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Developing an organizing framework to guide nursing research in the Children's Oncology Group (COG)

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Abstract

Objectives—To describe the development and application of an organizing research framework to guide COG Nursing research.

Data Sources—Research articles, reports and meeting minutes

Conclusion—An organizing research framework helps to outline research focus and articulate the scientific knowledge being produced by nurses in the pediatric cooperative group.

Implication for Nursing Practice—The use of an organizing framework for COG nursing research can facilitate clinical nurses' understanding of how children and families sustain or regain optimal health when faced with a pediatric cancer diagnosis through interventions designed to promote individual and family resilience.

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The Children's Oncology Group (COG) is the sole National Cancer Institute (NCI)-supported cooperative pediatric oncology clinical trials group and the largest organization in the world devoted exclusively to pediatric cancer research. It was founded in 2000 following the merger of the four legacy NCI-supported pediatric clinical trials groups (Children's Cancer Group [CCG], Pediatric Oncology Group [POG], National Wilms Tumor Study Group, and Intergroup Rhabdomyosarcoma Study Group). The COG currently has over 200 member institutions across North America, Australia, New Zealand and Europe and a multidisciplinary membership of over 8,000 pediatric, radiation, and surgical oncologists, nurses, clinical research associates, pharmacists, behavioral scientists, pathologists, laboratory scientists, patient/parent advocates and other pediatric cancer specialists. The COG Nursing Discipline was formed from the merger of the legacy CCG and POG Nursing Committees, and current membership exceeds 2000 registered nurses. The discipline has a well-developed infrastructure that promotes nursing involvement throughout all levels of the organization, including representation on disease, protocol, scientific, executive and other administrative committees (e.g., nominating committee, data safety monitoring boards). COG nurses facilitate delivery of protocol-based treatments for children enrolled on COG protocols, and Nursing Discipline initiatives support nursing research, professional and patient/family education, evidence-based practice, and a patient-reported outcomes resource center. The research agenda of the Nursing Discipline is enacted through a well-established nursing scholar program.

Keywords

Childhood cancer; Pediatric oncology nursing; Cooperative group; Nursing research; Clinical trial; Theoretical framework, Resilience

Historical Background of COG Nursing Discipline

Prior to the merger of the pediatric cooperative groups at the turn of the millennium, leaders of the CCG and POG Nursing Disciplines had begun to explore the feasibility of nursing research collaboration. A series of discussions held in conjunction with CCG and POG group meetings and Association of Pediatric Oncology Nurses (APON; currently the Association of Pediatric Hematology Oncology Nurses) conferences positioned nursing well for the merger by establishing mutual understanding that areas of shared interest outweighed differences across the two groups. CCG and POG nursing leaders recognized the opportunity for nursing to make unique scientific contributions within the COG, and agreed to undertake the first State of the Science Summit in Pediatric Oncology Nursing Research¹.

A strength of both nursing groups was strong representation from advanced practice nurses (APNs) who were well integrated into the cooperative group structure, knowledgeable about cooperative group processes, and familiar with protocols^{2,3}. However, the APNs lacked the expertise of doctorally prepared nurse scientists to successfully develop and lead nursing research within the cooperative group structure. At the same time, there was a very small cadre of doctorally prepared pediatric oncology nurse researchers available and they had limited experience working within the cooperative groups. These gaps in nursing intellectual capital led to the development of a research structure that paired APNs who were very familiar with cooperative group processes with doctorally prepared nurses who had expertise

in the design and implementation of nursing research. The initial APN/PhD dyads focused on four areas of priority identified during the State of the Science Summit in Pediatric Oncology Nursing and included: neurocognitive effects of childhood cancer therapy⁴, fatigue and related symptoms⁵, coping effects of patients and families⁶, and self-care⁷. A second group of nursing scholar teams was added in 2005 after a second State of the Science Summit. These included nursing scholars focused on developing research in the areas of end of life/palliative care⁸, parent treatment decision making⁹ and complementary and alternative medicine¹⁰. Table 1 provides a timeline summarizing development of key COG Nursing Discipline activities.

