PRIVACY ISSUES IN YOUNG ONSET COLORECTAL CANCER PATIENTS AND SURVIVORS

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DEDICATION

I dedicate this to the children of young onset colorectal cancer patients and survivors, especially to my own children; Riley, Mikey, and JR. No child should go through what you three have. No child should see their parents experience what you saw me experience. You three are my everything; this is for you. I love you more than my…

And to my mother, WE DID IT! I love you!

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Tiffany Marie Hecklinski

PRIVACY ISSUES IN YOUNG ONSET COLORECTAL CANCER PATIENTS AND SURVIVORS

The occurrence of colorectal cancer among those over the age of 50 is decreasing; conversely, the rate of diagnosis for those under 50 years old is increasing. While medical researchers scramble to identify the cause for this increase, young onset colorectal cancer (YOCC) patients and survivors are left to navigate a new normal. This new normal often includes awkward and troublesome concerns such as scarring, colostomy bags, and bowel problems. Contrary to those diagnosed with colorectal cancer later in life, those that are diagnosed at a younger age are forced to deal with these issues for many years.

The purpose of this exploratory study was to identify privacy issues surrounding YOCC. Because of the significant increase in diagnoses, YOCC is now being researched independently from colorectal cancer in general. The topic of privacy has been researched in academic disciplines, including medicine. Privacy issues surrounding cancer have been researched, as well. Yet, the topic of privacy concerns facing YOCC patients/survivors has been overlooked. It is important to identify privacy concerns specific to YOCC patients/survivors as the information could help health care providers, communication scholars, and caregivers.

Patient narratives were analyzed employing thematic analysis to identify privacy concerns of YOCC patients/survivors through the lens of Communication Privacy Management theory (CPM theory). Results indicated that participants discussed disclosure of their YOCC journey as a process.

Within this disclosure process, YOCC patients/survivors identified specific privacy issues that influenced the way they disclosed or concealed information specific to their illness.

There is a growing need for more research into the YOCC community due to the increase in diagnosis rates and their unique privacy concerns. Potential topics for future research include the impact of COVID-19, patient desire to help others, social media influence on disclosure, how patient disclosure could impact provider training, dating with YOCC, and specific demographic research.

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LIST OF ABBREVIATIONS

CPM theory: Communication Privacy Management Theory

CRC: Colorectal cancer

NED: No evidence of disease

YOCC: Young onset colorectal cancer (those diagnosed under the age of 50)

Chapter 1: Introduction

The subject of privacy in communication has been researched in a plethora of academic disciplines, including the medical field. Topics of research have included patient confidentiality (Ngwenya, et al., 2016), disclosure of medical illnesses (Bril-Barniv et al., 2017) and stigma associated with certain diseases (Delgado-Guay et al., 2013). More specifically and recently, research has been aimed at communication privacy issues surrounding cancer patients and survivors in terms of how patients talk about their disease (Baider, 2010; Donovan-Kicken et al., 2011).

Extant research regarding patients' decisions about restricting or sharing private information about their cancer has provided knowledge that is important and applicable to research on cancer patients and survivors as well as to the study of communication. There is, however, a gap in the research in that few scholars have considered how YOCC patients and survivors communicate private information about their disease. A major factor contributing to the neglect of this topic is its newness (Ahnen et al., 2014). Although the occurrence of colorectal cancer among those over 50 is decreasing, the rate of diagnosis for those under 50 is increasing (You et al., 2012). You and colleagues maintain that the rate of YOCC is "alarming" due to the high proportion of diagnoses at the later stages of the disease within that demographic.

Another disquieting statistic is that those who are diagnosed under 50 years of age have a poorer five-year survival rate (61.5%) versus those who are diagnosed between the ages of 60 and 80 years (64.9 %) (Ahen et al., 2014). Even more disturbing, is that the reason for the disparity in the survival rate is unknown to healthcare professionals and researchers. What is known, is that because of the age of YOCC patients, this

demographic represents the greatest loss of life from the time of diagnosis (Mauri, et al., 2019). In 2018, this compelling trend caused the American Cancer Society to lower the recommended age of routine colonoscopy screenings in those with average risk from age 50 to age 45 (Cavallo, 2019).

Because of the significant increase in diagnoses, YOCC is now being researched independently from colorectal cancer in general. In addition to the vital research seeking to uncover reasons why the incidence of colorectal cancer is increasing in those under 50 years of age and to discover a cure, related psychosocial research topics are beginning to be explored. Researchers have examined a somewhat limited number of topics within the demographic such as quality of life, financial concerns, and racial and ethnic disparities (Blum-Barnett et al., 2019; Holowatyj et al., 2016). In what manner YOCC patients communicate about privacy issues regarding their disease has yet to be addressed in a notable way.

The concept of how YOCC patients and survivors make decisions about disclosing or protecting private information is of particular importance because of the unique consequences of the disease they face as well as the length of time they have to deal with those consequences. For example, a 25-year-old survivor who has a colostomy bag could be obliged to communicate about the bag while dating. An initial decision would have to be made regarding disclosure of the bag to a potential love interest. As the relationship progresses, the survivor would potentially need to share delicate information about leaking or changing the bag in public. Additionally, the life expectancy of a 25-year-old could require them to deal with the ramifications of a colostomy bag for over 50 years.

Privacy issues can be stigmatizing. Although not every patient or survivor may see a colostomy bag as a privacy issue, some patients or survivors may be uncomfortable disclosing about the bag, due to the stigma surrounding it. Smith et al. (2007) posit that those with colostomy bags may experience negative reactions from others regarding the bag. These reactions are based on issues such as odor from the bag, the possibility of noise and leakage, and the fact that feces exits the body in a location that is out of the ordinary.

In addition, Smith et al. (2007) found that non-patients are uncomfortable with being in close proximity to a patient with a colostomy bag. Thus, the non-patients are likely to give a negative reaction to someone who discloses they have a colostomy bag. These negative reactions contribute to stigmatization (Cottrell & Neuberg, 2005).

Not only does this possible privacy issue have the potential to be stigmatized, it has the potential to affect the patient or survivor for a long time. A patient diagnosed in their 20s could deal with the potential privacy issue for 50 years. Conversely, a patient diagnosed at 70 years of age would not have to deal as long with the privacy issue.

Possible stigma associated with a privacy issue, as well as the length of time the issue must be contended with, makes the experiences of YOCC patients and survivors distinct from those who suffer from other cancers and from those diagnosed with colorectal cancer at a more advanced age. With the disturbing rise in the occurrence of YOCC and the unique issues they face, there is an appealing case for not only expanding scientific research but also for pursuing insight regarding the psychosocial effects this disease has on those who are afflicted (Ahnen et al., 2014; Blum-Barnett et al., 2019).

Statement of Problem

While medical researchers scramble to identify causes for the increase in colorectal cancer in those under 50 and to initiate calls to action to health care providers, YOCC patients and survivors are often left to navigate their new normal on their own (Ahnen et al., 2014). This new normal often includes awkward and troublesome concerns such as scarring, ostomy bags, bowel problems, and reproductive matters. These worries are common and sometimes unique to colorectal cancer sufferers. For YOCC patients and survivors, the impact of the disease on their daily lives can be distressing and quite different from the experiences of older individuals who face their own set of challenges.

It has been established that colorectal cancer patients diagnosed over 50 years of age suffer from physical and emotional side effects (Breukink & Donovan, 2013; Pereira et al., 2012; Gray et al., 2014). The physical side effects of dealing with a colostomy bag or sexual issues often lead to emotional side effects such as depression and anxiety (Gray et al., 2014).

Because of the increasing number of YOCC cases, initial research has begun into the physical and emotional side effects specifically within this demographic, exploring the differing concerns of someone diagnosed at 30 years of age as opposed to someone diagnosed at 65 years of age. The differences in the impact of the disease on patients and survivors at the age of diagnosis is supported by the establishment of the Young-Onset Colorectal Cancer Center at Dana-Farber Cancer Institute at Harvard. The director of the Institute states that the center was established to address the "unique physical and psychosocial needs, such as fertility and sexual health concerns" of YOCC patients (Cavallo, 2019).

The creation of a center focused on YOCC supports the notion that the experiences of YOCC patients are different from those who are diagnosed over 50 years of age. Each demographic is distinct and the needs of YOCC patients and survivors can result in stigmatized issues they may be hesitant to disclose. Slade et al. (2007) posit that a person suffering from a stigmatizing condition is less likely to disclose that issue. Although cancer is generally not considered a stigmatizing disease, side effects such as colostomy bags and infertility have been shown to be stigmatized (Slade et al., 2007; Smith et al., 2007). These issues are distinctive to YOCC patients and survivors.

With the acceptance that concerns surrounding YOCC patients and survivors are unique, research has indicated that those needs are not being met (Blum-Barnett et al., 2019). Concerns about fertility and employment typically are specific to those diagnosed at a younger age. A patient diagnosed in their 30s could still have a child and could expect 30 more years of employment. Colorectal cancer treatment can affect fertility in men and women which could make it difficult to conceive a child. This could be an issue difficult to disclose to a romantic partner.

The impact of treatment on a colon cancer patient frequently leaves them unable to work (Blum-Barnett et al. 2019). For a YOCC patient, the potential damage to the beginnings of a job and career can be devastating and financially overwhelming. Research has shown that these issues have the potential to be difficult to disclose (Levontin & Yom-Tov, 2017). For example, a patient undergoing treatment may not want to disclose the difficulties of treatment to those at work for fear of negative repercussions (Von Schrader et al., 2014).

The needs of YOCC patients and survivors are unique and unmet (Blum-Barnett et al., 2019). Traditionally thought of as a disease occurring in older individuals (those over 50 years of age), treatment and research regarding colorectal cancer has obviously been targeted to that demographic. With the rise of diagnoses in younger individuals, the paradigm needs to be adjusted to include issues specific to those under 50, including concerns such as employment, dating, and fertility in addition to the scientific research such as the molecular makeup of tumors (el Din, et al., 2020). Issues typically specific to the younger demographic could be considered by patients and survivors as private information which could trigger communication privacy dilemmas.

Because of the unmet needs of YOCC patients and survivors, there have been calls for an increase in applicable research encompassing psychosocial issues (Blum-Barnett et al., 2019; el Din et al., 2020). However, gaps in the research—including overall care of and support for YOCC patients and survivors—need to be addressed. Because of this call for research on the unique, unmet needs of YOCC patients and survivors, it is imperative to first identify issues of concern.

Inclusive within the unique, unmet needs of YOCC patients and survivors are communication issues regarding when to share and when to restrict access to private information. Privacy management issues can include financial concerns, fertility issues, and sexual dysfunction. Researching and addressing unmet needs that are private in nature can contribute to an improved quality of life for the YOCC patient and survivor who sometimes faces anxiety and depression. Identifying the privacy issues of concern to YOCC patients and survivors is a vital first step in addressing the needs of this under-researched demographic.

Research Questions

The purpose of this research is to explore how YOCC patients and survivors communicate about their cancer journey and to identify privacy issues confronting young (under 50) colon cancer survivors and patients. Specifically, the following research questions are answered:

RQ1: What influences YOCC patients and survivors to communicate about their YOCC diagnosis and treatment?

RQ2: What are the privacy issues regarding YOCC patients and/or survivors, especially those issues that influence the way they disclose or conceal private information to others?

Overview

In Chapter 2, I will examine literature relevant to privacy concerns in YOCC patients and/or survivors when communicating about their illness. As there is little research on this particular demographic, research about colorectal cancer that focuses on older patients, other cancers, and chronic illnesses affecting those under 50 years of age will be incorporated.

Chapter 3 will focus on the methodology of the research by first justifying the use of a qualitative approach and the selection of CPM theory as the guiding theoretical construct. This chapter will also discuss participants, sampling, and data collection and analysis.

Results of participant interviews will be the focal point of Chapter 4. The outcomes are categorized into themes reflective of CPM theory concepts.

Chapter 5 includes a summary of the findings to ensure that I have answered the research questions, recommended directions for future research as well as discussing the implications of the research.

Chapter 2: Review of Literature

This chapter examines relevant research surrounding YOCC, as well as the context for the study. It is divided into sections reviewing literature on 1) CPM theory and cancer research, 2) disclosure of illness, 3) the importance of support for patients going through illness and survivors recovering from it, and 4) how patient narratives illuminate the survivor experience.

Applicable literature will be reviewed through the five tenets of CPM theory (Petronio, 2002). These tenets include private information, privacy boundaries, control and ownership, rule-based management system, and privacy management dialectics. Each section will discuss relevant YOCC literature in terms of the specific CPM theory tenet.

Tenet 1: Private Information

The first tenet of CPM theory is the concept of private information (Petronio, 2002). Private information is what is disclosed by one person to another. It is not public information, it is information a person feels belongs to them (Petronio, 2002; Petronio & Durham, 2008). Petronio (2002) posits that information cannot be "defined" private, because each person makes their own determination of privacy. It is a personal decision. What is private information to one person may not be considered private information to another.

Petronio and Durham (2008) argue that individuals own their personal information and have the right to control it, especially in the case of disclosure. One way a person discloses private information is through personal narratives. Personal narratives reflect the way one sees the world. Further, these narratives allow others to be involved and share in an individual's worldview (Sharf & Vanderford, 2003).

In the field of health communication, personal narratives have made it possible for patients and survivors to share their private information regarding their experiences of illness. Through this sharing of private information, patients can develop a more complete understanding of their illness (Charmaz, 2009). In this research, I will ask research participants to share personal narratives to identify privacy issues.

Analysis of personal narratives can help us comprehend human behavior (Fisher, 1987). Sharf and Kahler (1996) suggest that personal narratives have extended the view of illness beyond the scientific to a more holistic assessment. Through health narratives, the focus is not just on the biomedical but on the experiences surrounding it. Charmaz (2009) agrees, stating, "[f]requently, however, stories of illness become stories of redemption, transformation, and transcendence of self" (p. 245). By analyzing the narratives of research participants, I will gain an understanding of their cancer journey and the decisions they made regarding disclosure of private information regarding illness, treatment, and side effects.

Narratives have a way of bridging the science of illness with the life experience of the patient (Goodall, 2004). As Charmaz (2009) explains, the story needs to be understood from the patient's perspective: It is their reality. In the current research, I will explore the reality of YOCC patients and survivors through a privacy lens. Narratives paint the picture of the patient experience (Charmaz, 2009). As Bruner (1990) states, narratives help people make sense of something that is very difficult to understand. YOCC privacy issues have yet to be explored so narratives serve as an appropriate way to identify and understand them, particularly for those that are not familiar with YOCC.

Narratives appeal to others because they entail familiar concepts of storytelling (Sharf & Vanderford, 2003). There is a setting, characters, and a plot, for example (Charmaz & Mitchell, 1996), just like a traditional bedtime story. Because of the narrative form is familiar, it aids in comprehending that which is new and perhaps strange. In this case, narratives can help to understand the concept of private information, specifically privacy issues, surrounding YOCC.

Stories are a primary mode of human communication (Fisher, 1987). Because of this, narratives have the potential to bridge understanding. In a study by Lee et al. (2016), the researchers argue that stories are needed in the health field to help explain health disparities in minority populations. Hall and Powell (2011) discuss the importance of patient stories to enhance nurses' understanding of culturally important information that might otherwise be missed. Pallai and Tran (2019) argue that narratives are the channel for health care centers to gain insight into the communities they serve. For YOCC patients and survivors that are a part of underrepresented populations, narratives about privacy issues can provide insight and help individuals navigate the cancer experience.

Tenet 2: Privacy Boundaries

The second tenet of CPM theory is that of privacy boundaries. Petronio (2002) uses this metaphor to identify ownership of private information. Information does not flow freely in and out of the boundary, it is controlled within it. According to CPM theory, the boundary indicates who controls private information, as individuals within the boundaries are considered owners of the private information (Petronio, 2002).

There are two types of boundaries, personal and collective. A personal boundary contains information that is owned by only one person. The private information within a

personal boundary has not been disclosed to anyone else. In contrast, collective boundaries contain information that is shared with at least one other person. For example, the side effects of YOCC, such as incontinence, would be in a personal boundary until shared with another person. Once a person discloses information about incontinence, it would be surrounded by a collective boundary encompassing the original owner and the person to whom the private information was disclosed.

When deciding whether to disclose private information, an individual will often consider the concept of similarity with the other person. Similarity was identified as an attribute in the decision-making process (Derlegaet al., 2008) regarding self-disclosure. Individuals are more likely to include someone they consider similar to themselves in a privacy boundary than those seen as dissimilar. In the case of YOCC patients and survivors, it is probable that disclosures would occur between those that share the illness and the experience of YOCC.

Similarity is important because private disclosures can reveal intimate details about a person. For example, Gibbs et al. (2006) concluded that those in the early stages of a dating relationship only disclose information that will portray them in a positive light. These individuals want to portray a positive self-presentation in the early stages of relationship development. Disclosure of privacy issues surrounding CRC (e.g., incontinence and sexual dysfunction) could cause issues in a relationship, especially if that relationship is in its early stages. Further, some privacy issues carry a stigma, such as a colostomy bag that could cause the person to not be viewed in a positive light. When disclosures could cast a negative shadow, individuals may not want to disclose certain privacy issues and let the other person into their privacy boundary.

A fear of relational turbulence is a potent reason to keep someone outside of a privacy boundary (McLaren & Steuber, 2012). Feelings of anger, fear, and hurt can be a result of privacy violations. Privacy violations and subsequent turbulence may not result in the termination of the relationship. However, even if the relationship did not end, people will still have negative emotions because of a violation regarding private information such as incontinence for YOCC patients and survivors.

People may conceal a diagnosis for fear of losing the relationship (Greene et al., 2006). Arguably, any type of health information can be considered in-depth. But the stigma often attached to a mental health diagnosis or a genetic condition makes it potentially even more risky to disclose (Greene et al., 2006; Smith & Applegate, 2018). Similar to the stigma attached to some privacy issues faced by YOCC patients and survivors, there is a high risk in letting someone co-own the information regarding a health issue. There is a high cost in the disclosure and letting someone into the privacy boundary may not be worth the risk of losing the relationship (Greene et al., 2006).

However, if a person believes there will be a favorable response to the disclosure, even a health concern, then that person will be more likely to disclose and let the person become a co-owner of the information (Derlegaet al., 2008; Greene et al., 2012). Disclosures can also lead to greater relational intimacy. Manne et al. (2018) found that those within the privacy boundary (i.e., co-owners of the information) experienced positive relationship development. This supports the idea that even though a person may be concerned about disclosing a privacy issue, the result may not always be negative (Bombard et al., 2012). This lends itself to the possibility that YOCC patients and survivors can disclose privacy issues without fear of negative repercussions.

Tenet 3: Control and Ownership

The sharing of information leads to the third tenet of CPM theory regarding control and ownership (Petronio, 2002). With the assumption that one owns their private information, it is logical to also want to control and manage that information. Control of information is easier within a personal boundary. When only one person owns the private information, that person has total control over whether they choose to disclose. Once the information is shared and the boundary includes other people, however, controlling information can potentially be challenging. More than one person now owns the private information. The original owner gives up sole control over what can be done with it.

As Petronio (2002) posits, control is a tenet of CPM theory. Control is also important to cancer patients (Charmaz, 1991). Cancer is full of uncertainty. The patient and their caretakers often feel vulnerable (McWilliam et al., 2002). The patient is seemingly not in control of treatment, finances, and other aspects of daily life, so being able to control the message of their illness is important (Donovan-Kicken et al., 2011). When a person shares private information about a health journey, they demonstrate control over the information in terms of what information is shared and the context in which the information is shared. Further, there is control over how the private information is framed.

Yet disclosing information about illness, even if initially controlled by the patient or survivor, brings about challenges. One of these challenges is loss of control. According to CPM theory, once an owner discloses information to another, that person becomes co-owner of that information (Petronio, 2002). Even if the original owner makes rules about disclosing the information to others, there is no guarantee those rules will be followed.

Donovan-Kicken et al. (2011) found that this loss of control was extremely stressful and upsetting for the participants as control was seen as critical.

Disclosure of private information through narrative can aid in the understanding of a complex or unfamiliar event. This can be seen in the context of cancer. Not everyone has experienced this disease, yet narrative can help enhance understanding (Larson, 2007). An important way to understand illness is through the narratives of the patient. This is seen in the clinical context in a study by Hall and Powell (2011). The researchers encouraged nurses to ask, “What is your story?” in order to gain a more complete understanding of their patients. This question acknowledges patient ownership of their health information and their control over their health history. The health care provider can gain insight into the patient’s experience by listening to the narrative of the patient who is the expert on their own lived experience.

