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# The Transition from Health to Illness: Best Practices For Education of Parents with Children Newly Diagnosed with Cancer

Karlie M. R Wolf

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THE TRANSITION FROM HEALTH TO ILLNESS: BEST PRACTICES FOR EDUCATION  
OF PARENTS WITH CHILDREN NEWLY DIAGNOSED WITH CANCER

by

Karlie M. R. Wolf, BSN, RN

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An Independent Study

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of the

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## PERMISSION

Title           The Transition from Health to Illness: Best Practices for Education of Parents  
                  with Children Newly Diagnosed with Cancer

Department   Nursing

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### **Abstract**

Each year in the United States, there are about 13,500 new childhood cancer diagnoses (Children's Oncology Group, 2018). When facing this diagnosis, caregivers require significant education about the child's diagnosis and home treatment plans (Haugen et al., 2016). A lack of early and continuing education can lead to immediate and long-term adverse effects (Lown, Phillips, Schwartz, Rosenberg & Jones, 2017). There are few standards that describe education to best support the patient and family (Haugen et al., 2016). This project sought to identify the gaps in providing necessary education and to make evidence-based recommendations for education of families experiencing childhood cancer.

A comprehensive search of the National Library of Medicine, PubMed and CINAHL, using key search words "childhood cancer," "pediatric oncology," "pediatric cancer," "cancer education," "pediatric education," and "pediatric" was completed. Inclusion criteria was peer-reviewed, English, and publications from 2010 through 2018 with a focus on children younger than twenty at the time of cancer diagnosis. Nineteen articles met the inclusion criteria. Melnyk's Pyramid was used to evaluate the evidence. Resulting evidence emerged from systematic reviews, cohort studies, meta-analyses and practice guideline reviews, or level one evidence.

Evidence is emerging related to effective family education when children are diagnosed with cancer. Nevertheless, additional studies are needed to establish evidence-based standards for educating families experiencing cancer (Rodgers et al., 2018; Slone, Self, Friedman & Heiman, 2013; Szalda & Ginsberg, 2014; Withycombe, Andam-Mejia, Dwyer, Slaven & Landier, 2016). Meanwhile, individualized education needs to begin early and continue throughout treatment (Landier et al., 2016).

Each year in the United States, there are about 13,500 new childhood cancer diagnoses and with significant improvements in treatment options, we are seeing an increased survival rate in this population (Children's Oncology Group, 2018). The diagnosis of cancer in children is devastating news and involves a life-altering illness that affects not only the child with cancer, but also their families and caregivers (Sigurdardottir, Svavarsdottir & Gokun, 2014; Rodgers, Stegenga, Withycombe, Sachse & Patterson Kelly, 2016b).

Complicated cancer treatment for children with cancer can occur over months to years and involves multiple procedures, medications, hospital admissions, and clinic visits (Sigurdardottir et al., 2014). This new diagnosis and concurrent treatment are exceptionally stressful for both the parents and the child (Rodgers et al., 2016b). During the transitional time of diagnosis and treatment, there is an increased need for a significant amount of education for the patient, family, and caregivers (Gunter & Duke, 2018; Haugen, Landier, Mandrell, Sullivan, Schwartz, Skeens & Hockenberry, 2016; Landier et al., 2016; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone, Selft, Friedman & Heiman, 2013; Wilson Smith et al., 2018; Withycombe et al., 2016). This education provided to families experiencing cancer of a child generally includes information about the child's diagnosis and home treatment plans which can include complex medication regimens, gastrointestinal tube feedings, and dressing changes (Haugen et al., 2016; Landier et al., 2016).

Education is of utmost importance for the caregivers as the education lays the foundation to ensure safe care for the patient at home, but also can influence patient outcomes and reduce stress for both patient and caregiver (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). It is imperative that we know how best to teach this special

population. There are very few standards that describe education to best support the patient and family (Withycombe, et al., 2016; Haugen et al., 2016; Slone et al., 2013; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Rodgers et al., 2016b). Given the immense need for improved education, a comprehensive literature search was completed to determine and make recommendations for best-practices to educate caregivers of patients newly diagnosed with cancer with the goal of facilitating the family transitions that occur during this time.

### **Purpose**

There were two primary aims of this project. The first was to define and identify the extent of the gap in the families experiencing a cancer diagnosis in a child, and the second was to develop evidence-based recommendations to meet the needs for family education. The comprehensive, evidence-based literature review sought evidence for defining the concept of family education and for best practices for effectively educating families of children newly diagnosed with cancer. The evidence-based recommendations for the development of education incorporated the most effective teaching methods for educating families coping with the stress of a new and devastating diagnosis of childhood cancer.

### **Significance**

There is limited evidence as to how to best serve this special population with effective education necessary for caring for a child with a cancer diagnosis (Kahn et al., 2017; Withycombe, et al., 2016; Haugen et al., 2016; Slone et al., 2013; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Rodgers et al., 2016b). Healthcare professionals also need to understand the best time to present specific content to inform, but without overwhelming the parents (Kahn et al., 2017; Haugen et al., 2016; Slone et al., 2013;

Gunter & Duke, 2018; Withycombe et al., 2016; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Rodgers et al., 2016b). Without adequate knowledge of effective educational practices, health care providers are not equipped to provide appropriate information to families, which ultimately puts the affected child at risk for immediate and long-term adverse events (Kahn et al., 2017; Matutina, 2010; Gunter & Duke, 2018; Slone et al., 2013; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Rodgers et al., 2016b).

There are significant obstacles that prevent families from receiving the information. The psychological and emotional distress that comes with the new cancer diagnosis is one of the major barriers to being able to absorb and use the large amount of complex material (Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Sigurdardottir et al., 2014). Beyond the expected emotional response after this devastating diagnosis, there are different individual family needs that need to be taken into consideration when planning education. For example, education needs to be customized for non-English speaking parents to meet varied educational backgrounds, literacy levels, and learning preferences (Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Sigurdardottir et al., 2014). These individual needs will also influence the extent of teaching required to adequately prepare the parents for at-home care of the child (Kahn et al., 2017; Slone et al., 2013; Rodgers et al., 2016a; Landier et al., 2016; Sigurdardottir et al., 2014; Rodgers et al., 2016b).

Health care providers working with the pediatric oncology population need evidence-based methods to educate parents to safely and efficiently take care of their child's complex medical needs resulting from the cancer diagnosis. Effective education also has the potential to

empower the parents to be present in their child's care, which will reduce the chances of long-term adverse and psychological effects (Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Sigurdardottir et al., 2014).