Development of an Organizing Framework for COG Nursing Research

In 2009, the COG Nursing Research Sub-Committee engaged in a strategic planning process that included a comprehensive review of the first decade of the nursing scholar program. During COG's inaugural decade, nursing scholar teams had variable success in developing concepts for COG research protocols. Two of the 4 original teams successfully implemented COG studies, one as a freestanding protocol (ANUR0631) and one as an embedded aim in a therapeutic protocol (ACNS0331 – refer to Table 1). During this time, group-wide open meetings moved from a semi-annual to an annual schedule due to reduction in cooperative group funding, and changes in the study concept development process required that pilot work, for the most part, be completed outside of the cooperative group, with fully developed clinical trials given primary consideration for conduct within the COG. Since the majority of nursing scholars were young investigators, their programs of research were generally not mature enough to support large scale multi-site clinical trials. These changes needed to be weighed in the strategic planning process to ensure future COG Nursing research success.

The Nursing Research Sub-Committee co-chairs documented all nursing scholar team activities completed to date and conducted individual scholar interviews. Themes from these interviews were presented to the nursing scholars during a strategic planning session at the Fall 2009 group meeting. In general, scholars reported positive experiences within the cooperative group and were in agreement that APN-PhD synergy had been accomplished. However, nurse scientists new to cooperative group procedures identified the added time for cooperative group study concept development and approval (as compared to external funding mechanisms), and the cooperative group oversight required during study implementation and dissemination (as compared to studies conducted independently) as challenging. These challenges were balanced by the extensive expertise and support for multi-site protocol implementation and administrative support provided by the cooperative group. Nurse scientists now incorporate the added time needed for study development, implementation and dissemination to accommodate cooperative group approval processes into their study timelines.

Scholars described facilitators and barriers of developing study concepts into protocols and listed the characteristics of a successful concept, which included having good fit with cooperative group priorities, being a common care problem and a mature idea with completed preliminary data, filling a key knowledge gap, being an elegantly simple idea/intervention and having a champion within the COG disease and/or discipline committee

structure. Scholars described the components of a good scholar match and how to define their success in the group; i.e., with the same expectations for all researchers: successful funding and study conduct, and dissemination of findings. Scholars recognized the need to build capacity for the next generation of scholars through mentoring, outreach to doctoral students, and the critical importance of regular cooperative group meeting attendance. Scholars acknowledged that COG was the appropriate venue for Phase III intervention trials and that mechanisms were needed to support pre-COG pilot work. Recommendations included expanding the nursing scholar group to include new members, ensuring multidisciplinary representation, and facilitating the professional development of new PhDs by having the COG nursing scholars serve as a think tank, as well as a sounding board for scientific review and critique.

During the strategic planning session, three key questions were explored: (1) What is one thing we need to do to continue our success? (2) What area might we want to lead as a domain of expertise? and (3) How do we model interdisciplinary work? A key theme that emerged from this process was the need to identify a theoretical framework to help define the scope and sharpen the focus of nursing research within COG. Subsequent discussions highlighted both the promise and potential pitfalls of adopting a theoretical framework. Concerns included the need to align focus and language of the framework with cooperative group priorities, which could potentially exclude future nursing studies if they did not fit the framework. However, the consensus was that the potential gains in terms of advancing science overshadowed potential drawbacks. Terms such as “guiding framework” and “conceptual orientation” were used to describe the emerging picture of the type of organizing framework that would facilitate the focus of nursing research within the cooperative group. Values that guided the development of this framework are listed in Table 2.