Thus, narratives have the potential to bridge understanding, particularly for minority populations (Lee et al., 2016). As owners of their information, members of minority populations can disclose their concerns and experiences through narratives to enhance others’ understanding. Disclosure also allows the patient who is a minority to control their narrative as they are the ones disclosing the information. They decide what information to disclose.

Hall and Powell (2011) discuss the importance of patient stories to increase nurses’ understanding of culturally important information that might otherwise be missed. Pallai and Tran (2019) argue that narratives are the channel for health care centers to better understand the communities they serve. For the purposes of my research,

narratives will give insight into privacy concerns of YOCC patients and survivors from underserved populations.

This research could be helpful for providers who support cancer patients such as nurses and advocates. After an initial cancer diagnosis, a person does not necessarily think “who should I tell first?” or “what do I tell people?” Yet, based on this research, it is something they should think about. Having a plan regarding who and what to tell may alleviate some of the stress brought on by turbulence from communication interactions regarding their illness. Patients can become empowered by taking control of the message they choose to share with others (Donovan-Kicken et al., 2011).

In a qualitative study done on cancer survivors, researchers explored how and why they disclosed issues surrounding their illness (Donovan-Kicken, et al., 2011). Using grounded theory, the researchers developed a framework for how cancer patients communicate about their illness. Because the participants were cancer patients, they owned the information. Results of the study showed that patients disclosed information about their illness as a way to control it. Control can lead to empowerment, especially during a stressful time such as a cancer diagnosis.

When a cancer diagnosis occurs, communication issues can add stress to an already stressful situation. This is particularly true for a partner who may experience more strain than the patient (Hagedoorn et al., 2011). Another study by Venetis et al. (2014) examined the burden of a cancer diagnosis on both the patient and their partner and found that the partner let the patient determine what topics were discussed regarding cancer, as well as the depth and breadth of those topics. The researchers speculated that this is because the patient is the owner of the information and the partner is the co-owner

as posited by CPM theory (Petronio, 2002). However, even though the partner intended to help the patient, the study found that partners deliberately avoided topics that the patient may not have wanted to discuss. As a result, the partner would continue to worry about the topic because of insufficient communication about the patient's health situation (Manne et al., 2006; Venetis et al, 2014).

Tenet 3 provides important insight into how CPM theory can be applied in real life situations. Research has found that even when patients disclosed information, the disclosures were not adequate for the partner (Manne et al., 2006; Venetis et al., 2014). Petronio (2002) states that not all disclosures reveal the most private of information. Further, the disclosures do not necessarily bring the couple closer together. Disclosure does not equal intimacy (Petronio, 2002).

Tenet 4: Rule-Based Management System

When information is shared and control of the information is needed, rules are established. This is the fourth tenet of CPM theory (Petronio, 2002). Rules regulate the flow of private information out of the boundary. Rules about private information are often established and adapted based on the context of a life event (Petronio, 2002). Petronio (2002) posits that a traumatic event, like a cancer diagnosis, can change the way private information is disclosed. A cancer diagnosis can be considered a catalyst criterion that causes a person to consider how to disclose information that they had not previously considered (Petronio, 2013). The diagnosis is the catalyst to examining a new disclosure process including issues such as to whom the information will be disclosed and rule management regarding information about the diagnosis.

It is assumed that those within the collective boundary assume a certain level of responsibility for controlling the information. It is also assumed that those in the collective boundary will follow the rules set forth about controlling the information within that boundary. Regardless of the disclosure, the person sharing the information feels comfortable doing so because of the rules controlling the information.

Petronio (2002) posits that this is an important component of CPM theory because if the rules are not agreed upon, turbulence could occur. Turbulence occurs when there is disagreement among those who share private information (Petronio, 2002). For example, there could be a disagreement over the rules of the private information such as whether the information should be shared outside of the boundary. Patients are often reluctant or embarrassed to discuss family medical problems regarding CRC (Gupta et al., 2020). Because a family has rules against speaking about topics such as bowel movements, for example, a YOCC patient may not be willing to disclose health details because rules state that they should not share that type of information.

Because CRC patients struggle to share private information about their illness, Carmack et al. (2011) developed an intervention for patients who are experiencing distress. The study found that CRC patients who experience embarrassment and anxiety because of their illness are not likely to talk about their illness to loved ones. Similar to the Gupta et al. (2020) research, familial rules often dictated what topics were deemed appropriate. Carmack et al. (2011) found that when CRC patient felt their illness did not fit within those rules, they were unwilling to share.

Side effects from cancer and treatment can have a negative effect on a patient's quality of life (Lu et al., 2018; Sodergren et al., 2019; Soveri et al., 2019). This is

compounded when a patient is not able to share these psychological and physical concerns with their support system (Sodergren et al., 2019). Thus, not being able to share information because of privacy rule violation can have a negative effect on quality of life.

Finding a group to share concerns about illness can have a positive impact for CRC patients and survivors (Carmack et al., 2011 & Sapp et al., 2003). In order for CRC patients and survivors to increase their quality of life, it is important for them to be involved in social networks where they feel comfortable sharing issues and concerns regarding their illness and where the social network rules allow such information to be shared.

As Petronio (2002) states, there is no definition of what is private information except that it is information that a person feels belongs to them. Because defining private information is a personal decision, it stands to reason that disagreement could occur over rules surrounding the information. But if a person is involved in a group that shares similar information that is normalized as “private” then the chance of turbulence occurring over what is or isn’t private information would be reduced. For example, a CRC patient could share side effects of treatment, such as uncontrollable bowel movements, to another CRC patient and know that the information would remain private because of the shared understanding of the potential embarrassment it could cause. A person who is not a CRC patient may not understand that and could share the side effect with others not knowing it causes embarrassment for the CRC patient. Thus, it is important for CRC patients and survivors to find a group of people to share concerns about their illness.

Tenet 5: Privacy Management Dialectics

A dialectic exists during the decision-making process of whether to disclose private information (Petronio, 2002). The person who owns the information weighs the costs and rewards of disclosing the private information to another individual. Careful evaluation of the potential repercussions of disclosure is important as a person decides whether to allow someone to become a co-owner of their private information.

The decision to disclose private information can be difficult as some information is riskier to disclose than others. Petronio (1991) posits that the degree of risk and the sensitivity of the disclosure are variables individuals consider when deciding whether to disclose private information. According to Petronio, there are two types of risks considered during the disclosure decision making process. These are relational risk and role risk.

For example, a person must weigh the risk of disclosing their colorectal cancer diagnosis or the resulting side effects. It can be embarrassing to disclose a sexual side effect to an intimate partner; thus, this would be considered a relational risk (Petronio, 1991). In contrast, disclosing the need to use the bathroom at work multiple times a day would be considered a role risk as it could result in repercussions from an employer (Petronio, 1991). Soveri et al. (2019) found that side effects from CRC treatment affected both social and role functioning.

These types of risks are important to identify and examine in YOCC patients and survivors. Research has shown that side effects from CRC and resulting treatment have lasting physical and psychological impacts (Mohler et al., 2008; Van Veeneet al., 2020).

Yet, these risks have not been identified and explored in YOCC patients and survivors. It has also not been researched how these risks are shared by YOCC patients and survivors.

Petronio (2002) argues that an important part of the value of information shared, such as issues regarding a chronic illness, is how vulnerable it makes the person. Disclosing private information could make a person feel extremely vulnerable in an already high stress situation like fighting or recovering from illness such as YOCC.

Because a patient or survivor could feel vulnerable disclosing information about their illness, that information is important (Petronio, 2002). When high value is placed on information, the potential for turbulence when that information is disclosed increases (Yuni & Rachmat, 2017). This potential for turbulence could influence whether the patient or survivor discloses the private information.

Yet, disclosures are a vital component to relationship development (Petronio, 2002). In the case of YOCC patients and survivors, many are in their 20s and 30s. They are in the course of developing and maintaining romantic relationships and friendships. Many have young children and must decide if and how to disclose private information to them. Patients and survivors find themselves in the midst of a cost-benefit scenario. They must decide if disclosing the information (cost) is worth the risk of potential negative effects to the relationship. Further, if the patient or survivor does not disclose private information regarding the illness, will that serve as a barrier to relationship development?

Researchers have applied CPM theory (Petronio, 2002) to an array of situations where one feels tension about whether to disclose private information. Helens-Hart (2017) used CPM theory to analyze how females disclosed sexual identities in the workplace. Through interviews, criteria were identified for deciding whether to disclose

sexual identity as well as the discursive strategies used to disclose private information. It was found that women weighed the risk-benefit of disclosure by considering the risk to employment status, professional image, and the ability to complete tasks.

In-depth disclosures, such as sexual identity, are extremely private in nature. Thus, this type of disclosure can potentially put the person in a precarious position. It is risky. These disclosures come at a potentially high cost. This is an important consideration when weighing whether to disclose, especially when the disclosure of private information could affect something as valuable as a job.

While jobs are important, so are interpersonal relationships. Romo et al. (2016) examined the costs and benefits for disclosing alcohol use disorder through the lens of CPM theory. The authors concluded that, in general, participants did not disclose their illness in social situations unless they felt a similarity with someone else such as helping them to maintain sober or if they wanted to further a relationship.

In-depth disclosures can be made even in early stages of a relationship when there is a perceived similarity between persons (Malloch & Zhang, 2019). While someone might not disclose alcohol use disorder in a room full of people they just met who are sharing a bottle of wine, that person may share their illness to another person if they notice that person acting in an uncomfortable manner and drinking water. Similarity is also a key component in the development of the relationship process (Altman & Taylor, 1973).

Disclosure during a health crisis can further the intimacy of the relationship (Manne et al., 2018). In fact, the lack of disclosure can impede a relationship from moving forward (Altman, 1993). These ideas give further insight into the Romo et al.

(2016) study. If a person with alcohol use disorder wants a relationship to proceed to a more intimate stage, even though there is a potentially high cost, disclosure would seem essential.

In a 2013 opinion piece about her health choices, American celebrity Angelina Jolie stated that she chose "not to keep my story private because there are many women who do not know that they might be living under the shadow of cancer" (Jolie, 2013). Her goal was to be helpful and to potentially empower other women to make difficult decisions.

But as the old saying goes, "No good deed goes unpunished." Jolie's disclosure about her genetic testing and resulting decision opened the door for others to weigh in. *A New York Times* op-ed published the following month (Grady et al., 2013) challenged Jolie's decision to have a double mastectomy. While appreciating Jolie's experience of losing her mother to breast cancer and her motivation to decrease her risk for the sake of her children, the authors voiced concerns that because of Jolie's celebrity status, women would be persuaded to have the same procedure even if it was not needed. "Angelina's situation is very unique. People should not be quick to say 'I should do like she did,' because you may not be like her" (Grady et al., 2013).

This example highlights the dilemma of disclosing private information regarding an illness. Petronio and Durham (2008) discuss the tension that occurs when someone is deciding whether to make a private health condition public. While the desire to make the genetic condition public was motivated by Jolie's desire to help others, it also opened her up to criticism from others. Jolie had shared the personal details with others and thus was no longer the sole owner of the information (Petronio, 2002).

Need for YOCC Research

There is a significant amount of research applying CPM theory to health issues, including cancer. Yet, there is a gap in research when it comes to YOCC. There have been calls for research on this demographic because of this gap (Barg et al., 2007; Blum-Barnett, 2019; el Din et al., 2020). In addition, Bleyer and Barr (2009) posits that there is a need for more awareness by providers of issues surrounding YOCC. Thus, research is warranted and needed.

The need for research on YOCC issues is also supported by the creation of the Young-Onset Colorectal Cancer Center at the Dana-Farber/Brigham and Women's Institute. The creation of this center is grounded in the unmet needs of YOCC patients and survivors (Cavallo, 2019). These unmet needs include physical and psychosocial needs such as fertility and sexual concerns. For example, the effect of infertility on the quality of life for women with ovarian cancer, breast cancer, and lymphoma has been researched (Duffy & Allen, 2009). There is a gap when it comes to the effect infertility has on women with not only YOCC, but CRC in general.

It has been established that YOCC patients and survivors have unmet needs (Barg et al., 2007; Cavallo, 2019). Privacy concerns for cancer patients have also been studied. Although both of these are important, the physical and psychosocial needs of YOCC patients and survivors have not been identified and examined through the lens of CPM theory, thus warranting exploration.

The next chapter examines the methodology of the exploratory study including philosophical foundations, sampling, data collection, and data analysis, as well as ethical and trustworthiness considerations.

Chapter 3: Methodology

This is an exploratory study, designed to identify privacy concerns of YOCC patients and survivors through patient narratives. This chapter explains the qualitative approach taken for the study as well as the rationale for using Communication Privacy Management Theory. It also includes information about sampling, data collection, data analysis and a discussion of trustworthiness in the study.

Philosophical Concepts

Qualitative Approach

According to Marczyk et al. (2005), qualitative research allows for the exploration of how and why a phenomenon occurs. Qualitative research involves investigation of a concept that goes beyond numbers to produce data the researcher can use to understand the underlying aspects of a specific phenomenon. Qualitative research examines the feelings, values, beliefs, and insights of the participants and can deepen an analysis and interpretation of measured and quantifiable data (Marczyk et al., 2005).

An article by Sandelowski (2001) and an editorial by Morse (2007) discuss some of the issues surrounding qualitative versus quantitative research. It is important to examine both to understand the justification for selecting qualitative research. Even when utilizing qualitative research for a project, Sandelowski (2001) suggests that there is still a concern with numbers, though different than if the research was strictly quantitative. For example, when coding a transcript, the number of times a code is identified is counted. If a code is observed a notable number of times, a pattern or theme could be identified. Sandelowski (2001) suggests that qualitative researchers keep count of codes

somewhat unconsciously as they begin coding and then may start to recognize patterns and themes. My study seeks to identify privacy issues. If a certain privacy issue is identified and coded repeatedly in multiple patient narratives, that issue could indicate a theme.

Another element of qualitative research that needs to be examined is the justification for the sample used in the study. Morse (2007) emphasizes the importance of sampling in research as qualitative researchers sometimes do not have access to a representative sample. In my study, I will utilize convenience sampling based on the population given to me by the Colorectal Cancer Alliance. Morse (2007) states, “[t]he numbers in the sample mean little if the sample is demographically biased in one dimension or another” (p. 287). She cautions that numbers that are not representative could be misleading. Once I have this exploratory research completed using convenience sampling, a representative sample might be more easily identified and contribute to more specific research targeting specific demographics.

Morse (2007) argues that qualitative research should only be employed when it boosts the explanation of the research. This contention is further explored by Sandelowski (2001) who states, “researchers strive to emphasize something more than the numbered nature and meaning of events and experiences” (p. 231). Because my study seeks insights into the reasons for human behavior, qualitative research will allow me to identify and explore privacy issues and generate future research that could contribute to improving YOCC patients and survivors' quality of life. Additionally, I do not have access to a representative sample. Identifying the issues and exploring them using a qualitative approach are important first steps to filling the void of research in this area.

There is a call for an increase in research on psycho-social topics in YOCC (Blum-Barnett et al., 2019; Carmack et al., 2011; Trentham-Dietz et al., 2003). Because there is no notable research regarding privacy concerns in YOCC patients and survivors, this study is also important as the rate of YOCC is increasing at a startling pace. There are unique privacy issues to this group that have not yet been identified and explored, indicating that an exploratory qualitative study is warranted. Such a study can examine how participants view their world and interpret their experiences in it (Merriam et al., 2016) and can encourage further investigation. Exploratory studies are useful because they can provide information that can launch more robust research (Hallingberg et al., 2018).

Because the topic of privacy issues in YOCC patients and survivors has not been explored, it is essential to attempt to establish initial areas of concern through the participants' lived experiences. Qualitative research allows for the in-depth exploration of a phenomena including participant feelings and beliefs rather than hypothesis through analysis of numerical data (Marczyk et al., 2005). This in-depth qualitative study, then, could create insights leading to more definitive research.

Patients and survivors of colon cancer face unique privacy concerns that demand attention from health communication researchers. Researchers use theories as lenses through which to view topics (Gringeri et al., 2013). Theories are integral parts of the research process. Gringeri et al. (2013) suggest specifying the theory that will be used in the research project and the reasons for the theoretical selection. I selected CPM theory as the lens for my research. I will now discuss the theory.

Communication Privacy Management Theory

This study utilized Communication Privacy Management Theory (CPM theory) to focus on how YOCC patients communicate about their diagnoses as well as identifying privacy issues that influence their decisions about disclosing or concealing private information. Data were gathered through narrative interviews. The design is consistent with the purpose of the study due to its exploratory nature (Marcczyk et al., 2005).

CPM theory provides a useful lens to view privacy issues surrounding YOCC patients and survivors (Petronio, 2002). Although it is critical to first identify the privacy concerns of YOCC patients and survivors, it is also imperative to frame these issues using a proven theoretical model.

CPM theory allows for the examination of privacy rules such as those patients and survivors use in their personal and professional lives. CPM theory also provides a framework to examine the boundaries patients and survivors construct regarding the private information associated with their disease. Coordination of privacy boundaries is a characteristic of healthy interpersonal relationships (Hawk et al., 2009). Healthy relationships are essential to humans, especially when a person is battling a serious illness such as colorectal cancer. In order to achieve a healthy relationship, effective communication is essential.

The tension between privacy and self-disclosure is an important tenet of the CPM theory (Derlega et al., 2008; Petronio, 2002). Exploring the tension a cancer patient feels when deciding whether to disclose private issues regarding their cancer provides a lens for examining that private information. Certain information can be embarrassing to disclose even to the closest of associates. CPM theory has proved effective in explaining

the decision-making process people navigate when determining whether to share private information.

Method

Study Design

The design of this exploratory study will be qualitative in nature. I will utilize patient narratives obtained through interviews to identify privacy concerns of patients when they communicate about their disease. These patient narratives will then be analyzed employing thematic analysis (Braun & Clarke, 2012). The process of thematic analysis provides a framework to identify, categorize, and explore privacy concerns and address the research questions appropriately.

The purpose of this research is to give voice to YOCC patients and survivors through Communication Privacy Management theory (CPM theory) (Petronio, 2002) and to identify privacy concerns unique to those under 50 years of age who have been diagnosed with colorectal cancer. My exploratory study seeks to bring insight into an increasing demographic that has not been explored thoroughly, particularly in the field of communication.

Participants

This study of YOCC patients and survivors focused on respondents who were between 21 and 49 years of age. The upper age of 49 is the threshold for “young” in colon cancer diagnosis (Ahnen et al., 2014). The age of 21 was selected to ensure that participants were well beyond their teens. Teenagers could be perceived as a different demographic with their own unique worries such as balancing YOCC and homework or attending Prom with an ostomy bag. Patients with colorectal cancer who are 20 years or

younger suggest another population for future research, as patients in their early teens increasingly are being diagnosed.

For this study, respondents were either undergoing treatment for colorectal cancer or exhibited no evidence of disease (NED). The two groups were combined in order to gain an overall picture of the YOCC demographic. Privacy issues regarding colorectal cancer do not end once treatment ends or a patient is NED. I wanted to identify issues of concern within both groups as there is no previous research to indicate if significant differences in privacy issues are seen after treatment. During the interview process, I specifically noted the participant's situation on their cancer journey.

Research participants were associated with the Colorectal Cancer Alliance (CCA). The CCA was founded in 1999 and is the leading nonprofit organization dedicated to advancing the awareness and investigation of colorectal cancer and serving those who suffer from it. The CCA's membership includes substantial numbers of a broad range of colorectal cancer patients and survivors who volunteer their time or participate in the support systems that CCA offers. In the spirit of disclosure, I have been an active volunteer for the CCA. The alliance has featured me in outreach materials, and I participate in the CCA Facebook support groups and serve on the YOCC advisory board. CCA is an appropriate, credible organization to recruit participants for this study.

Sampling

Initial recruitment of participants took place through email. I made the CCA aware of the characteristics of potential participants for the study. The CCA then made the initial contact by emailing a one-page overview of the study to prospective

participants which included my email address. Those interested in participating in the interview could then contact me via email.

When I received an email from a prospective participant, I responded via email. A draft of this email is attached as Appendix A. This email confirmed the criteria for study participation requiring that the subjects were between the ages of 21 and 49 and were YOCC patients or survivors. Once a participant agreed via email to an initial phone call, in that call I discussed in detail the intent of the subsequent phone interview and arranged a convenient interview time. I alone know which participants were contacted and interviewed. No one from the CCA has knowledge of the email or phone contacts or who chose to participate in the study.