### **Theoretical Framework**

Changes in health status can reveal the need for knowledge related to new concepts, as well as the need to begin a process of transition from health toward the illness continuum for the patient and caregivers. This process of the health/illness transition forces patients and caregivers to use coping strategies for these changes and outcomes. Patients and caregivers progress through the transitions by utilizing personal, family, social, and community resources to advance to a successful transitional response (Blum & Sherman, 2010). Transitions can be generated by alarming events and changes in the environment or the circumstances within individuals (Meleis, 2010). Health care providers need to identify and address possible problems that patients meet during the experience and create ways to provide support during this time (McEwen & Wills, 2014; Im, 2011; Meleis, Sawyer, Im, Hilfinger Messias & Schumacher, 2000). By identifying and addressing these problems, interventions can be created to assist with coping with changes and be able to function up to their full capacities (Meleis et al., 2000). A health/illness transition can take multiple pathways, and without appropriate identification and acknowledgment of transitional problems, patients and caregivers can experience a variety of negative emotions (Blum & Sherman, 2010; Cerqueira, Pereira & Barbieri Figueiredo, 2016). Emotions such as anxiety towards the unknown and a sense of loss of familiarity and disconnectedness from peers and family can occur and create a barrier to successful transition through the experience (Blum & Sherman, 2010; Cerqueira et al., 2016).



The transitions theory by Afaf Meleis may provide a framework for health care providers to assist families experiencing the health transition when a child is diagnosed with cancer. This theory was chosen to frame this project because of the alignment of the concepts with the purpose of the project. The major theoretic concepts of the Transitions Theory that align with the project are: (a) the nature of and reactions to change; (b) the experience at hand; (c) the response to the different phases; (d) promotion of health and well-being before, during, and after the event (Im, 2011; Meleis et al., 2000). These concepts are present during any transition, regardless of the type, situation or person (Meleis et al., 2010). The transitions theory also helps explain the interaction between patients and nurses, as nurses focus on patient experience and well-being as the patient progresses through the health/illness continuum (McEwen & Wills, 2014, p. 237).

There are different transitional conditions with which nurses tend to be involved, including (a) developmental; (b) situational; (c) organizational; (d) health-illness transitions (McEwen & Wills, 2014). Transition conditions refer to the variation between individuals and families, making each transition unique (Meleis et al., 2010). These include things such as socioeconomic status, cultural beliefs and attitudes, preparation, knowledge and skill level, and emotional well-being (Meleis et al., 2010; McEwen & Wills, 2014). These variations, or factors, can be identified as “facilitators” and “inhibitors” of the conditions (Meleis et al., 2010). All of these conditions can have a positive or negative influence on how individuals react to transition (Meleis et al., 2010; Im, 2011).

Health care providers need to be aware of these conditions to facilitate an individual or family to achieve a healthy transition (Meleis et al., 2010; Im, 2011). The theoretic components provide a structure for health care providers to individualize and deliver effective care before,

during, and after the transition takes place (Meleis et al., 2010). Understanding patterns of response, or process and outcome indicators are prominent indicators that individuals or families are moving in the direction of health or towards negative outcomes and could allow the healthcare provider to devise interventions that better support the healthy transition (Meleis et al. 2000). For example, positive emotional responses of an individual or family that could indicate a transition toward health might include the sense of feeling connected, interaction among others experiencing a similar situation, and developing confidence and coping skills (Meleis et al., 2000; McEwen & Wills, 2014).

Health care providers' awareness of transitional conditions and patterns of response better prepares them to complete early assessments and create nursing interventions to facilitate healthy outcomes (Meleis et al., 2010; Im, 2011). The goal of the interventions is to assist a healthy transition process along with healthy outcome responses (Meleis, 2010). Nursing interventions associated with transitions seek out to explain what the individual is currently experiencing, as well as what the individual may experience by providing support, education, skills, and strategies to deal with the transition experience (Meleis, 2010).

This theory was chosen as the framework for the project because in the unfortunate scenario of a child newly diagnosed with cancer, there is a health-illness transition in which the patient and family are suddenly thrust, as the child moves from a state of well-health to illness (McEwen & Wills, 2014; Meleis et al., 2010). Transitions Theory served as the theoretical framework for interpreting and identifying the best practices for the education of patients and caregivers experiencing a new diagnosis of childhood cancer. The concepts and context associated with the Transitions Theory helped to organize and utilize the identified evidence to create an informational pamphlet to educate pediatric oncology nurses and providers about the

transition that parents experience and measures that can be taken to ensure that a healthy transition occurs.

### **Process**

A comprehensive literature search of CINAHL, PubMed, and the National Library of Medicine was completed to search for evidence related to the education of children and caregivers experiencing childhood cancer. A combination of the following key words was used, “childhood cancer,” pediatric oncology,” “cancer education,” “pediatric cancer,” “pediatric,” “pediatric transitions,” “cancer coping,” and “cancer transitions.” Inclusion criteria include peer-reviewed publications between 2010 and 2018 and written in the English language. Publications were further included with information regarding (a) children and adults younger than twenty years old at the time of cancer diagnosis; (b) patient and caregiver education about childhood cancer; (c) patient and caregiver transitions during acute and chronic diseases. A combination of the search terms in the databases identified 568 articles; after analysis a total of 19 were retained. Eleven of the articles directly related to patient and caregiver education of those experiencing childhood cancer, and seven discussed transitions experienced in the health/illness continuum. Other articles were excluded if they were written before 2010 and if they weren’t written by at least one health care provider who practiced in the United States. The evidence emerging from the retained articles was analyzed using the Melnyk’s Pyramid. This pyramid categorizes evidence based on quality, validity, and how applicable they are to patient care (Melnyk & Fineout-Overholt, 2011). There are seven levels involved; the lower the level, the lower the quality (Melnyk & Fineout-Overholt, 2011). The retained literature represented all but two of the levels of evidence from Melnyk’s Pyramid (see Table 1) (Melnyk & Fineout-Overholt, 2011). See Table 1 for further detail regarding levels of evidence found. Most of the articles

gathered information from both parent questionnaires, expert reports from the Children's Oncology Group (COG), and systematic literature reviews of descriptive and qualitative studies.

Table 1

<b>Melnyk Levels of Evidence (Melnyk &amp; Fineout-Overholt, 2011)</b>	
<b>Level 1</b> - Systematic review & meta-analysis of randomized controlled trials; clinical guidelines based on systematic reviews or meta-analyses	<b>5 Studies</b>
<b>Level 2</b> - One or more randomized controlled trials	<b>0 Studies</b>
<b>Level 3</b> - Controlled trial (no randomization)	<b>1 Studies</b>
<b>Level 4</b> - Case-control or cohort study	<b>9 Studies</b>
<b>Level 5</b> - Systematic review of descriptive & qualitative studies	<b>0 Studies</b>
<b>Level 6</b> - Single descriptive or qualitative study	<b>3 Studies</b>
<b>Level 7</b> - Expert opinion	<b>1 Studies</b>

A personal interview with Samantha Porter, CNP was also conducted to discuss the pediatric oncology patient-caregiver population, special considerations, and to help identify important aspects of education. The goal of this activity to was to gather information and professional insight into the concept of patient and caregiver education, caregiver transitions and things that either prevent or inhibit those healthy transitions, as well as gaining further knowledge about current practices in a local children's hospital. A variety of questions were asked about both patient and caregiver education practices, and parent transitions. Questions included (a) what education methods are currently utilized in your practice; (b) when do you think education should be done, and how much should it be spaced out; (c) where is the best place to teach this information; (d) what topics do you find to be most important; (e) are learning

needs assessments completed prior to teaching; (f) what do you find to be barriers and facilitators to transitions and learning; (g) what kind of teaching interventions would you like to see implemented; (h) what are some positive and negative patterns of response that you see in caregivers? Ms. Porters responses and the articles obtained from the comprehensive literature search, provided ample information to consider when thinking about parent education and the health/illness transition after a child is newly diagnosed with cancer. The following section will present and critique the evidence obtained from the literature review as it pertains to the components of the Transitions Theory.