During additional strategic planning discussions, members noted that while the nursing scholars’ research spanned diverse areas within pediatric oncology, a common denominator was the human response to illness. Scholars recognized that their mutual goal was to improve the patient’s and family’s illness experience, and that they shared the belief that coping and even growth was possible throughout the illness trajectory. As the group interacted, members identified resilience as the collective outcome of interest, and noted that Dr. Joan Haase, a member of the nursing scholar group, had developed and tested a resilience model¹¹. A small task force was subsequently convened to develop the organizing framework to guide nursing research within the COG. The 4-member task force worked over 6 months to develop a draft framework that was then presented to the nursing scholar group for consideration.

The Resilience in Individuals and Families Affected by Cancer¹² (Figure 1) was adapted by the task force from the Resilience in Illness Model (RIM). The RIM was developed from a positive-health perspective that emphasizes the combined contributions of biological, behavioral and psychosocial factors to outcomes of resilience, disease prevention, and wellness¹³. RIM development and evaluation was accomplished through a series of mixed methods studies of pre-adolescents, adolescents, and young adults with chronic illness, primarily those having cancer^{11,14–16}. Exploratory and confirmatory research indicates RIM

well predicts resilience-related outcomes ($R^2 = 0.62$ to 0.72)¹⁵. The RIM factors reflected in the COG Nursing research organizing framework are depicted within the inner circle that is focused on the individual. These factors include two risk factors (illness-related risk and defensive coping); four protective factors (family environment, social integration, courageous coping, and derived meaning), and one outcome factor (well-being). The well-being factor includes positive health outcomes such as global quality of life, resilience resolution and self-transcendence. The organizing framework was expanded to incorporate individual biological factors and family factors that are both impacted and have impact on resilience in the child and adolescent/young adult (AYA). Table 3 provides definitions and specific variables associated with each RIM factor incorporated in the COG Nursing research organizing framework. The list of RIM variables in column 3 are those used in the COG studies of interventions to promote AYA resilience; the list will certainly expand as COG Nursing scholars use the framework to guide studies that focus on, or include, physiologic variables, younger children and family units, diverse ethnic/racial groups, and different points on the cancer continuum. The organizing framework for COG Nursing research expanded RIM into an ecological model by adding the family, culture and cancer continuum constructs, as well as moderators (e.g., age and developmental level of the child and family, illness and treatment characteristics, and genetic characteristics of the child and family).

Scholars were asked to evaluate the framework for fit with their programs of research and to consider how the framework might inform their future research. Concerns voiced by scholars included the framework being too narrow and restrictive, an absence of biological indicators and mechanisms of injury and a focus on the psychosocial concepts of stress and coping. Scholars encouraged a broader view and also discussed ways the framework could be used to interpret the variable symptom patterns identified within specific disease groups. Scholars also encouraged broad definition of outcomes. The potential to identify a core set of measures that could be applied across studies was identified as an opportunity to build science and theory. Scholars discussed a number of potential nursing research priority areas and where each would fit. As the discussion progressed, it became clear that with the fine-tuning reflected in Figure 1, the framework could inform a broad group of research interests. The group also clarified that individual investigators might use other theoretical/conceptual frameworks to guide specific studies, to provide knowledge that would also inform components of the organizing framework.

During a subsequent discussion, one of the scholars presented an emerging research concept within the proposed organizing framework. While this researcher's program of research was grounded in a different theoretical model, she identified how she could add measures and/or contribute findings to the organizing framework. Through this presentation, scholars were able to visualize how an organizing framework might help COG nursing leaders and grant reviewers better articulate the scientific knowledge being produced by nurses in the cooperative group. The framework was helpful in describing the kind of work nurses do. It outlined nursing's focus and expertise and framed how nursing research is conducted.

After the organizing framework was endorsed by the nursing scholar group, presentations to the greater COG Nursing Discipline membership and other relevant COG committees were

completed to obtain broader feedback. The organizing framework was well received. No changes to the framework were necessary after these presentations; explanatory text was added to the diagram to facilitate stand-alone understanding before posting to the Nursing Discipline website.