After the initial recruitment process was completed, it became clear that the sample was not as diverse as needed. Most participants identified as women and Caucasian. Because of this, I began to reach out to specific individuals who were active in CCA support groups on Facebook. I messaged those whose image or posts indicated membership in marginalized groups relevant to underrepresented demographics in the research. After receiving a favorable response that the individual would consent to being interviewed, I returned to the contact process detailed above. A summary of participant demographic characteristics follows in Table 1.

Table 1

Participant Demographic Characteristics

Participant	Diagnosis Age	Current Age	Ethnicity	Gender	Marital Status
Julie	48	48	White	Female	Married
Jenn	41	41	White	Female	Married
Tami	46	50	White	Female	Married
Pam	40	41	White	Female	Married
Stephanie	46	59	White	Female	Married
Mike	47	52	White	Male	Married
Nancy	41	44	White	Female	Married
Kim	47	49	White	Female	Married
Tim	28	29	Asian/Indian	Male	Single
Todd	49	50	White	Male	Married
Donna	44	45	White	Female	Married
Sue	33	43	Black	Female	Single
Carol	40	41	Black	Female	Married
Marlo	31	34	Black	Female	Married
Tania	32	37	Hispanic	Female	Married
Christina	33	36	White	Female	Divorced
Laura	38	40	White	Female	Married
Gina	33	35	White	Female	Married
Anna	24	30	White	Female	Separated
Betty	35	39	White	Female	Single
Eleanore	42	Over 60	White	Female	Married
Maria	39	52	White	Female	Married
Katie	30	34	Hispanic	Female	Divorced
Scott	33	40	White	Male	Single
Matthew	22	23	Hispanic	Male	Engaged

Interviews occurred via phone or FaceTime depending on the preference of each individual respondent. Contact via phone, iPad, or computer provided convenient access to participants no matter their location. In person interviews would limit contact with

participants to those easily reached by car. The goal of this approach was to gain secure, convenient access to participants while protecting their privacy.

Data Collection

Data collection consisted of a one-time, semi-structured interview lasting approximately 60 minutes. Interviews ranged from 45 minutes to nearly 2 hours. Semi-structured interviews allowed me to focus on gaining insight into privacy concerns surrounding patients and survivors of colorectal cancer as well as give the participants an open opportunity to share their personal journeys. The interview guide is attached as Appendix B. From participant oral narratives, I identified privacy concerns and anecdotal information expanding upon those concerns.

When introducing myself to the interview participant, I reiterated that I am a Stage III colorectal cancer survivor. Reflexivity is important in qualitative research (Gentles et al., 2014). By identifying myself as a cancer survivor, I kept my own cancer experience as a conscious reminder to myself and making it known to the participants. Cohen and Crabtree (2008) posit that this type of reflexivity is essential for effective data evaluation. In this research, I needed to recognize any influence I might unconsciously inject into the research that might not be present for researchers without cancer experience. Gentles et al. (2014) argue that reflexivity can be applied universally to all qualitative research. In addition, they suggest that reporting reflexivity, as revealed here, should be commonplace amongst researchers.

The first question in the interview was general and open to allow the participant to share in a self-determined way their narrative about their personal cancer journey. These anecdotal stories provided initial and unique information about the participant’s privacy

issues during their cancer experience. Loosely structured follow-up questions encouraged participants to share their personal journeys with some control over the pace and direction of the interview (Anderson & Kilpatrick, 2016).

Data collection occurred through a single interaction with each participant on a recorded phone call (or FaceTime interaction). The interviews were recorded on the Tape-A-Call application on my iPhone. Once the interview was completed, I used the transcription service offered on this app. Once the transcription was completed, I listened to the interview while reading the transcript to ensure accuracy as well as to de-identify the interviewee by eliminating any identifying participant information.

Each interview was given an identification number to protect the identity and privacy of the participant. The interview recording was then deleted. Direct quotes from participants are de-identified during the transcription process. Participants were asked if it would be acceptable to use direct quotes from them.

Data Analysis

Thematic Analysis

When choosing a method to analyze the data, I focused on finding a process that supported the purposes of my research as well as answered the research questions (Mills et al., 2006). Thematic analysis (Braun & Clark, 2012) is appropriate due to the exploratory nature of the research questions.

As stated in the first step in the thematic analysis process, I familiarized myself with the data to fully understand participants' lived experiences as YOCC patients or survivors. This familiarity allowed me to extract information relevant to the research questions (Braun & Clark, 2012).

Using an iterative style for the next step in the analysis, I initially looked for emergent codes and then interpreted those codes through the lens of CPM theory (Saldana, 2015). A combination of inductive and deductive approaches allowed the findings to be driven by what was in the data and what was revealed through theoretical constructs of CPM theory. Because this was an exploratory study, it was appropriate to follow this sequence of approaches. Young onset colorectal cancer patients' experiences have not been examined in the context of CPM theory and the resulting codes from this research can serve as a bedrock for future research.

I first used an inductive approach, enabling the analysis to be centered on the data found in the transcript (Saldana, 2015). These codes were developed from the data without being bound by a theoretical framework. The goal of the research was to give a voice to the lived experiences of the participants by identifying emergent codes from the data. The stories of the participants were the focal point of this approach, as the codes reflected the meanings of the participants' experiences and their worldviews (Saldana, 2015).

The codes assigned resembled the semantics of the participants (Saldana, 21015). This analysis approach is effective for exploratory research, as it is imperative that the privacy issues were derived from the participant discourse.

After using this inductive approach for establishing initial codes, a deductive approach was implemented which applied CPM theory constructs to the data in the interview transcripts. The deductive approach allowed me to identify privacy issues that study participants did not state explicitly but which could be interpreted from the data (Saldana, 2015). CPM theory concepts such as rules, boundaries, and turbulence drove

this phase of analysis. Unlike the inductive approach where the codes resembled the semantics of the participants, codes in the deductive approach reflected the concepts of CPM theory. Using both approaches, the evolution of the codes was tracked in a codebook detailed in Table 2. This process was ongoing throughout the analysis process.

Table 2

Code Book

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
Privacy Boundaries	Delineation between public and private information. People manage two main types of privacy boundaries: personal and collective.	"I told my immediate family, like I told my siblings, I told my parents and my in-laws." (3,3)
Personal Boundaries	A personal privacy boundary manages private information about the self. This information belongs to one person, it is singularly owned.	"I had my yearly visit with my gynecologist. And normally I go in, I don't really say much of anything because nobody really likes that visit. So, I was having a little bit of pressure down in the female area. So, I just mentioned that at my visit. They did an ultrasound and they saw that I had a cyst, which they weren't worried about, but the ultrasound happened to reach what looked like a mass above it." (1, 1)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
Collective Boundaries	A personal privacy boundary fundamentally changes into a collective privacy boundary when private information is disclosed or access is granted.	"So, I'm an administrator at a school and there's my principal and a couple of our office ladies that, we are all very close. So, I told them." (1, 2)
Control & Ownership	Because the information belongs to a person, that person wants to determine who is privy to it and who is not. Control is a way to prevent unwanted exposure.	"So, with my mom, everything always somehow turns about her and how it's affecting her. And I am always somebody who I feel like I have to be in control. And of course, at that time I was not in control. And I just felt like if I talked to her, I would get angry. So, I just, I asked my sister, you tell mom and just ask her not to tell anybody right now." (1, 2)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
Co-Owner	When private information is shared with another person they become a co-owner of that information. When we are told private information, we become responsible for that information.	"I mean, they were very helpful in filling out all my paperwork and they did ask, I remember one of my supervisors asked if she could put it in an email to my coworkers. She asked me first and I said yes. Cuz that would have been a problem if she hadn't asked me." (3, 5)
Rule-Base Management System	The management system provides a structure for understanding the way that private information is handled. This regulation can occur through a	"...we started a Caring Bridge page cuz I was like, I am not doing this. You know, 700 people calling or emailing or were texting you. Are you okay? No, I can't. I can't, I can't do it. So, we set up a Caring Bridge...I was thinking Caring Bridge was a little, I can control it a little bit better." (3,6)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	personal management system or a collective management system.	
Personal	Managing private information that belongs to only us.	"I worked in a satellite office, and I was the only person in my office. And so, I have a private bathroom. So, I could yell and cry and scream. And nobody knew." (3, 1)
Collective	Once a disclosure is made, there is a need for boundary coordination because the person takes on a level of responsibility for managing the revealed information.	"I didn't tell any other, like I told my close core group of friends, I didn't tell acquaintances, I didn't blast it on social media. I just...I asked everybody to keep it quiet." (3, 3)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
Privacy Rule Development	Criteria that are used to formulate rules for the way private information is handled.	"I didn't tell any other, like I told my close core group of friends, I didn't tell acquaintances, I didn't blast it on social media. I just...I asked everybody to keep it quiet." (3, 3)
Privacy Orientations	When individuals seek out private information to establish boundary linkages or the boundaries are extended to incorporate more information that is private.	"So, the side effects and stuff that I don't tell people about, I use Colontown. I use that Facebook page a lot." (4. 6)
Cultured Expectations	People are socialized into certain norms for privacy in their culture and these	"I would say when it comes to like talking about my emotions, it's less than my parents. It's more, we have more of a formal relationship. But I do more with my friends, like I'm very open with my friends." (9.7)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	norms are basic to the way they conceive of privacy.	
Personality Characteristics	The characteristics that people have influence the way boundary linkages are produced.	The majority of people who participated in this study considered themselves "open books."
Motivational Goals	Judgments for disclosure are based on particular motivations.	"So that's kinda the reason I wrote the book in part to educate the world. And I've had people who have said to me, oh my God, I read your book, I went and got a colonoscopy, they found seven polyps." (5, 8)
Risk-Benefit Goals	Rules that are developed take into consideration the level of felt vulnerability and expected advantages	"And I do feel very self-conscious because I'm like, if I had to run to the bathroom, I've just always been very capable, very, you know, my work ethic is thrown all of these things, and now, I don't wanna be the person, the coworker that has health issues, you know? So, I'm very quiet about that." (4, 6)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	from revealing or concealing.	
Situational Concerns	The context of the situation may function as a critical element in formulating rules that regulate revealing and concealing. (Work or personal setting)	"And so now with this substitute teaching. Like, I don't know, you know, you go into schools and it's just a random, it's just a school one day, another school the next day. So, I don't know people really. And I find myself just being really quiet because I don't want to talk about, I don't wanna over share." (4, 6)
Emotional Needs	When a disclosure takes into account the feelings of the co-owner. (Shimanoff, 1987 as in Petronio, page 149).	"I went, I met this surgeon, and he was amazing. He came in and he just said…the new normal is not that great and he was just giving up options and saying…right now you're thinking what sounds like the worst possible thing that could happen to you, but I have to tell you,

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
		sometimes that is not the case. (4, 2) -This is in contrast to another physician that did not take the emotional needs into consideration. (4,2)
Boundary Coordination	This is a process that reflects how privacy is regulated through rules when people are engaged in managing collective boundaries.	"So, one of my first phone calls was to a former school board member who now does crisis communications for a law firm. so I called her and said, ok, what do I do? So, she helped me put together an entire communication plan. So, the first piece was meeting with the board and telling them...". (6, 6)
Turbulence	When boundary coordination goes a stray and rules become asynchronized.	"I think it annoyed me on two levels. One its my cancer and these are my kids. And two, as a mental health professional, I feel like I have a pretty good grip on what is appropriate and what is not appropriate when talking about traumatic things. " (3,4)
Intentional Rule Violations	When people deliberately tell collectively held	"You know, Mom, this really, this really hurts. I asked you not too." (3,6)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	private information without following agreed upon rules.	
Boundary Rule Mistakes	When people erroneously apply privacy management rules that are at odds with other members' perspectives.	"So, my uncle, I would've never told him, and my mom waited a while. I think like in two months into chemo before she mentioned it to him. Nobody who I was necessarily trying to hide it from, but if it would have been up to me, it would've only been maybe ten people." (1,5)
Fuzzy Boundaries	When people are ambiguous about who owns or co-owns private information, changing the rights to determine rules.	"And like, I knew life she as my principal she wasn't supposed to tell anybody. But it is hard when you have those blurred lines between professional and friend by trying to get people to support me." (1, 3)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
Dissimilar Boundary Orientation	When individuals are not flexible about rule changes and are dependent on privacy rules that are firmly held.	"And in our marriage, we usually go with the more conservative viewpoint. I feel like there's less damage. There potentially could be less damage." (3,4)
Boundary Definition Predicaments	When there are dissimilar definitions for the borders of the boundaries.	"So, I call my best friend and she offered to come with my husband and I to the appointments with the surgeon and the oncologist to take notes. So, my husband was like, I don't think we need her, and I go, sweetheart, you're not going to remember anything the doctor says, I sure as hell will not remember." (3,2)
Justification for Rule Violation	People change the rules to fit their needs, accommodating new situations and different	"And I just couldn't deal with having her feeling bad as I was also going through my stuff. So yeah. I just knew where her heart was. (1,3)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	requirements so that they can maintain a certain level of control over privacy boundaries.	
Recalibration of Relationships	When a person copes with a disclosure issue by adjusting the amount, frequency, and depth of personal information they disclose in consideration of their relational boundary.	"And I'm like you are really going to be that person that breaks up with someone over cancer?" (9, 6)
Management Dialectics	The forces pulling between and with the needs of being both private through	"I always thought my stool looked a little weird...but you kind of like keep it to yourself because it's, you know, not like a table kind of conversation topic that you talk to, you know, your newlywed husband,

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	concealing and public through revealing.	too. That's not very attractive. So, you just kind of like hide it and keep it to yourself, you know?" (16, 2)
Private Information	Information that belongs to us, the information is singularly owned.	"No, I didn't share. I'm a very private person, so I didn't share it with anyone." (12,1)
Disclosure Timing	Selecting the circumstances for disclosure may be a way to attempt to control the risk of the revelation.	"So, our family was split apart so we can't even have a family meeting. And we're not going to sit down and tell these kids today what's going on because we don't have any information yet." (3, 2)
Choosing a confidant	Credibility refers to choosing a confidant based on trust, prior knowledge of a similar experience, or	"So, over the months I had been talking to my best friend who is a nurse midwife and an RN, and I would mention something about what I was experiencing, and she was like, just go to the GI and get it checked out." (3, 1)

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	a combination of these factors.	
Selecting a setting	Refers to the circumstance in which the disclosure is made. It is important for the person to feel comfortable when disclosing information.	"Interestingly enough, my parents, who live out east and were in Asia at the time, at a wedding. So, me and my sister and cousins decided, let's not tell them until they land in the US because we don't want them like on an 18-hour flight freaking out like my kid has cancer kinda thing." (9, 2)
Supportiveness	Refers to the importance of disclosing to someone that offers support and comfort.	"I called my younger sister first. I have three other siblings. She and I, I'm close to all my siblings but my older two siblings were 5 and 6 years apart and my younger sibling and I are two years apart for it's kind of like 2 and 2." (3,6)
Strength	The person disclosing the information must feel that	"I wouldn't let them see me upset. I used to wait; I would cry in the bathroom at night after my mom would go to sleep. Or I would lay in

Code Name	Code Description	Code Example (Participant Number, Transcript Page Number)
	the recipient is strong enough to handle the disclosure.	the bed and try to cry as quietly as I could, but I wouldn't want him up." (14, 7)

According to Strauss (1987), “The excellence of the research rests in large part on the excellence of the coding” (p. 27). In qualitative research, codes can be in vivo, descriptive, or interpretive. In vivo codes use the participants’ own words. For example, if a participant used the phrase “I was angry” to reflect a privacy violation, those exact words could be coded. Descriptive codes summarize the data to be represented by the code (Saldana, 2015). In the above case, I could use the term “turbulence” to describe the anger felt by the participant. I chose the term turbulence because it is a term used in CPM theory (Petronio, 2002). Interpretive codes require digging deeper into the participant’s own words (Saldana, 2015). The meaning must be interpreted if it is not explicitly stated.

Regardless of the type of code, the codes should reflect a piece of the data that is germane to the research question (Merriam et al., 2016). The codes should be concise and should capture a particular element in the data (Saldana, 2015). This process allows the research to see interconnections in the data by looking for similarities, differences, and frequency of codes. To accomplish this objective, it is important to not only record the codes themselves but also record a brief definition of the code and examples from the data (Braun & Clark, 2012; Tracy, 2013).

In this study, once all the transcripts were coded and definitions and examples were recorded in the codebook, themes were developed from the data. This was a dynamic process where I looked for patterns in the data set that encapsulated important ideas related to the research question (Braun & Clark, 2012). Looking for similarities and differences in the codes allowed me to look for relationships in the data that reflected its richness (Tracy, 2013).

In interpretive research, themes should work together to tell the story of the overall data, not of just one participant (Braun & Clark, 2012). It is impossible to reflect all the data from the participant interviews, so a theme should reflect a pattern found across the data that answers the research question. Tracy (2013) refers to second level coding of data where the researcher looks for patterns of information and the relationships between them. At the end of this process, themes are recorded so connections and relationships can be visually comprehended, perhaps through a table or thematic map. Regardless of how the themes are tracked, the process should be continuous and consistent throughout the analytic process.

The next phase of thematic analysis involves reviewing the themes in relation to the data that was coded and the interview transcripts as a whole (Braun & Clark, 2012). In this project, I re-read the interview transcripts to ensure that the established themes reflected the most important elements of the data (Tracy, 2013). The goal of this stage is to check the quality of the themes with a focus on examining the breadth and depth of each theme. Is there enough data to support the finding as a theme (depth) or is it just a code for a piece of data? (Saldana, 2015; Tracy, 2013). Further, the data that supports the theme must be meaningful and clear and boundaries should be established. What does the theme include? What does the theme exclude?

An extension of those questions leads to the next step of thematic analysis in which characteristics of the themes are more explicitly defined (Braun & Clark, 2012). Each theme needs to be explained clearly and concisely in a few sentences and include what is unique about each theme. While the themes should be related, each should represent a unique, singular focus of the data (Saldana, 2015). Representing this

information visually assists in justifying each individual theme and demonstrating how the themes are interconnected.

The themes need to be related because they come together to portray the overall picture of the data. Analysis will include not only each individual theme, but how the themes interconnect. In addition to showing the relationships between the themes, the analysis also must ensure that each theme is developed individually (Braun & Clark, 2012).

In order to paint an overall picture, it is vital to select data that are vivid and compel the reader to want to learn (Saldana, 2015). In addition to selecting vivid and compelling examples from the data, researchers should also be specific in explaining why each example is engaging and how it answers the research question (Tracy, 2013).

In this research, once the process was completed, the final report comes together in the dissertation document (Braun & Clark, 2012). While this step is defined as the production of the report, analysis and writing are included in every step of the process (Tracy, 2013). In this case, as I progressed through the study, I continuously attended to the formulation of an argument that answers the research question.

Ethical and Trustworthiness Considerations

To validate the reliability of the coding, I used my committee and fellow scholars as a resource throughout the analysis process. In the initial coding process, I sought opinions on codes that emerged to ensure that my analysis was well thought out and reflective of the data. Conversations with colleagues and mentors helped me make sense of the data. While developing themes, I consulted my committee and fellow scholars to help me confirm that the findings encompassed emergent themes as well as themes

reflective of CPM theory, all within my overarching focus on answering the research question. Recording codes and themes was strategic as I needed to show my thought processes and justify decisions in order show transparency in data analysis

As referenced earlier, the concept of reflexivity in qualitative research is important. Lincoln and Guba (1985) suggest keeping a journal or diary with entries reflecting the research process. Tracy (2013) discusses a similar concept referred to as analytic memos in which the researcher tracks thought processes. In this research, I documented decisions made and the justifications for those decisions. These memos served as a worthwhile aid from data coding to data analysis and serve as a way to show rigor through transparency during the analysis process (Tracy, 2010)

Recording my thought processes throughout the study also allowed for an inquiry audit (Lincoln & Guba, 1985). Inquiry audits can be performed by another researcher in order to examine my research process. Audits can also be used to review the accuracy of codes, themes, and other conclusions. The use of an audit in this project increased the reliability of my findings (Lincoln & Guba, 1985).

