conceptualization of an EOL plan). Conceptualization has been moved outside of the EOL preparedness construct. The remaining attributes (knowledge about EOL, acknowledgement of grief and emotions, and identification of the meaning of death and spirituality) have been restructured to incorporate additional constructs, such as discussions with HCP and acceptance of death or incurable prognosis. This is discussed in more detail under the revised conceptual model.

The final consistency between the original data and theory is communication of personal EOL plan. Communication of plan occurred after processing the possibility of death and after conceptualizing EOL preferences or priorities.

#### *Discrepancies between Theory and Data*

There were several discrepancies between the original conceptual model, proposed theory and the data that were collected and analyzed for this study. First, awareness, acceptance, and willingness to take action were conceptualized as a process known as readiness. It was hypothesized that awareness, acceptance and willingness to take action were interrelated and occurred as an antecedent prior to EOL preparedness. However, in this study, awareness of incurable cancer and willingness to take action were independent influences on EOL preparedness; whereas acceptance of incurable cancer

occurred within the construct of EOL preparedness. The attributes of the readiness process are discussed individually in the following paragraphs.

Awareness remained an antecedent to EOL preparedness. However, there were varying degrees of awareness. It became more conceptually clear that knowledge of incurable cancer, which was a criterion for entry into this study, did not correlate with a cognitive recognition of incurable prognosis. Adolescents recruited into this study were aware that they were living with cancer that *is not* cured; however, it was not necessary for them to believe that their cancer *could not be* cured. Furthermore, awareness was not static. There was a back and forth movement within the awareness construct that was not only connected to their perceived curative intent, but also connected to their ability to cope with the full cognizance of an incurable prognosis.

Discussions about death and dying were led by the adolescent. In other words, if the adolescent did not initiate the topic, it was not discussed. Sometimes death and dying were implied and further probing would result in an actual discussion about death or dying. At other times, death and dying were implied, but further probing would re-direct the conversation away from death. It became clear during the analysis that adolescents were operating in different levels of awareness of death. Therefore, during analysis, the four awareness contexts (closed awareness, suspected awareness, mutual-pretense awareness, and open awareness), based on the work of Glaser and Strauss (Glaser & Strauss, 1965) were used to analyze the adolescent's cognitive recognition of incurable prognosis.

Results from this case study show awareness contexts would fluctuate within the same adolescent case and even within the same interview. For example, an adolescent might operate in an open awareness context (fully aware of impending death) and mutual pretense awareness (aware of death, but acting as if death will not occur); or a closed awareness context (unaware of impending death) and suspected awareness context (showing some awareness that death might occur). The fluctuation of awareness was consistent across time, as adolescents chose to go back and forth between various awareness contexts. Participating in the discussions during the interview was very similar to a dance; and as long as I stayed within the awareness context of the adolescent,

probing a little but not too much, we were able to confront their worries and fears together, and stay at the degree of comfort for each adolescent.

The results in the current study were different from the findings of Bluebond-Langner or Glaser and Strauss (Bluebond-Langner, 1978; Glaser & Strauss, 1965). In Bluebond-Langner's work (1978), children and adolescents who acknowledged an open awareness context, generally chose to return to a mutual pretense awareness context and remain there; or would use distancing strategies if mutual pretense was too hard to maintain. Mutual pretense occurred based on the social norms and acceptance of others (Bluebond-Langner, 1978). Glaser and Strauss found that in adults who were facing death, awareness was sequential, and those who moved from mutual-pretense to an open awareness would remain in the open awareness context (Glaser & Strauss, 1965).

In our study, adolescents fluctuated between awareness contexts within the same time point. For example, data showed fluctuation between closed awareness and suspected awareness in one case; and mutual pretense awareness and open awareness in the second case. A distinct difference in our study was noted when mutual pretense was initiated as a type of emotional reprieve for the adolescent discussing the reality of an incurable prognosis.

Acceptance was defined as the emotional ability to come to terms with an incurable prognosis. In this study, the measurement of acceptance through the Peaceful Acceptance of Illness subscale shed light on the differentiation between acceptance of a cancer diagnosis, and acceptance of an incurable prognosis. Acceptance of advanced cancer diagnosis was measured on the Peaceful Acceptance of Illness scale. This was present at the beginning of the study in both cases, regardless of awareness context. However, the emotional acceptance of an incurable prognosis, or acceptance of death appeared more evident in the discussions about grief and emotions, and the existential struggle to find meaning in an abbreviated life, and early death. Acceptance in this sense became part of the EOL preparedness process; and was related to the awareness context. There were fluid changes between accepting death and struggling to accept death during discussions within the EOL preparedness construct. Qualitative themes that were linked with the struggle to accept an incurable prognosis included the struggle to accept

separation from family, and the struggle to accept unfulfilled dreams. In the current study, acceptance was never quite resolved.

Acceptance was measured using the Peaceful Acceptance in Illness subscale, which is part of the PEACE scale (Mack, et al., 2008). Peaceful Acceptance in Illness scores ranged from 16 to 17 for both Case 1 and Case 2. There were slight variations in acceptance scores across time. This is similar to the peaceful acceptance scores in the study conducted by Mack, Prigerson and colleagues for initial validation of the PEACE scale, who found Peaceful Acceptance in Illness scores ranged from M (SD) 16.92 (2.74) to 17.14 (2.51), in patients with advanced cancer who did not have a psychiatric diagnosis (Mack, et al., 2008). They found no differences in peaceful acceptance scores in those who were aware they had a terminal illness and those who were not aware. This is similar to what we found. Cameron and Jennifer had different awareness contexts but similar Peaceful Acceptance Scores.

The factors that contribute to peaceful acceptance of illness have been difficult to tease out in the literature. Studies have shown that individuals who struggle accepting their incurable prognosis are also more likely to be younger, and more likely to have smaller social networks (Thompson, et al., 2009), are sad and terrified (Ray, et al., 2006), or more often meet the diagnostic criteria for depressive or anxiety disorders (Mack, et al., 2008; Thompson, et al., 2009). In our study, Jennifer more openly expressed her sadness and emotional struggle to accept her incurable prognosis, also had less perceived social support from friends, measured by the MSPSS (Zimet, et al., 1990).

Unfortunately, we know very little about emotional acceptance of death and dying in adolescents living with incurable cancer. However, we do know adolescents living with advanced and incurable cancer face an uncertain future filled with anticipatory grief. Since they are dying so young, they have more to lose, in terms of future hopes, dreams, and time spent with family and friends. In Jennifer's case, acceptance is occurring in increments of confronting, struggling with, and accepting each loss.

Willingness to take action was present regardless of awareness or acceptance of incurable prognosis. Willingness to take action occurred prior to EOL preparedness, but did not predict involvement in EOL preparedness. Additionally, willingness to take action changed across time. Change occurred in both directions (increased and decreased)

depending upon the case. It appears that willingness to take action to find out more about what to expect as disease progresses decreased as perceived time to death became closer. This information is important for clinical practice. Discussions about disease progression and options for EOL preferences may be occurring too late in the disease trajectory. George and Hutton (2003), propose that all cases of adolescent cancer should be managed in light of clinical uncertainty (George & Hutton, 2003). Recent studies show that adolescents want to be involved in decisions involving advance directives or EOL (Lyon, 2010; Pousset, et al., 2009). Furthermore, Lyon et al. (2010) conducted an intervention to assist adolescents and their families with advance care planning. They found no significant difference in treatment versus control groups for anxiety or depression (Lyon, 2010).

Another discrepancy between the original conceptual model and data for this study involved the influence of contextual factors (demographic, environmental, personal and family characteristics) on EOL preparedness and communication of personal EOL plan. Originally, it was hypothesized that contextual factors, such as open communication, perceived social support, advanced and incurable cancer and decisional control preference would influence involvement in EOL preparedness and affect communication of personal EOL plan. However, in this study, Cameron's Case showed that even high levels of perceived social support, open communication, and active involvement in prior decisions about treatment did not influence his engagement in EOL preparedness or communication of a personal EOL plan. While one can argue that contextual factors, such as perceived social support would certainly support discussions within the EOL preparedness construct, evidence from this study could not clearly describe the connection. However, perceived social constraint did influence discussions about death. This is discussed further under new concepts that emerged.

The final discrepancy involved quality of life. It was originally proposed that QOL was influenced by the EOL preparedness process and communication of a personal EOL plan. The original conceptual model did not take into account how QOL may be affected regardless of EOL preparedness and communication of personal plan. Indeed, contextual factors such as physical and psychosocial symptoms, family support and communication, relationship with HCP, involvement in decisions, etc., directly

influenced quality of life, regardless of involvement in EOL preparedness. Furthermore, due to the limited time frame of the study, it is not fully understood how involvement within each of the attributes of the EOL preparedness construct influence communication of a personal EOL plan. For example, information about knowledge about EOL was lacking. This interfered with conceptualization of EOL preferences and communication of personal EOL plan. Additionally, it is not known if communication of EOL preferences and priorities will indeed improve QOL at EOL.

#### *New Concepts that Emerged*

In this study, there were new concepts and unexpected findings about existing concepts that emerged during data analysis. First, there was an important discovery on the construct of readiness. Readiness was originally conceptualized as a process of awareness, acceptance and willingness to take action. In this study, we found readiness is not a linear process. Awareness did not precede acceptance; and acceptance did not precede willingness to take action. On the contrary, the willingness component was equally present at Time 1, regardless of the awareness context. Adolescents were very willing to have discussions about their concerns with individuals who were part of their social support system, such as a family member or HCPs; and somewhat willing to share their feelings, such as things that make them sad or afraid, with their family members and HCPs. Similarly, a degree of acceptance was evident at baseline regardless of awareness context. Acceptance at baseline on the Peaceful Acceptance of Illness subscale (Mack, et al., 2008), may be measuring acceptance of advanced disease, in addition to acceptance of a terminal disease. One might accept a diagnosis of advanced cancer, but not accept that cancer is terminal. These are two separate constructs. Acceptance related to terminal disease occurred more within the construct of EOL preparedness. Therefore, the model has been adapted to accommodate this change.

Another important discovery was the adolescent's willingness to find out more about what will be happening if cancer progresses; and willingness to engage in discussions about EOL options to determine preferences in the event that cancer is not cured. There was both willingness and desire to have discussions in order to conceptualize EOL preferences regardless of awareness context. For example, Cameron who operated in both a closed awareness and a suspected awareness context felt the need

to discuss EOL options and preferences. He did not, on the other hand, see a need to identify immediate priorities/goals to accomplish in the near future or the need to discuss his priorities/goals with his physician. Jennifer expressed an immediate desire to find out information about disease progression at Time 1, before it was too late. At Time 2, even though her willingness to find out more about what will be happening decreased, she still acknowledged the importance of having conversations to determine options for EOL Care. In addition, Jennifer operated between mutual pretense awareness and an open awareness context. As she struggled with the reality of an incurable prognosis, she also conceptualized her immediate priorities and by Time 2 had communicated those priorities with her mom. In this proposed change to EOL preparedness, discussions regarding knowledge about EOL can occur independently from discussions about grief and emotions, and the identification of the meaning of death and spirituality. In the revised model, there are two boxes embedded into the EOL preparedness process to reflect this change.