Application of the Organizing Framework in COG Nursing Research

There are multiple ways the organizing framework can be used to guide research. In 2001, potential intervention applications of RIM to enhance resilience and well-being in AYA with cancer were proposed during an APON pre-conference workshop^{11,17}. Similar application approaches are being used with the COG organizing framework. Here, we identify four approach options. First, investigators could focus on descriptive and/or theory generating work for a single variable within any risk or protective factors (e.g., symptom clusters within illness-related distress) and use the framework to speak to the larger significance of their work. In such cases, investigators would likely use other frameworks to guide their focused work (e.g., symptom representation, motivational coping, communication theory). Second, investigators could focus on multiple mechanisms within a single factor (e.g., develop a model to specify factors that influence provider-patient connectedness) prior to developing interventions that strengthen social integration to ultimately enhance “downstream” protective and/or risk factors. A third option could be to target multiple factors in the model through a single intervention. An example of this option is ANUR0631, “Stories and Music for Adolescent/Young Adult Resilience During Transplant” (SMART I) (R01NR008583; U10CA098543; U10CA095861). This randomized clinical trial of a therapeutic music video intervention targeted all factors in RIM in a sample of AYA undergoing stem cell transplant. Results showed significant improvements in 3 protective factors and moderate, but non-significant improvement in 2 additional factors. A fourth approach option could be to target one or two factors in the model. The follow-up study for ANUR0631, “Stories through Music for Adolescent/Young Adults and Parents (SMART+P) during Treatment; ANUR 1131” provides an example of this approach (R01CA162181; U10CA098543; U10CA095861). This 2 group randomized controlled trial is in process in a dyadic sample of AYAs with high risk cancer and/or high palliative care needs and one parent. The SMART + P study aims to enhance the family protective factor and also target the middle (family) circle of the COG Nursing research organizing framework by adding a parent focused, nurse delivered intervention to the previously tested therapeutic music therapy intervention the AYA receives.

The organizing framework has also informed COG Nursing Research Traineeships. These biennial traineeships, funded by the Nursing Discipline portion of the Chair’s grant, are designed to support the development of young investigators. Traineeship calls are purposefully focused on areas of research in which the discipline leadership wishes to generate interest and focus. Applicants are asked to include how their proposed study is linked to the framework. Figure 2 demonstrates how one trainee’s study, designed to explore the relationship between self-reported fatigue and physical activity in survivors of Hodgkin disease treated as AYA on COG AHOD0331, was linked to aspects of the organizing framework¹⁸.

Since its adoption, the COG Nursing Discipline's organizing framework has shaped the Discipline's research agenda by guiding the development of new knowledge through a focus on understanding ways that children and families sustain or regain optimal health when faced with a pediatric cancer diagnosis, and by grounding the Discipline's research in positive health constructs that set the stage for the development and testing of interventions to promote resilience. The COG Nursing Discipline's current research agenda, informed by the organizing framework, is described in detail in the Children's Oncology Group's 2013 Blueprint for Research: Nursing Discipline¹².

Conclusions/Future Directions

The adoption of an organizing framework to guide COG Nursing research is indicative of the transformational change in the Nursing Discipline that has occurred since the merger of the pediatric cooperative groups in 2000. Other indicators of discipline maturity include a recent initiative to develop evidence summaries to translate nursing research into nursing practice, even as COG nurses continue to have a key role in both the development of and effective translation of medical research from "bench to bedside." Indeed, the majority of pediatric cancer treatment innovations are delivered to patients and families through the hands of a bedside clinical nurse. At the same time, nurses participate in and lead key COG committees, and constitute the largest COG membership category. The successful integration of the Nursing Discipline within the COG, and the resilience-focused organizing framework that has been established to explore and address key gaps in knowledge related to the experience of individuals and families affected by pediatric cancer, may be useful in facilitating collaborative nursing research across cooperative clinical trials groups as cooperative group nursing moves forward within the National Clinical Trials Network (NCTN).