Rigor in qualitative research refers to the trustworthiness of the study (Amankwaa, 2016). The work must be clear,unambiguous, and rich. It is important to show rigor in all research, both qualitative and quantitative, but demonstrating rigor is often neglected in qualitative research (Baruschet al., 2011). Tracy (2010) posits that rigor can be established in qualitative research through face validity and during the data collection and analysis process. Face validity is defined as “whether the study on it’s face appears to be reasonable and appropriate” (p. 841).

In a qualitative study completed by Bril-Barniv et al. (2017), a rigor section specifically detailed their research procedures step by step, clarifying and enhancing the trustworthiness of their study. Clarity is important to the rigor and subsequent credibility of a study. Tracy (2010) supports the idea that data transparency of data collection and analysis enhances the rigor of qualitative research. Morse et al. (2002) declare that "without rigor, research is worthless, becomes fiction and loses its utility" (p. 14).

Reflection can also strengthen rigor in qualitative research. Bril-Barniv et al. (2017) suggest that researchers utilize a process called "bracketing" which allows for reflection practices throughout the research process. The concept of reflection is displayed in Braun and Clarke's (2012) thematic analysis. During the six-step process, the researcher is given the opportunity to verify the process and the information. This process also helps to establish rigor through face validity of the research because of the earnest attempt to show thoroughness as well as through transparent data collection and analysis (Tracy, 2010). For example, step four of the thematic analysis process explicitly states that the researcher should review themes to make sure they are representative of the data (Braun & Clarke, 2012).

Peer debriefing is when the researcher discusses the research process with a disinterested peer, allowing that person to question the researcher's perceptions, intuitions, and interpretations and helping the researcher explore various aspects of the work (Gringeri et al., 2013). This can be accomplished through the audit analysis described above (Lincoln & Guba, 1985) and contributes to the richness of the study through examination of the context of the research (Tracy, 2010)

The process of verification augments the reliability and validity of a qualitative study (Morse et al., 2002). Reliability refers to the consistency of the research and validity refers to the accuracy of the measure. The study should be replicable, and the results should measure what was intended. According to Lindlof and Taylor (2011), qualitative research does not lend itself easily to the concept of reliability because of "non-repeated operations" (272). Other researchers such as Altheide and Johnson (1998) and Leininger (1994) go so far as to say that reliability and validity were terms only applicable to quantitative research.

For example, in the case of interviews, Lindlof and Taylor (2011) argue against repeatability because the participants in a study are only asked the questions once. In addition, questions may vary across participant interviews. I acknowledge this limitation within the research for this study as I will be conducting semi-structured interviews where the questions asked may not be the same within each interview. As stated earlier, a data gathering advantage of using participant narratives is that the participant feels comfortable communicating as they are in some control of the interview as they share their journey. Yet, it is a limitation from a reliability standpoint. Amankwaa (2016) counters this limitation by positing that if researchers describe the process in detail, the conclusions made can be transferable.

In qualitative research, validity consists of two measurements, internal validity and external validity. Internal validity refers to the precept that the study measures what it is intended to measure. External validity refers to the generalizability of the study (Lindlof & Taylor, 2011). In this study, the interview guide (my instrument) elicited responses regarding privacy concerns of the participants. That is the focus of the study. I

am already aware that external validity could be of concern with my work as I will be utilizing convenience sampling. Thus, the participants may not be representative of the YOCC population.

Thick description is described by Lincoln and Guba (1985) as a way of achieving a type of external validity in an effort to counter limitations of qualitative research. This type of description requires the researcher to provide a specific explanation of concepts (more than one word) that paints a vivid picture of the research. Amankwaa (2016) suggests the researcher maintain specific records in order to accomplish this. The specificity of records is vital in qualitative research as this is a repetitive concept throughout (Tracy, 2013; Braun & Clark, 2012).

While it is understood that reliability and validity are integral to quantitative research, Morse et al. (2002) assert that reliability and validity are also applicable to qualitative research. They suggest that using a verification process throughout the study results in reliability and validity. The researchers posit that "a good qualitative researcher moves back and forth between design and implementation to ensure congruence among question formulation, literature, recruitment, data collection strategies, and analysis" (p. 17).

To achieve verification, Morse et al. (2002) suggest adhering to the following strategies. Methodological coherence refers to the research question matching the elements of the methodology which must be examined throughout the research process and adapted as necessary. Qualitative research is iterative (Lindlof & Taylor, 2011; Tracy, 2013). In addition, the sample must be representative of the population being studied. As acknowledged above, this will likely be a limitation in my study, but the

sample does adhere to the notion that participants have knowledge of the topic as they have the disease.

The next element in verification is the constant comparison of collecting and analyzing data. This is clearly laid out in the steps of thematic analysis. According to Morse et al. (2002), this concept is essential in accomplishing reliability and validity. The last two aspects of verification refer to the application of the theory. Data that are collected should support the theoretical base and expand it. The theory should be enhanced because of the data collected (Morse et al., 2002). For example, the concepts of CPM theory should be seen in the data I collect from participant interviews. In turn, the data should help expand the use of CPM theory.

In this chapter, the methodology of the research study was discussed, including the rationale for using a qualitative methodology as well as Communication Privacy Management Theory. Topics covered specifically included sampling, data collection, data analysis, and how I ensured trustworthiness in the research process.

Chapter 4: Results

This chapter contains the results of interviews with YOCC patients and survivors. The purpose of this chapter is to answer the following research questions:

RQ1: What influences YOCC patients and survivors to communicate about their YOCC diagnosis and treatment?

RQ2: What are the privacy issues regarding YOCC patients and/or survivors, especially those issues that influence the way they disclose or conceal private information to others?

Research Question 1The first research question refers to what influences YOCC patients and/or survivors communicate about their diagnosis and treatment. Analysis of the interviews revealed four categories that explain considerations YOCC patients and/or survivors think about. These themes can be considered catalyst criteria (Petronio, 2018) as each category triggered a potentially new set of decisions regarding disclosure decisions (Petronio, 2013). Catalyst criteria differ from core criteria in that catalyst criteria represent factors that are more irregular and uncertain whereas core criteria are stable and predictable (Petronio, 2018).

The first identified catalyst criterion is when patients tended to disclose only their symptoms. Next, patients were inclined to disclose their diagnosis and treatment plan. Then, patients were apt to describe elements of their treatment journey. Finally, patients divulged self-selected post-treatment issues.With each identified catalyst criterion, YOCC patients and survivors identified specific privacy issues that influenced the way they disclosed or concealed information regarding their medical situation.

The first catalyst criterion identified by participants surrounds the decision to disclose symptoms. When participants in this study first felt symptoms that were unusual, they had to decide whether to disclose them. The symptoms are the catalyst criteria that triggers another, different decision-making process about disclosure (Petronio, 2013). Sue relayed this story about her decision to disclose her symptoms to a healthcare provider:

> Now I don't remember, to be honest, how often the blood came or when I started to notice it. But the blood came into the equation…and then I started losing weight. And in my mind, I was like something's wrong. So I went in for an appointment. I'm a very private person, so I didn't share it (the symptoms) with anyone.

Usually a private person who keeps matters to herself, Sue re-evaluated how she would normally handle this information because she felt that something was wrong. The symptoms of blood in the stool and weight loss served as the catalyst for the change.

Symptoms of YOCC were often a surprise to the participants, a characteristic of catalyst criterion (Petronio, 2018). Because of this, participants relayed that they had to navigate a new decision-making process (Petronio, 2018). Tami was in "the best shape of her life" when she started to feel run down and became constipated. The bloating was so bad that a client came into her office and asked if she was pregnant. As a healthy 46 year old, this comment shocked her and she decided to disclose her symptoms to a friend who was also a nurse. Together, they decided she should see a GI doctor. Soon after, a colonoscopy was scheduled and a 4-centimeter tumor was found in her colon.

The surprise of the symptoms of YOCC led her to reevaluate how she disclosed her healthcare issues. Normally, she would just get treated by her friend who was a nurse. This time, she knew that she needed more help. She probably didn't think a healthy

woman should feel or look like she did which led her to change how she disclosed her private health information.

The next identified catalyst criterion concerns the decision to share the diagnosis. This decision is a vital one to the patient because the chosen person will then become co-owner of the information (Petronio, 2002). Participants noted that because a cancer diagnosis is full of uncertainty, the initial disclosure was important and made them consider a different set of people to consider as confidantes. Julie shared the decision to share her diagnosis with her sister:

> Actually, we (Julie and her sister) didn't speak for many, many, many years. She was married and her husband really came between the two of us. And we were barely speaking when I got diagnosed and all I had to do was call her and she was there and now we talk every day.

The YOCC diagnosis served as a catalyst criterion to disclose the diagnosis to her sister. Julie explains that she would not have reached out to her sister if it weren't for her diagnosis. As she states, "My diagnosis brought us back together."

Previous research supports the vulnerability a cancer diagnosis can place on a patient and to whom information is disclosed (McWilliam et al., 2002). For example, Todd relayed that his cancer diagnosis was kept from his son who is autistic. "He couldn't handle it," Todd said bluntly. Other participants relayed that certain family members could not handle hearing the initial diagnosis so they were not until more information about the treatment was known because there is a shared responsibility for the information. But, Matthew's concerns were unfounded when he disclosed to his then girlfriend, now his fiancé. He states:

> I was in the main part of campus and as I was walking home all of these things are running through my head and I thought, what if she wants to leave? And I can't blame her. I could technically die from this and the treatments and surgery and

> that can happen. And if I die, why, why should I hold her back because of my health? Why should I hold her back? And after I told her, she told me I was fucking crazy, to be exact. We would get through this together. She was going to be there every step of the way. And she was and still is to this day.

Matthew's diagnosis forced him to consider the repercussions of sharing this information with his then girlfriend. He was terrified of losing her, and other participants shared that relationships ended because of their YOCC diagnosis. However, Matthew and his fiancé are still together and planning their wedding. A true testament to the concept of shared responsibility.

According to participants, when and where the information was disclosed were additional significant issues in the disclosure decision-making process. The participants were genuinely concerned about how the disclosure would affect the other(s) and took pains to make the disclosure event as comfortable as possible.

The third catalyst criterion identified is disclosure during treatment. After the initial disclosure of diagnosis, participants shared that there were a new set of challenges regarding disclosure during the treatment process. The beginning of YOCC treatment is a catalyst which resulted in a new and different set of decision-making criteria regarding whether to disclose about issues regarding treatment and related side effects, a catalyst criterion (Petronio, 2013). Laura shared that disclosing information about her treatment was challenging because the treatment would change depending on her latest scans or blood work:

> I waited several weeks to put it (treatment) on the Facebook page. So sometimes with the cancer journey, you have initial information and pretty quickly you learn that that initial information may not be accurate, it may change. And you don't wanna be sensationalizing anything. So I try to keep the Facebook page, as this is the final call. Like this is what is happening and it is happening now. I don't do a whole lot of emotional wondering on Facebook.

Laura indicated that disclosing about treatment and its related side effects presented a different set of decision-making criteria than other catalysts because of the uncertainty of the treatment.

In addition to uncertainty, treatment side effects caused participants to reexamine the information they disclosed. Scott relayed that the embarrassment of treatment side effects played an integral role in whether he disclosed.

> I usually try to stay more general. I don't try to talk about things…I usually try to stay more of a general description…I'll just say my bowels didn't cooperate with me for a month. I won't say to them I couldn't take a shit for 3 weeks.

Another treatment side effect identified as embarrassing was a colostomy bag. Participants that indicated a colostomy bag was a part of their treatment journey, shared that it was not always easy to disclose this aspect as it can be embarrassing. Nancy stated, "I haven't really shared with my friends, I have, like a couple of them, but like it wasn't something that I shared with them being life, oh, I had to go out and get the colostomy bag and all of that." The uncertainty of the treatment journey as well as embarrassing side effects led participants to reexamine how and what they disclosed.

The final identified catalyst criterion is the disclosure of post-treatment/long-term side effects. Since the effects of treatment are chronic for YOCC patients and/or survivors, participants shared that they felt the repercussions of YOCC treatment everyday. The challenge of deciding whether to disclose the resulting physical, mental, and emotional difficulties leads participants to consider another set of decision-making criteria.

Nancy explained that she initially shared her YOCC diagnosis on social media and continues to remind others about the important of getting screened. But, when it

comes to discussing the long-term repercussions of YOCC treatment, she made a clear distinction.

> I know for some, fertility and sexual issues, that those are private things. But for me, I'm actually very willing to share those things…in our community. Not necessarily share those things to my friends and family and tell them all the ins and outs. I think it's important to share the private things with the people that are going through the challenges and making sure that they know that it's normal or what they can do to fix it. But to share that outside the community…it probably would not be something that I would do.

The importance of helping others was identified in almost every interview as motivation for disclosure. Betty expanded on this concept by explaining that it isn't only about helping others in the YOCC community, it's about making sure people know that they are not alone on their YOCC journey.

> I guess we don't always want to share the bad side of stuff…but then I started getting involved in the online communities and with the support groups and I resales that your story has impact on people…people need to know that they are not alone…I guess you go back. To the educational piece of saying, 'Hey, you know you are normal. This is normal stuff and you're not alone in this.'

Catalyst criteria answer Research Question 1 concerning what influences YOCC patients and survivors to communicate about their YOCC diagnosis and treatment. There are four catalyst criteria identified by participants including disclosure of symptoms, disclose of diagnosis, disclosure of treatment plan and associated side effects, and finally disclosure of post-treatment or long-term side effects. Each catalyst criterion caused participants to consider a new set of decisions regarding disclosure and the issues surrounding the disclosure.

Research Question 2

The second research question seeks to identify the privacy issues regarding YOCC patients and/or survivors, especially those issues that influence the way they disclose or conceal private information to others. In answering Research Question 1, it was established that 4 catalyst criteria triggered a new set of decisions for the participants about whether to disclose privacy issues regarding their cancer journeys. These four catalyst criteria represent the privacy issues that YOCC patients and/or survivors face during their cancer journey which answer the second research question. This section discusses each catalyst criterion and the privacy issues that influence participants' decision to disclose.

Identified Catalyst Criteria

Disclosure of Symptoms

The first catalyst criterion identified surrounds the decision reached by the patient concerning disclosure of symptoms. The type of the receiver was significant in a patient's decision to disclose. Petronio (2002) explains that the role of a confidant is one of the most important issues to examine in the disclosure process because of the influence a confidant has on disclosure rules and boundary coordination. For this analysis, disclosure options were categorized into three areas.

1. Participant disclosure of symptoms to a health care provider
2. Participant disclosure of symptoms to a friend or family member
3. Participant non-disclosure of symptoms

Disclosure to a Health Care Provider

In this study, disclosure to a health care provider was defined as patient disclosure of symptoms to a medically licensed person in an office setting. The type of provider varied, including health professionals such as nurse practitioners and OBGYNs. Petronio (2002) refers to this category as a deliberate confidant where the purpose of the interpersonal interaction is to gain insight into a person's private information. A health care provider is there to help the patient and to do that, must elicit private information about their health. The purpose of the interaction is for the patient to disclose information about what they are experiencing. Disclosure is expected by the confidant (Petronio, 2002). It is important to note that this category does not include disclosures to family and friends who are licensed providers occurring outside of a professional setting. Those disclosures are included in the next category of *disclosure to a friend or family member.*

Several participants reported that their symptoms were downplayed by the provider. For example, participants were told that they were too young or that they had no family history of colorectal cancer. Tim stated:

> I started having stomach issues like gas, diarrhea, bloating and then I was just on the toilet for like three to four hours a day and I was like, okay, something is totally wrong. But being 28 at the time, it wasn't a huge deal. So I went to primary care and they did a stool sample and then from there she prescribed antibiotics.

In the case of some female participants, symptoms were downplayed or attributed to being pregnant or to having just given birth. Marlo relayed this story. She was eventually diagnosed with Stage IV colorectal cancer and is still undergoing treatment. It has been four years. She stated:

> I initially went to the doctor because while I was pregnant with my son, my only child, when I was about seven or eight months pregnant, I started to have severe

> abdominal pain and bleeding. A lot of it. And uhm, cramps and everything that goes along with it. And of course, the nausea and bloating. So, I went to see my obstetrician, who I was seeing regularly at the time. And of course, all those symptoms sound like pregnancy. Those are pregnancy hemorrhoids. I'll give you this, and that should clear up. It didn't work. So, my son was born, happy and healthy and then all the pains and rest of it did not stop. So, after I dealt with that for another year, I went to see a primary care physician and he did refer me to a GI doctor and I remember when I did my consultation, he said, well, we'll just do a colonoscopy to rule out all this stuff because you're way too young to have anything serious going on. So, he looked at me like this is just gonna be just a routine procedure.

Participants reported that if the disclosed symptoms were downplayed, the colorectal cancer diagnosis was sometimes delayed. This is problematic, because a delay in diagnosis can result in cancer's detection at a later stage. A Stage IV diagnosis can risk a patient's chances of a cure. One female participant, Stephanie, reported that the delay in her diagnosis resulted in a terminal diagnosis. An accurate detection of her cancer came too late. She can never be cured. She exemplified her frustration in a story about her conversation with a physician who began treating her after her diagnosis. She stated, "The doctor told me … we're starting here (Stage IV) and it's too bad that you couldn't have been Stage I or II … I could have saved your life. But that ship has sailed. You are a terminal project."

Another effect of downplaying symptoms is the misguided sense of comfort patients reported. Some patients were first told that the symptoms were "no big deal," that they were "too young for colorectal cancer," or that "you are probably bleeding because of a hemorrhoid due to pregnancy." Patients lulled into believing in a less serious diagnosis were then taken off guard by the subsequent cancer diagnosis. Participants expressed that the colorectal cancer diagnosis came as a devastating shock because they were under the impression that nothing significant was wrong.

According to participants, a cancer diagnosis causes anxiety and stress. These emotions can be unnecessarily increased when symptoms are downplayed by the health care provider, a situation reported by most participants. As deliberate confidantes, health care providers are viewed as experts in the eyes of the participants so their responses to participants disclosures are important. Initially, a patient might not have been worried that their symptoms were indicative of serious illness. A cancer diagnosis, then, comes as a thunderbolt. Multiple participants relayed stories of surprise due to the downplaying of symptoms.

Anna was 17 weeks pregnant and made multiple visits to the emergency department because of a pain in the lower left area. She was told each time that she was either constipated or had irritable bowel syndrome. It wasn't until after an ultrasound that a small mass was spotted. Even then, though, she was told that the laparoscopic procedure would be "quick." Five hours later she woke up with a colostomy bag, her mother crying at her bedside, and eventually a Stage IV diagnosis.

Participants became frustrated when they disclosed their symptoms to a healthcare provider and those symptoms were not taken seriously.. Respondents indicated that this adversely affected the patient-provider relationship. Because patients were not getting the answers they wanted or needed from a deliberate confidant, whom is seen as an expert, respondents investigated their symptoms on their own. There became a distrust of the provider on the part of the patient. Multiple respondents reported that they reached out to support groups on Facebook, googled symptoms or visited multiple providers because they were frustrated that their disclosure of symptoms was not being taken seriously.

In the following example, Christina was understandably frustrated at a provider's insensitivity. Even more unsettling, the patient eventually had to face a shocking, possibly later stage diagnosis because the symptoms were not initially taken seriously by the health care provider. Christina described the frustration of continually going back to the doctor with symptoms but leaving each appointment with no answers. She stated:

> I had just had a baby, so when I went to the OBGYN [with her symptoms] and she thought I was being dramatic and making up my symptoms. Because I had a high- risk pregnancy, so she thought I was just nervous about just having a baby or was just paranoid. So then I started looking around and searching for treatment on my own. I just kept seeing all kinds of different doctors because I knew something was wrong with me. I just didn't know what it was because I had so many different symptoms.

Christina was eventually diagnosed with Stage IV colorectal cancer and is now deceased. She left a four-year-old daughter. Had the patient and her complaints been taken seriously by the health care provider, it is possible that her life would have been extended and she would have had more time to spend with her daughter.

One group of participants reporting frustration with downplayed symptoms were those who identified as Black. Participants in the sample suspected that their symptoms were ignored or not taken seriously because of their race. But patient narratives have the potential to bridge understanding between the patient and provider, particularly in minority populations (Hall & Powell, 2011; Lee et al., 2016; Pallai & Tran, 2019). Participants represented the west coast, southwest, and southeast regions of the United States. Results indicate that the experiences of people of color when disclosing their symptoms to a healthcare provider are not limited to a particular area of the country.