There were new concepts that emerged while analyzing the data. During the interviews, a salient theme that became apparent was coping. In this study, coping was broadly categorized into coping behaviors, defined as ways of dealing with the difficult situation of living with advanced cancer. Adolescents used different cognitive and behavioral strategies to help them deal with advanced cancer. Since coping was not measured quantitatively, themes were determined based on the adolescents' qualitative descriptions. Coping behaviors included cognitive strategies such as, having a positive mindset, focusing on the positives, identifying with others, fighting back, letting go of what you can't control, and spending time alone. Coping behaviors also included behavioral strategies, such as, talking about it, exercising independence and using methods of diversion (i.e. reading, writing, and art activities). Coping behaviors provided intermittent relief for the physical and psychosocial symptoms prominent with advanced disease. Discussions about coping behaviors stood out in the adolescent interviews as ways dealing with the physical and emotion challenges of living with advanced cancer.

In studies involving adults with advanced cancer, coping style is related to emotional distress and QOL (O'Brien & Moorey, 2010), although not fully understood. Some coping behaviors that were helpful in early stage cancer such as resignation and

acceptance were correlated with depression in advanced disease. In addition, fighting spirit and positive attitude had less of an impact on psychological adjustment and QOL in advanced cancer. Helplessness, hopelessness, and escape-avoidance behaviors were linked to greater psychological distress regardless of disease stage (O'Brien & Moorey, 2010).

In the literature on adults living with advanced cancer, there are many factors that trigger a coping response. These include trying to find meaning, searching for support, minimizing the impact of cancer, experiencing the reality of advanced cancer physically, mentally, and emotionally, living with uncertainty, and threats of autonomy and control (Thomsen, Rydahl-Hansen, & Wagner).

In this study, coping played a significant role in helping adolescents adapt to advanced and incurable cancer. Additionally, having a social support system of nurses, doctors and family members was identified as an essential component for facing and confronting the challenges of advanced cancer. Adolescents identified words and actions from others that were not helpful while living with advanced disease. It was not helpful to be reminded of their illness, to have someone make decisions on their behalf, or do things for them when they were capable of being independent. Empowering adolescents to express their needs to family, friends, and members of the health care team may benefit quality of life in adolescents living with advanced cancer, and merits further exploration.

Another concept that emerged during analysis was social constraint. Social constraint blocked communication about death or dying. There were both active and inactive methods of social constraint identified. In this study, active constraint occurred when conversations were verbally re-directed by changing the topic or using humor to lighten up the mood. Anderson and colleagues (2008) describe a bio-medically focused response can constrains a conversation about patient emotions. For example, a patient with advanced cancer says, "I'm worried about these headaches"; and the oncologist responds, "Do you feel nauseated with the headaches?" The response may have clinical relevance; however, it does not invite discussion about underlying emotions such as fear that cancer is returning (Anderson, et al., 2008).

In this study, inactive constraint was evidenced through body language and facial expressions. For example, the look of sadness in someone's eyes, the inability to make eye contact, the frowning of brows, or massaging of temples or forehead. Cues were identified that nonverbally communicated to the adolescent the discomfort of talking about death. Even more enlightening was the adolescent's recognition that if a family member or HCP that was "too depressed" or "too stressed out", he/she would not be emotionally available to provide the necessary support. Adolescents recognized support was a vital part of coping with advanced disease.

Most likely, the reason for social constraint includes protection from the painful emotions associated with loss and separation associated with death. Confronting death can trigger emotions not only for the adolescent who is dying, but also for the family and HCPs. Social constraint therefore emotionally protects the family member and HCP as well as the dying adolescent. In EOL communication intervention studies, self-reflection is used to help participants become aware of their own emotions while communicating with patients near the end of life (S. C. Alexander, Keitz, Sloane, & Tulskey, 2006; Fryer-Edwards, et al., 2006; Han, Keranen, Lescisin, & Arnold, 2005; Okon, Evans, Gomez, & Blackhall, 2004; Zapka, Carter, et al., 2006). Recognition of caregiver and HCP emotions is an important step toward being able to respond to the emotional cues of the individuals facing death.

### *Revised Conceptual Model*

Evaluation of consistencies and discrepancies in data and description of findings on new concepts and discoveries have led to a revised conceptual model. Proposed changes are described in the following section, along with a figure that represents the revised conceptual model. The following changes are included in the revised conceptual model:

1. The attributes of the readiness process have been separated.
  - a. Awareness is a fluid construct and precedes EOL preparedness
  - b. Acceptance has been moved within the EOL preparedness construct and relates to acknowledgment of grief and emotions, and identification of the meaning of death and spirituality
  - c. Willingness to take action is linked to contextual factors, EOL preparedness, and conceptualization/communication of EOL preferences and priorities
2. End-of-life preparedness is divided into 2 sections.
  - a. Knowledge about EOL and discussions with HCP
  - b. Acknowledgment of grief and emotions, acceptance of death and incurable prognosis, and identification of meaning of death and spirituality
3. Conceptualization of EOL plan has been changed to conceptualization of EOL preferences and conceptualization of EOL priorities.
  - a. Conceptualization of EOL preferences and EOL priorities is moved outside of the EOL preparedness construct
  - b. Conceptualization occurs prior to communication of EOL preferences and priorities
4. Contextual factors have been slightly modified and are directly linked to QOL

### *Proposed Changes when Considering Data*

Proposed changes to the conceptual model when considering the findings of this study include separating the readiness construct. The readiness process of awareness, acceptance, and willingness to take action is separated. During analysis, it became more conceptually clear that acceptance of death and incurable prognosis, occurs within the

construct of EOL preparedness while processing grief and emotions, and the meaning of death. Acceptance of death and incurable prognosis is a fluid concept of back and forth movement between accepting and struggling to accept incurable prognosis and is tied to the emotional and existential issues related to death and dying.

Awareness precedes EOL preparedness. It is a fluid construct and includes four levels of awareness, ranging from totally unaware of impending death to fully aware of impending death. The four awareness contexts (closed awareness, suspected awareness, mutual pretense awareness and open awareness) are derived from the work of Glaser & Strauss (Glaser & Strauss, 1965). Awareness is influenced by contextual factors, such as disease progression, changes in symptoms and prognostic EOL discussions. Level of awareness is directly related to involvement in the EOL preparedness construct.

Willingness to take action is now a separate construct. It is influenced by contextual factors, such as disease progression, and physical and psychosocial symptoms evident with advanced disease. Willingness to take action influences EOL preparedness and discussions related to knowledge about EOL and/or influences discussions about grief and emotions, and the identification of the meaning of death and spirituality. Willingness to take action also influences discussions to conceptualize EOL preferences and priorities.

In the revised conceptual model, EOL preparedness is separated into 2 sections. The first section addresses knowledge about EOL and what to expect as disease progresses. An important part of this process is the ongoing discussions with a HCP so that EOL preferences can be determined. This will result in conceptualization of EOL preferences, or advance care planning. Conceptualization of EOL preferences occurs prior to communication about preferences with HCP or family. It is proposed that communication of EOL preferences will lead to a better QOL at EOL.

The second part of EOL preparedness includes acknowledgement of grief and emotions, and identification of the meaning of death and spirituality. During this process of confronting multiple losses and examining existential meaning, the struggle of accepting death occurs. As one faces the possibility of death, priorities and immediate goals become more clearly conceptualized. The second part of EOL preparedness leads to conceptualization of EOL priorities or goals. This also includes memory-making and acts

of altruism or legacy. Conceptualization of EOL priorities will lead to communication about priorities with HCP or family. It is proposed that communication of EOL priorities will lead to a better QOL at EOL.

Contextual factors are directly related to QOL, and as previously mentioned also influence awareness and willingness to take action. In the revised conceptual model, social constraint negatively influences discussions about EOL. Contextual factors have been more clearly conceptualized within the four domains previously described as demographic, environmental, personal and family characteristics. In the revised conceptual model, contextual factors include demographic factors, environmental factors, personal characteristics, and social support/constraint. The four domains are further clarified in the following paragraphs.

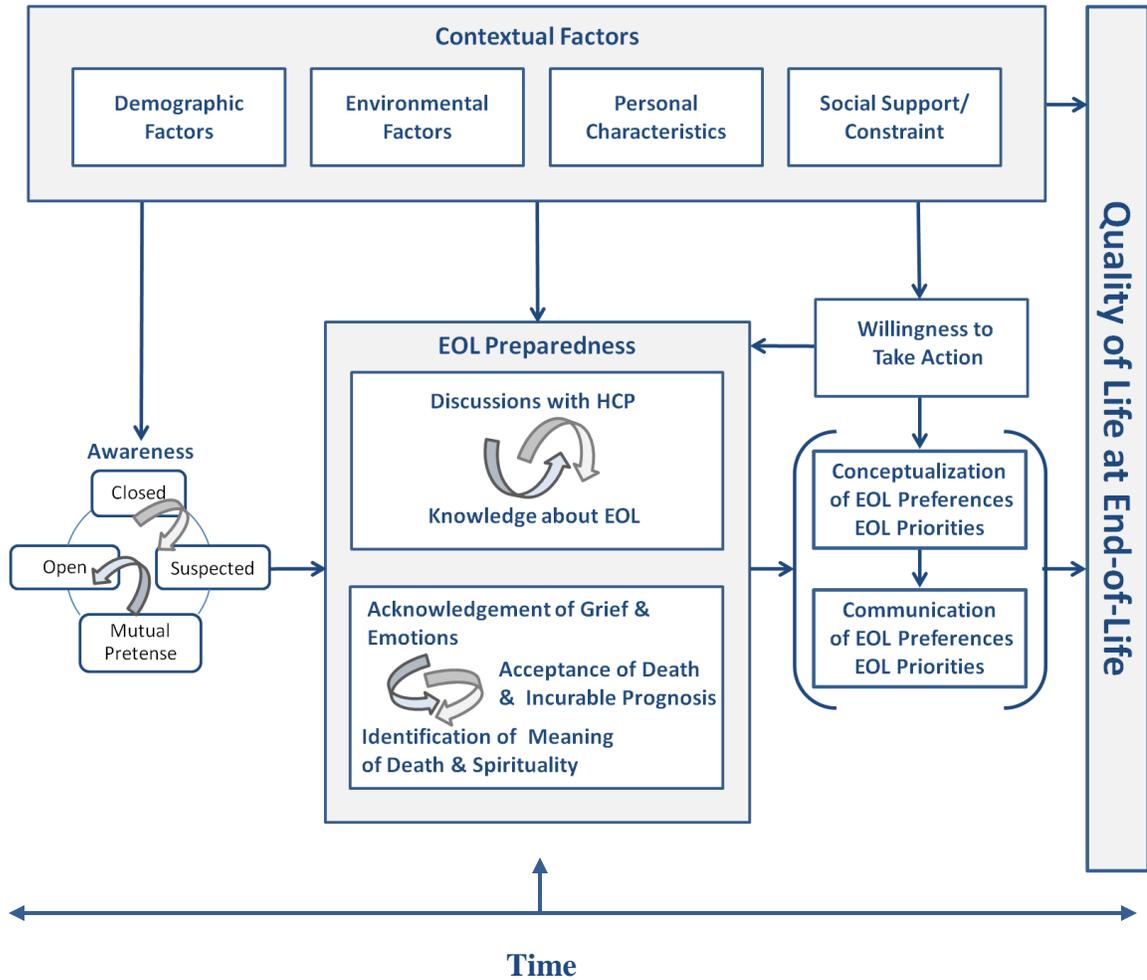
Demographic factors include age, sex, education, race, and disease progression. Demographics are often used to statistically compare groups within a population. In this study, demographic factors were used to describe the adolescent population.

Environmental factors are external to the person and include treatment, EOL discussions, continuity of care, place of care, and culture of neighborhood or family. Environmental factors are generally static conditions that form the setting or surroundings of the adolescent.

Personal characteristics are those things that part of the adolescent's being. Characteristics in this category include decisional control, information preference, symptoms (physical and psychosocial), spiritual beliefs, and coping behaviors.