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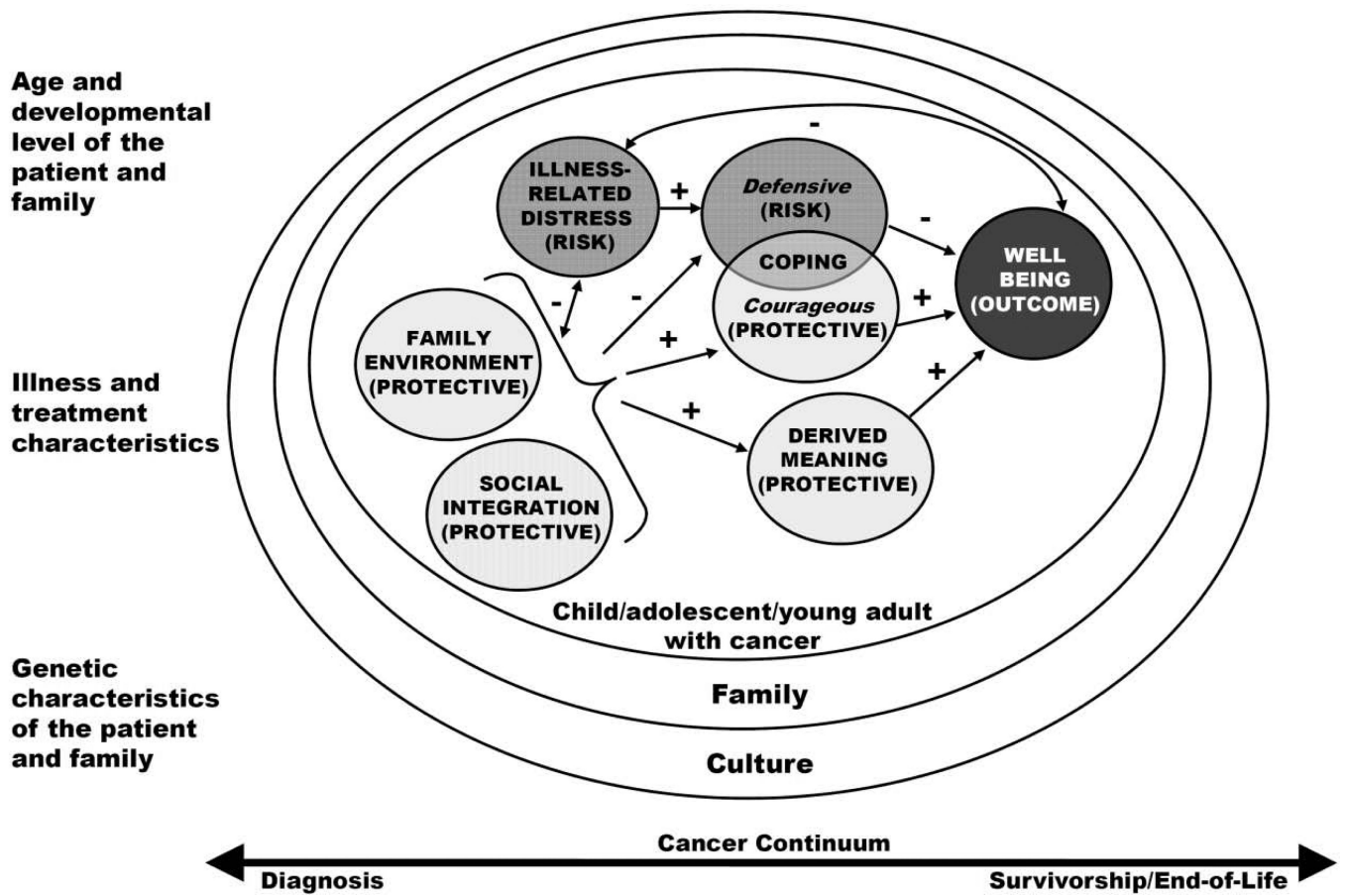


Figure 1. COG Nursing Research Organizing framework
 Adapted from Landier, W., M. Leonard, et al. (2013). "Children's Oncology Group's 2013 blueprint for research: nursing discipline." *Pediatr Blood Cancer* **60**(6): 1031–1036 with permission.