In addition to participants of color indicating that they did not feel their symptoms were taken seriously, they also express frustration that many of their health care providers

did not look like them. Marlo, who is currently receiving treatment for Stage IV colorectal cancer, worried that this difference could affect how her symptoms were handled by her White health care provider who initially dismissed her symptoms. She explained:

> I was watching this special, and they had on a bunch of medical professionals, and they were talking about how like for African Americans, we go to the doctors, all your doctors might be white. They might be older white males and they are not giving you the type of care; you know what I mean, that they might give to someone else. And I was like, that was just very interesting, and it prompted my thinking. I'm like yeah, it was kind of brushed off. They didn't really do anything.

In sum, results indicated that participants disclosed symptoms reflective of YOCC, but symptoms were often downplayed, dismissed, or attributed to something else. This finding is important because if YOCC is diagnosed in its early stages it is not only treatable, but curable. Providers can gain insight into a patient's healthcare experience in order to gain a more complete understanding of the patient experience by listening to their stories in the medical interview (Hall & Powell, 2011; Lee et al., 2016;Pallai & Tran, 2019). As deliberate confidantes, providers are intentionally soliciting information from the patients (Petronio, 2002). The goal is to gain as much private health information as possible. The later the diagnosis, the higher the likelihood of the disease progressing to a later stage which is more difficult to treat and cure. Listening to the patient's stories, as previous research suggests, could help provider understanding of the patient's symptoms earlier.

Not all participants disclosed their symptoms to a healthcare provider. Many participants shared that they disclosed symptoms to a friend or family member. While a friend or family member would not be able to give a YOCC diagnosis, these types of

disclosure are important to examine as they influence the YOCC journey and could lead to the friend or family member encouraging the participant to seek medical advice.

Disclosure to a Friend or Family Member

The second subcategory involves disclosing symptoms to a friend or family member. For this study, disclosure to a friend or family member was defined as a participant disclosing symptoms to a person whom they knew on a personal level such as a spouse, partner, or best friend. This disclosure did not occur in a healthcare provider's office or other official setting, though the person receiving the disclosure could have had a medical background.

When deciding whether to disclose symptoms of colorectal cancer, participants first considered the credibility of the receiver or the participant's relationship with the person. For example, the receiver of the disclosure could have been respected by the participant for their background in healthcare and their potential to offer reliable advice. Because the participant anticipated a helpful or favorable response to the disclosure, they were more likely to disclose about their health issue (Derlegaet al., 2008; Greene et al., 2012). For example, Tami stated:

> So, over the months I had been talking to my best friend who is a nurse midwife and an RN, and I would tell her what I was experiencing, and she was like, just go to the GI and get it checked out. Neither of us were thinking of cancer. We were thinking that I needed to go back on Whole 30, like it was a diet thing.

If the receiver was a partner or spouse, participants expected that the potential recipient had an intimate knowledge of the participant and would see the symptoms the participant was experiencing as unusual and a possible cause for concern. Petronio (2002) identifies this person as an inferential confidant where "disclosure is expected based on the

relational role (p. 111).” For example, Jenn explained that she disclosed to her husband because he was familiar with her eating habits: “I mentioned it to my husband (increase of loose stools) and I sort of said … maybe it’s just because I’m like eating greasy fatty foods.” Jenn’s husband has an expectation of hearing about her health because of their marital relationship.

Proximity was another determining factor in the decision to disclose information about YOCC symptoms. In addition to credibility or intimate familiarity, some participants reported disclosing to a person simply because it was convenient, accessible, or “there.” Tim was starting a new job on the opposite coast of many family members when his symptoms started. Thus, he disclosed the symptoms with relatives living in the same area rather than those on the opposite coast. Tim said, “I was sharing it (symptoms) with my family that I’m close with that live near me. I like had dinner at their house and I told them I was on antibiotics and having stomach problems.”

When symptoms were disclosed to those in proximity, participants first considered the consequences of the disclosure. Participants explained that when a person discloses any information to another person—in this case very personal health information—a level of responsibility for that information falls upon the confidant. . Petronio and Durham (2008) argue that the decision to disclose is enhanced because of the control each person has over their private information. Thus, the decision to give up control by disclosing the information to another is significant.

Because of this responsibility, the confidant might feel protective of the discloser and obligated to encourage the person suffering from the symptoms to consult a healthcare professional. Participants reported feeling motivated to seek out healthcare

support based upon feedback from their disclosure of symptoms. Mike was very grateful that his assistant kept reminding him about getting a physician-suggested colonoscopy. He explained:

> And fortunately, because my schedule is so crazy, I cancelled two or three times (the colonoscopy) and my assistant made sure I did it. I just thought I had like a long slow flu. But the only person who knew, my assistant, because she knew I was trying to schedule a colonoscopy, she made sure that I got it done.

Non-disclosure of Symptoms

As important as it is to discuss the disclosure of YOCC symptoms, it is just as important to explore the reasons for not disclosing symptoms. Those suffering from YOCC symptoms cannot be diagnosed and treated if symptoms are not disclosed. In this analysis of participant interviews, reasons for nondisclosure were categorized as personal and/or professional. Participants reported personal concerns as a reason for not disclosing the symptoms they were experiencing. Personal reasons included protecting others, maintaining privacy, and fear.

When discussing reasons to not disclose symptoms, participants shared that protecting others such as a spouse or child was of utmost importance. The disclosure of any symptom could cause the person receiving the information to become worried or scared. Being a confidant can cause stress due to the importance of the disclosure. Therefore, those that disclose often consider a person's capability to deal with the private information (Petronio, 2002) Consequently, participants chose not to disclose their symptoms even though they reported they "knew" something was wrong and might have been worried themselves. The strain of a health issue can be taxing on the patient's partner (Hagedoorn et al., 2011). Participants prioritized safeguarding the emotional

response of the other person over their own physical and emotional health. Christina was newly married when she developed symptoms and didn't want to disclose them to her new husband because she worried it might upset him or make him uncomfortable. Petronio classified this as a face risk where a person considers whether the disclosure would be embarrassing to either party. She explained:

> You kind of like keep it to yourself because it's not like a table kind of conversation topic. It wasn't something you talked to your newlywed husband about. That's not very attractive. So, you just kind of like hide it and keep it to yourself, you know?

Previous research supports that disclosing health issues that can be stigmatizing are even more risky to disclose due to the potential for disapproval (Greene et al., 2006; Smith & Applegate., 2018).

Another personal reason reported for non-disclosure of symptoms was that the participants found non-disclosure necessary to maintain privacy. Healthcare and related concerns were judged as personal in nature and not to be shared. Some participants reported that guardedness about disclosing health issues, among other personal issues, was a learned behavior, acquired over many years. Some participants reported that they rarely, if ever, discussed personal issues of any kind with others. Habitually, personal issues were hidden from family and friends alike.

The final reason offered by participants for not disclosing symptoms was fear. Disclosing symptoms was perceived by some participant as a personal—potentially public—acknowledgement that something was not right with them. The fear that disclosing troubling information about themselves might be perceived as weakness or vulnerability overwhelmed participants to the point that they were reluctant to talk to anyone about their symptoms. In addition, the disclosure to others that something was

wrong was an acknowledgement that there was a health issue. If an acknowledgment wasn't made, there would be no issue.

In addition to personal concerns influencing non-disclosure of symptoms, participants indicated that professional concerns weighed into their decision-making process. Participants reported that disclosure of symptoms could have a potentially negative effect on their career, leading to possible demotion or job loss. This type of disclosure is classified by Petronio (2002) as a role risk. Apprehension over the prospect of loss of income and inability to support family pressured participants to feel disinclined to disclose symptoms.

Multiple participants reported that they kept symptoms private because of the potential negative impact on their career. Tim shared how he would have to be in the bathroom for extended periods of time during the workday. He did not share this with his co-workers because he was newly hired and was on the "fast-track" to promotions within his company. He stated:

> I was just starting a job. I was having diarrhea and pain and frequency. I'd like, and specifically I remember being in the office one day and I had been on the toilet for like three hours and it was in the office too. It was like if I get up, I feel like I have to go. It'd be hurting. There'll be some blood and I'm like, oh my God, why is this happening? And so it definitely got in the way of work.

In addition, Matthew explained that as a military officer, if he disclosed symptoms to his superiors, he would be at risk for not being able to be deployed, and deployment was essential for promotion. Due to the potential negative impact the disclosure could have on his career, Matthew had to consider the role risk of sharing the private information (Petronio, 2002). He said, "If I told anyone about what was going on, they wouldn't let me go (deployment). This is my family, my life." His diagnosis and resulting surgery

were done privately, not through the military. The interview with Matthew was conducted while he was deployed in the Middle East. He is now safely home with no evidence of disease.

The impact of deciding whether to disclose symptoms affected participants' personal and professional lives. Participants explained that the stress of this decision added to the already difficult situation that participants face when dealing with a potential health condition.

Disclosure of Diagnosis and Treatment Plan

The second catalyst criterion identified is disclosure of the initial diagnosis and treatment plan. Once a participant was given a colorectal cancer diagnosis by a health care provider, the participant had to decide not only who to tell, but also when and where. A catalyst criterion that sets in motion another, different decision-making process about disclosure (Petronio, 2013). Participants explained that decision to share the diagnosis is important because that person will then become co-owner of the information (Petronio, 2002). In addition, participants explained that they made every effort to ensure the confidant would be as comfortable as possible when receiving the disclosure. Therefore, sub-themes in this section are organized into the categories of who, when, and where.

Who

Participants indicated that their first consideration was the decision regarding who to share with; that is, who would become a co-owner of the information? Who would become a confidant? Participants recounted that sometimes the person was in the room with the patient at the time of diagnosis and learned of the diagnosis and/or treatment

plan in the instant the patient did. Thus, co-ownership of the information happened immediately and automatically (Petronio, 2002).Kim was one of many that reported a significant other was in the room when they received their diagnosis: “My husband was sitting next to me. So he knew immediately.”

Jenn was grateful her husband was in the room with her at the initial diagnosis. While she was quite emotional, he was able to focus on how the cancer would be treated. She relayed the story of when she was initially diagnosed:

> It’s almost like it was businesslike where it was like, okay, what’s next? Like that’s sort of how he reacted at that moment. How do we fix this? I, on the other hand, I was, I was crying. I wasn’t sobbing, but I was definitely crying.

If the patient was alone with the healthcare provider at the time of diagnosis, they had to decide who would be the initial person to learn of the diagnosis and treatment plan. Participants reported contemplating if and how the person would cope with the difficulties of the diagnosis. Confidant selection is important because that person will now be linked based on a shared knowledge of the private information (Petronio, 2002). According to participant interviews, the person’s age and mental health, as well as physical proximity to the patient, played roles in the decision of making them a confidant. Some participants indicated that the chosen person could be tasked with relaying the diagnosis and treatment information to others as well as enforcing rules about the disclosure. Based on information gained from interviews, the role of the receiver of the diagnosis information is a critical one in the journey of the cancer patient. This finding is supported by previous research (Hagedoorn et al., 2011; Venetis et al., 2014).

Julie discussed the concern she felt over disclosing information about the diagnosis and treatment to her mother. She believed her mother would struggle with the

news, so she decided to make the initial disclosure to her sister who would be considered an inferential confidant (Petronio, 2002) Julie said:

> I didn't even, I didn't even tell my mom. My sister told my mom. So with my mom, everything always turns about her and how it's affecting her. So I just, I asked my sister, you tell mom and just ask her not to tell anybody for right now.

The importance of the decision to choose her sister as an inferential confidant is amplified because Julie tasked her sister with not only telling their mother but also making sure that their mother understood the explicit rule of not telling anyone else about the cancer diagnosis.

When

Participants indicated that the next consideration in disclosure of diagnosis and/or treatment plan is when to disclose. The timing of the disclosure is essential to consider. Petronio (2002) explains that a person disclosing strives for the most "appropriate and optimal" time for the disclosure (p. 94). Before disclosing, participants wanted to know as much information as they could about their healthcare situation. They wanted to be able to give an informed and thorough account of their situation and condition to someone else.

Some participants knew the diagnosis would be jarring to others. Interview results indicated that the participants attempted to educate themselves as much as possible in order to prepare for any questions that could arise after the disclosure. As Tami stated:

> So our family was apart (at the time she received the diagnosis) so we can't even have a family meeting. And we're not going to sit down and tell these kids today what's going on because we don't have any information yet. I mean, yes, I know I have cancer but I don't know what any of this means. I don't, I had no idea. I've never even heard of a colon resection. Nobody tells you anything. We told our children once we got the treatment plan in place, once we knew I was going to have surgery and have to have chemotherapy.

This example shows how the participant felt a need to prepare for the recipient's response and their ultimate questions. The diagnosed patient was well aware that the news of their cancer diagnosis would probably be shocking to the recipient. The patient wanted to be as informed as possible to ease the burden on the person to whom the information was disclosed. The timing of the disclosure was predicated on ensuring the participant had as much information as possible about their cancer diagnosis.

Previous research confirms the importance of timing the disclosure when there is sufficient information about a patient's health issue. If there is inadequate information, it can cause more stress on the caregiver (Manne et al., 2006 & Venetis et al, 2014). Because of this, Tim chose his uncle, a doctor, to disclose his diagnosis and treatment plan to his parents because he knew that the news of his diagnosis would be difficult for them: "So my uncle [a physician] sat down with them [my parents] and told them in person. So I wasn't there for the real conversation, but it's really hard on them."

Where

The final consideration identified by participants was where the disclosure would take place. Participants reported that, ideally, the disclosure of the cancer diagnosis would be done in person. Participants communicated their desire to harbor the recipient at disclosure time, to ensure that the other party was not at work or that they were sitting down. Before telling his children, Mike made sure he had sufficient information about his diagnosis and treatment. He also made sure to tell them in person and at home where they would be most comfortable, explaining:

> I'm a big believer in putting your cards on the table. So as soon as I came back with the cancer diagnosis, we just gathered the family into the kitchen, put our arms around each other and I told them everything. And they're great.

As much as most patients attempted to make the timing of disclosure as easy as possible for the recipient by being well-informed and trying to tell them in person, that was not always possible. There is not always a perfect time. Due to logistics, such as living in different parts of the country or the recipient being in transit, the disclosure sometimes had to be done over the phone. Not only did Tim live on the other side of the country from his parents, his parents were out of the country when he was diagnosed. This situation was delayed when they were given his diagnosis. He recounted:

> Interestingly enough, my parents were out of the country at a wedding at the time. So basically me and my sister and my cousins decided, "let's not tell them until they land in the US because we don't want them on an 18 hour flight freaking out, like my kid has cancer kinda thing.

Some interview participants explained how COVID-19 introduced an additional challenge to disclosure in person. Participants who received their cancer diagnosis during the pandemic were often in isolation. Julie received her diagnosis by herself and had to call her husband, who would have normally been in the appointment to let him know. She said:

> Because of COVID, you know, I had to immediately leave and call my husband. And of course, you know, when you're getting news like that, my head was swirling. I wouldn't have all the information when he asked me questions.

Disclosures of cancer diagnosis and/or treatment plans had to be accomplished over the phone or using Zoom because patients could not be in the same room as those they had chosen to tell. Jenn relayed the difficulty of disclosing the diagnosis, stating:

> It took me about two days to be able to reach everyone because I was not going to leave a voicemail. I wasn't going to send an email. I wanted to tell certain people as in person as possible (due to covid), which at that point was over the phone.

Participants also reported that social media proved to be a factor in the decision of where to disclose the initial diagnosis and/or treatment plan. For some participants, use of social media made the disclosure process easier. Through platforms such as Facebook or CaringBridge, the patient could make the diagnosis announcement at one time to many recipients with control over who received the information and control over the content of the message. Control is an integral component of CPM theory (Petronio, 2002) and is important to cancer patients.Jenn explained, "So we set up a CaringBridge and then you could update surgery and all this … I was thinking CaringBridge because you can control who sees your posts." Because the patient is seemingly not in control of treatment, finances, and other aspects of daily life, being able to control the message of their illness is important (Donovan-Kicken et al, 2011).

Disclosure During Treatment

The third catalyst criterion identified is disclosure during treatment. Participants shared stories that, after the initial disclosure of diagnosis, there remained challenges of disclosure during the treatment process. A catalyst criterion that forced the participants to consider new and different factors about whether to disclose (Petronio, 2013)Decisions to disclose information about treatment, the resulting side effects, and other associated obstacles were complex and stressful, compounded by the fact that participants were at times quite sick suffering from the horrendous effects of treatment.Four sub-themes were identified regarding the decision to disclose information about the treatment process:

1. Tension of wanting to talk about treatment
2. Disclosure to help others

3. Impact of social media
4. Non-disclosure of treatment symptoms

Tension of wanting to talk about treatment

The first sub-theme regarding disclosure during the treatment process addresses the tension created for participants as a result of the conflict between needing to talk about what they were experiencing as they underwent treatment and the desire not to be seen as a sick person. Petronio (2002) describes the push a person feels to disclose private information to get needed support while considering the risks involved with that disclosure. This tension is seen as participants discussed aspiring to be (and be seen as) strong and independent individuals. Yet participants also wanted people to understand that the treatment experience placed limits on their previous abilities to be strong and complete normal tasks. Jenn explained this tension:

> And I'll tell them [people that ask] because I want them to know. I don't want to give them the false impression that everything's okay … when I'm not. But I also don't want them to think I'm bedridden and I can't, you know, get out of bed and I can't do anything.

Participants were frustrated at being incapable of completing normal tasks they would otherwise be able to perform were they not undergoing treatment. Julie, an educator, stated:

> I'm not one to ask for help but during some of our first meetings, neuropathy started in the fingers. Typing is hard and it's challenging. So we had one of our first meetings and I'm trying to type and the meeting was just dragging out and it was embarrassing and so my staff is emailing me now and saying, "Are you up to it? Are you able to do the typing or do you need me to do the typing?" I think on one level it comes from a place of concern and best intentions. (But) do I want my teachers to know I have trouble typing? Not really.

Tension was reported by participants not only professionally, but on a more personal level, as well. Interestingly, unlike other cancer patients, most YOCC patients do not lose their hair during treatment. Some participants stated that their lack of hair loss contributed to the tension of disclosure during treatment because they did not "look" like a cancer patient. Petronio (2002) confirms the importance of social validation with disclosure. While not seeking sympathy, participants expressed a yearning for acknowledgement of what they were experiencing. When Laura was diagnosed with Stage IV colorectal cancer, she described a discussion with her oncologist, pondering the misplaced emphasis on hair loss for cancer patients:

> Somehow, somewhere along the line, we've decided, for females, that the worst thing that could happen is that you're gonna lose your hair and I feel like it's across the board for females. I remember my first day in the oncologist office and he said, well, the good thing is you won't lose your hair. And I'm looking at my son. My 14-day-old son and all the shit he just told me … yeah, uhm, hair grows back.

Participants indicated that it was difficult to disclose what they were experiencing during the treatment process. They wanted people to know that treatment was difficult, to have validation, but it was difficult to acknowledge that they were not capable of doing the things they could do pre-YOCC. Tension also was identified by participants because YOCC patients do not look like they have cancer based on the stereotype of hair loss. Although participants indicated that they didn't necessarily want others to know they were ill, it was also frustrating to be sick yet not "look" sick. This tension is cited by Petronio (2002) as the weighing of costs and rewards as a person decides whether to disclose private information.

Disclosure to help others

The second sub-theme in the disclosure of the treatment process is that patients undergoing treatment were inclined to share their experiences to help others undergoing treatment or who were soon to go through treatment. It was almost unanimous amongst participants that their motivation for disclosure was to help others. Charmaz (2006) supports this stating, "Frequently, however, stories of illness become stories of redemption, transformation, and transcendence of self" (p. 245).

Sue indicated that her cancer diagnosis has given her a life's mission to give assistance to fellow YOCC patients and survivors. Petronio (2002) states that self-clarification is an important reason to disclose as the disclosure helps one to understand and make meaning of what they are experiencing. Sue stated:

> So I feel like with my cancer journey, I call it purpose through adversity because now I know what my purpose is. People live their whole life finding, trying to find their purpose. And I know that my purpose is to educate people on a grand scale within my community about the disparities within the healthcare system. And how we can contribute and help to overcome something because we do have some control.

Participants reported that because they themselves often did not receive adequate information detailing the side effects of treatment and offering strategies to cope with those effects, they felt an obligation to share with others what they learned from their own experiences. Participants chose to disclose their experiences to other patients so that the difficulties of treatment might be better prepared for or even minimized. Nancy simply stated, "It's like, I feel it's important for me as a patient to help other patients."