### **Review of the Literature and Expert Opinion**

#### **Nature of Transition After a Childhood Cancer Diagnosis**

When a parent learns that their child has cancer, a rapid change in role expectations, abilities, and relationships begins (Meleis, 2010). This change identifies as a health/illness transition (Meleis, 2010). The review of the literature identified many essential aspects regarding caregiver education and the process of the health/illness transition that both patients and caregivers experience after this new diagnosis.

Most of the research that related to the emotional reaction after a family receives a diagnosis of cancer emerged from qualitative studies (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Patterson Kelly et al., 2018; Rodgers et al., 2016b). Of these four qualitative studies, sample sizes ranged 12 - 20 parents (Aburn & Gott, 2014; Patterson Kelly et al., 2018; Rodgers et al., 2016b). One study also included 76 caregiver participants, which consisted of 45 mothers, 28 fathers, and three aunts (Gage-Bouchard et al., 2013). Of the four qualitative studies, small sample size and (Aburn & Gott, 2014; Patterson Kelly et al., 2018; Rodgers et al., 2016b) an over-representation of mothers based on participant response (Aburn & Gott, 2014; Gage-

Bouchard, 2013) were common limitations. The sample of a study conducted by Rodgers et al. (2016b) involved only parents of children on an inpatient oncology unit, which limited generalizing findings because not all children are diagnosed on inpatient units, e.g., some are diagnosed in an outpatient setting (Rodgers et al., 2016b). However, there were also quantitative studies (Rodgers et al., 2016a; Sigurdardottir et al., 2014; Wilson Smith et al., 2018), as well as one integrative literature review (Gunter & Duke, 2018). Rodgers et al. (2016a) completed a systematic review of 83 articles. The reviewed articles consisted of systematic reviews (n = 2), research studies (n = 80), and one unpublished dissertation. Overall, the quality of the evidence was low (Rodgers et al., 2016a). Rodgers et al. (2016a) also identified small sample sizes and utilization of non-validated tools to measure outcomes as limitations of the reviewed studies.

The evidence that emerged from this literature review will be presented in the framework of Meleis' Transitions Theory. The first section relates to properties of transitional experiences. The second section presents evidence pertinent to transitional conditions. The third section illustrates the patterns of responses when families are thrown into transition with a diagnosis of childhood cancer. The final section of the literature review critically describes nursing interventions that have been used to assist families during this transitional challenge.

### **Properties for Transition Experiences**

Meleis (2000) asserted that five main properties exist for transition experiences (a) awareness; (b) engagement; (c) change and difference; (d) time span; (5) critical points and events. The following will present parent-specific findings that aligned with four of the five properties of the transition experience including (a) awareness; (b) engagement; (c) change and difference and; (d) critical points and events. Time span is the only property that Meleis (2000) has identified that will not be described as the literature didn't support a specific time frame.

Meleis (2000) notes that while transitions progress over time, it can be problematic to frame the time span within some transition experiences.

**Awareness.**

Awareness is defined by Meleis (2000) as being the knowledge, perception, and recognition of a transition experience. Often, the level of awareness is based on how the individual reacts to the critical event that initiated the transition (Meleis, 2000). Studies reviewed found parents and loved ones experience a variety of emotions when they receive the initial diagnosis of childhood cancer (Aburn & Gott, 2014; Gage-Bouchard, Devine, & Heckler, 2013; Gunter & Duke, 2018; Patterson Kelly, Withycombe, Stegenga, & Rodgers, 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Sigurdardottir, Svavarsdottir, & Gokun, 2014; Wilson Smith, Sachse, & Perry, 2018). All of these experiences and feelings described by parents highlight a period of emotional and physiological vulnerability in which they face problems with self-care, caregiving, and overall awareness of the situation (Meleis, 2010).

The state of mental shock of the family after receiving the initial life-altering diagnosis was one commonly documented theme related to transition awareness that was uncovered from qualitative studies (Aburn & Gott, 2014; Patterson Kelly et al., 2018; Rodgers et al., 2016b). Quantitative studies also identified the common feelings of shock, uncertainty, being overwhelmed, and scared upon initial diagnosis (Aburn & Gott, 2014; Gunter & Duke, 2018; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Rodgers et al., 2016a; Sigurdardottir et al., 2014; Wilson Smith et al., 2018). An integrative literature review was completed by Gunter & Duke (2018) to assess uncertainty in families experiencing childhood cancer. The researchers analyzed 29 descriptive or qualitative studies of samples consisting of primarily Caucasian mothers (Gunter & Duke, 2018). The study found that uncertainty exists

during the initial diagnosis, but also before the diagnosis is confirmed, and as well as when treatment was progressing, or a quick intermittent change occurred (Gunter & Duke, 2018). Once the diagnosis is confirmed, the period of awareness intensifies as the reality of what is occurring sinks in. As their new reality is setting in, these other emotions such as shock, and being overwhelmed intensify as well.

### **Engagement.**

While parents' level of awareness varies depending on their reaction to the initial diagnosis, their level of awareness is also said to influence their level of engagement (Meleis, 2000). Engagement in the transitions theory is said to be the amount of involvement that a person shows during the transition process itself (Meleis, 2010). Parental engagement after their child is newly diagnosed with cancer was found to be heavily influenced by their emotional reactions (Aburn & Gott, 2014; Patterson Kelly et al., 2018; Rodgers et al., 2016b).

Patterson Kelly et al. (2018) completed a descriptive qualitative study with the help of the Children's Oncology Group (COG) that explored parental question-asking during the initial cancer diagnosis period. In this study, parents overwhelmingly described "feeling inundated with information" and being too affected by emotions after diagnosis to think of and ask questions (Patterson Kelly et al., 2018). These parents also mentioned that they became more overwhelmed when information was being directed at them (Patterson Kelly et al., 2018) or when they encountered the healthcare team (Rodgers et al., 2016a).

A systematic review by Rodgers et al. (2016a) was conducted to determine the current state of knowledge about the delivery of education to newly diagnosed childhood cancer patients and their families. This study noticed that parents felt overwhelmed at initial diagnosis but also had the same feeling during different scenarios and at different points of time, such as when



multiple providers entered their child's room at the same time to examine the child. Rodgers et al. (2016a) determined that these emotional reactions made it harder for parents to hear and comprehend relevant information. This outcome of the emotional toll was confirmed in the subsequent qualitative study by Rodgers et al. (2016b). In this study, parents also recounted the feeling of being overwhelmed and the interference with trying to process relevant information. One mother said, "...it's like the lady [physician] was saying it...but I couldn't hear it" (Rodgers et al., 2016b, p. 456).