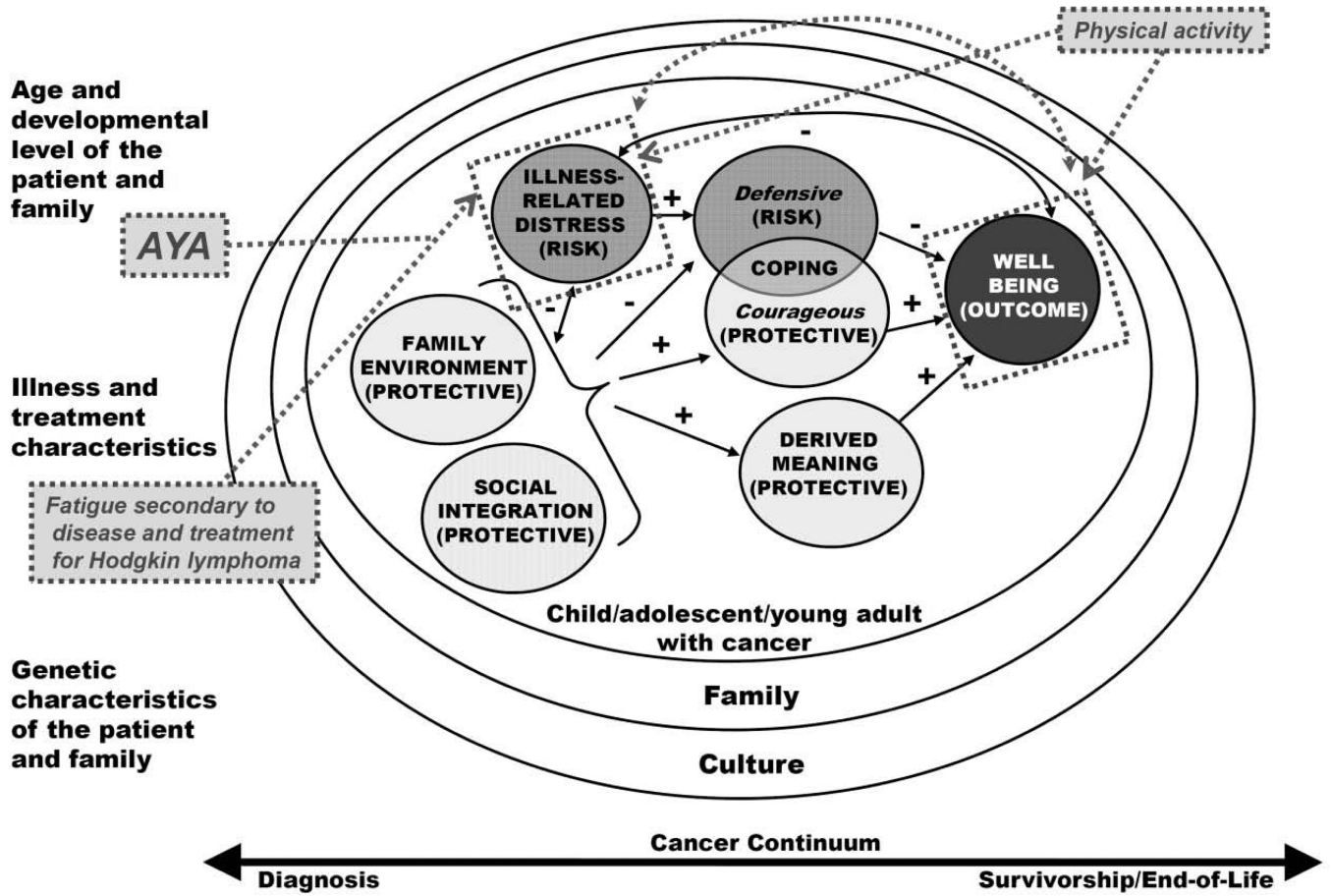


Figure 2. Example of research trainee’s study linkages to the COG Nursing Research Organizing Framework