Tami went into more detail as she explained her frustration with the lack of information given to her by health care providers and why she is motivated to help others, saying:

> How can you as a surgeon discharge me and not say you need to go to PT? Rehab your stomach muscles because I just cut you from sternum to pubic bone? Oh, exercise to tolerance, are you kidding me? How much crap do we have to try and muddle through? Now, after surgery had they given me a belly band to help … and I said to my husband one time, you know it's not like I'm a stupid human being. I'm a smart woman and I enjoy exercise and yet I didn't put two and two together and say, you just had major surgery, you should go to rehab. Like nobody will say, hey, you're getting radiation near your vagina, that going to hurt when you have sex. And by the way, we have vibrators and dilators and all kinds of things. Why can't we be compassionate and caring? I'm just so grateful that he saved my life but how can you be so brilliant and so stupid at the same time?

Further, participants described how they wanted to provide emotional support to other patients to demonstrate that they were not alone in experiencing and coping with the side effects of treatment. A contributing factor to this decision to disclose is that participants reported some of the treatment side effects as embarrassing. Participants shared that they tend to feel most comfortable talking about these side effects with others experiencing the same treatment consequences. Disclosure happens more often when there is similarity between the persons (Derlegaet al., 2008). In addition, the face risk of the disclosure is reduced or even eliminated because persons are sharing similar side effects.

In order for YOCC patients and survivors to increase their quality of life, it is important for them to be involved in social networks where they feel comfortable sharing issues and concerns regarding their illness (Carmack et al., 2011 & Sapp et al., 2003). Petronio (2002) posits that it can be difficult for cancer patients to share their experiences with those that have not experienced cancer. Through no fault of their own, the confidant does not have the personal resources available to help the person who is on a cancer journey. Kim relayed the importance of finding others who were having similar experiences, explaining:

> Once I found CCA (Colorectal Cancer Alliance), it was like a whole different thing … those guys have been just a huge lifeline for me. We talk about

> everything. I mean, there's nothing off the table. We talk about chemo treatments, dilators are a big thing for women. Wanting to feel normal with people. Like if you have friends over and you're having a meal and you aren't going to be like, I had a really hard time pooping today or I've had diarrhea for three days. The poop is still a kind of taboo topic to others.

Helping fellow YOCC patients and survivors was an important reason participants disclosed their treatment symptoms. Angelina Jolie chose "not to keep my story private" about her experience with cancer and its impact on her life in order to help others (Jolie, 2013). Because YOCC is in the early stages of being examined from a psychosocial perspective, participants were adamant about sharing their lived experiences in order to help others as they received little information about practical treatment side effects such as bathroom and sexual issues. Participants saw themselves as experts, and they wanted to pass what they have learned on to others.

Impact of social media

The third sub-theme is the use of social media in disclosing information about undergoing cancer treatment. Participants indicated that there were both positive and negative aspects of disclosing through this format. Petronio (2002) confirms that when a person looks for social validation through disclosure, it can have positive and negative outcomes. This is seen even when there is similarity such as a colorectal cancer diagnosis. Jenn explained that discussing experiences on social media such as Facebook can increase anxiety. She explained:

> And based on everything I've read and in the Facebook group, you know, everyone's pretty forthcoming about their side effects but it also lends itself to a little bit of paranoia. Like, is yours (side effects) going to happen to me or not?

In addition to increasing anxiety about whether other's experiences could happen to them, participants reported that controlling the members of the group could become

overwhelming, making them uncomfortable about disclosing. Laura stated that because of the number of people in her Facebook group, she was not comfortable disclosing on the page. She stated:

> So overall I would say far too many people, more than I was comfortable with, found out. Let's say a previous employer I worked with 15 years ago and I invite one person that is a good friend from that portion of my life and then they invite someone else that we worked with and then another and then another. And then the same thing with a college friend. And you know, it just got out of hand. And once they were in the group and they knew and they were commenting, it was like, well, what am I supposed to do now? And I can't control it. And it's frustrating when you can't control it.

However, participants reported that disclosure through social media allowed them to potentially reach a large group of individuals in order to raise awareness and potentially help others. As Betty relayed:

> I'm very much the person that I'm going to put it all out there, like I'll put it out there and I don't want anybody to … I don't want anybody to brush it off because in the long run it might save a life. That education piece is always a big part of my post (on Facebook). I believe that is the teacher. People need to know that they're not alone and so it can start those conversations.

In addition to the number of people that can be contacted, participants explained that social media was used to show what YOCC looks like. Showing what cancer looks like was important to Jenn as she stated:

> And you know, I guess because, you know, it was nice to be able to show people like I don't look bad. Like I don't look, I know this isn't making me turn into like a zombie or something. And I can still find ways to have a smile on my face and things are good … don't have a false impression about what you think I might be going through and don't think of me too differently than you have before.

Participants explained that social media also allowed patients/survivors to connect with each other, support each other, and share medical advice. The importance of similarity is confirmed in previous research (Derlegaet al., 2008). Support through social media was

identified as especially important in interviews when participants were not being supported at home. As relayed by Christina:

> So I feel like social media was the perfect place for me to go and ask for help and to hear people's feedback. I had this person (her husband) who was embarrassed by me. He didn't understand. I didn't want to explain things to people, I just wanted, I needed help and I just didn't know how to get it.

Interestingly, while participants didn't agree about whether sites like Facebook or CaringBridge were beneficial, the fact that social media was discussed frequently during the interviews indicates its significance

Non-disclosure of symptoms

The fourth sub-theme identified in analysis was the non-disclosure of treatment symptoms. The previous three sub-themes discussed the concept of disclosing symptoms during treatment. This sub-theme examines when participants chose not to disclose symptoms. It is important to identify and examine the reasons why participants did not disclose symptoms because disclosing symptoms to either a healthcare provider or to a friend/family member was identified as the first step in getting treatment for a potential YOCC diagnosis.

Participants relayed that treatment took a toll not only on themselves, but also on their family and friends. Petronio (2002) explains that inferential confidantes can find it difficult to continually listen to disclosed problems. It can cause distress for the confidant (Petronio, 2002). Because of the stress of treatment and its associated side effects, participants sometimes did not disclose what they were experiencing on their treatment journey. Carmack et al. (2011) found that CRC patients who experience embarrassment and anxiety because of their illness are not likely to talk about their illness to loved ones.

Laura explained that her reason for non-disclosure was because it made her husband upset when she talked about her neuropathy in her fingers, saying, “I think it makes him (my husband) really sad when I talk about not being able to feel things.” Participants shared that dealing with YOCC treatment is difficult on a patient. Knowing that the treatment also adversely affects others that the participant cared about can, at times, be too much to bear.

To not make others upset, participants explained that they would not disclose what they were experiencing. They would put others' feelings before their own. Marlo, battling a Stage IV diagnosis, relayed the impact non-disclosure had on her. She shared:

> I wouldn’t let them [mom and husband] see me upset. I used to wait, I would cry in the bathroom at night after my mom would go to sleep. Or I would lay in the bed and try to cry quietly as I could, but I wouldn’t wake him up. You know, I don’t like to … I don’t know. I don’t know.

Marlo further explained that a contributing factor for non-disclosure was to avoid turbulence stemming from disclosures. Fighting for her life, she stated that at times it was easier to keep the effects of treatment to herself. She did just not have the energy to deal with her cancer battle as well as the frustration of how people reacted to her disclosures. When a patient is not able to share information about their issue with their support system or inferential confidant, it can have a negative impact on their quality of life (Petronio, 2002;(Sodergren et al., 2019). Cancer treatments were difficult and tiring, and all of Marlo’s energy went to fighting that battle. She could not afford to become emotionally drained by disclosing treatment symptoms which did not result in making her feel better, but worse. She stated:

> It got really kind of difficult to talk to, like your friends and your family when you feel that way [bad about the way you look from side effects] because for the most part they kept saying, oh you’re still so beautiful. I wish someone would say that I

> look terrible … it would make me upset when people would be like, oh you're beautiful, you know? No, I'm like, no. Do you see this rash all over my face? So I did [talk to people about side effects] but it would make me emotional, so I didn't do it often.

Non-disclosure of treatment symptoms can be attributed to participants protecting others and themselves. Participants explained that the cost of the disclosure did not outweigh the benefit. A dialectic exists during the decision-making process of whether to disclose private information (Petronio, 2002). The person that owns the information weighs the costs and rewards of disclosing the private information to another individual. It was easier for the participants to keep the information to themselves even if it was difficult or caused the participant to be somewhat emotionally distraught. The cost of upsetting another person or having another person's reaction upset the participant—compounded with the YOCC cancer journey—was not worth the benefit of the disclosure (Venetis et al., 2014).

Disclosure of Post-Treatment Effects

The disclosure of post-treatment/long term side effects is the final identified catalyst criterionFor YOCC survivors, effects of treatment are chronic. Research has shown that side effects from CRC and resulting treatment have lasting physical and psychological impact (Mohler et al., 2008; Van Veeneet al., 2020). Participants explained that while cancer no longer may be in their body, the ramifications of fighting YOCC remained and were felt every day. They shared that effects are physical, mental, and emotional. Thus, participants explained the challenges of navigating through their own experiences and reactions to those experiences while deciding what or if to disclose to

others (Petronio, 2002) which lends this theme to be considered the final catalyst criterion (Petronio, 2013)

According to participants, the tension generated for the YOCC survivor about whether and to whom to disclose post-treatment side effects markedly affected their personal lives. Participants who were still dating and looking for partners, especially those in their 20s, found this tension particularly exacting. While Malloch and Zhang (2019) posit that disclosures can be made in the early stages of a relationship, but only when there is a perceived similarity. Participants acknowledged that because the potential dating partner was not similar, disclosure was more complicated. Christina explained this tension:

> So then you feel guilty about bringing anyone into my life because why would I want to do this to someone that I care about and then hurt them eventually by losing me? And so then it's like at what point do I tell somebody I have stage 4 cancer? Like if they fall in love with you and then you tell them, then you kind of trick them and then if you tell them too early then they get scared and they lead. So it's just like a Catch 22. But it's just I feel like I should have something else in my life besides just being a mom and just being a cancer girl. And you know, why can't I have all these things that everybody has?

Participants explained further that post-treatment side effects can include complications unique to YOCC survivors involving bathroom use or sexual behaviors. Survivors described the challenge at the beginning a relationship with someone and being faced with decisions about disclosing information about cancer and post-treatment side effects. Sue explained that she was hesitant to begin a new relationship for fear of the person leaving once her side effects were disclosed. By disclosing this private information, a relational risk occurs (Petronio, 2002). Sue relayed:

> But now I have very high anxiety about getting in a new relationship with my issues that I have. It's like I have, like I have bathroom issues. Some days I'm

> very gassy. So it's embarrassing. It's embarrassing. I just want to be normal again. And I know there's no such thing as normal again.

For Sue, the anticipated threat to the continuation of the relationship upon disclosure was crushing. This could be categorized as a high-risk episode where the disclosure could potentially cause severe embarrassment or trauma to the person disclosing (Petronio, 2002).

Many participants took to social media for support during this time and became advocates for others who shared similar experiences. Previous research has found that a person is more likely to disclose in order to further a relationship if they felt a similarity with the other person (Romo et al., 2016). In addition to relationship complexities, YOCC survivors in this research also described post-treatment burdens including lingering anxiety, mental fogs, or dealing with the encumberment of a colostomy bag.

Participants shared that for someone diagnosed and cured in their 30s, life expectancy is still quite long, leaving YOCC survivors to deal with side effects for decades. Because of this longevity, side effects and persistent decisions about disclosures can leave the survivor physically and emotionally drained over time. Christina explained it this way:

> In the beginning, I used to share things with my family but then I noticed that it was such an emotional rollercoaster that I would tell my parents one day, my blood work looks great and then I would get a phone call about a scan that didn't look good a week later. Like I told my mom that the other day and she said, that's what you said 23 months ago, that doesn't mean anything. So, I think it's like when they shut you down like that, then you just kind of keep stuff to yourself because it changes so much, it's hard for people to keep up with, to understand.

Tami relayed a comment her teenage daughter shared with her after she called her daughter after a scan. As Petronio (2002) explains, it can be difficult for inferential confidantes to listen to disclosures, particularly when they are continual. Tamishared,

"When I had my MRI, my daughter was like mom, stop calling me. I'm on vacation, I don't want to think about it." It was difficult for participants to establish a balance between disclosing what was going on with their health but also not overwhelming others with continual disclosures.

For some participants, treatment can be required for years, if not for life. For patients whose maintenance treatment is their new normal to stay alive, side effects from treatment will never cease. In this research, such participants explained that interminable treatment can be a relentless challenge, because such treatment affects personal and professional relationships, especially for those YOCC survivors who are dating, newly ensconced in a relationship, or raising young children. Previous research supports that the side effects from cancer treatments have a negative impact on a person's quality of life (Lu et al., 2018; Sodergren et al., 2019: Soveri et al., 2019). Participants reported the difficulty of living with YOCC treatments and its effects while also trying to maintain a somewhat "normal" life.

A young mom, Marlo, discussed the hardship of taking care of her only child after her surgery. She explained:

> I couldn't take care of my child. All I could do was watch my husband take care of him. And then it's very painful to not be the mom that I was, because before I was just, like, all over it. I had given him all of his baths from the time he was born. Until the time he was 18 months. Like I just loved it. His wardrobe was color coded, all of that. But after the triple surgery, it just totally took a turn. I couldn't play with him.

Similarly, Christina simply stated, "I'm trying to save my life and be a mom." The challenge of balancing life after YOCC cancer treatments and maintaining a quality of life was evident in participant answers.

Chapter Summary

This chapter detailed the results of interviews with YOCC patients and survivors. Analysis revealed four themes considered catalyst criteria as each theme triggered new and different disclosure considerations: disclosure of symptoms, disclosure of diagnosis and treatment plan, disclosure during treatment, and disclosure of post-treatment effects.

The first theme identified during the analysis process was in regard to the disclosure of symptoms. The decision of whether to disclose their symptoms was important to the participants because that confidant became a shared owner of the health information (Petronio, 2002). Participants indicated that they either disclosed symptoms to a healthcare provider, to a friend or family member, or they did not disclose their symptoms.

It is significant that participants reported frustration when they disclosed symptoms to a health care provider, but the symptoms were downplayed, dismissed, or attributed to something else. This frustration was particularly noticeable with participants who were Black and were concerned that their race could have negatively influenced how seriously their symptoms were taken. Compounding this frustration was the eventual YOCC diagnosis that could have been diagnosed sooner. Previous research notes that patient narratives can bridge the understanding between patient and provider (Hall & Powell, 2011; Lee et al.2016Pallai & Tran, 2019). This was not seen in participant interview results. In some cases, participants were given a terminal diagnosis because of a lack of understanding between patient and provider. In some cases, this terminal diagnosis could have been prevented as YOCC is treatable and curable when diagnosed in the early stages.

The second theme was the disclosure of the initial diagnosis and treatment plan. Similar, to the first theme, the decision to disclose was amplified because the confidant became a co-owner of the information (Petronio, 2002). Participants also discussed the importance of the timing of the disclosure.. Specifically, participants noted that having as much information as possible about the health concern was important, as well as having the news delivered in person, if possible. Comparable to previous research, there was a conscious effort on the part of the participants to make the cancer diagnosis disclosure as easy as possible for the other person (Hagedoorn et al., 2011; Venetis et al., 2014).

The third theme identified was disclosure during treatment. The tension described by the participants regarding whether to disclose what they were experiencing was noted by almost all participants. Risks and benefits of disclosure were weighed by participants. It is notable that participants considered the concept of similarity as important in deciding whether to disclose to others (Derlegaet al., 2008; Romo et al., 2016). The need for similarity led participants to seek out fellow YOCC patients/survivors on social media support groups to find others who were experiencing or had experienced similar things.

The most important finding for the third theme is that participants disclosed information about YOCC to help others. This was nearly unanimous in participant responses and supported by Charmaz (2006), who posits that patient disclosure can help not only others, but the patient themself. Petronio (2002) notes that self-clarification can occur through disclosure helping the participant to understand their experience, as well. Yet, it is important to note that comparable to the findings in theme one about why participants did not disclose symptoms, participants stated that protecting others was a

reason for not disclosing what they were experiencing. For these participants, disclosure was not worth upsetting the other person (Venetis et al., 2014).

The final identified theme was the disclosure of post-treatment/long term side effects. Participants explained that the effects of YOCC are chronic and are often felt every day. For participants diagnosed in their 20s or 30s, physical, mental, and emotional side effects will be dealt with for decades. This finding is supported by the previous research of CRC patients by Mohler et al. (2008) and Van Veeneet al. (2020). In this research, participants noted that the extended length of time involved was exhausting for self and others, and this was considered when deciding whether to disclose ongoing experiences. Petronio (2002) relays that continual disclosures also take their toll on inferential confidantes.

Now that issues related to disclosure in YOCC have been identified, the next chapter will explore the implications of the findings. There is a significant amount of research applying CPM theory to health issues, but there are gaps in the research when it comes to YOCC addressed by the current research.

CHAPTER 5: Discussion, Implications, and Conclusion

In this final chapter, implications of the research will be discussed based on the previous results described in Chapter 4. Connecting the implications to the results is essential to both show how the study can contribute to the body of health communication literature and provide practical applications for those affiliated with the medical community including providers, patients, and caregivers. Implications of this research are particularly germane to YOCC patients and/or survivors, as previous research has not focused on psychosocial effects in this context. Two research questions were posed for this study:

RQ1: What influences YOCC patients and survivors to communicate about their YOCC diagnosis and treatment?

RQ2: What are the privacy issues regarding YOCC patients and/or survivors, especially those issues that influence the way they disclose or conceal private information to others?

Interview results support the concept that identified themes can be considered catalyst criteria that require participants to evaluate their decision-making criteria as each catalyst presented (Petronio, 2013; Petronio, 2018). At the beginning of the experience, patients tended to disclose only their symptoms. Next, patients disclosed their diagnosis and treatment plan. Then, participants explained that they disclosed the elements of their treatment journey. Finally, they divulged post-treatment issues. These catalysts are integrated into the discussion below and have implications for health communication scholars, providers in the medical community, as well as patients and caregivers.

Implications

Based on participant interview analysis, YOCC patients and survivors identified specific privacy issues that influenced the way they disclosed or concealed information regarding their medical situation. The results of this analysis indicated that there are three primary audiences for research implications:

1. Communication scholars
2. Healthcare providers and medical educators
3. Patients/survivors and caregivers

These three groups were selected based on who could benefit from the implications and potentially contribute more to research on YOCC psycho-social issues. The application of implication categories is rooted in the identified themes from participant interviews. These themes provide the base for how this research can be utilized.

Communication Scholars

In this section, I will discuss implications of findings that could be of interest to communication scholars. The first implication is that disclosures are influenced by previous experiences. This implication could affect other disclosure issues such as who health issues are disclosed to and possible barriers to disclosure. A final concept that could be of interest to scholars is that disclosure by participants is done to help others.

The results of this research suggest that previous experience with a person influences choices regarding disclosure. Specifically, if the person is supportive during a disclosure, then an individual is likely to disclose to that person again. In this research,

disclosures that occurred before the diagnosis affected how participants disclosed and to whom they disclosed their YOCC diagnosis. If there was a negative experience with disclosure before the diagnosis, the participants relayed that this affected their decision on whom to disclose to as well as when and where. This implication could interest communication scholars as it gives insight into how YOCC patients/survivors make the decision to disclose information about their health situation. The finding contributes to existing CPM literature about the disclosure process (Petronio, 2002). It also supports research done by Grant et al. (2011) where a participant relayed an experience regarding a negative reaction to a disclosure about a colostomy bag and the participant was reluctant to ever disclose again.

Previous experience with disclosure was also seen with disclosures during the participants' cancer journey. If the disclosure of diagnosis went well, the participant would continue to disclose. If the disclosure did not go well, then the participant recalibrated how they communicated with the person to whom the information was disclosed, including limiting what information was disclosed.

Previous experience with disclosure changed not only the content but also the context. Participants reported that if using social media to disclose their diagnosis was effective, they would continue to use this channel of communication to disclose information about treatment and other issues associated with the YOCC journey. While I was unable to identify research specific to YOCC disclosures on social media, research regarding online disclosures about mental health issues reported when disclosures were met with positive feedback, participants were able to build supportive communities where disclosures continued (Ernala et al., 2018; Saha & Sharma, 2020). In addition to social

media being used as a vehicle to build a support system, Attai et al., (2015) reported that respondents who received support from others regarding their breast cancer journey disclosures on Twitter saw a decrease in anxiety.