Parents in the study by Aburn & Gott (2014) described similar feelings pertaining to information processing. Aburn & Gott (2014) investigated parent perceptions and experiences after a new diagnosis of acute lymphoblastic leukemia (ALL) for 12 parents in New Zealand, and as with other studies, identified the common theme of parents being overwhelmed after the initial diagnosis and how this feeling hindered the processing of information. The intense feeling of being overwhelmed, along with other emotional aspects have immediate consequences such as ineffective coping, and also significantly impacted parents' ability to learn how to safely care for their child during treatment (Aburn & Gott, 2014).

### **Change and difference.**

Sigurdardottir et al. (2014) conducted an exploratory study to (a) explain the development of a web-based educational and support intervention for patients and families experiencing a new diagnosis of childhood cancer; (b) assess whether or not the intervention was useful; (c) determine if the intervention had any impact on the quality of life in patients and family members. While this study focused on a specific educational intervention, the researchers identified that once the initial state of shock subsides, parents reported being frightened, upset, overwhelmed, and scared (Sigurdardottir et al., 2014). Sigurdardottir et al. (2014) also found

that parents weren't only overwhelmed and shocked about the diagnosis but also experienced emotional pain (such as immense sadness) resulting from seeing their child experiencing treatment and the side effects, such as hair loss, loss of appetite, decreased functional ability, and fatigue after chemotherapy or radiation (Sigurdardottir et al., 2014).

While parents experience feelings of shock and uncertainty before and upon diagnosis, parents' studies reported negative emotions upon the first discharge home from the hospital (Rodgers et al., 2016b; Wilson Smith et al., 2018). Parent participants in the two studies described feelings of shock, fear, and being overwhelmed after initial diagnosis at the time of discharge from the hospital for the first time (Rodgers et al., 2016b; Wilson Smith et al., 2018). In both studies, parents reported an increase in stress related to not feeling prepared to take care of their child at home after initial discharge (Gunter & Duke, 2018; Rodgers et al., 2016b; Wilson Smith et al., 2018). Rodgers et al. (2016b) found that out of 20 parents only 20% felt prepared and comfortable to take care of their child at home following a child's cancer diagnosis. This left 30% feeling unprepared and nervous for discharge, particularly about medication administration, care of the child's central line, and neutropenic precautions (Rodgers et al., 2016b).

### **Critical points and events.**

When a parent is experiencing a new diagnosis of childhood cancer, their awareness of the severity of the diagnosis, and the engagement in the current situation all become factors in the transition process (Meleis, 2010). However, in order for awareness and engagement to occur, a critical event also needs to occur (Meleis, 2010). Critical events are said to be scenarios that increase the awareness of the change, such as a serious diagnosis in a child (Meleis, 2000).

Three articles observed critical points and events that parents experience after their child is diagnosed with cancer (Gunter & Duke, 2018; Rodgers et al., 2016a; Rodgers et al., 2016b).

The literature review completed by Gunter & Duke (2018) discovered that parents reported that once the diagnosis was confirmed and they were aware of the treatment plan for the child, they felt as though they were living in a “permanent state of emergency” (p. 33). While parents and health care experts have identified that the state of being overwhelmed after diagnosis exists, Gunter & Duke (2018) mentioned that processing takes time, but no specific time period for adaptation was seen among their research. In addition, similar findings were mentioned in the literature review by Rodgers et al. (2016a). Rodgers et al. (2016a) found that emotional strain after diagnosis hindered parents’ ability to understand information, but no time frame for adaptation was mentioned either.

In a personal interview with Porter (January 15, 2019) it was reported that parents tended to show positive signs of adaptation within two to three months after the initial diagnosis. S. Porter stated that while parents were overwhelmed and in shock during and shortly after initial diagnosis, once they were able to go home and process the information on their own, they returned to the hospital or clinic as new ‘experts’ in their child’s cancer. In addition, she also opined that the stress of having a child with a life-threatening illness doesn’t go away, parents simply adapt to their ‘new normal’ (S. Porter, personal communication, January 15, 2019). Similarly, Rodgers et al. (2016b) found the diagnosis and treatment continued to be stressful even at twelve months leaving parents uncertain about what the diagnosis meant for their family and that they “needed to figure out their life” (p. 456-457) and to make necessary modifications about jobs, the child's school, and potentially, their homes and living arrangements (Rodgers et al., 2016b).

### **Transition Conditions**

A variety of components can either inhibit or facilitate a healthy transition. These transition conditions can be environmental or personal conditions that influence progress towards a healthy transition (Meleis, 2010). In this special population of families experiencing a devastating diagnosis of a child's cancer, education methods, individual considerations, and a lack of trust in the healthcare team were found in this literature review to be major elements that can influence an individual's progress.

Seventeen articles reviewed uncovered different aspects of transition conditions. Three main themes for transitional influencers were distinguished from the literature (a) education; (b) communication; (c) socioeconomic conditions. Most of the research that related to transition conditions, e.g. facilitators or inhibitors, was designed as qualitative studies (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Granek et al., 2012; Landier et al., 2016; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2018; Rodgers et al., 2016b). However, there was one mixed method literature review (Gunter & Duke, 2018) and six quantitative articles (Haugen et al., 2016; Kahn et al., 2017; Matutina, 2010; Rodgers et al., 2016a; Slone et al., 2013; Withycombe, Andam-Mejia, Dwyer, Slaven & Landier, 2016).

Participants in the qualitative studies were primarily parents (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Granek et al., 2012; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b), while other qualitative studies included teams of experts within the pediatric oncology specialty (Landier et al., 2016; Rodgers et al., 2018). Conversely, most of the quantitative study participants consisted of registered nurses, advanced practice registered nurses, and pediatric oncologists (Haugen et al., 2016; Kahn et al., 2017; Rodgers et al., 2016a; Slone et al., 2013; Withycombe et al., 2016). In the following sections, transition conditions

such as personal and community conditions from the literature will be identified. The progression from a state of well health to illness is directly influenced by the individual transition conditions (Meleis, 2000). There was a wide variation of prior knowledge, socioeconomic status, family dynamic, and emotional coping abilities among families and parents, therefore, it is important that healthcare providers know of the conditions that influence transition within the affected families. This knowledge is essential so that the providers can best address and facilitate the individual and family's transition experience (Meleis, 2010).

### **Personal conditions.**

Meleis (2000) identified that personal conditions such as cultural beliefs, socioeconomic status, and knowledge are situations that can ultimately influence the way individuals advance through the transition process. Evidence related to effective and ineffective methods of educating patients and families emerged from both quantitative and qualitative studies. This evidence is vital to clarify, because if parents don't understand the information being presented, they won't be able to use it to adapt to the critical situations occurring in the family or to provide care for their child (Aburn & Gott, 2014; Gunter & Duke, 2018; Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Matutina, 2010; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Rodgers et al., 2018; Slone et al., 2013; Withycombe et al., 2016). The literature also exposed other influences of parental learning, such as the reading level to engage in education, native language, and individual learning needs (Aburn & Gott, 2014; Matutina, 2010; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone et al., 2013; Withycombe et al., 2016).

Rodgers et al. (2016b) conducted 20 parent interviews within the year after their child's initial diagnosis with the goal of exploring the actual and preferred educational experience of the parents (Rodgers et al., 2016b). During these individual parent interviews, Rodgers et al.