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Table 1

Nursing Discipline Development Timeline

Year	Development activity	Comments
1955	Pediatric cooperative groups funded by National Cancer Institute (NCI)	
1979	Nursing Committee established in Children's Cancer Group (CCG)	
1981	Nursing Discipline established in Pediatric Oncology Group (POG)	
1981–1997	Nursing activities in the pediatric cooperative groups	<ul style="list-style-type: none"> Initial focus on facilitating protocol implementation Moved toward developing nursing research studies over time Growing support of nursing committees in the cooperative groups Paucity of nurse scientists within the cooperative groups
1997	Initiation of intergroup nursing collaboration (independent of cooperative group merger)	
2000	Merger of 4 pediatric cooperative groups to form the Children's Oncology Group (COG)	<ul style="list-style-type: none"> Provided opportunity to create a new structure for clinical trials nursing and nursing research in cooperative group setting. Recognized need to recruit nursing scientists to build a nursing research agenda.
2000	Inaugural State of the Science in Pediatric Oncology Nursing Research	<ul style="list-style-type: none"> Highlighted new and promising nursing research programs to align with and contribute to scientific mission of COG Strengthened working relationships among researchers, staff registered nurses (RNs), Advanced Practice Nurses (APNs) Fostered collaboration with other disciplines
2000-present	Nursing scholars	<ul style="list-style-type: none"> PhD-APN (nursing scholar dyad) partnership to move specific area of research forward in group based on inaugural state of the science groups. Appointment to disease and scientific committees (Neurocognitive effects – Central Nervous System tumor, Fatigue - Acute Lymphocytic Leukemia outcomes, Coping – Adolescent and Young Adult, Self-care - Supportive care) Oncology Nursing Foundation funded initial travel expenses for nursing scholars to attend COG meetings Unanticipated outcome of nursing scholar program included significant number of COG APNs completing doctoral studies (n=10 since inaugural nursing scholar assignments) and now becoming novice nursing researchers.
2004	Second State of the Science in Pediatric Oncology Nursing Research	Added 3 nursing scholar groups: Complementary and Alternative Medicine (CAM), Parent treatment decision making, End of life/Palliative care
2006	Developing Nurse-Led Interdisciplinary Research in the Cooperative Group Setting	Oncology Nursing Society invitational meeting for interdisciplinary cooperative group teams to develop a nurse-led research study concept. COG team focused on fatigue and related symptoms in Hodgkin Disease.
2008–2012	Nursing Research Traineeships	Nursing Discipline portion of COG Chair's grant included funding for developing the next generation of nursing scholars. Three rounds of 2 year traineeships have been awarded to six trainees thus far.
2000-present	Nursing Discipline Protocol Development	<ul style="list-style-type: none"> ACCL01P3: Differences in Parental Caregiving Demands in Childhood Acute Lymphoblastic Leukemia by Length of Infusion Therapy