If social media brought unwanted stress resulting in turbulence for the participant during the disclosure of diagnosis, then this channel was eliminated altogether, or the amount of information shared was adjusted. Lazard et al., (2021) reported that while social media provided a positive avenue for connecting young adults with cancer, social media was not a useful way for cancer patients to connect with peers who were not part of the cancer community. This was due to the negative responses regarding disclosures about their cancer journey. The ways in which previous disclosure experience affects future health disclosures is important for communication scholars to explore further. These factors could have implications for patients in the decision-making process as to whether to disclose information about their symptoms, treatment, or related issues.

This finding could also lead to understanding other concepts such as who symptoms are disclosed to and barriers to disclosure. In this research, if a person had a negative experience after they disclosed information to another person, that experience influenced subsequent disclosure decisions with that person. The participants learned from their previous disclosure experience.

This finding is especially important because participants reported that with YOCC, there is a potential that disclosures about their journey could last decades. If a person is diagnosed and cured in their 30s, they could still be experiencing side effects of treatment for 50 years. It can be tiring to continually disclose to others about the cancer

journey; thus, it is important to find people who are receptive to the repeated disclosures over the years.

The importance of previous experience extended to the channel of disclosure. If a participant had a negative experience with an aspect of their health journey being disclosed on Facebook (e.g., their diagnosis), then this experience influenced how they disclosed information about treatment, for example. For example, participants reported choosing another social media channel, such as Caring Bridge, or steering away from social media platforms all together.

Conversely, it can be argued that a positive experience with disclosure would lead to a patient disclosing to someone again about their health care experience. In this research, if a participant received a supportive response to a disclosure, then the patient was likely to disclose to that person again. This also extended to positive experiences with the channel of disclosure. Participants indicated that the ease of disclosing over Facebook led them to continue to disclose there about their YOCC journey. This supports research done by Sapp et al. (2003) and Derlegaet al. (2008) where it was found that positive disclosures over social media were helpful for the person revealing personal information. Disclosures met with positive feedback allowed the person to feel better about their situation.

Barriers to disclosure such as a previous negative experience with disclosure are important to examine by communication scholars, as are other barriers such as the impact of COVID-19 on the disclosure process. For example, participants indicated that COVID-19 affected how they disclosed their diagnosis as well as other aspects of their YOCC journey. Participants reported the difficulty of being told they had cancer while they were

alone because others were not allowed in appointments, as well as the pressure of telling others their diagnosis over the phone when the news would normally be delivered in person. This finding contributes to existing literature about communication during the COVID-19 pandemic as it shows the impact the pandemic had on how people communicate. This finding could also springboard to more research about COVID-19 as a barrier to disclosure through the lens of CPM theory.

The nextconcept that is of interest to communication scholars is that the most important reason identified for disclosure was to help others. YOCC patients and survivors see themselves as experts. Their knowledge is often transmitted via social media such as support groups on Facebook. Because participants reported the importance of disclosure on social media to help others, this concept is amplified. Disclosure to help others, particularly on social media, could be of interest to communication scholars as it contributes to the reason why people disclose. For example, future research could explore the question of why YOCC patients and survivors look to social media for information regarding their disease.

It is important to recognize that this is the first time YOCC has been examined through the lens of CPM. This initial evaluation has produced theoretical implications that are of interest to communication scholars that extend as well as contrast CPM.

The first implication adds to the understanding of catalyst criteria affecting the communication of YOCC patients and/or survivors regarding their diagnosis and treatment. Petronio (2013) posits that catalyst criteria trigger privacy rule changes. My research supports that catalyst criteria such as a YOCC diagnosis can impact how a person discloses private information. This research also extends this concept as catalyst

criteria were identified by participants as affecting their decision to disclose throughout the YOCC journey. When a new catalyst criterion presented itself, participants indicated that the criterion triggered a new and different set of decision-making issues.

The next theoretical implication concerns violations of boundary rules. Petronio (2002) states that when a confidant violates a boundary rule, boundaries are then renegotiated by the original owner of the private information. I found that the privacy rules were not renegotiated. Participants indicated that if a boundary rule was violated, communication ended. There was no renegotiation, communication ended about that particular topic. This is important theoretically but also practically as participants indicated that they still needed to talk about these topics. Participants shared that they looked elsewhere to talk about issues designating social media support groups as the primary alternative.

Another theoretical implication extends CPM work by Venetis et al. (2012) regarding the uniqueness of disclosing health information versus other personal information. Results showed "why" participants disclosed to be significant. Nearly all participants shared that the motivation to disclose information about their YOCC journey was to help others.

The next theoretical implication contrasts previous research of El Din et al. (2020) where results indicated that patients do not disclose symptoms indicative of YOCC. Participants in this study indicated that they continuously disclosed their symptoms to healthcare providers and these were dismissed or attributed to other health issues. Not only is this a theoretical implication, but a practical one as well since healthcare providers

should be aware of this finding as it could impact their communication practices with patients.

Healthcare Providers and Medical Educators

The second group affected by the implications of this research is healthcare providers and medical educators. Providers can include physicians, physician assistants, nurse practitioners, and others. Future research could distinguish the impact on each of these groups individually. Medical educators are considered those that train and educate the above-mentioned groups. This section will discuss how the following implications are significant for those groups: misdiagnosis of symptoms, minimizing symptoms, patient frustration, and the influence of social media.

According to participant interviews, YOCC symptoms were often disclosed to a health care provider. Blood in the stool, difficulty using the restroom, and abdominal pain are examples of symptoms reported to providers. Unfortunately, many of these symptoms were attributed to other health issues such as irritable bowel syndrome, hemorrhoids, or even postpartum. Some symptoms were even attributed to emotional concerns such as a new mom "being dramatic."

In addition to symptoms being overlooked or attributed to another health issue, symptoms were often downplayed, making the ultimate diagnosis more surprising and upsetting. Being told by a healthcare provider that one is "too young" for colon cancer or that the symptoms were "nothing to be worried about" only make the YOCC diagnosis more shocking because participants reported that their guards were down. They did not believe that anything was seriously wrong because the healthcare provider minimized the situation.

Attribution of symptoms to other conditions and minimizing symptoms resulted in frustration for the participant. Often, the participants went numerous times to the healthcare provider, in discomfort and pain, only to be sent home with no answers regarding their condition. Participants believed they were supposed to do—visiting a provider and disclosing their symptoms—only to have their concerns dismissed, minimized, or attributed to other illnesses. To add to the frustration, participants told stories of this being done over the course of months and years.

Even more concerning than the patient's frustration is that the delay in diagnosis due to the attribution of symptoms to other conditions can result in a later stage YOCC diagnosis. Thereshould beconcern byhealthcare providers and medical educators as YOCC is treatable and curable if caught in the early stages. This is supported and contrasted by a systematic review where the focus was on the reasoning behind the delay in colorectal cancer delay in diagnosis (Mitchell et al., 2008).This study supports the idea that patients need to continue to disclose their symptoms to their providerBut this research found that patients continually go back to providers disclosing symptoms that are attributable to YOCC and providers did not consider this diagnosis. This finding contrasts that of Mitchell et al. (2008) that delays in diagnosis were attributed to the patients failure to recognize and disclose possible YOCC symptoms to providers. Previous research puts the onus on the patient (Swift, 2020) but this research finds that patients are disclosing information and the provider is not diagnosing. Providers need to be aware of YOCC symptoms and not dismiss them or attribute them to other health issues.

Further, patient frustration can lead to further disclosure issues. When patients disclose symptoms and these symptoms are dismissed, they may be less likely to disclose symptoms in the future. They also may be less likely to trust their provider with any health concern. Quality of care could be directly affected.

Frustration based on previous care contributes to the fact that the main reason patients and survivors disclose about their YOCC journey is to help others. Ray (1996) relayed those survivors of incest disclosed their experience to help other incest survivors. Similarly, based on their lived experiences, participants in this research saw themselves as the experts in YOCC and disclosed their experiences in order to help others affected by YOCC.

They also expressed frustration that providers did not provide other information to deal with side effects such as sexual dysfunction. Because of the lack of information given to them by providers, participants said they felt compelled to disclose their experiences to others. Sodergrenet al. (2019) found that colorectal cancer patients had unmet needs that affected their quality of life. Looking for answers, participants in this study relayed that they looked to social media to find answers about their colorectal cancer journey. This research supports the idea that health care professions are not meeting the needs of their patients.

Social media platforms were identified as an important channel to communicate with fellow patients and survivors about the YOCC journey. Participants stated that the majority of their disclosures to help other patients and survivors are done on social media such as Facebook. Social media platforms were seen as both positive and negative places for disclosures.

Participants stated that social media platforms allowed them to disclose to a large group of people without the stress of repeating the same information over and over again. Platforms also allowed participants to make connections with fellow patients and survivors who were looking for information about YOCC. While these positive results were reported, there were also negative repercussions regarding disclosure on social media.

Participants reported adverse effects from disclosure on social media. While reaching a large number of people can be a positive, it can also be a negative if disclosures are seen by people that were not part of the intended audience. Participants reported turbulence and a lack of control over who saw what was disclosed about their YOCC journey. This was upsetting and caused participants to recalibrate what was disclosed over that medium.

Whether positive or negative, the importance of social media cannot be overlooked. It was brought up in nearly all participant interviews. Because of this, health care providers and medical educators should be aware of the importance of social media in the patient's life during their YOCC journey. Providers could pre-emptively address the positive and negative aspects of researching on social media. Patients would then know that their provider acknowledges their need for more information and discussions can openly take place about why the patient feels it necessary to reach out to social media. What is the patient not getting from the provider that leads them to turn to social media? How can the provider fulfill this need?

Social media can be influential due to disclosures from other patients and survivors. This information could conflict with information from health care providers

and affect overall quality of care. Future research could examine the accuracy of information learned on social media and how it affects YOCC patients and survivors and the decisions they make about care.

In addition to social media, healthcare providers and medical educators could be interested in the frustration exhibited by participants when their symptoms were attributed to other health issues or minimized. Because empathy is an integral emotion in treating patients, the feelings of patients are important to identify. By recognizing the frustration of patients, healthcare providers can better empathize with their patients and medical educators can utilize the information in training future physicians.

Patients/Survivors and Caregivers

The final group that is affected by the implications of this research is that of patients/survivors and caregivers. This section will consist of a discussion on the importance of disclosure, the effects of disclosure, the personal impact of disclosure, and importance of social media.

For the purposes of this exploratory research, patients currently undergoing treatment for YOCC and survivors who are not receiving treatment and considered NED (no evidence of disease) were grouped into the same category. Future research should examine these groups separately to determine the similarities and differences between them. Caregivers should also be studied individually. In fact, I was contacted by many caregivers hoping that I would hear their stories at some point. Their experiences and point of view could paint a more holistic picture of the YOCC experience.

The first critical concept for patients/survivors and caregivers is to establish the importance of disclosure. Whether the disclosure is about symptoms associated with

YOCC or side effects as the result of treatment, the decision to disclose should not be taken lightly. Interview results indicated that participants considered the credibility of the person when deciding whether to disclose information about their symptoms or issues related to their cancer journey. They also considered if the person would be strong enough to handle the disclosed information. For example, participants described concerns such as "are they able to emotionally handle a disclosure of a cancer diagnosis or would this cause them to become emotionally unstable?" This affects the patient because if they are not able to disclose the diagnosis, then it can cause an increase in stress to an already stressful situation. This is not healthy for the YOCC patient.

Due to the amount of thought put into selecting a person to whom to disclose information, caregivers should be aware of the importance of the disclosure and the associated information. The person to whom the information is disclosed is not only a support system for the patient/survivor but can be tasked with disseminating and managing information about the patient/survivor. Participants reported an awareness of the weight this can put on a person, especially when disclosures occur over a period of time.

Patients can be undergoing treatment for years and YOCC survivors can live decades with the side effects of treatment. While this is a credit to medical science and talented healthcare providers, it poses a challenge for patients and caregivers who must deal with and live with the repercussions of treatment. Side effects are not only difficult to live with as a patient/survivor but can also be difficult for a caregiver to watch or continually hear about. This difficulty is not lost on the patient/survivor. There are effects to the disclosure including tiring of disclosure, guilt, and turbulence.

The continual disclosure of information regarding a patient/survivor's YOCC journey can produce negative repercussions. Participants indicated that it is not only tiring to continually disclose about a YOCC diagnosis, but it can become exhausting to disclose side effects for years or even decades. Disclosing over social media allows for disclosure all at once, but as mentioned above, can have issues regarding lack of control. Yet, disclosing day after day for months or even years can be overwhelming for the patient. Part of the emotion is the guilt of knowing how difficult disclosure can be for their caregivers.

Participants discussed the guilt they feel when disclosing information about their YOCC journey. Continually disclosing about side effects can make the caregiver feel bad as there is often nothing to be done to help the patient/survivor. The patient/survivor knows this and feels guilty about disclosing because it only makes the caregiver feel bad. Derlega et al. (2008) also found that there is a hesitancy to disclose personal information when it could upset the other person resulting in turbulence in the relationship. This research supports the notion that a person weighs how the disclosure will impact the person to whom the information is disclosed. There is tension that results because the person must weigh the pros and cons of the disclosure.

This tension creates turbulence for the patient/survivor. Participants reported doing whatever possible to avoid such turbulence, including not disclosing to a caregiver. When fighting for your life, participants noted, it was too much to also have guilt and worry about upsetting another person. It was easier to keep information to themselves. Multiple participants reported that their focus was making things easier on themselves and avoiding turbulence was a way to do this. This is important for caregivers to know as

patients/survivors may not be disclosing everything because they have guilt and want to avoid turbulence. Patients/survivors also need to be aware that there are other means of support where they can disclose to if they want to avoid burdening caregivers.

Multiple patients/survivors reported the importance of social media support groups as a way to share their own experiences. Participants indicated that communicating with those who were also experiencing or had experienced YOCC was beneficial. This finding supports the concept of similarity in disclosure (Petronio, 2002). It is essential that caregivers understand the importance of patients/survivors talking to others with similar lived experiences so that they can effectively and compassionately support the patient/survivor.

Disclosure about YOCC is difficult for the patient/survivor. Until this point, the discussion has surrounded disclosure to those already in the life of the patient/survivor, such as a spouse. But with YOCC patients/survivors being in their 20s and 30s, not all participants were married or in a relationship. Participants indicated that it is difficult to disclose to a potential partner about their YOCC status. When does disclosure about YOCC happen? The first date? The second? Future research should explore how YOCC patients/survivors navigate the dating and relationship process. Social media support groups were also identified as an important channel for disclosure by participants. Future research should investigate why YOCC patients/survivors disclose to these groups as well as implications as a result of these disclosures.

Limitations

This section discusses identified limitations and what I did to minimize them during various stages of the research process. Limitations include the nature of participants and researcher bias.

Participants

Participants in this study were affiliated with the Colorectal Cancer Alliance. My relationship with the CCA allowed me access to a large number of potential YOCC patients and survivors. However, convenience sampling (Morse, 2007) also serves as a limitation in that there are many other YOCC patients and survivors that are not affiliated with this organization. It is quite possible that similar types of people reach out to support groups as well as answer calls for participant volunteers.

Another limitation is that the people who responded to the call for participants were probably more likely to share information than those who did not respond. For example, one of the major themes was that participants disclosed in order to help others. This is perhaps not surprising coming from this group, as they responded to help me. Would this theme still be there with other YOCC patients and survivors who did not feel called to respond to the post about participating in research?

Finally, after initial interviews were completed, it was evident that there was a lack of participants from marginalized groups. It can be argued that this is a result of convenience sampling. I interviewed those who responded to the call for participants. In order to gain insight into this demographic, I needed to be more proactive. I reached out individually to those representing marginalized communities in CCA Facebook groups. I sent direct messages to them via Facebook messenger and asked if they would be

interested in participating in my research. While I was able to reach more participants this way, it is obviously a limitation as these participants were recruited directly by me, which is different from how the other participants were recruited. Because these participants did not reach out to me initially during the recruitment process, it is possible that they might not be as forthcoming about their YOCC journey as those that contacted me when the initial call for participants was posted. For example, multiple participants who responded initially stated how excited they were to share their YOCC journey with me and wanted to schedule the interview as soon as possible. When I recruited participants from marginalized groups, there was more initial hesitation. I answered many questions about my research, the institution which I was affiliated with and myself in general. In fact, one participant stated, "Exactly who are you?"

Researcher Bias

As with every researcher, I bring my own lived experiences to this study. In this case, I am a Stage III YOCC survivor. This topic is quite personal to me as I share many experiences with the participants including the challenges of disclosing information about my cancer journey and living with the chronic side effects of YOCC treatment. Because of this, I apply the concept of crystallization posited by Ellingson (2009) that allows reflexivity by the researcher to embrace their own experiences during the research process. As stated, one of the principles of crystallization includes a degree of "reflexive consideration of the researcher's self and roles in the process of research design data collection and representation" (p.10). This section focuses on reflexivity during the interview process, transcript analysis, and the recruitment process

First, I disclosed to participants in the initial email that I was a fellow YOCC survivor. This was also reiterated at the beginning of each interview. Gentles et al. (2014) stress the importance of reflexivity in the research process. I believe that establishing this connection was a good way to gain the confidence of the participants. I could empathize with their experiences because I had shared many of them such as the shock of a YOCC diagnosis, the horrors of chemotherapy and radiation, and the day-to-day struggles of treatment side effects that will last as long as I am alive.

While this shared experience allowed me to gain what I believe to be rich data because they trusted me, I was also challenged to not become emotionally vested during the interview process and the resulting analysis. Further, I had to make sure that the themes emerged from participant interviews, not from my own experiences.

It was challenging at times to not become emotional during the interview. I found that staying true to my interview script as much as possible allowed me to focus on the content of the interview and not the emotion. While I asked follow-up questions and probes, when necessary, I found that staying close to my initial interview guide allowed me to make sure that the participants told their story without me guiding them from my own experiences. Following the guide also allowed me to focus on ensuring that the same questions were asked during each interview regardless of my own emotion.

Another challenge with being a YOCC survivor was during the analysis process (Cohen & Crabtree, 2008). I wanted to ensure that the themes emerged from participant interviews and not my own YOCC experiences. Following the thematic analysis process (Braun & Clark, 2012) helped me to stay focused on the participants' experiences and not my own. I began with an inductive approach where codes emerged from the transcripts.

These codes resembled the words of the participants (Saldana, 2015). Once this approach was completed, I used a deductive approach where the codes resembled CPM constructs (Saldana, 2015). Utilizing the inductive and deductive approaches helped to ensure that my own experiences did not drive the research results yet through crystallization, I was able to connect participant experiences. My journey as a YOCC survivor helped me make connections that might not be made if I did not have this lived experience

In addition to making connections with the data, being a YOCC survivor assisted in the recruitment of participants from underrepresented communities. When it became clear that there was a lack of participants from this demographic, I made a concerted effort to reach out to potential participants and when met with hesitation about their participation, I shared that I was a YOCC survivor. This disclosure seemed to ease the tension of the potential participant speaking to me since we had a shared experience.

Directions for Future Research

This study was exploratory in nature with the goal of learning more about psychosocial issues facing YOCC patients and survivors. Merriam et al. (2016) posit that with a study such as this there are many opportunities for future research. At the time of this writing, there is no significant research on psychosocial issues focusing on YOCC patients and/or survivors. Future research is an opportunity to launch more vigorous studies into concepts identified here (Hallingberget al., 2018). Enhancing this opportunity is a growing need for more research into the YOCC community due to the unfortunate increase in diagnosis rates. The following areas

have been identified as potential topics for future research:

1. Impact of COVID-19

2. Patient desire to help others
3. Social media's influence on disclosure
4. How patient disclosure could affect provider training
5. Dating with YOCC
6. More specific demographic research
7. Patient Credibility

Impact of COVID-19

The first area that has been identified as a potential research topic is the impact of COVID-19 on disclosure. Participant interviews were conducted during the COVID-19 pandemic. While this topic was not specifically addressed in the interview guide, as it did not exist when the guide was developed, it was evident that it had a significant effect on participants who were diagnosed during the pandemic and who were receiving treatment during the pandemic.