The last category of contextual factors is social support/constraint. Potential sources of social support include family, members of the health care team, friends, and social networks within the community. Several examples of social support were given for each adolescent case in this study. Social support has been studied extensively within the disciplines of psychology, sociology, and nursing. It is considered a buffer against the stressful events of life, which held true for this study. Social constraint, on the other hand, interfered with support by blocking communication about incurable prognosis and the fears and emotions that accompany death. Lastly, the entire model was influenced by time. Changes within the constructs of the model were identified across time. The revised conceptual model is represented in Figure 3.

**Figure 3: Revised Conceptual Model**



### SECTION THREE: SUMMARY

There are several limitations to the current study on understanding the process of EOL preparedness and the impact on quality of life in adolescents living with advanced cancer. The limitations will be described first, followed by proposed recommendations for future research and the study conclusions.

#### *Limitations*

Case study method, like all methods of research, has its limitations. A frequent concern regarding case study method is how scientific generalizations can be made about one or two cases? Case studies do not generalize to populations. In other words, one cannot take the findings and enumerate the frequencies to adolescents themselves. Rather, the case study findings are generalizable to theoretical propositions (R. Yin, 2009). The goal for case study is to expand and generalize theories. Furthermore, in case study method, empirical results are considered more compelling if two or more cases support the same theory. In this study, the empirical results of each case were compared to a template or conceptual model, illuminating consistencies and discrepancies to the proposed theory. Adolescents were at differing points along the continuum of awareness and acceptance of their incurable prognosis. While this information provided some valuable insight into the theory, it also limits the strength of the EOL preparedness analysis, in that only one case had an adolescent operating in the context of open awareness which affected involvement in the EOL preparedness process.

In both cases, adolescents self-reported affiliation with the African-American race. End-of-life research has been understudied among minorities, including African-Americans. For the current study, there were no cultural traditions or beliefs reported that were unique to the African-American population. However, there may be cultural needs for adolescents of the African-American race, or of differing races and cultures who are facing death, that were not represented by the current study.

There were age differences between the adolescent cases. However, there were developmental similarities. Adolescents in both cases were capable of abstract thinking. For example, in each case the adolescent was able to reflect on emotions, and engage in discussions about current or future goals, as well as hypothetical situations. In each case, adolescents were dependent upon a parent or guardian for daily needs. All this said, there

may be developmental differences or age differences that influence the processes of readiness or EOL preparedness, that were not accounted for in this study.

Another limitation to the current study involves the limited perspective regarding EOL preparedness and quality of life. This study used multiple sources of information from the medical record, from direct observation, and from the adolescent's perspective; incorporating qualitative and quantitative data. However, most of the data were obtained from the adolescent perspective. The current study could have been strengthened by collecting additional data from the perspective of the HCPs and family members involved in caring for and supporting the adolescents living with advanced cancer.

As in all studies, there is the risk of sampling error. Adolescents who met eligibility criteria were recruited into the study by a convenience sampling technique. For this study, five adolescents were approached by their primary physician to introduce the study. One adolescent developed complications and subsequently died, shortly after she was approached by the physician. The other four adolescents were introduced to the study, by the researcher. Two adolescents agreed to participate and two declined. Adolescents who declined were similar in age and gender to the adolescents who were willing to participate (18 year old male and 14 year old female). Reasons for not wanting to participate were refusal to acknowledge incurable prognosis, and not wanting to talk about it. It is quite possible that adolescents who did not wish to participate in the study, or who did not meet the eligibility criteria, have different experiences pertaining to awareness, QOL, or to the process of EOL preparedness.

This study was conducted across time. However, there were only two times points that compared data to the constructs in the theoretical model. This provided a limited glimpse of how time may impact the processes of readiness and EOL preparedness.

Lastly, some of the instruments used in this study have not been formally tested in the adolescent population, namely the PEACE Scale (Mack, et al., 2008) and QUAL-E (Steinhauser, et al., 2004). Both instruments have been shown to be reliable and valid in adults with advanced diseases, who may or may not be aware of their terminal prognosis. In addition, the 3-item Willingness to Take Action scale was created specifically for this study, based on theoretical assumptions. Psychometric testing was not performed prior to

this study, and it is quite possible that other items are needed in order to fully measure this construct.

In summary, although the current study was grounded in theory, awareness, acceptance, and willingness to take action, EOL preparedness, and QOL have not been fully explored in adolescents with advanced and incurable cancer. Additional cases that incorporate adolescents from different races or cultures, of various ages, and at differing points in their awareness context will provide additional information to support or refute the current theoretical assumptions. Collecting data across multiple time points will also provide greater understanding of the influence of time on EOL preparedness. Furthermore, collecting data from the HCP and family perspectives will broaden our understanding of how adolescents become ready to engage in discussions and prepare for EOL and how these factors along with contextual factors, impact QOL in adolescents living with advanced cancer.

#### *Future Directions*

This study provides an important theory-based foundation on which to build future EOL research in adolescents living with advanced and incurable cancer. Findings from this study provide much needed information to guide future research addressing the psychosocial needs of adolescents living with advanced cancer.

This study generates several ideas for future research. The first recommendation is to expand our current theoretical understanding. This can be accomplished by incorporating additional adolescent cases. Information from adolescents who are operating in different awareness contexts, from different races or cultures, and with different personal and family characteristics will allow us to support or refute the current theoretical assumptions. Collecting data across multiple time points will also provide greater understanding of the influence of time on EOL preparedness. And lastly, we could expand our theoretical understanding by collecting data from HCP and family perspectives. Incorporating additional perspectives will also generate knowledge for future interventions that incorporate family and professional caregivers who are supporting adolescents living with advanced and incurable cancer.

Next, further descriptive work needs to be done on the link between willingness to take action and participation in discussions with HCPs about EOL preferences. This

would contribute to a better understanding of the knowledge about EOL component within the EOL preparedness construct. Findings from the current study showed a discrepancy between information preference and willingness to participate in discussions about disease progression, and actual participation in discussions with HCPs to determine preferences for EOL. Hack, Degner and Parker (2005) summarize a growing body of literature that addresses the communication goals and needs of cancer patients (Hack, Degner, & Parker, 2005). Cancer patients have communication needs that include not only discussions about treatment decisions, but also preferences related to advance care planning and EOL (Hack, et al., 2005; Innes & Payne, 2009; Saraiya, Arnold, & Tulskey, 2010; Wiener, et al., 2008). Comparing information preference and intent or willingness to communicate about options at EOL with actual physician/adolescent advance care planning conversations on a larger sample of adolescents would be beneficial. Also, determining physician willingness to engage in discussions based on information preference and willingness of adolescent would provide helpful information on the feasibility of conducting EOL communication interventions in this population.

There are several possibilities for intervention research that may positively influence QOL in adolescents living with advanced cancer. Interventions could be developed to promote positive coping, facilitate the expression of emotions, particularly fears related to death and dying, empower adolescents to communicate preferences for support with family and friends, and help adolescents to develop and communicate EOL priorities with family members or HCPs.

In closing, findings from this study provide insight for clinical practice to address the psychosocial needs of adolescents living with advanced cancer. Nurses are in a key role to provide the much needed continuity of support as disease progresses. Clearly, the health care relationship was a significant factor contributing to a positive quality of life. For adolescents in this study, health care relationship included involvement in treatment decisions, feeling a sense of control over treatment options, honest communication, emotional support from the health care team, and feeling value and respect as a young adult. Strengths of the health care relationship among members of the health care team should be supported. In the same way, HCPs should be encouraged to inquire about information and decisional control preferences of the adolescent and level of willingness

to engage in discussions. This will facilitate adolescent and HCP communication to better ensure the adolescent's EOL communication needs are met.

### *Conclusions*

Despite study limitations, there were several important findings that have helped to advance our theoretical understanding of how adolescents living with advanced cancer become ready to prepare for, and communicate about EOL, and how EOL preparedness influences QOL. This study rigorously examined awareness, acceptance, and willingness to take action and the process of EOL preparedness, through semi-structured interviews with adolescents living with advanced and incurable cancer. Additional data from quantitative measures and from the medical record provided yet another viewpoint for constructs in the theoretical model. Data were measured across two time points. Each case was analyzed individually across time and then cases were compared for the final analysis. Case study method was used to examine data according to a proposed theory. Data were organized according to the constructs in the conceptual model and qualitative data was coded in the NVivo software program. Therefore, our findings can be easily traced back to the original data. The following paragraphs briefly summarize the contribution this study makes to the EOL literature.

This study provides a greater theoretical understanding of the fluid nature of awareness, acceptance, and willingness to take action, within a broader understanding of readiness. Awareness and acceptance of incurable prognosis, and willingness to take action varied within each case and across time. Awareness was most influential for participation in discussions about EOL preparedness. Additionally, we found that willingness to take action could lead to discussions with HCPs about EOL knowledge and preferences, so that advance care planning could occur, regardless of awareness context. In contrast, some degree of awareness was necessary prior to EOL discussions in order to conceptualize and communicate EOL priorities. Without an awareness that one is dying, there is not a need to prioritize EOL goals.

This study also shed light on social constraint or the blocking of EOL communication through non-verbal and verbal cues. Social constraint was identified in both health care professionals and family members. Clearly talking about death and the fears and worries associated with dying is an emotionally laden topic. However,

adolescents in this study clearly identified benefit in talking about their feelings. In the field of interpersonal communication, generation of emotions has been identified as a factor that may disrupt the ability to provide supportive communication (Burlison & MacGeorge, 2002). Likewise researchers studying EOL communication recognize that HCP emotions may interfere with effective communication (Anderson, et al., 2008; Back, et al., 2008; Fryer-Edwards, et al., 2006; Han & Arnold, 2005; Okon, et al., 2004; Zapka, Hennessy, Carter, & Amella, 2006).

Importantly, this study accounted for many contextual factors that are linked to QOL, awareness, willingness to take action, and EOL preparedness. Case Study Method incorporates the context of the phenomenon under study. For adolescents living with advanced and incurable cancer, the context includes demographic and environmental factors, personal characteristics and social support/constraint. This study contributes insight on how contextual factors influence EOL preparedness and QOL. For example, physical and psychosocial symptoms (pain, weakness, and death-related fears) that increased or became more bothersome were linked to an increase in discussions about EOL preparedness. Likewise these same factors negatively influenced quality of life. Perceived family and social support, coping behaviors, and health care relationship positively influenced quality-of-life. Lastly, knowledge preference and willingness to find out more about disease progression were incongruent with actual knowledge about disease progression. This interfered with the ability to make decisions about EOL preferences which may ultimately affect QOL at EOL. Final analysis led to theory expansion and modification as reported in Section Two of this chapter.

This study gives voice from the adolescent perspective to authenticate the theoretical generalizations that were made to the proposed theory of EOL preparedness and QOL. Very few prospective studies have been conducted on adolescents living with advanced cancer. It is a difficult population to access due to the vulnerable age, complexity of managing advanced disease, and concern about possible burden of participating in research with advanced disease. However, adolescents who participated in this study reported no adverse affects from participating in the study; and reported benefit from talking about their feelings.

APPENDICES  
APPENDIX A  
EXAMPLE OF INFORMED CONSENT

**IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR  
UNDERSTANDING QUALITY OF LIFE IN ADOLESCENTS  
LIVING WITH ADVANCED CANCER**

You are invited to participate in a research study about adolescents living with cancer that is not cured. You were selected as a possible participant because you are an adolescent with cancer that is not cured. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Cynthia J. Bell, PhD(c), RN and Victoria Champion, DNS, RN, FAAN; Indiana University School of Nursing.