Year	Development activity	Comments
		<ul style="list-style-type: none"> • ANUR0631: Stories and Music for Adolescent/Young Adult Resilience During Transplant • ACNS0331: A Study Evaluating Limited Target Volume Boost Irradiation and Reduced Dose Craniospinal Radiotherapy 18.00 Gy and Chemotherapy In Children with Newly Diagnosed Standard Risk Medulloblastoma: A Phase III Double Randomized Trial (Embedded aim examining child functional status and quality of life led by nursing scholars) • ANUR1131: Stories through Music for Adolescent/Young Adults and Parents (SMART+P) during Treatment provides
2007-present	PRO-Resource Center	Nursing Discipline collaborated with Cancer Control Committee to develop a Patient Reported Outcomes (PRO) resource center to advance inclusion of pediatric PROs on disease trials.
2009	Strategic planning	With expansion of nursing scientists and growing cadre of young investigators, need to move from nursing scholar dyad approach to capitalize on growing network of pediatric oncology nursing scientists – nursing scholar network now open to all interested individuals. Monthly conference calls provide support and networking and identifying promising studies to move forward in group.
2011	Organizing framework adopted	Strategic planning yielded a number of suggestions including need for an organizing framework to define the focus of Nursing Discipline.
2012	Evidence-Based Practice initiative	Mentored opportunities for nurses to develop evidence summaries to inform clinical trials nursing practice.
2013-ongoing	Areas for future focus	Current focus on research to inform effective delivery of patient/family education and reducing illness-related distress

Table 2

Guiding values used to develop a framework for nursing research in the cooperative group.

<ul style="list-style-type: none">• Child and adolescent/young adult (AYA) with cancer at the core• Application of methods to solicit the child's perspective directly• Child experiences cancer within a family with reciprocal impact• Additional social ecological features such as context important• Importance of applying salutogenic approaches to studying the child and family's experiences• Strengths-based perspective with focus on meaning of the cancer experience• Importance of the child's symptom experience• Distal outcome of care=sense of wellbeing in the context of illness• Goal of helping children and their families transcend the illness
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Table 3

Organizing framework factors originally derived from the Resilience in Illness Model with definition and potential variables for study

Factor	Definition	Variables	Examples of Potential Additional Variables
Illness-related Distress (Risk)	The degree of perceived illness-related uncertainty and disease and symptom-related distress	<ul style="list-style-type: none"> • Uncertainty in Illness--Ambiguity and Complexity; • Symptom Distress 	Unmet information needs Patient reported outcomes measurement information system (PROMIS) measures Depression/anxiety
Social Integration (Protective)	The degree to which the patient/family perceives a sense of connectedness with and support from friends and health care providers in the midst of having cancer.	<ul style="list-style-type: none"> • Perceived Social Support <ul style="list-style-type: none"> ◦ -Friends ◦ -Healthcare Providers 	Patient/provider connectedness Patient/parent involvement in treatment decision making Trust in provider
Family Environment (Protective)	The degree to which the patient/family member perceives the family as adaptable, cohesive, effectively communicating, and having family strengths.	<ul style="list-style-type: none"> • Family <ul style="list-style-type: none"> ◦ Adaptability ◦ Cohesion ◦ Communication ◦ Perceived Strengths 	Psychosocial Assessment Tool risk category Use of standardized family demographics for all COG studies
Defensive Coping (Risk)	The degree to which the patient/family member uses evasive and emotive coping strategies to deal with the cancer experience.	<ul style="list-style-type: none"> • Coping Strategy Use/Effectiveness <ul style="list-style-type: none"> ◦ Avoidant ◦ Emotive ◦ Fatalistic 	
Courageous Coping (Protective)	The degree to which the patient/family member uses confrontive, optimistic, and supportant coping strategies to deal with the cancer experience.	<ul style="list-style-type: none"> • Coping Strategy Use/Effectiveness <ul style="list-style-type: none"> ◦ Confrontive ◦ Optimistic ◦ Supportive 	Activity during treatment
Derived Meaning (Protective)	The degree to which the patient/family member uses hope and spiritual perspective to derive meaning from the cancer experience.	<ul style="list-style-type: none"> • Hope • Spiritual Perspectives <ul style="list-style-type: none"> ◦ Beliefs ◦ Practices 	
Well-being	The process of identifying or developing resources and strengths to flexibly manage stressors to gain a positive outcome, a sense of confidence/mastery, self-transcendence, and self-esteem.	<ul style="list-style-type: none"> • Resilience Resolution • Self-transcendence • Sense of Well-being 	Health related quality of life