(2016b) found that the parents' reactions and initial emotions inhibited their ability to process information that was being delivered. Parents also reported that their ability to process this important information was affected by how much or how quickly information was being delivered by the health care team (Rodgers et al., 2016b). Parents stated that they were able to process the information more effectively when information was paced or spread out during their inpatient stay (Rodgers et al., 2016b). One of the main themes that the researchers were able to identify in the literature review was that parents of children with cancer need appropriate time to process the needs of the diagnosis before teaching about crucial information can occur (Rodgers et al., 2016a). However, they also concluded that no specific time period for effective teaching was established (Rodgers et al., 2016a).

Language barriers and lacking language competencies were found in two studies to inhibit effective parent education (Rodgers et al., 2016a; Slone et al., 2013). Slone et al. (2013) administered a web-based survey to pediatric oncologists to determine their assessment of facility resources for new cancer diagnosis education and the availability of language appropriate materials available for use. This group of 429 pediatric oncologists reported that language barriers have seemed to negatively impact the parents' understanding and limited their assimilation into other appropriate medical services (Slone et al., 2013). Some facilities don't have access to suitable language services and in general, non-academic institutions have fewer resources for non-English speaking patients as opposed to academic institutions (Slone et al., 2013). This situation was attributed to the low volume of non-English speaking patients at non-academic institutions, versus the high volume of non-English speaking patients at larger academic institutions (Slone et al., 2013). On the other hand, the problem may reside with the respondents' knowledge of resources available for non-English speaking patients. Slone et al.

(2013) calculated that only two-thirds of responding pediatric oncologists were aware of the availability of important education documents in languages other than English.

In the parent interviews, Aburn & Gott (2014) found that overall, parents were satisfied with education when it was presented in an individualized manner, and when education was done consistently by one health care provider such as a nurse (Aburn & Gott, 2014). However, the parents preferred the format for the most current information be consistently delivered with less medical language (Aburn & Gott, 2014). This preference was supported by parental reports that the learning materials utilized for teaching are too complex and consist of too much medical jargon (Aburn & Gott, 2012; Rodgers et al., 2016b; Matutina, 2010). During their review of 83 articles, Rodgers et al. (2016b) identified the parents desire to learn things in ‘layman’s terms’ as opposed to medical language. Parent 17 stated “...everyone here explains things on a normal person’s level” (p. 455). This aligns with the findings of Matutina (2010) and the American National Cancer Institute, which recommended printed education materials should be at the reading level of a typical ten or 11-year-old. Progression towards a healthy transition is inhibited when education isn’t provided in a way that parents can use it.

While parents have reported that they have particular learning styles, (Matutina, 2010; Rodgers et al., 2016b), it was also found that assessment of individual learning needs was not frequently initiated (Rodgers et al., 2016b; S. Porter, personal communication, January 15, 2019). Porter stated (personal communication January 15, 2019) that while a basic learning needs assessment is completed by nurses during admission in her institutions, those results aren’t referenced or utilized when it comes time to educate the families. This perspective aligns with findings from Rodgers et al. (2016b) in which parent participants stated that they did not recall ever being asked about their learning styles. The ability of parents to process and use

information can be hindered when teaching content is not presented in a way that parents can understand. Subsequently this has the potential to inhibit a successful, and healthy transition (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016).

Socioeconomic status (Gage-Bouchard et al., 2013) and family dynamics (Granek et al., 2012; Patterson Kelly & Ganong, 2011) were also observed in the literature as personal conditions that posed potential barriers to learning and a healthy transition process. Family dynamics vary from family to family and need to be considered when assessing learning readiness and parent coping abilities (Granek et al., 2012; Patterson Kelly & Ganong, 2011). For example, Patterson Kelly & Ganong (2011) conducted interviews with 13 parents of six stepfamilies to explain the impact of a childhood cancer diagnosis on parental relationships in stepfamilies. This study found that the diagnosis resulted in a significant alteration in parental relationships, which ultimately transformed prior family boundaries by altering co-parenting dynamics, role expectations, and the role of the step parent in the child's care (Patterson Kelly & Ganong, 2011). Ultimately, the altered relationships prevented healthy coping mechanisms and contributed to further instability (Patterson Kelly & Ganong, 2011). In the stepfamily dynamic, more adults are potentially involved in decision making, which can result in heightened tension between former partners (Patterson Kelly & Ganong, 2011). They found that combining new and former spouses tend to simply make an already tense situation more stressful and hinders coping (Patterson Kelly & Ganong, 2011). Parents mentioned that the overall stress of the new cancer diagnosis, combined with any lingering resentment from the former relationship had the potential to adversely affect the ability of parents to work together and safely care for their child (Patterson Kelly & Ganong, 2011).



While Patterson Kelly & Ganong (2011) found that more adults making decisions within the family increased stress, having fewer parents to carry the burden also poses a challenge to transition (Granek et al., 2012). Granek et al. (2012) conducted a qualitative study to explore the experience of single parents (n=29) of children with cancer. These parents identified emotional, informational, and physical tasks involved with being the only caregiver, such as needing to act as the ‘emotional barometer’ for their families and needing to put on a façade that everything was okay to make other family members feel okay (Granek et al., 2012). One mother stated that her brother and sister had recently moved in with her and the child to help with cares. But, the mother felt that she had to hide her emotions and “take control of it” to show them things would be okay to prevent any further distress for the child (Granek et al., 2012).

#### **Community conditions.**

Community conditions are circumstances within a community that influence the parents’ advancement through the transition process (Meleis, 2000). Community resources and social conditions are examples of community conditions that have this influential potential in either a positive or negative manner. For the purpose of this project, the resources provided by health care providers was considered community and social resources.

Communication between parents and health care providers, and amongst health care providers can either inhibit or facilitate learning and a healthy transition in a parent experiencing a new diagnosis of childhood cancer (Aburn & Gott, 2014; Gunter & Duke, 2018; Withycombe et al., 2016). The literature gathered by Gunter & Duke (2018) stated that a solid and encouraging relationship between the parents, patient, and healthcare team was helpful to facilitate healthy coping behaviors. However, they found that families often felt that the healthcare team was withholding important information from them, or not treating them with

respect (Gunter & Duke, 2018). These feelings ultimately resulted in a lack of trust and immense frustration which can influence transition experience and hinder a healthy transition from occurring (Gunter & Duke, 2018). Kerr et al. (2007) noted that when physicians weren't available for further questions, it left some parents feeling frustrated and led to further distrust in the healthcare team (as cited in Gunter & Duke, 2018). This feeling of frustration was mirrored in the study by Aburn & Gott (2014), which included mixed parental feelings about support, frustration, trust, and partnership between the provider and family (Aburn & Gott, 2014). The frustrated parents reported that the source of their feelings was associated with "not being kept in the loop" (Aburn & Gott, 2014, p. 246). One father gave an example of this phenomenon when the providers changed doses within his son's medication protocol, and the parents wouldn't be informed before they picked up the refill of the medication at the pharmacy (Aburn & Gott, 2014). He reported that this experience led to frustration and lack of trust in the healthcare team (Aburn & Gott, 2014).