**STUDY PURPOSE**

The purpose of this study is to find out more about how we can better help adolescents like you who are living life with cancer that is not cured. The research does not involve the use of any investigational drug or device.

**NUMBER OF PEOPLE TAKING PART IN THE STUDY:**

If you agree to participate, you will be one of 10 adolescents who will be participating in this research.

**PROCEDURES FOR THE STUDY:**

If you agree to be in the study, you will do the following things:

You will answer some questions about yourself and about living with cancer that is not cured. We will ask you to talk about your experiences in dealing with cancer that is not cured and share any thoughts you might have about how families or doctors and nurses can help as you live this part of your life. This study will take place in your home or at the hospital, or the outpatient clinic where you see your doctor. We will meet with you 3 different times. The study will last about 4-6 weeks.

The sessions will be audio recorded so that we can hear and review everything you have to say. The tapes will not be shared with anyone except the researchers directly involved in the study. You will have the opportunity to get a copy of the tape recordings after your sessions are complete if you want them. We will talk to you at 3 different times. After each session you will receive a \$25.00 gift card as a token of our appreciation for your time. If you stay in the study for all three sessions, you will receive a total of \$75.00 in gift cards.

The following information will be covered at each session:

1. The first time we meet, we will have you sign the consent and then complete some forms about your cancer and how you are thinking and feeling.
2. The second time we meet, we will find out how you are feeling physically and emotionally and then ask you to talk about your experience with living with cancer that is not cured
3. The third time we meet, we will have you fill out some more forms and ask you to talk some more about what you are thinking and feeling and your experience with living with cancer that is not cured

### **RISKS OF TAKING PART IN THE STUDY:**

While on the study examples of possible risks include:

1. Feeling uncomfortable, sad, anxious or afraid after you complete the study questions or discuss information with us about your cancer that is not cured.
2. Possible loss of confidentiality

Not all of these things may happen to you. None of them may happen. However, if they do, we will make sure that you get help to deal with anything that bothers you. Measures that will be used to minimize the risks and side effects listed above include:

You can tell the researcher that you feel uncomfortable or do not care to answer a particular question.

There will be counseling or social support services available when needed or requested. Costs associated with counseling services will be handled by insurance, payer source or the patient as in normal care.

The investigator will terminate the study if you are too sad or too upset.

You may withdraw from the study at any time by simply saying you don't want to continue in the study for any reason. If you become upset or agitated, the investigator will stop the interview and talk with you or refer you to counseling if needed or desired.

### **BENEFITS OF TAKING PART IN THE STUDY:**

We don't know if you will receive any personal benefits from participating in the study.

However, you might personally benefit from talking about what is happening and exploring what is important with a professional nurse.

You might receive a sense of satisfaction by helping us understand how to help others in your situation.

## **ALTERNATIVES TO TAKING PART IN THE STUDY:**

Instead of being in the study, you have the option of not participating in the study. Or you may wish to explore your questions and concerns with your medical doctor, psychologist or social worker.

## **CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and in databases in which the results may be stored. Tape recordings will be stored on a password protected computer with limited access. Only the researchers involved in the study will have access to the recordings. You will have the opportunity to receive a copy of the audio recordings after your final session is completed. They will not be used for educational purposes and will be properly destroyed after the study is completed and findings have been published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, the and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP) and the Food and Drug Administration (FDA) [for FDA-regulated research and research involving positron-emission scanning], the National Cancer Institute (NCI) [for research funded or supported by NCI], the National Institutes of Health (NIH) [for research funded or supported by NIH], etc., who may need to access your medical and/or research records.

## **COSTS**

There is no cost associated with participating in this study.

## **PAYMENT**

You will receive payment for taking part in this study. There will be 3 times you meet with a researcher. You will be given a \$25.00 gift card after each session.

## **CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study or a research-related event, contact the researchers Cindy Bell or Dr Victoria Champion at (317) 274-4187 (Center for Research and Scholarship). If they would happen to be out of the office when you call, just leave a message with your name, your telephone number, and who you would like to speak to. Cindy Bell or Dr Champion will call you back. Or you can talk to Cindy Bell the next time you see her.

If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

### **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any change in your medical care. Your decision whether or not to participate in this study will not affect your current or future relations with your doctor, the hospital or Indiana University.

Your participation may be terminated by the investigator without regard to your consent in the following circumstances: you become too emotionally upset to continue. Alternatively this study may be terminated by the Clinical trials Monitoring Committee (CTMC) based on review of the investigators reports.

### **SUBJECT'S CONSENT**

*(This section should be in first person)* In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

**Subject's Printed Name:** \_\_\_\_\_

**Subject's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_ (must be dated by the subject)

**Printed Name of Person Obtaining Consent:** \_\_\_\_\_

**Signature of Person Obtaining Consent:** \_\_\_\_\_

**Date:** \_\_\_\_\_

*If the study involves children who will be providing their assent on this consent document, rather than on an assent document, use the following signatures:*

**Printed Name of Parent:** \_\_\_\_\_

**Signature of Parent:** \_\_\_\_\_

**Date:** \_\_\_\_\_

APPENDIX B  
TABLES FOR ACROSS CASE COMPARISON

**Table 38: Comparison of Changes in Case 1 across Time.**

<b>Case 1 Time 1</b>	<b>Case 1 Time 2- (Four Weeks Later)</b>
<p><i>Context Demographics</i></p> <ul style="list-style-type: none"> <li>• Phase 1 clinical trial (Experimental Therapy)               <ul style="list-style-type: none"> <li>- <b>ADVLO911</b>, A Phase I Dose Escalation Study of Seneca Valley Virus (NTX·OI0), A Replication-Competent Picornavirus, in Relapsed/Refractory Pediatric Patients with Neuroblastoma, Rhabdomyosarcoma, or Rare Tumors with Neuroendocrine Features (Infusion of Seneca Valley Virus 5-18-2010)</li> </ul> </li> </ul>	<p><i>Context Demographics</i></p> <ul style="list-style-type: none"> <li>• New Phase 1 clinical trial (Experimental Therapy)               <ul style="list-style-type: none"> <li>- <b>ADVLO919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia 6-28-10</li> </ul> </li> </ul>
<p><i>Context Demographics</i></p> <ul style="list-style-type: none"> <li>• Age, sex, race education, religious affiliation same across time</li> <li>• Cancer advanced, slow progression</li> </ul>	<p><i>Context Demographics- Same</i></p> <ul style="list-style-type: none"> <li>• Age, sex, race education, religious affiliation same across time</li> <li>• No change in cancer</li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• Place of Care               <ul style="list-style-type: none"> <li>- Home with frequent visits to Tertiary Care Center on Outpatient basis</li> </ul> </li> </ul>	<p><i>Context Environmental- Same</i></p> <ul style="list-style-type: none"> <li>• Place of Care               <ul style="list-style-type: none"> <li>- Home with frequent visits to Tertiary Care Center on Outpatient basis</li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care</b> <ul style="list-style-type: none"> <li>- <b>Curative</b></li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care</b> <ul style="list-style-type: none"> <li>- <b>More uncertain</b></li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff</b> <ul style="list-style-type: none"> <li>- Ongoing care with primary oncologist</li> <li>- Oncologist at Tertiary Care Center</li> <li>- Mentions support of nursing staff related to hospitalization</li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff</b> <ul style="list-style-type: none"> <li>- Ongoing care with primary oncologist</li> <li>- Oncologist at Tertiary Care Center</li> <li>- No continuity of Nursing staff identified while on Phase 1 clinical trials</li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Initial or Ongoing EOL Discussions</b> <ul style="list-style-type: none"> <li>- None documented in medical record</li> <li>- Not discussed in Time 1 interview</li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Initial or Ongoing EOL Discussions</b> <ul style="list-style-type: none"> <li>- Documentation of long discussion with MD regarding tumor and therapeutic options</li> </ul> </li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Decisional Control Preference</b> <ul style="list-style-type: none"> <li>- Active-Collaborative Role</li> </ul> </li> </ul>	<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Decisional Control Preference</b> <ul style="list-style-type: none"> <li>- Active-Collaborative Role</li> <li>- Exercises a more active approach in decisions about his treatment</li> </ul> </li> </ul>

<b>Case 1 Time 1</b>	<b>Case 1 Time 2- (Four Weeks Later)</b>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge Preference</b> <ul style="list-style-type: none"> <li>- Desires all information, both good and bad news</li> </ul> </li> </ul>	<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge Preference</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>
<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Physical Symptoms</b> <ul style="list-style-type: none"> <li>- Pain, Fatigue and Shortness of Breath, more problematic and increased during Time 1 interview</li> </ul> </li> <li>• <b>Psychosocial Symptoms</b> <ul style="list-style-type: none"> <li>- Fears related to unknown</li> </ul> </li> </ul>	<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Physical Symptoms</b> <ul style="list-style-type: none"> <li>- Pain, Fatigue and Shortness of Breath, stable during interview</li> <li>- Heart monitored per EKGs</li> </ul> </li> <li>• <b>Psychosocial Symptoms</b> <ul style="list-style-type: none"> <li>- Fears related to death</li> <li>- Worry</li> </ul> </li> </ul>
<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Positive Coping Behaviors</b> <ul style="list-style-type: none"> <li>- Having time alone</li> <li>- Drawing</li> <li>- Positive mindset</li> <li>- Talking about it</li> </ul> </li> </ul>	<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Positive Coping Behaviors</b> <ul style="list-style-type: none"> <li>- Talking about it</li> <li>- Letting go of what you can't control</li> <li>- Exercising independence</li> </ul> </li> </ul>
<p><i>Context: Family and Social Support Characteristics</i></p> <ul style="list-style-type: none"> <li>• Strong Social Support System <ul style="list-style-type: none"> <li>- Family (Grandmother and brother)</li> <li>- HCPs (nurses and doctors)</li> <li>- Hospital Staff (Social Workers, Child Life, volunteers)</li> <li>- Teachers</li> <li>- Community &amp; Friends</li> </ul> </li> </ul> <p><b>MSPSS- (Scale 1 to 7)</b>  <b>Social Support Total Score = 6.75</b></p> <ul style="list-style-type: none"> <li>- <b>Significant Other Subscale = 6.75</b></li> <li>- <b>Family Subscale = 6.75</b></li> <li>- <b>Friends Subscale = 6.75</b></li> </ul>	<p><i>Context: Family and Social Support Characteristics</i></p> <ul style="list-style-type: none"> <li>• Strong Social Support System- <b>Same</b> <ul style="list-style-type: none"> <li>- Family (Grandmother and brother)</li> <li>- HCPs (doctors)</li> <li>- Community &amp; Friends</li> </ul> </li> </ul> <p><b>MSPSS- Measured at Time 1 only</b></p>
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Communication</b> <ul style="list-style-type: none"> <li>- Honest, open communication</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Communication</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Cultural &amp; Spiritual Practices</b> <ul style="list-style-type: none"> <li>- Christian Faith</li> <li>- Attends Church</li> <li>- Reads Bible</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Cultural &amp; Spiritual Practices</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Coping</b> <ul style="list-style-type: none"> <li>- Perceives family is doing well</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Coping</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>