Participants that were diagnosed with YOCC noted the difficulty of hearing the news alone. They relayed that COVID-19 protocols restricted who could be in the room with them during office visits or during procedures such as colonoscopies. Participants stated that it was overwhelming to not only hear the diagnosis, but to process the information and then have to tell someone else such as their spouse.

It was also reported that participants had to disclose their diagnosis over the phone or zoom when they would have normally delivered the news in person. Participants reported struggling with being forced to deliver their cancer diagnosis through another channel rather than in person. They not only felt badly for themselves but also for the person who had to hear the information.

Finally, because of hospital restrictions, participants reported that they often had to undergo treatments alone. Usually, a visitor is allowed to sit with a patient during a chemotherapy treatment or while a patient is waiting to be taken back for a colonoscopy. Because of COVID-19, the participants reported being alone and it was very difficult.

Future research could explore these concepts as they have not been previously identified. Obviously, COVID-19 is a relatively new health concern. Unfortunately, there could very well be another health issue that causes similar issues with patients being isolated during diagnosis and treatment as well as being challenged with disclosing in person. These ideas could also be looked at from a historical perspective to see how previous public health concerns were handled in comparison.

Participant desire to help others

An important theme that emerged during the analysis of interviews was the participants' desire to help others. It was nearly unanimous that the reason for disclosure was to help others. Whether this involved bringing awareness to the YOCC cause, convincing others to get a colonoscopy, or to supporting current YOCC patients/survivors, it was evident that participants were motivated to help others.

In the case of bringing awareness to the YOCC cause, participants reported feeling a responsibility to share their stories in order to let others know about colorectal cancer. Participants were willing to disclose their symptoms, their diagnosis (or misdiagnosis), and their treatment journey. This disclosure was done to bring awareness to YOCC and to dispel the traditional stereotype that colorectal cancer is only diagnosed in those over 50 years of age.

In addition to bringing awareness of YOCC, participants stated that they disclosed to convince others to get a colonoscopy. Participants noted that the hesitancy of friends and family regarding colonoscopies. Participants disclosed information about their cancer journey to persuade others to undergo the procedure versus running the risk of being diagnosed with colorectal cancer.

Finally, as noted in the limitations, all participants were associated with the Colorectal Cancer Alliance (CCA) and active on CCA message boards and support groups. This is significant because participants were not only motivated to help those that have not been diagnosed with YOCC, but to help current patients/survivors navigate their cancer journeys, as well. Participants noted that they wanted to share their stories with others so that they would not have to go through similar negative experiences. They also felt a responsibility to share what helped them through treatment. Participants viewed themselves as experts and want to share their expertise to help other patients/survivors.

The desire to disclose information to help others is worth further exploration. Some participants are Stage IV, fighting for their lives, yet they still take time to share their stories and experiences to help others. As YOCC is still a relatively unexplored disease, do patients/survivors feel a responsibility to disclose because limited information is available?

Social media's influence on disclosure

An overarching theme throughout participant interviews was the impact of social media on disclosure. Participants noted that social media played a role in how they disclosed their diagnosis and treatment plan and how they made connections with other

patients/survivors, but there was no unanimity regarding whether social media was seen as a positive or negative.

Participants reported positive reasons for disclosing information about their diagnosis and treatment on social media such as Facebook or CaringBridge. Social media allows patients to reach a large number of people with one post, and participants struggled with disclosing a diagnosis repeatedly. It became exhausting for them to relay the same information repeatedly and disclosing the diagnosis on social media allowed them to share the news a single time.

While reaching a large number of people at one time was seen as a positive for some participants, others noted that reaching a larger audience was not always a desirable outcome. Participants relayed that a negative aspect is that social media groups can easily grow to include people that the patient may not want included. This caused frustration for participants.

Participants reported that they also used social media to make connections with other patients/survivors. These connections were identified as social in nature and also a way to gain more information about YOCC. Facebook support groups centered around colorectal cancer and YOCC are filled with people sharing their experiences with each other. As a member of many of these groups, I see firsthand the interactions between group members.

It is common knowledge that social media is an integral part of modern life. Thus, it is no surprise that social media was mentioned in nearly all participant interviews. Examining how social media is used by YOCC patients/survivors could be an interesting concept for future research. I also think it is important to understand why

patients/survivors utilize social media. For example, do they look for advice on social media support groups because they feel they don't get enough information from health care providers? Should healthcare providers be concerned that YOCC patients/survivors look to social media for input on their treatment? This question will be further addressed in the next section.

How patient disclosure could affect provider training

Some participants shared their frustrations about disclosing symptoms of YOCC to healthcare providers only to have these symptoms minimized, dismissed, or misdiagnosed. It is easy to understand why a patient would be angry that they disclosed YOCC symptoms, sometimes repeatedly, to providers only to eventually receive a late stage YOCC diagnosis that could have been at an earlier stage if disclosed symptoms had been addressed differently.

Future research should maintain a focus on effective communication between patient and provider. Patients must continue to be their own best advocates and providers must continue to listen to the concerns of their patients. Exploring how to best listen to patient concerns and symptom disclosure is essential. Further, it was identified that participants reach out to other participants/survivors to learn about their YOCC diagnosis and treatment. Does there need to be more training on YOCC in general so providers can provide this information and not Facebook support groups? If not provider training, then who should provide this support?

Dating with YOCC

Dating is hard. YOCC is hard. Participants explained that the challenges of this combination were hard to overcome. Two issues most identified were deciding when to

disclose a YOCC diagnosis to a potential dating partner and the embarrassment of YOCC side effects affecting romantic relationships.

Participants attempting to date after being diagnosed with YOCC shared the difficulties in deciding when to disclose their diagnosis with a potential dating partner. Some of these participants were in the 20s and early 30s and found it difficult to navigate the tension of wanting to be in a relationship but not knowing the best way to share their YOCC diagnosis. Guilt was also associated with this as participants reported that they often wondered if they should even bring another person into a relationship knowing that they might not live that long.

Another concern stated by participants was the embarrassment of side effects resulting from YOCC. Side effects reported by participants are not pleasant and can cause pause when trying to begin a relationship with someone, especially in a romantic setting. Participants who were in long-term relationships at the time of diagnosis reported struggling with YOCC side effects in romantic settings. These individuals were already in loving relationships. Trying to begin a relationship with the embarrassing side effects of YOCC can prove even more difficult.

Exploring the challenges of dating after a YOCC diagnosis is warranted. While this study identified some challenges and provided initial insight into the difficulties of dating, more research is needed. This research could contribute to the quality of life for YOCC patients/survivors.

More specific demographic research

More specific demographic research is needed. In this study, patients and survivors were studied together. The age range was from 21-49 years. Men and women

were both included, as well. In addition, there were some patients that had colostomy bags, some that did not, and even some that had the colostomy bags reversed. Each of the above-mentioned groups has the potential to have their own issues. For example, a person with a colostomy bag faces different issues such as leaking and smell than a person without a colostomy bag. Each demographic group should be studied individually so strategies can be developed to help the quality of life of each type of individual.

Patient Credibility

Finally, examination is needed into the lack of patient credibility and the impact this has on the diagnosis process. If patients are disclosing symptoms attributable to a YOCC diagnosis, why are they not believed? Participants indicated that they continually went back to providers with complaints yet shared that their symptoms were being dismissed or attributed to another health issue. In addition to patient credibility, it is important to look at how this impacts the diagnosis process. Because the patients are not seen as credible, this could impact a YOCC diagnosis.

Conclusion

This chapter examined the implications of the study results. Implications were organized into how they could affect communication scholars, healthcare providers and medical educators, and patients/survivors and caregivers. The chapter also included limitations of the study and indicated areas that could be of interest for future research. As this was an exploratory study, there are many result areas that could serve as springboards for more in-depth examination.

Communication scholars could be interested in this work due to the identification of issues related to disclosure. These issues indicate that great thought goes into the

decision of whether or not to disclose. This supports the work done by Petronio (2002) where disclosures are influenced by previous experiences. Based on previous experiences, a person may adjust to whom information is disclosed and the channel of disclosure. If a negative experience happened with a previous disclosure to a particular person, for example, the person disclosing the information may adjust a future disclosure to the person. Petronio (2002) refers to this as recalibration. The channel could get recalibrated, as well. If a person did not have a good experience disclosing a health issue on Facebook due to the number of people seeing the post, they could recalibrate disclosing a future health issue on social media by adjusting the settings or not disclosing on social media at all.

Possible barriers to disclosure of a health issue and the motivation of participants to disclose could be of interest to communication scholars, as well. The influence of COVID-19 on the disclosure process cannot be understated, especially for those diagnosed with YOCC during the pandemic. Participants indicated that being alone for their cancer diagnosis was upsetting and challenging as they had to delay disclosing their diagnosis and information surrounding it to others (such as a partner) who would normally be in the room. Participants were also forced to disclose news of their diagnosis over the phone to loved ones when they would normally do so in person. The channel of communication was affected.

Yet, even with barriers to disclosure such as COVID-19, participants were motivated to disclose in order to help others. Communication scholars should be aware that the motivation of patients and survivors to help others by sharing their experiences was uniform across all interviews. Could this serve as a persuasive tool?

Patients and caregivers are also affected by the implications of this study. Participants were extremely passionate about their stories as they shared the misdiagnosis of symptoms and the minimizing of symptoms disclosed to healthcare providers. Compounding the frustration of disclosing and then being misdiagnosed or minimized, several participants indicated that because this, their diagnosis was delayed. Some participants have died since giving their interview because of their late-stage diagnosis and limited treatment options.

Healthcare providers and medical educators could be interested in these findings, as well. Because there is always a motivation to improved quality of care for patients, the fact that YOCC patients identified issues such as misdiagnosis of symptoms and minimizing of symptoms as important, providers and educators should be aware. In addition, because the patients/survivors indicated the perceived lack of support for issues such for YOCC side effects such as sexual concerns, providers and educators could explore where YOCC patients and survivors could receive that support. It was identified that YOCC patients and survivors look to social media support groups to gain information. This could be concerning, as the people offering advice and support are not medical professionals

Appendix A

Sample Recruitment Letter

Dear __________,

My name is Tiffany Hecklinski and I am a PhD student in Health Communication at IUPUI doing dissertation research. I am also a Stage III young onset colorectal cancer survivor. This experience has led me to develop an interest in studying privacy issues surrounding young onset colorectal cancer patients and/or survivors (those diagnosed before the age of 50). With diagnosis of young onset colorectal cancer on the rise, it is important to explore issues that can potentially help patients and/or survivors deal with this disease and its aftermath. The purpose of this research is to identify privacy issues that are unique to this group of cancer patients and/or survivors.

The purpose of this letter is to ask you if you are interested in participating in a one-time interview. To participate in this study, you would be asked to consent to a phone interview that would last approximately 90 minutes. This interview would consist of questions regarding privacy issues specific to your experience with colorectal cancer. Please answer the questions to your comfort level. While I will know your name, all identifying information will be removed to protect your privacy. You will not be able to be identified. As I transcribe the recording, I will remove your identifying information. If it is okay with you, I might want to use direct quotes from you, but these would be deidentified. The recordings will then be deleted.

Further, if you are uncomfortable at any time, you do not have to answer questions. You can also ask for the interview to be concluded. You do not have to participate in this research and you have the right to terminate the interview at any time. This is completely voluntary and you may say no if you do not want this information used in the study. There is no expected risk to you for helping me with this study. There are no expected benefits, as well. You may also request to read the final research project.

If you are willing to participate in this study please respond to this email so that we may set up a time to talk. I appreciate your consideration and look forward to learning about your experiences.

Sincerely,

Tiffany Hecklinski

Appendix B

Interview Script

Thank you for taking time to talk with me today. I would like to tell you about my research on issues regarding young-onset colorectal cancer patients and/or survivors, what you can expect from our conversation, some information about the research process and then, if it is ok with you, I will go ahead and ask you some questions about your experiences with colorectal cancer.

Before we get started, I want confirm that you are 21-49 years of age and that you are a colorectal cancer patient or survivor.

So, let me begin by telling you about my research. I am collecting data for my dissertation which will focus on privacy issues for young onset colorectal cancer patients and survivors. I'm sure you know that the number of people affected by this disease is growing. The goal of my research is to contribute to the body of knowledge surrounding the psychosocial effects of this disease. Do you have any questions about the research?

As far as our conversation today, we are going to be discussing your diagnosis, your treatment, and the impact these issues have on privacy. Please answer the questions to your comfort level. While I will know your name, all identifying information will be removed to protect your privacy. You will not be able to be identified. As I transcribe the recording, I will remove your identifying information. If it is okay with you, I might want to use direct quotes from you, but these would be deidentified. I will be recording the interview but after it is transcribed and deidentified, the recordings will then be deleted. Do you have any questions so far?

If you are uncomfortable at any time during the interview, please let me know and we can stop. As mentioned above, I will be asking you questions about your cancer diagnosis and treatment. There are no physical risks to the interview, but if you become emotional or uncomfortable we can stop at any time. I anticipate this lasting around 90 minutes. Does this sound acceptable?

Interview Questions:

Do you mind telling me how you learned you were diagnosed with colorectal cancer?

-After learning about your diagnosis, who did you tell? Why?

-Who did you keep the information private from? Why?

-Did any of these decisions cause problems in your relational life? If so, how did you handle these problems?

While you were undergoing treatment, do you mind telling me about any side effects you experienced?

-Did you keep any of these side effects private from others?

-How did you keep this information private?

-Who did you keep it from? Why?

-Who did you choose to tell? Why?

-Did any of these decisions cause problems in your relational life? If so, how did you handle these problems?

Are there any other privacy concerns related to your diagnosis and treatment of colorectal cancer?

Appendix C

Definition of Terms

Colorectal Cancer: "Colorectal cancer is a cancer that starts in the colon or the rectum. These cancers can also be named colon cancer or rectal cancer, depending on where they start. Colon cancer and rectal cancer are often grouped together because they have many features in common." (American Cancer Society, para. 1)

Young onset- colorectal cancer (YOCC): According to Mauri et al. (2019), a consensus is needed on the definition (age range) of YOCC. It is commonly accepted that those diagnosed with colorectal cancer under 50 are considered to have YOCC, but as more diagnoses occur, there is a call for this group to be sectioned into more definitive age groups. Due to the increase in diagnoses at younger ages, some researchers argue for the identification of another group to address the unidentified, unique needs and concerns of adolescents and young adults. This group would encompass those 21 years of age and younger (Mauri et al, 2019). For the purpose of this research, participants are between 21 and 49 years of age.

Communication Privacy Management Theory (CPM theory): Developed by Petronio (2002), CPM theory offers a systematic way of examining the decision-making process through which people reveal and conceal information. The theory consists of five suppositions defined below.

Private Information: Information that one person owns, either personally or collectively, and chooses to reveal or to limit access to (Petronio, 2002).

Privacy Boundaries: The metaphorical lines that signify what is public information and what is private information and serve as a sign of who owns the information (Petronio, 2002).

Control and Ownership: Private information is owned and controlled by an individual. These terms are linked together because if a person owns private information, they want to be in control of disseminating that information (Petronio, 2002).

Rule-based Management Systems: These includes both personal and collective systems. A personal system is when the information is owned by a singular person. A collective system is characterized by information co-owned by more than one person (Petronio, 2002).

Privacy Management Dialectics: CPM theory is grounded in the dialectic tension of disclosure-privacy. It is important to recognize that the decision of whether to disclose or conceal private information is at the core of this theory (Petronio, 2002).

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Curriculum Vitae

Tiffany Marie Hecklinski

Professional Experience

Hecklinski Communications – Ann Arbor, MI
2012-Present

Independent Communication Specialist

Partnered with companies and individuals to provide professional instruction and mentoring in communication. Formulated and executed marketing strategies to grow client base. Analyzed and improved several key communication practices of University of Michigan Health System Urology Department. Coordinated with entire health system.

- Utilized Six Sigma exercise involving potential residents sitting back-to-back to recreate building made of Legos, testing verbal communication skills, ability to work in team environment, patience, and situational ownership. Exercise was cited as favorite during interview process.
- Managed interdisciplinary team in development of new paging system for nighttime on-call residents. Created and led team after identifying as critical need on hospital floor.
- Interviewed potential residents and created survey system to measure communication skills; led to project-identifying characteristics of past residents classified as “successful” to isolate themes and commonalities in applications.
- Presented on numerous communication topics during Grand Rounds and delivered need-specific presentations to groups within department.
- Served as advocate for patients undergoing colorectal cancer treatment. Assisted patients and families navigating issues such as treatment options, insurance, and hospice care decisions.
- Joined patients during appointments with providers to ensure full situational comprehension by patients and families.
- Worked with leadership team of JDRF (Michigan Chapter) to create and implement training session to identify potential donors; formulated communication strategy to encourage participation in fundraising events.

Indiana University-Purdue University Indianapolis (IUPUI) – Indianapolis, IN
2016-2020

Research Assistant (2018-2020)

Applied research theory, strategy, and technique to research projects of 3 tenured professors in Department of Communication. Performed qualitative research, developed themes, and coded data.

- Contributed research and data that served as a chapter in a book, paper under review for pain journal, and presentations at national healthcare and communication conferences.

Teaching Assistant (2016-2018)

Taught 2 sections of Basic Public Speaking course each semester. Observed and evaluated student performance in meeting course level objectives and student learning outcomes through assignments, projects, discussions, and examinations. Provided feedback to student inquiries in class, online, or during consultation office hours. Maintained records of course enrollment, attendance, student academic progress, course curriculum, and student learning outcomes.

- Member of Themed Learning Community team for Criminal Justice majors which integrated topics from students' major into public speaking curriculum. Selected to lead bi-weekly visits to Pendleton Maximum Security Correctional Facility for students to participate in Toastmasters program.

Indiana University School of Medicine – Terre Haute, IN | Indianapolis, IN
2016-2018

Adjunct Lecturer

Recruited to teach as co-instructor on Disease of Systems curriculum to 2nd year medical students, while concurrently serving in consulting role. Provided 1st year instruction on medical interview process and delivered strategies for communicating and building relationships with patients. Provided one-on-one coaching to medical students to aid in preparation for residency interviews. Taught students to build rapport with patients / families and navigate ethical decision-making processes. Helped students prepare for medical interview / standardized patients in simulation lab.

- Member of IUSM Curriculum Committee; researched, compiled, and delivered information in presentation to 20 members on curricula and subject matter incorporated into year 3 and 4 programming of other medical schools.
- Assisted faculty with transmission of curriculum from main campus.
- Co-instructed Foundations of Clinical Practice course with medical preceptor.
- Contributed as facilitator at two professional development seminars for Indiana University students in health care field.

Ball State University – Muncie, IN
2004-2014
Distance Education Instructor (2007-2014)

Engaged students via distance education, teaching multiple sessions each semester. Interacted with students and provided feedback through written communication.

- Developed online curriculum for communications courses such as Communication 201 (The Fundamentals of Public Speaking) and Communication 320 (Theories of Persuasion).

Director of the Basic Course (2008-2009)

Directed the program for Communication 210 course, taken by all students to fulfill university graduation requirement. Taught multiple sessions of weekly lecture, addressing 500+ students per lecture. Managed 20+ graduate assistants. Taught breakout sessions to ensure course consistency and adherence to university expectations. Created exams to ensure students met course / university objectives. Ensured course alignment with university core curriculum objects.

- Worked with university academic executive leadership team as largest course on campus.

Instructor (2004-2008)

Taught several courses that included Fundamentals of Public Speaking, Business and Professional Communication, Presentational Communication, Educational Communication – Public Speaking for Teachers, Theories of Persuasion, Argumentation and Debate, and Interviewing. Contributed as academic advisor. Applied interpersonal communication strategies to optimize engagement and content comprehension.

- Served as advisor for National Communication Association Student Club (COMM Club).

Education

PhD Health Communication (Minor in College Pedagogy)
Indiana University-Purdue University – Indianapolis, IN

- Dissertation research focus on identification and exploration of privacy concerns in young onset colorectal cancer patients and survivors.

MA, Speech Communication
University of Central Missouri – Warrensburg, MO

- Thesis: "Persuasion in the Athletic Recruiting Process: An Examination of Influence Issues in Division II Football"

BA, Speech Communication
University of Illinois – Urbana-Champaign, IL

Publications

Morhardt D., Luckenbaugh A., **Hecklinski T.**, Killian J., Rodgers, L., Mellem, A., Reames, C., Alhassan, A. & Faerber, G. (2017, September). *Improving resident and nurse communication practices: results of a collaborative culture initiative*. Urology Practice published online. https://doi.org/10.1016/j.urpr.2017.08.002

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