Lack of communication amongst the healthcare team was also uncovered as a barrier for parents' healthy transition. For example, families expressed frustration and inhibited coping when they were presented teaching components multiple times, in different ways, and by different providers (Withycombe et al., 2016). Withycombe et al. (2016) completed a quantitative study of a group of registered nurses and advanced practice nurses within 201 COG registered institutions. The participants completed a survey to determine the current practice regarding patient and family education upon a new diagnosis of cancer. This study discovered that providers used a wide variety of methods to communicate within the team as to the education completed, and that which still needed to be addressed (Withycombe et al., 2016). Patterson Kelly & Ganong (2011) stated that a lack of clear communication among the team was

twice as likely to result in a delayed discharge of the patient, resulting in increased parent frustration (Withycombe et al., 2016). Other discrepancies were found in team communication, such as poor communication techniques and incomplete or inadequate documentation practices (Withycombe et al., 2016). All of these things result in a decreased quality of care and a lack of trust in the healthcare team (Withycombe et al., 2016).

Financial resources or lack thereof was another aspect of community conditions that affected parents coping with the cancer diagnosis of their child. For example, 79% percent of parents also reported stress related to financial strain (Granek et al., 2012). The majority of parents in this study described their financial condition as ‘dire,’ and many didn’t have financial savings before the diagnosis (Granek et al., 2012). Parents reported that they had to stop working to care for their sick child, and 24% reported fear of homelessness due to not being able to pay mortgage or rent (Granek et al., 2012). A staggering 41% of parents reported having to change residences to be closer to the hospital or having to move into more appropriate living conditions for their sick child (Granek et al., 2012). Granek et al. (2012) concluded that these cumulative stresses have a continuing and magnifying impact over an individual’s life and coping abilities (Granek et al., 2012).

### **Patterns of Response**

According to the transitions theory, evolvment of a transition can be viewed and examined through a group of expected results known as patterns of response (Meleis, 2000). These patterns of response are signs of a healthy transition (Meleis, 2010). Transitions can take multiple paths and unfold over a period of time. Thus the competence to identify and recognize the standard signals that mark the route of transition vital to the role of the nurses and other team members involved in patient and family care (Meleis, 2000). There are a variety of indicators, or

patterns of response, of a healthy transition and Meleis (2000) divided them into two groups: process indicators and outcome indicators. The following will present the literature relative to process and outcome indicators of the health/illness transition in parents of children newly diagnosed with cancer.

Most of the research that related to patterns of response in parents of a child with cancer was designed as qualitative studies (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Granek et al., 2012; Kelly & Kelly, 2013; Rodgers et al., 2016b; Sigurdardottir et al., 2014). However, there was one integrative literature review identified (Cerqueira, Pereira, Barbieri Figueiredo, 2016). The participants of these studies were primarily parents, and the sample sizes were relatively small (ranged 12-29) (Aburn & Gott, 2014; Granek et al., 2012; Kelly & Kelly, 2013; Rodgers et al., (2016b).

Cerqueira et al. (2016) completed an integrative literature review of 18 articles with a wide range of methodologies. The purpose of this study was to identify patterns of response of parents with children newly diagnosed with cancer (Cerqueira et al., 2016). Through their review of the literature, they identified four major themes: (a) caring for one's child with cancer, (b) becoming a partner in caring for one's child, (c) caring for the family, and (d) living with one's child with cancer (Cerqueira et al., 2016). However, only two of the four major themes were uncovered in the other six articles examined for this project. These two themes were caring for the child and living with the diagnosis (Aburn & Gott, 2014; Cerqueira et al., 2016; Gage-Bouchard et al., 2013; Granek et al., 2012; Kelly & Kelly, 2013; Rodgers et al., 2016b; Sigurdardottir et al., 2014). The reviewed articles identified both positive and negative patterns of response in parents of children with childhood cancer. See Figure 1 for further detail of positive patterns of response identified in this review of literature.

Figure 1

<b>Positive Patterns of Response</b>	
<b>Caring for Your Child with Cancer</b>	<b>Living with Your Child's Cancer Diagnosis</b>
<ul style="list-style-type: none"> <li>• Identifying changes in the child's physical condition</li> <li>• Symptom Management</li> <li>• Monitoring features of illness and treatment</li> <li>• Protecting the child's best interest</li> <li>• Advocating for your child</li> <li>• Finding further education and support materials</li> <li>• Searching for education about the diagnosis and treatment</li> <li>• Using resources available</li> <li>• Protecting the child by preventing exposure to infections.</li> <li>• Protecting the child from physical injury</li> </ul>	<ul style="list-style-type: none"> <li>• Maintaining the family routine</li> <li>• Managing family finances</li> <li>• Requesting help from other family members</li> <li>• Showing confidence in one's abilities</li> <li>• Learning to live with the diagnosis</li> <li>• Recognizing changes in life</li> <li>• Identifying daily troubles</li> <li>• Accepting the new responsibilities as a caregiver of a child with cancer</li> </ul>

### **Process indicators.**

Process indicators are elements that guide the individual into either a healthy or negative transition (Meleis, 2000). The literature identified initial emotional reactions, coping, and interactions as being process indicators for parents of children newly diagnosed with cancer (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Rodgers et al., 2016b; Sigurdardottir et al., 2014).

Parents and caregivers widely describe the act of 'shutting down' throughout the literature (Gage-Bouchard et al., 2013; Rodgers et al., 2016b; Sigurdardottir et al., 2014). Rodgers et al. (2016b) interviewed 20 parents in the months after their child's initial diagnosis to describe the parents' initial emotional reaction and state of mind after the diagnosis (Rodgers et al., 2016b). These emotional states influence how the parent progresses through the health/illness transition. Some parents in this study described shutting down immediately after hearing the word "cancer"

and not hearing anything else after that, while others reported other initial feelings such as sadness and stress after hearing the diagnosis (Rodgers et al., 2016b). Similarly, Sigurdardottir et al. (2014) found that parents' initial shock after diagnosis ultimately impaired their ability to hear and process information such as important education and instructions for the care of their child. The initial shock that parents and caregivers experience was also found to inhibit coping strategies necessary to absorb information (Gage-Bouchard et al., 2013). One mother from the study completed by Rodgers et al. (2016b) stated that after the diagnosis and about a week in the hospital, she "blanked out" once discharge teaching started.

However, once more time had passed from the initial diagnosis, parents were able to cope sufficiently to acquire a new vocabulary and gain a new understanding of complex medical skills (Aburn & Gott, 2014). Once parents gain appropriate knowledge, they tend to feel connected, and more confident in the situation they're experiencing. There is a flip side to parents gaining more knowledge. Research found that once parents have increased their own knowledge of medical treatment and processes, they become aware that healthcare professionals can make mistakes. This awareness prompts them to remain vigilant, and to assume the role of being an advocate for their child (Cerqueira et al., 2016; Kelly & Kelly, 2013). Cerqueira et al. (2016) concluded that parents often make it their mission to protect their vulnerable child's rights and best interest. By taking on the role of advocate, the parents are showing a positive pattern of response in the health/illness transition.