Case 1 Time 1	Case 1 Time 2- (Four Weeks Later)
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness</b> <ul style="list-style-type: none"> <li>- <b>Closed awareness context:</b></li> </ul> </li> </ul>	<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness</b> <ul style="list-style-type: none"> <li>- <b>Closed awareness context</b></li> <li>- <b>Suspected awareness context:</b></li> </ul> </li> </ul>
<p><i>Readiness- Acceptance</i>  <b>PEACE- Peaceful Acceptance of Illness Subscale (Scale 1 to 4)</b></p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>4</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>2</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = 16</b></p>	<p><i>Readiness- Acceptance</i>  <b>PEACE- Peaceful Acceptance of Illness Subscale (Scale 1 to 4)</b></p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>4</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>3</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = 17</b></p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness (Scale 1 to 4)</b> <ol style="list-style-type: none"> <li>1. How willing are you to discuss your concerns or things that you're worried about? <b>4</b></li> <li>2. How willing are you to talk about your feelings, (the things that make you sad or afraid)? <b>3</b></li> <li>3. Do you want to find out more about what will be happening if your cancer progresses? <b>4</b></li> </ol> </li> </ul>	<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness (Scale 1 to 4)</b> <ol style="list-style-type: none"> <li>1. How willing are you to discuss your concerns or things that you're worried about? <b>4</b></li> <li>2. How willing are you to talk about your feelings, (the things that make you sad or afraid)? <b>4</b></li> <li>3. Do you want to find out more about what will be happening if your cancer progresses? <b>4</b></li> </ol> </li> </ul>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge.</b> <ul style="list-style-type: none"> <li>- No discussion about EOL Knowledge or EOL preferences</li> </ul> </li> <li>• <b>Acknowledgment of fear and emotions</b> <ul style="list-style-type: none"> <li>- Hinted about his fear of death, but mainly focused on impact of how living with cancer will affect future</li> </ul> </li> <li>• <b>Identification of the meaning of death and spirituality</b> <ul style="list-style-type: none"> <li>- No discussion</li> </ul> </li> <li>• <b>Conceptualization of Plan</b> <ul style="list-style-type: none"> <li>- Goals futuristic</li> <li>- No thought of EOL plan, suggestions of memory-making and legacy were foreign</li> </ul> </li> </ul>	<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge</b> <ul style="list-style-type: none"> <li>- Discussed hypothetical situations about EOL preferences</li> </ul> </li> <li>• <b>Acknowledgment of fear and emotions</b> <ul style="list-style-type: none"> <li>- Described some of his deepest fears including his fear of death.</li> </ul> </li> <li>• <b>Identification of the meaning of death and spirituality</b> <ul style="list-style-type: none"> <li>- No discussion</li> </ul> </li> <li>• <b>Conceptualization of Plan</b> <ul style="list-style-type: none"> <li>- Goals futuristic, but less concrete</li> <li>- Open to discussions about advanced directives</li> </ul> </li> </ul>

<b>Case 1 Time 1</b>	<b>Case 1 Time 2- (Four Weeks Later)</b>
<p data-bbox="280 233 743 262"><i>Communication of EOL Personal Plan</i></p> <ul data-bbox="334 268 836 331" style="list-style-type: none"> <li data-bbox="334 268 836 331">• Has not developed a plan, therefore no communication of plan</li> </ul>	<p data-bbox="873 233 1333 262"><i>Communication of EOL Personal Plan</i></p> <ul data-bbox="922 268 1424 331" style="list-style-type: none"> <li data-bbox="922 268 1424 331">• Has not developed a plan, therefore no communication of plan</li> </ul>
<p data-bbox="280 338 456 367"><i>Quality of Life</i></p> <ul data-bbox="334 373 711 403" style="list-style-type: none"> <li data-bbox="334 373 711 403">• Not measured quantitatively</li> </ul>	<p data-bbox="873 338 1045 367"><i>Quality of Life</i></p> <p data-bbox="873 373 1273 403"><b>QUAL-E (1-5 Likert-type scale)</b></p> <ul data-bbox="922 409 1354 709" style="list-style-type: none"> <li data-bbox="922 409 1354 472">• <b>Symptom Impact</b> - Mean Score = 2.25</li> <li data-bbox="922 478 1354 573">• <b>Relationship with Health Care System</b> - Mean Score = 5</li> <li data-bbox="922 579 1354 642">• <b>Preparation</b> - Mean Score = 4</li> <li data-bbox="922 648 1354 709">• <b>Life Completion</b> - Mean Score = 4.85</li> </ul> <p data-bbox="873 716 1101 745"><b>Total Score = 4.19</b></p> <p data-bbox="873 751 1149 781"><b>Global QOL = 3 (Fair)</b></p>

**Table 39: Comparison of Changes in Case 2 across Time.**

<b>Case 2 Time 1</b>	<b>Case 2 Time 2- (Three Weeks Later)</b>
<p><i>Context Demographics</i> Not enrolled in clinical trial</p>	<p><i>Context Demographics</i></p> <ul style="list-style-type: none"> <li>• Enrolled in Phase 1 clinical trial (Experimental Therapy)               <ul style="list-style-type: none"> <li>- <b>ADVLO919</b> Phase 1 study of R04929097, an oral small molecule inhibitor of gamma-secretase in children with recurrent or progressive tumors, or leukemia 7-20-10</li> </ul> </li> </ul>
<p><i>Context Demographics</i></p> <ul style="list-style-type: none"> <li>• Age, sex, race education, religious affiliation same across time</li> <li>• Cancer advanced; rapid progression since diagnosis</li> </ul>	<p><i>Context Demographics-</i></p> <ul style="list-style-type: none"> <li>• Age, sex, race education, religious affiliation same across time</li> <li>• New tumors, cancer continues to rapidly progress</li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• Place of Care               <ul style="list-style-type: none"> <li>- Home with frequent visits to Tertiary Care Center on Outpatient basis</li> </ul> </li> </ul>	<p><i>Context Environmental- Same</i></p> <ul style="list-style-type: none"> <li>• Place of Care               <ul style="list-style-type: none"> <li>- Home with frequent visits to Tertiary Care Center on Outpatient basis</li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care</b> <ul style="list-style-type: none"> <li>- Palliative Care</li> <li>- Not Hospice</li> <li>- Work up for clinical trial and hope for cure</li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Focus of Care</b> <ul style="list-style-type: none"> <li>- Palliative Care</li> <li>- Not Hospice</li> <li>- Enrollment in experimental clinical trial</li> <li>- Perceives doctors are doing everything and not giving up on her</li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff</b> <ul style="list-style-type: none"> <li>- Ongoing care with oncologist at Tertiary Care Center</li> <li>- Mentions support of nursing staff related to inpatient hospitalizations at Tertiary Care Center</li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Continuity of Staff</b> <ul style="list-style-type: none"> <li>- Ongoing care with oncologist at Tertiary Care Center</li> <li>- No continuity of nursing staff identified at Tertiary Care Outpatient Center</li> <li>- Has private home health aide</li> </ul> </li> </ul>
<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Initial or Ongoing EOL Discussions</b> <ul style="list-style-type: none"> <li>- Initial EOL discussion with physician 6-15-10</li> </ul> </li> </ul>	<p><i>Context Environmental</i></p> <ul style="list-style-type: none"> <li>• <b>Initial or Ongoing EOL Discussions</b> <ul style="list-style-type: none"> <li>- Discussions with mom and sister about EOL</li> <li>- Discussions with social worker about EOL</li> <li>- No new EOL discussions documented with physicians</li> </ul> </li> </ul>

<b>Case 2 Time 1</b>	<b>Case 2 Time 2- (Three Weeks Later)</b>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Decisional Control Preference</b> <ul style="list-style-type: none"> <li>- Collaborative-Passive Role in</li> </ul> </li> </ul>	<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Decisional Control Preference</b> <ul style="list-style-type: none"> <li>- Collaborative-Passive Role</li> <li>- Desires parental involvement in decisions as disease progresses</li> </ul> </li> </ul>
<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge Preference</b> <ul style="list-style-type: none"> <li>- Desires all information, both good and bad news</li> </ul> </li> </ul>	<p><i>Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge Preference</b> <ul style="list-style-type: none"> <li>- Afraid to know what is going to happen as disease progresses; although she wants to know</li> </ul> </li> </ul>
<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Physical Symptoms</b> <ul style="list-style-type: none"> <li>- Pain, fatigue, shortness of breath, immobility and cachexia</li> </ul> </li> <li>• <b>Psychosocial Symptoms</b> <ul style="list-style-type: none"> <li>- Decreased motivation</li> <li>- Fears related to unknown</li> </ul> </li> </ul>	<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Physical Symptoms</b> <ul style="list-style-type: none"> <li>- Pain, fatigue, shortness of breath, immobility and cachexia continue unchanged over time</li> <li>- Minimal nausea</li> <li>- Progressive increase in weakness</li> <li>- Heart monitored per EKGs related to study drug</li> </ul> </li> <li>• <b>Psychosocial Symptoms</b> <ul style="list-style-type: none"> <li>- Motivation remains decreased</li> <li>- Death-related fears</li> <li>- Worry</li> </ul> </li> </ul>
<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Positive Coping Behaviors</b> <ul style="list-style-type: none"> <li>- Writing poetry</li> <li>- Reading</li> <li>- Art, crafts, and quiet activities</li> <li>- Talking about it</li> </ul> </li> </ul>	<p><i>Context: Personal Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Positive Coping Behaviors</b> <ul style="list-style-type: none"> <li>- Writing poetry</li> <li>- Reading</li> <li>- Art, crafts, and quiet activities</li> <li>- Talking about it</li> <li>- Focusing on positives</li> <li>- Exercising independence</li> <li>- Identifying with others</li> </ul> </li> </ul>
<p><i>Context: Family and Social Support Characteristics</i></p> <ul style="list-style-type: none"> <li>• Strong Social Support System <ul style="list-style-type: none"> <li>- Family (mom and sister)</li> <li>- Health Care Team (nurses, doctors, social workers and psychologists)</li> </ul> </li> </ul> <p><b>MSPSS- (Scale 1 to 7)</b>  <b>Social Support Total Score = 5.58</b></p> <ul style="list-style-type: none"> <li>- <b>Significant Other Subscale = 6.5</b></li> <li>- <b>Family Subscale = 6.5</b></li> <li>- <b>Friends Subscale = 3.75</b></li> </ul>	<p><i>Context: Family and Social Support Characteristics</i></p> <ul style="list-style-type: none"> <li>• Strong Social Support System- <b>Same</b> <ul style="list-style-type: none"> <li>- Family (Mom and sister)</li> <li>- Health Care Team (doctors, social workers)</li> <li>- Home health aide</li> </ul> </li> </ul> <p><b>MSPSS-</b> Measured at Time 1 only</p>
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Communication</b> <ul style="list-style-type: none"> <li>- Honest, open communication about concerns</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Communication</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>

Case 2 Time 1	Case 2 Time 2- (Three Weeks Later)
<ul style="list-style-type: none"> <li>- Social Constraint with emotional topics related to death and dying</li> </ul>	
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Cultural &amp; Spiritual Practices</b> <ul style="list-style-type: none"> <li>- Acknowledges Christian faith and belief in God</li> <li>- Claims no cultural, spiritual or religious practices help with advanced cancer</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Cultural &amp; Spiritual Practices</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>
<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Coping</b> <ul style="list-style-type: none"> <li>- Perceives family is not coping well, particularly sister</li> </ul> </li> </ul>	<p><i>Context: Family Characteristics</i></p> <ul style="list-style-type: none"> <li>• <b>Family Coping</b> <ul style="list-style-type: none"> <li>- <b>Same</b></li> </ul> </li> </ul>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness</b> <ul style="list-style-type: none"> <li>- <b>Open awareness context</b></li> <li>- <b>Mutual pretense awareness context</b></li> </ul> </li> </ul>	<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Awareness</b> <ul style="list-style-type: none"> <li>- <b>Open awareness context</b></li> <li>- <b>Mutual pretense awareness context</b></li> </ul> </li> </ul>
<p><i>Readiness- Acceptance</i>  <b>PEACE- Peaceful Acceptance of Illness Subscale (Scale 1 to 4)</b></p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>4</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>3</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = <u>17</u></b></p>	<p><i>Readiness- Acceptance</i>  <b>PEACE- Peaceful Acceptance of Illness Subscale (Scale 1 to 4)</b></p> <ul style="list-style-type: none"> <li>• To what extent are you able to accept your diagnosis of cancer? <b>3</b></li> <li>• To what extent would you say you have a sense of inner peace and harmony? <b>3</b></li> <li>• To what extent do you feel that you have made peace with your illness? <b>4</b></li> <li>• Do you feel well-loved now? <b>4</b></li> <li>• To what extent do you feel a sense of inner calm and tranquility? <b>3</b></li> </ul> <p><b>Total Subscale Score = <u>17</u></b></p>
<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness (Scale 1 to 4)</b> <ol style="list-style-type: none"> <li>4. How willing are you to discuss your concerns or things that you're worried about? <b>4</b></li> <li>5. How willing are you to talk about your feelings, (the things that make you sad or afraid)? <b>3</b></li> <li>6. Do you want to find out more about what will be happening if your cancer progresses? <b>4</b></li> </ol> </li> </ul>	<p><i>Readiness</i></p> <ul style="list-style-type: none"> <li>• <b>Willingness (Scale 1 to 4)</b> <ol style="list-style-type: none"> <li>4. How willing are you to discuss your concerns or things that you're worried about? <b>4</b></li> <li>5. How willing are you to talk about your feelings, (the things that make you sad or afraid)? <b>3</b></li> <li>6. Do you want to find out more about what will be happening if your cancer progresses? <b>2</b></li> </ol> </li> </ul>

<b>Case 2 Time 1</b>	<b>Case 2 Time 2- (Three Weeks Later)</b>
<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge.</b> <ul style="list-style-type: none"> <li>- No discussion about EOL Knowledge or EOL preferences</li> </ul> </li> <li>• <b>Acknowledgment of fear and emotions</b> <ul style="list-style-type: none"> <li>- Acknowledges and discusses grief and emotions</li> <li>- Death-related fears</li> </ul> </li> <li>• <b>Identification of the meaning of death and spirituality</b> <ul style="list-style-type: none"> <li>- Death causes physical separation, but will always stay connected in spirit</li> </ul> </li> <li>• <b>Conceptualization of Plan</b> <ul style="list-style-type: none"> <li>- Goals futuristic, somewhat unrealistic (attend college, exercise leg to walk again)</li> <li>- No conceptualization of plan, regarding priorities</li> <li>- Planning trip with family</li> <li>- Mostly wants to make memories by spending time together with family</li> <li>- Verbalized EOL preference with her mom to be cremated rather than buried</li> </ul> </li> </ul>	<p><i>EOL Preparedness</i></p> <ul style="list-style-type: none"> <li>• <b>Knowledge</b> <ul style="list-style-type: none"> <li>- Discussed hypothetical situations about EOL preferences</li> </ul> </li> <li>• <b>Acknowledgment of fear and emotions</b> <ul style="list-style-type: none"> <li>- More openly acknowledges and discusses grief and emotions</li> <li>- Death-related fears</li> </ul> </li> <li>• <b>Identification of the meaning of death and spirituality</b> <ul style="list-style-type: none"> <li>- Discusses belief in afterlife</li> <li>- Death means separation from family</li> <li>- Discusses existential struggle</li> </ul> </li> <li>• <b>Conceptualization of Plan</b> <ul style="list-style-type: none"> <li>- Has made a list of priorities which involve immediate future</li> </ul> </li> </ul>
<p><i>Communication of EOL Personal Plan</i></p> <ul style="list-style-type: none"> <li>• Communication of preference to be cremated, but no EOL personal plan,</li> </ul>	<p><i>Communication of EOL Personal Plan</i></p> <ul style="list-style-type: none"> <li>• Communication of priorities with her mom</li> </ul>
<p><i>Quality of Life</i></p> <ul style="list-style-type: none"> <li>• Not measured quantitatively</li> </ul>	<p><i>Quality of Life</i>  <b>QUAL-E (1 - 5 Likert-type scale)</b></p> <ul style="list-style-type: none"> <li>• <b>Symptom Impact</b> <ul style="list-style-type: none"> <li>- Mean Score = 3.25</li> </ul> </li> <li>• <b>Relationship with Health Care System</b> <ul style="list-style-type: none"> <li>- Mean Score = 4.4</li> </ul> </li> <li>• <b>Preparation</b> <ul style="list-style-type: none"> <li>- Mean Score = 3</li> </ul> </li> <li>• <b>Life Completion</b> <ul style="list-style-type: none"> <li>- Mean Score = 3.71</li> </ul> </li> </ul> <p><b>Total Score = 3.6</b>  <b>Global QOL = 4 (Good)</b></p>

APPENDIX C  
PERMISSIONS FOR STUDY INSTRUMENTS

From: Lesley Degner [[mailto:Lesley\\_Degner@umanitoba.ca](mailto:Lesley_Degner@umanitoba.ca)]  
Sent: Monday, February 23, 2009 2:12 PM  
To: Bell, Cynthia Jean; Sylvie Winslow  
Subject: Re: **Decisional Preferences Scale**

I would be pleased for you to use the CPS--Sylvie, can you send her along the cards.

Have you seen the article in the Canadian Journal of Nursing Research on the CPS? Also, our JAMA article is a good reference for the methodology. Lesley Degner

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**From:** Terry Kaasa [<mailto:terryrae@telus.net>]  
**Sent:** Tuesday, June 23, 2009 1:49 AM  
**To:** Bell, Cynthia Jean  
**Subject:** Re: **EFAT-2**

My apologies, Cindy. I have been away for a bit and forgot to send you the items you requested before I went.

You have my permission to use the EFAT - 2 for your study. I'm delighted that you are interested I hope it works well for you and that it satisfies your criteria.

There is no fee associated with using the tool. My only request is that you acknowledge the work done previously with the EFAT-2.

I'm attaching the Test manual, addendum to the Test manual and two forms we used for recording when I last worked with the tool.

Blessings upon your project.

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**From:** Mack, Jennifer [[mailto:Jennifer\\_Mack@dfci.harvard.edu](mailto:Jennifer_Mack@dfci.harvard.edu)]  
**Sent:** Friday, March 06, 2009 4:05 PM  
**To:** Bell, Cynthia Jean  
**Cc:** Prigerson, Holly G, Ph.D.  
**Subject:** RE: PEACE questionnaire

Cindy, thank you for your email. We would be happy for you to use the questionnaire. I have cc'd Holly Prigerson, PhD, who is the study PI. Good luck with your work! Jenny Mack

**From:** Karen Steinhauser [<mailto:karen.steinhauser@duke.edu>]  
**Sent:** Tuesday, February 24, 2009 9:40 AM  
**To:** Bell, Cynthia Jean  
**Subject:** Re: QUAL-E

Cindy,

You are welcome to use the QUAL-E for your dissertation. It is in the public domain and available for public use. We do like to keep track of who is using it and updates, so that is helpful. Of course citing the validation articles is necessary, more generally, for academic standards. The only question I would raise is whether the content of the tool is developmentally appropriate for your population. We developed the tool based on qualitative and quantitative data from adults living with serious illness — many of whom were older adults. So, the content is related to the tasks of that age population. The measure was validated within that population, as well. So, I would confer with your advisors and committee over whether you think the content is appropriate for your population — knowing it was not designed for use with adolescents and has not been validated therein.

Hope that helps and I am happy to correspond further, if necessary.

Karen

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Karen E. Steinhauser PhD  
VA and Duke Medical Centers  
508 Fulton Street  
Durham, NC 27705  
919-668-2148  
919-668-1300 (FAX)  
[Karen.steinhauser@duke.edu](mailto:Karen.steinhauser@duke.edu)

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**From:** Zimet, Gregory D  
**Sent:** Sunday, February 01, 2009 4:38 PM  
**To:** Bell, Cynthia Jean  
**Subject:** RE: Proposal defense date

Hi Cindy,

You are certainly welcome to use the MSPSS in your study, if you think it will tap what you're interested in. I think the scale works fairly well as a research instrument, though there may be a tendency for a ceiling effect due to social desirability bias.

I've attached a copy of the scale and a chapter I wrote about it (from a while ago). Also attached is a document listing a bunch of articles that assess the reliability & validity of the MSPSS. I look forward to reading your proposal! Greg

APPENDIX D  
INSTRUMENTS FOR STUDY

Edmonton Functional Assessment Tool (EFAT-2)

	<b>0: Functional</b>	<b>1: Minimal dysfunction</b>	<b>2: Moderate dysfunction</b>	<b>3: Severe dysfunction</b>
<b>Communication</b>	Independent	Effective > 50% but < 100% of time	Effective < 50% of time	Unable to Communicate
<b>Mental status (six tasks on memory and orientation)</b>	Oriented and memory intact	Two-six tasks impaired, but follows simple commands	Three-four tasks impaired or responds inconsistently	Five-six tasks impaired or unresponsive to verbal commands
<b>Pain</b>	No impact on function	Inhibits function minimally	Inhibits function moderately	Unable to do any activity due to pain
<b>Dyspnea</b>	No shortness of breath	Urgency with counting or shortness of breath on exertion or intermittent use of oxygen	One extra breath with counting or oxygen at 1-3 liters	At least 2 breaths with counting or oxygen at $\geq 4$ liters
<b>Fatigue</b>	Rarely needs to rest	Rest < 50% of day	Rest > 50% of day	Bedridden due to fatigue
<b>Motivation</b>	Participates in all activity	Participates > 50% of time	Participates < 50% of time	No desire to participate
<b>ADL</b>	Independent	Independent using equipment	Requires some assistance	Totally dependent
<b>GI Distress*</b>	No impact on function	Inhibits function minimally	Inhibits function moderately	Unable to do any activity due to GI distress
*Item added to assess GI symptom distress including nausea, vomiting or diarrhea <i>The following items are part of the EFAT-2 but will not be used for this case study:</i>				
<b>Balance (sitting or standing)</b>	Independent	Requires equipment of one person: minimal safety risk	Requires moderate assistance, one or more persons: unsafe on own	Requires maximal assistance, one or two persons or unable to evaluate
<b>Mobility (bed mobility and transfers)</b>	Independent and safe	Requires one assistant to move safely	Requires two assistants to transfer safely	Unable to assist with position change, Requires mechanical lift
<b>Locomotion (walking or wheelchair)</b>	Independent	Requires walking aid or one person to walk or supervision with wheelchair	Requires two persons to walk or assistance with wheelchair	Unable to walk. Dependent wheelchair management
<b>Performance status (room/unit)</b>	Independent	Independent with minimal assistance	Requires moderate assistance	Requires maximal assistance

**PEACE: Peaceful Acceptance of Illness Subscale** (First 5 items) will be measured.  
**PEACE, EQUANIMITY AND ACCEPTANCE IN THE CANCER EXPERIENCE (PEACE) SCALE**

	<b>Peaceful Acceptance of Illness Subscale</b>	<b><u>Not at all</u></b>	<b><u>To a slight extent</u></b>	<b><u>To some extent</u></b>	<b><u>To a large extent</u></b>
1.	To what extent are you able to accept your diagnosis of cancer?	1	2	3	4
2.	To what extent would you say you have a sense of inner peace and harmony?	1	2	3	4
3.	To what extent do you feel that you have made peace with your illness?	1	2	3	4
4.	Do you feel well-loved now?	1	2	3	4
5.	To what extent do you feel a sense of inner calm and tranquility?	1	2	3	4
<b>Lack of Acceptance/Struggle with Illness</b>					
6.	To what extent do changes in your physical appearance upset you?	1	2	3	4
7.	To what extent does worry about your illness make it difficult for you to live from day to day?	1	2	3	4
8.	To what extent do you feel that it is unfair for you to get cancer now?	1	2	3	4

- |     |  |   |   |   |   |
|-----|--|---|---|---|---|
| 9.  | To what extent do you feel that your life, as you know it, is now over?          | 1 | 2 | 3 | 4 |
| 10. | To what extent do you feel angry because of your illness?                        | 1 | 2 | 3 | 4 |
| 11. | To what extent do you think your illness has beaten you down?                    | 1 | 2 | 3 | 4 |
| 12. | To what extent do you feel ashamed of, or embarrassed by your current condition? | 1 | 2 | 3 | 4 |

### Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree**

Circle the “4” if you are **Neutral**

Circle the “5” if you **Mildly Agree**

Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

	<b>Very Strongly Disagree</b>	<b>Strongly Disagree</b>	<b>Mildly Disagree</b>	<b>Neutral</b>	<b>Mildly Agree</b>	<b>Strongly Agree</b>	<b>Very Strongly Agree</b>
1. There is a special person who is around when I am in need	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7

	<b>Very Strongly Disagree</b>	<b>Strongly Disagree</b>	<b>Mildly Disagree</b>	<b>Neutral</b>	<b>Mildly Agree</b>	<b>Strongly Agree</b>	<b>Very Strongly Agree</b>
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

### Scoring Information

To calculate mean scores:

Significant Other Subscale: Sum across items 1, 2, 5, & 10, then divide by 4.