Even though parents are taking on additional roles as a caregiver and advocate for their child with cancer, they also must learn to live and adapt to their child's diagnosis, all the while maintaining the other demands of being a parent (Cerqueira et al., 2016; Granek et al., 2012;

Kelly & Kelly, 2013). Parental assumption of new roles is evidence of a process indicator and positive coping mechanisms related to becoming situated within a new ‘normal.’

Parents who participated in observations and interviews in the study by Kelly & Kelly (2013) described parenting after their child’s diagnosis as a ‘balancing act.’ Parenting after a new diagnosis not only involves adding the specialized care of the child with cancer, but also maintaining previous obligations of getting siblings to and from school or childcare, household tasks, and maintaining a financial income (Cerqueira et al., 2016; Kelly & Kelly, 2013). Parents involved in the study by Kelly & Kelly (2013) reported that when the role became too burdensome, they requested help from family members or friends for assistance with transportation or childcare of the siblings. Cerqueira et al. (2016) recognized parents who reach out to other family members for assistance, as using a positive coping mechanism and classified it as a positive pattern of response related to the task of living with the child’s cancer diagnosis.

### **Outcome indicators.**

Outcome indicators are behaviors or skills that demonstrate whether a healthy transition has or has not occurred (Meleis, 2010). These behaviors or skills often times include embracing a new identity, or mastering new skills (Meleis, 2000). Parents and loved ones’ fear for the child’s life, as a diagnosis of childhood cancer is a serious illness with unexpected events (Cerqueira et al., 2016). Therefore, an outcome indicator for a positive pattern of response could be when parents learn to live in their ‘new normal’ and embrace the coping strategies, and technical medical skills learned to continue with their day to day lives (Cerqueira et al., 2016).

Cerqueira et al. (2016) stated it’s the parents’ job to adapt and assist the child through the process of healing from the disease and its treatment that may continue into the indefinite future. The time it takes for each family to reach the “new normal stage” is unique to the family. For

example, Kelly & Kelly (2013) completed observations of eight families throughout 22 months with the intent of describing the day to day management of this unique population. Some of the skills parents reported learning and using included vigilance of their child for early identification of fevers, and other potential side effects of the child's treatment (Kelly & Kelly, 2013). One mother stated that within a few months after initial diagnosis, she was able to understand the reasoning for treatment decisions and use that knowledge to monitor her child for potential future events (Kelly & Kelly, 2013). On the other hand, some parents reported feeling like 'experts' once the feeling of shock and fear dissipated and accurate education was delivered and absorbed (Aburn & Gott, 2014).

Parents described that processing information may have been delayed until after going home when they were able to use that information to care for their child (Rodgers et al., 2016b). But the parents also reported recognizing their need for additional information shortly after discharge, which prompted them to seek additional information from healthcare providers and cancer organizations to assist them to better care for their child (Rodgers et al., 2016b). In a personal communication, Porter (January 15, 2019) stated that parents are often in shock at the time of diagnosis however, within about a month they report that they are now 'in control' of their emotions, knowledge, and full partners in their child's care. This identification of skill and knowledge is an example of an outcome indicator for a positive pattern of response.

### **Nursing Therapeutics**

Nursing therapeutics, or nursing interventions, aim to restore, improve, and facilitate a healthy transition (Meleis, 2010). The findings of this literature review have identified a wide variety of nursing therapeutics that can help parents of children newly diagnosed with cancer transition from a state of well health to illness (Aburn & Gott, 2014; Gunter & Duke, 2018;



Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Matutina, 2010; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Rodgers et al., 2018; Sirurdardottir et al., 2014; Withycombe et al., 2016). Appropriate nursing intervention can facilitate families' healthy transition.

Most of the research that related to nursing intervention considerations to assist parents through the period of transition was designed as quantitative studies, with a sample size ranging from 21 to 422 parent, provider, or institutional participants (Haugen et al., 2016; Kahn et al., 2017; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Sigurdardottir et al., 2014; Slone et al., 2013; Withycombe et al., 2016; Wilson Smith et al., 2018). Studies predominantly consisted of structured questionnaires (Haugen et al., 2016; Slone et al., 2013; Withycombe et al., 2016) and cohort studies with pre and post-test questionnaires to determine the effectiveness of the intervention (Kahn et al., 2017; Matutina et al., 2010; Sigurdardottir et al., 2014; Wilson Smith et al., 2018).

The participants in the quantitative studies were primarily health care providers such as registered nurses, advanced practice nurses, and physicians (Haugen et al., 2016; Kahn et al., 2017; Rodgers et al., 2018; Slone et al., 2013; Withycombe et al., 2016). The health care provider participants were currently working in a clinic or hospital pediatric oncology setting (Haugen et al., 2016; Kahn et al., 2017; Rodgers et al., 2018; Slone et al., 2013; Withycombe et al., 2016). One study surveyed 201 COG institutions in the United States, and (Withycombe et al., 2016) three articles involved parent participants (Matutina, 2010; Sigurdardottir et al., 2014; Wilson Smith et al., 2018). The data was collected in the qualitative studies by one expert panel consensus from the COG (Landier et al., 2016), and conducting four face to face interviews with an interpretive descriptive design (Aburn & Gott, 20124; Rodgers et al., 2016b; Patterson Kelly

& Ganong, 2011; Patterson Kelly et al., 2018). Additionally, there were two integrative and systematic literature reviews that addressed nursing intervention considerations (Gunter & Duke, 2018; Rodgers et al., 2016a).

Common themes related to nursing interventions among the quantitative studies include (a) formal staff training, (b) education methods and materials, (c) individualization of education, (d) what content should be taught, (e) when to teach, (f) language and, (g) assessment of learner understanding (Haugen et al., 2016; Kahn et al., 2017; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Sigurdardottir et al., 2014; Slone et al., 2013; Withycombe et al., 2016; Wilson Smith et al., 2018). The interventions explored included an interactive website, structured teaching methods, an interactive inpatient education tracking system, and the repetition of consistent information to the parents (Haugen et al., 2016; Kahn et al., 2017; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Sigurdardottir et al., 2014; Slone et al., 2013; Withycombe et al., 2016; Wilson Smith et al., 2018).

While most of the literature consisted of quantitative studies, there were five qualitative studies identified that addressed nursing intervention considerations for this special population (Aburn & Gott, 2014; Landier et al., 2016; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b). The participants primarily consisted of parents (n=12 to 20) (Aburn & Gott, 2014; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b) whereas one study consisted of an expert panel of health care providers (Landier et al., 2016). The qualitative studies, however, do have a limitation of small sample sizes (Aburn & Gott, 2014; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b). Common themes related to nursing interventions emerging from the qualitative research focused primarily on (a) assessment of learner understanding, (b) what content should be taught, and (c)

language (Aburn & Gott, 2014; Landier et al., 2016; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b). The interventions explored included interactive education methods, delivering structured, yet individualized information, and easily accessible outpatient materials for emergency situations (Aburn & Gott, 2014; Landier et al., 2016; Patterson Kelly & Ganong, 2011; Patterson Kelly et al., 2018; Rodgers et al., 2016b).