Family Subscale: Sum across items 3, 4, 8, & 11, then divide by 4.

Friends Subscale: Sum across items 6, 7, 9, & 12, then divide by 4.

Total Scale: Sum across all 12 items, then divide by 12.

**QUAL-E 2005**

**Measuring the Quality of Life of Seriously Ill Patients**

*I'd like you to think back over the last month. Please tell me the three physical symptoms or problems that have bothered you the most during that time. Some examples are pain, nausea, lack of energy, confusion, depression, anxiety, and shortness of breath.*

Symptom #1 \_\_\_\_\_ Symptom  
#3 \_\_\_\_\_  
Symptom #2 \_\_\_\_\_

- If no symptoms were elicited, then state the following:  
*So, just to be sure, over the last month, you have had no physical or emotional symptoms that bothered you.*  
If correct, skip to question #5.

**Which of these symptoms or problems has bothered you the most this past week?**

1. During the last week, how often have you experienced \_\_\_\_\_?  

<i>Rarely</i>	<i>A few times</i>	<i>Fairly often</i>	<i>Very often</i>	<i>Most of the time</i>
1	2	3	4	5
2. During the last week, on average, how severe has \_\_\_\_\_ been?  

<i>Very mild</i>	<i>Mild</i>	<i>Moderate</i>	<i>Severe</i>	<i>Very severe</i>
1	2	3	4	5
3. During the last week, how much has \_\_\_\_\_ interfered with your ability to enjoy your life?  

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5
4. How worried are you about \_\_\_\_\_ occurring in the future?  

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

5. In general, how important are your PHYSICAL SYMPTOMS OR PROBLEMS to your overall quality of life?

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

***Below is a list of statements that other people with a serious illness have said may be important. Please tell me how true each statement is for you.***

6. Although I cannot control certain aspects of my illness, I have a sense of control about my treatment decisions.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

7. I participate as much as I want in the decisions about my care.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

8. Beyond my illness, my doctor has a sense of who I am as a person.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

9. In general, I know what to expect about the course of my illness.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

10. As my illness progresses, I know where to go to get answers to my questions.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

11. In general, how important is feeling like an ACTIVE PARTICIPANT in your HEALTH CARE to your overall quality of life?

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

12. I worry that my family is not prepared to cope with the future.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

13. I have regrets about the way I have lived my life.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

14. At times, I worry that I will be a burden to my family.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

15. Thoughts of dying frighten me.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

16. I worry about the financial strain caused by my illness.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

17. In general, how important are CONCERNS ABOUT THE FUTURE to your overall quality of life?

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

18. I have been able to say important things to those close to me.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

19. I make a positive difference in the lives of others.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

20. I have been able to help others through time together, gifts, or wisdom.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

21. I have been able to share important things with my family.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

22. Despite my illness, I have a sense of meaning in my life.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

23. I feel at peace.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

24. There is someone in my life with whom I can share my deepest thoughts.

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

25. In general, how important is the feeling that your LIFE IS COMPLETE to your overall quality of life?

<i>Not at all</i>	<i>A little bit</i>	<i>A moderate amount</i>	<i>Quite a bit</i>	<i>Completely</i>
1	2	3	4	5

***Now, I have one last question.***

26. How would you rate your OVERALL QUALITY OF LIFE?

<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Excellent</i>
1	2	3	4	5

## QUAL-E scoring

Currently items 5,11,17, 25 and 26 are not used in the scoring.

We score by sub-scale. Usually, they are included separately in analyses. You may try to use them additively as well

### **Symptom impact sub-scale:**

Items 1-4, reverse scored; min.4 max 20

So,  $Q1r + Q2r + Q3r + Q4r$

### **Relationship with health care system sub-scale:**

Items 6-10

$Q6 + Q7 + Q8 + Q9 + Q10$

Min 5, Max 25

### **Preparation sub-scale:**

Items 12-16, reverse scored; min5, max 25

$Q12r + Q13r + Q14r + Q15r + Q16r$

### **Life completion sub-scale:**

Items 18 - 24. min 7, max 35

$Q18 + Q19 + Q20 + Q21 + Q22 + Q23 + Q24$

**Total score:** min 21, max 105

Global score may be used as single item: min1, max 5. Q26

We have not yet analyzed the global with the sub-scales as a total score.

## CONTROL PREFERENCES SCALE

Preference A



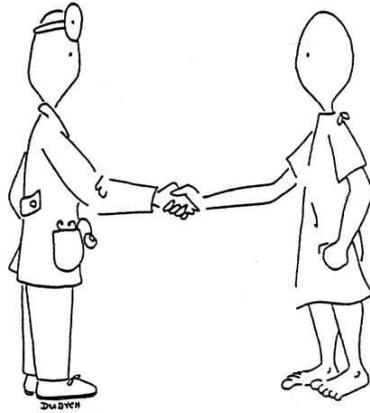
I PREFER TO MAKE THE FINAL SELECTION  
ABOUT WHICH TREATMENT I WILL RECEIVE.

Preference B



I PREFER TO MAKE THE FINAL SELECTION  
OF MY TREATMENT AFTER SERIOUSLY  
CONSIDERING MY DOCTOR'S OPINION.

Preference C



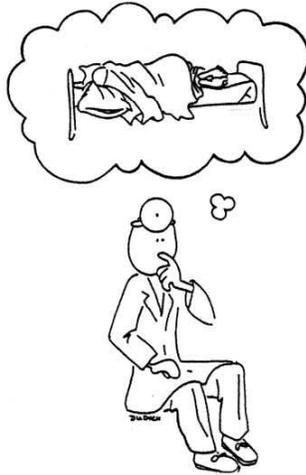
I PREFER THAT MY DOCTOR AND I  
SHARE RESPONSIBILITY FOR DECIDING  
WHICH TREATMENT IS BEST FOR ME.

Preference D



I PREFER THAT MY DOCTOR MAKES THE  
FINAL DECISION ABOUT WHICH TREATMENT  
WILL BE USED, BUT SERIOUSLY CONSIDERS  
MY OPINION.

Preference E



I PREFER TO LEAVE ALL DECISIONS  
REGARDING MY TREATMENT TO MY  
DOCTOR.

## REFERENCES

- AAP (2000). American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative Care for Children. *Pediatrics*, 106(2 Pt 1), 351-357.
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## CURRICULUM VITAE

Cynthia J. Bell

### EDUCATION/TRAINING:

INSTITUTION	DEGREE	YEAR	FIELD OF STUDY
Indiana Wesleyan University, Marion, IN	BSN	1980	Nursing
Indiana University, Indianapolis, IN	MSN	2006	Nursing; Pediatric Clinical Nurse Specialist
Indiana University, Indianapolis, IN	PhD	2011	Clinical Nursing; Behavioral Oncology Research

**CURRENT LICENSURE:** Indiana

### CURRENT CERTIFICATIONS:

Pediatric Chemotherapy and Biotherapy Provider Course (APHON)  
End of Life Nursing Education consortium (ELNEC) - Pediatric Palliative Care Trainer  
Pediatric Advanced Life Support (PALS) Provider, American Academy of Pediatrics,  
American Heart Association

### AWARDS AND HONORS:

<u>Year</u>	<u>Award/ Honor</u>
2006	Inducted into Sigma Theta Tau International
2008	Nominated for Medical Humanities Student Essay Award
2009	Selected to represent IU School of Nursing at the Student Poster Competition at 33rd Annual Midwest Nursing Research Society Research Conference- First Place Award for Doctorate Level Graduate Student Poster
2009	Indiana University Simon Cancer Center Annual Cancer Research Day- First Place Award for Graduate Student- Best Translational/Clinical Research Poster
2010	Selected Grantee to represent Great Lakes Division Researchers at the Relay for Life Summit 2010 Nationwide Focus on Leadership; American Cancer Society, Houston Texas

## GRANTS AND FELLOWSHIP AWARDS:

<u>Year</u>	<u>Grant/ Fellowship</u>
2004-2009	Multiple Travel Fellowship Recipient Awards, Indiana University School of Nursing
2004-2005	Advanced Nursing Traineeship Award, Department of Health & Human Services
2005-2006	American Cancer Society Master's Degree Scholarship in Cancer Nursing MSCN-05-190-01-SCN
Aug. 2005	Oncology Nursing Society Foundation Master's in Nursing Scholarship, National Award
2005-2006	Professional Nurse Traineeship Award, Department of Health and Human Services
2005-2007	Leadership Education in Adolescent Health (LEAH) Fellowship Selected as Nursing Fellow- Indiana University Division of Pediatrics Adolescent Section Department of Health & Human Services (DHHS), Maternal and Child Health Bureau (MCHB) Training Grant # T71 MC00008 Trainee
2006-2008	American Cancer Society Doctoral Degree Scholarship in Cancer Nursing DSCN-06-206-01
2006-2011	Pre-doctoral Fellowship Behavioral Cooperative Oncology Group (BCOG) of the Mary Margaret Walther Program of Cancer Care Research
2007-2010	Research Incentive Fellowship, Multiple Awards, Indiana University School of Nursing
2007	ONS Pre-Doctoral Research Travel Scholarship; 9 <sup>th</sup> National Conference on Cancer Nursing Research; Hollywood, California
2008-2009	Oncology Nursing Society (ONS) Foundation Doctoral Scholarship, National Award
2008-2010	American Cancer Society Doctoral Degree Scholarship in Cancer Nursing-Renewal DSCNR-06-206-03
2010	Dissertation Grant, Indiana University School of Nursing

## RESEARCH:

<u>Year</u>	<u>Research Position</u>	<u>Institution</u>	<u>Location</u>
May 2004-June 05	Research Assistant: <i>Therapeutic Music Video Pilot Study</i> (PI: Burns; Co-PI: Haase) ACS Institutional pilot study	Indiana University	Indianapolis, IN
June 2004-September 2004	Research Assistant: <i>Quality of Life and Life Satisfaction Among Parents of Children and Adolescents with Mental Health Problems</i> (PI: Gerkenmeyer) NIH, NINR- P30 NR05035	Indiana University	Indianapolis, IN

<b><u>Year</u></b>	<b><u>Research Position</u></b>	<b><u>Institution</u></b>	<b><u>Location</u></b>
January 2004 to December 2007	Co-Investigator & Project Manager: <i>Palliative Care and End of Life Communication between Nurses and Parents of Pediatric Oncology Patients</i> (PI: Ferguson; Co- PI Haase) ONS funded multi-site study	Indiana University	Indianapolis, IN
September 2005 to 2007	Evaluator, QA Monitor: <i>Stories and Music Video and Adolescent Resilience during Transplant</i> (PI: Haase; Co-PI: Robb) NIH/NINR/NCI RO1 NR0085830	Indiana University	Indianapolis, IN
December 2007 to 2009	Co-Investigator; Data Analysis for <i>Retrospective Pediatric EOL Chart Review</i> (PI: Pradhan)	Indiana University	Indianapolis, IN
December 2007 to Present	Co-Investigator; Data Analysis for <i>Quality of Life in Younger Breast Cancer Survivors</i> (PI: Champion) ACS-RSGPB-089-01-PBP	Indiana University	Indianapolis, IN
November 2009 to Present	Dissertation Research: <i>Understanding Quality of Life in Adolescents Living with Advanced Cancer</i> (PI: Bell and Champion)	Indiana University	Indianapolis, IN
December 2010 to Present	Co-Investigator; Intervener: <i>A Brief Family Intervention to Promote Adaptive Coping with the Stress of Parental Bone Marrow Transplantation</i> (PI: Fife) NR012260	Indiana University	Indianapolis, IN

## **PUBLICATIONS:**

### **Peer Reviewed Publications**

Decker, C.L., Haase, J.E., **Bell, C.J.** (2007). Uncertainty in Adolescents and Young Adults with Cancer. *Oncology Nursing Forum* 34 (3) 681-688.

**Bell, C.J.**, Skiles, J.L., Pradhan, K.R., Champion, V.L., (2010). End-of-Life Experiences in Adolescents Dying with Cancer-*Journal of Supportive Care in Cancer* 18 (7) 827-835, DOI 10.1007/s00520-009-0716-1.

### **Book Chapters**

Haase, J.E., Chen, C. , Phillips-Salimi, C.R., & **Bell, C.J.** (2009). Chapter 16: Resilience. In S. Peterson & T. Bredow (Eds.), *Middle-range theories: Application to nursing research*. (2<sup>nd</sup> Ed.) (Pp. 326-362) Philadelphia: Lippincott, Williams & Wilkins.

### **Other Publications**

**Bell, C.J.**, (2011). Palliative Care and the Family. In M. Craft-Rosenberg (Ed). *Encyclopedia of Family Health* Thousand Oaks, California: SAGE Publications, Inc.

### **Published Abstracts**

Decker, C.L., **Bell, C.J.**, Haase, J.E. (2006). Uncertainty in Adolescents with Cancer: A Descriptive Study. Abstract. *Journal of Adolescent Health* 38 (2) 115-116.

**Bell, C.J.**, Phillips, C. R., Haase, J.E., Monahan, P.O. (2007). Relationship of Communication to Family Adaptability and Cohesion in Adolescents Diagnosed with Cancer. Abstract. *Journal of Adolescent Health* 40 (2) S29.

**Bell, C.J.**, Ziner, K., Champion, V.L. (2009). Death Worries and Quality of Life in Younger Breast Cancer Survivors. MNRS Doctoral Student Award Abstract. *Western Journal of Nursing Research* 31 (8) 1076-1077.

### **Manuscripts in Progress**

Ziner, K., Sledge, G.W., **Bell, C.J.**, Johns, S., Miller, K.D., Champion, V.L. (Submitted). Fear of Breast Cancer Recurrence in Survivors Diagnosed at Younger and Older Ages  
Champion, V.L., Ziner, K., Monahan, P., **Bell, C.J.**, Smith, L., Sledge, G., (Submitted). Development and Psychometric Testing of a Breast Cancer Self Efficacy Survivor Scale

**Bell, C.J.**, Champion, V.L. (In Progress). Understanding Quality of Life at End-of-Life in Adolescents Living with Advanced Cancer: Revising a Conceptual Model

**Bell, C.J.**, Ziner, K., Bigotti, S., Sledge, G.W., Miller, K.D., Champion, V.L. (In progress). Death Worries and Quality of Life in Younger Breast Cancer Survivors

**Bell, C.J.**, Alexander, A., Champion, V. (In Progress). A Qualitative Understanding of Quality of Life and Health Care Priority Needs in Younger Breast Cancer Survivors and their Partners

Alexander, A., Monahan, P., **Bell, C.J.**, Maners, A., Champion, V. (In Progress). Predictors of Sexual Functioning in Breast Cancer Survivors

Skiles, J.L., **Bell, C.J.**, Champion, V.L., Pradhan, K.R. (In progress). Examining End-of-Life Communication in Pediatric Oncology Patients

**RESEARCH PRESENTATIONS:****\* Indicates Peer- Reviewed Process**

<u>Year</u>	<u>Research Title</u>	<u>Conference Location</u>	<u>Peer Review</u>
12/04	Haase, J., Phillips, C.R, <b>Bell, C.</b> , Harley, J., Hartman, D., Kight, Rubino, P., Swart, J., Wichman, L., Vonbergen J. <i>Strategies to establish collaborative research in the clinical Setting: A palliative care/end-of-life communication research initiative</i>	Podium presentation at the 30 <sup>th</sup> Clarian Patient Care Research Conference; Indianapolis, IN	Local
08/05	Haase, J., Phillips, C., <b>Bell, C.</b> , Burns, D., & Robb, S. <i>Evaluation of a Therapeutic Music Video Intervention to Enhance Resilience in Adolescents and Young Adults Undergoing Stem Cell Transplant</i>	Podium Presentation at the International Pediatric Transplant Association 3 <sup>rd</sup> World Congress; Innsbruck, Austria	International *
09/05	Harley, J., Haase, J., Phillips, C.R., <b>Bell, C.</b> , Hartman, D., Kight, K., Scott, S., Swart, J., Wichman, L., & Vonbergen, J. <i>Hands Across the Gap: Establishing Clinical Practice and Research Partnerships to Create a Palliative Care/End of Life Initiative</i>	Podium Presentation at the Association of Pediatric Oncology Nurses 29 <sup>th</sup> Annual Conference & Exhibits; Portland, Oregon	National *
11/05	Burns, D.S., Robb, S.L., Phillips, C., <b>Bell, C.</b> , Haase, J.E. <i>Parent Perspectives on Music Video Intervention for Adolescents and Young Adults Receiving Stem Cell Transplant</i>	Poster Presentation at AMTA National Conference, Orlando, Florida	National *
03/06	Decker, C., <b>Bell, C.</b> , & Haase, J., <i>Uncertainty in Adolescents with Cancer: A Descriptive Study</i>	Poster Presentation at Society for Adolescent Medicine Annual Conference; Boston, MA	National *
10/06	Burns, D., Haase, J., Robb, S., Phillips, C., <b>Bell, C.</b> , <i>Messages in the Music: AYA and Parent Perspectives of the TMV Intervention</i>	Podium Presentation at 8 <sup>th</sup> World Congress of Pyscho-Oncology International Conference; Venice, Italy	International *

<u>Year</u>	<u>Research Title</u>	<u>Conference Location</u>	<u>Peer Review</u>
03/07	Phillips, C., <b>Bell, C.</b> , Haase, J., Decker, C., <i>Implementation Treatment Fidelity Strategies Uses to Monitor Data Collection of a Multi-Site Behavioral Intervention</i>	Podium Presentation at 31 <sup>st</sup> Annual MNRS Research Conference: Pediatric Research section; Omaha, Nebraska	Regional *
03/07	Phillips, C., <b>Bell, C.</b> , Haase, J., Monahan, P., <i>Examination of Family Protective Factors in Adolescents Diagnosed with Cancer</i>	Podium Presentation at 31 <sup>st</sup> Annual MNRS Research Conference: Adolescent Health Research section; Omaha, Nebraska	Regional *
03/07	<b>Bell, C.</b> , Phillips, C., Haase, J., Monahan, P., <i>Relationship of Communication to Family Adaptability and Cohesion in Adolescents Diagnosed with Cancer</i>	Poster Presentation at Society of Adolescent Medicine (SAM) National Conference; Denver, Colorado	National *
05/08	Skiles, J., <b>Bell, C.</b> , Pradhan, K., Champion, V., Ciccarelli, M., Hubbard, N. <i>Patterns of Death and Dying in Pediatric Oncology Patients</i>	Podium and Poster Presentation at Pediatric Scholar's Day; Indiana University, Indianapolis, Indiana	Local *
02/09	<b>Bell, C.</b> , Skiles, J., Pradhan, K., Champion, V., <i>Factors Influencing Place of Death and End-of-Life Discussions in Adolescents with Cancer</i>	Podium Presentation at the 10 <sup>th</sup> National Conference on Cancer Nursing Research; Orlando, Florida	National *
03/09	<b>Bell, C.</b> , Ziner, K., Champion, V., <i>Death Worries and Quality of Life in Younger Breast Cancer Survivors</i>	First Place-Doctoral Student Poster Competition at 33 <sup>rd</sup> Annual Midwest Nursing Research Conference; Minneapolis, MN	Regional *
04/09	Skiles, J., <b>Bell, C.</b> , Pradhan, K., Champion, V., <i>Patterns of Death and Dying in Pediatric Oncology Patients: A Retrospective Review</i>	Poster Presentation at the 22 <sup>nd</sup> Annual Meeting of the American Society of Pediatric Hematology/Oncology (ASPHO); San Diego, California	National *

<u>Year</u>	<u>Research Title</u>	<u>Conference Location</u>	<u>Peer Review</u>
09/09	<b>Bell, C.,</b> Tucker, M., Berg, A., Harley, J., <i>Time for a Change: Collaborating with Parents to Improve Pediatric End-of-Life and Bereavement Care</i>	Poster Presentation at the Association of Pediatric Hematology Oncology Nurses (APHON) 33 <sup>rd</sup> Annual Conference and Exhibit; Orlando, Florida	National*
02/11	<b>Bell, C.,</b> Maners, A., Alexander, A., Ziner, K., Champion, V., <i>Understanding Quality of Life and Healthcare Priority Needs During Survivorship in Younger Breast Cancer Survivors</i>	Podium Presentation at the 11 <sup>th</sup> National Conference on Cancer Nursing Research; Los Angeles, California	National*
06/11	<b>Bell, C.,</b> Champion, V., <i>Understanding Quality of Life in Adolescents Living with Advanced Cancer</i>	Podium Presentation at the 10 <sup>th</sup> International Family Nursing Conference; Kyoto, Japan	International*

#### **PROFESSIONAL ORGANIZATIONS:**

<u>Dates</u>	<u>Organization</u>	<u>Membership/ Committee</u>
2004-present	Oncology Nursing Society (ONS)	Member
2004-present	Association of Pediatric Hematology Oncology Nurses (APHON)	Member
2005-2009	Indiana Chapter of the Association of Pediatric Oncology Nurses (IAPON)	Executive Committee Member/ 2005-2007; Scholarship Committee 2005-2006; Secretary 2006-2007
2006-present	Midwest Nursing Research Society	Member
2006-present	Sigma Theta Tau International Honor Society of Nursing	Member
2009-present	Hospice and Palliative Nurses Association (HPNA)	Member
2010- present	Children's Oncology Group (COG)	Associate Member of the Nursing Discipline