Meleis (2000) identified three therapeutic measures that are pertinent to therapeutic nursing interventions: (a) assessment of readiness, (b) preparation for transition and, (c) role supplementation. Assessment of readiness requires a full assessment of each transition condition to understand client readiness (Meleis, 2010). While assessment of learner readiness was observed in the literature, it has been critiqued in previous sections of the paper and therefore will not be mentioned in this sub-section. Refer to the *transition conditions* section for further information. Findings related to nursing interventions that surfaced in the literature will be organized by two of the measures, preparation for the transition, and role supplementation in the following sub sub-sections.

### **Preparation for transition.**

The preparation for transition measure in nursing therapeutics focuses on generating the best possible condition for the person undergoing the transition itself (Meleis, 2010). Meleis (2010) identified education as one of the primary modalities for creating this optimal condition. Ample preparation for a transition also requires sufficient time and an appropriate environment to promote the healthy assumption of new roles and responsibilities (Meleis, 2000). In the following text, optimal conditions and education topics are identified as being essential aspects of parent preparation for transition. Without these crucial components, parents may not be able to achieve a healthy transition from health to illness.

*Creating optimal conditions.*

Optimal conditions are needed to promote a healthy transition from health to illness in parents of children newly diagnosed with cancer. According to the literature, conditions such as timing and location of education, and appropriate staff training regarding appropriate education methods are all important components of creating optimal learning conditions (Aburn & Gott, 2014; Gunter & Duke, 2018; Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone et al., 2013; Wilson Smith et al., 2018; Withycombe et al., 2016).

The literature demonstrated the significance of proper education for parents and families of children newly diagnosed with childhood cancer (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). Without effective education, parents may not be able to successfully progress through the health/illness transition or safely take care of their child at home. Due to the importance of adequate education, the literature states that it's imperative that the individuals responsible for teaching are identified and appropriately trained (Kahn et al., 2017; Landier et al., 2016; Slone et al., 2013; Withycombe et al., 2016). Landier et al. (2016) recommended that all healthcare providers should receive formal training about the practice and principles of patient and family education. Likewise, Kahn et al. (2017) suggested that before being able to complete any clinical duties, oncoming staff should receive formal instruction about effective teaching and communication methods. However, there is no recommendation regarding what this formal education should specifically include. Withycombe et al. (2016) found some reassurance with 90% of COG institutions provided some sort of formal training to

prepare nurses to deliver this vital information. Sixty-seven percent of these institutions reported that formal classes or workshops were available to train staff (Withycombe et al., 2016).

Educating patients often falls to nurses at various level of practice. In a survey of 68 pediatric oncology health care providers from nine institutions, 58% reported that the registered nurses were solely responsible for patient education about home medications during clinic visits (Kahn et al., 2017). Conversely, in another survey of health care providers from 201 COG affiliated institutions, 32% reported that advanced practice nurses were responsible for bedside education and that only 25% of registered nurses completed education (Withycombe et al., 2016).

It is not only important for the specific providers responsible for education to be identified, but also that there is consistency with the individual who educates parents. Withycombe et al. (2016) also found 34% of providers from this study also reported that one single health care provider was responsible for parent education. Similarly, pediatric oncologists from a study by Slone et al. (2013) also noted one key educator in the process. These findings are reassuring, because they closely align with recommendations from the expert panel in Landier et al. (2016) that one person be responsible and held accountable for education to improve consistency of care of patients and parents. Gunter & Duke (2018) also emphasized the importance of having one key person in charge of education coordination to ensure consistency to reduce uncertainty or lack of clarity as to what had or had not been taught (Gunter & Duke, 2018). However, Landier et al. (2016) also recommended that all team members be aware of the content that was taught to reduce repeating unnecessary topics and frustrating the parents.

Effective communication builds trust, therefore, providers need to concentrate on effective communication with each other (Gunter & Duke, 2018). A variety of communication

methods were reportedly used to share the education which been taught, and that which still needed to be addressed (Wilson Smith et al. 2018; Withycombe et al., 2016). Withycombe et al. (2016) reported that 67% of the 201 COG institutions utilized checklists, forms, or documentation in discharge planning. Three other communication strategies were reported in this study (a) end of shift report, (b) informal modes of communication such as sticky notes and, (c) whiteboards or another similar device in the patient room (Withycombe et al., 2016). S. Porter also reported the use of documentation in patient care notes and discharge summaries in her institution (personal communication, January 15, 2019).

As mentioned previously, if a parent is provided with teaching materials in a language that they can't understand, effective learning might not take place (Matutina, 2010). However, beyond the language barrier and reading level of learning materials, it's reported that education should take place at certain times throughout the transition process to ensure a healthy transitional experience (Gunter & Duke, 2018). Aburn & Gott (2014) found that parents described a discussion with the health care team at the time of diagnosis as helpful because this interaction dissipated fears about their child potentially dying, and allowed parents to move forward, and further process the information. Moreover, presentation of certain types of education at transitional periods can make a meaningful impact on the parents' uncertainty and anxiety, thus facilitating a healthy adaptation (Gunter & Duke, 2018).

In a personal interview, Samantha Porter stated information should be presented immediately, but healthcare providers should also understand that the information will need to be repeated until sufficient understanding is demonstrated by the caregivers (personal communication, January 15, 2019). The idea of consistently repeating and reinforcing information was also in studies by Rodgers et al. (2016b) and Flury et al. (2011). Nurses

acknowledged the importance of repetition of content in the Rodgers et al. (2018) study.

Different reactions and coping methods influence how parents process information, ultimately affecting their learning ability (Rodgers et al., 2016a). Nevertheless, parents stated that when information was paced or spread out during their inpatient stay, they were able to process the information more effectively (Rodgers et al., 2016b). Gunter & Duke (2018) also concluded that administering education and accompanying resources was more effective in building parent confidence in their knowledge when it was conducted in a non-rushed manner, but also in short, frequent sessions.

Slone et al. (2013) and Rodgers et al. (2016a) found pediatric oncologists also concurred with the importance of early education. However, Rodgers et al. (2016a) additionally found that parents needed appropriate time to process the initial diagnosis before active learning could occur. Although they also pointed out that an optimal time frame for delivery of education has not been established (Rodgers et al., 2016a). Nonetheless, health care providers in the study by Kahn et al. (2017) did recommend a specific, or designated time be set aside for parent and patient teaching.

S. Porter also pointed out that the location of where teaching occurs is important (personal communication, January 15, 2019). She stated that during initial inpatient teaching in her institution, the parents are taken to a quiet, separate room away from the child's main hospital room (S. Porter, personal communication, January 15, 2019). Often, there will be a Child Life Specialist to interact and play with the child, so she (the Nurse Practitioner) can have time discussing information one on one with the parents. The purpose of this is that often, if the child is present during this initial teaching, they can be more of a distraction, or barrier for the parents (S. Porter, personal communication, January 15, 2019). By completing private teaching with the

parents first and waiting to bring the child into the conversation tends to allow the parents to process relevant information before the added stress of explaining what is going on to the patient occurs (S. Porter, personal communication, January 15, 2019).

***Education content.***

The literature presented a variety of actual and desired education topics for parents of children newly diagnosed with cancer (Aburn & Gott, 2014; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2016a; Rodgers et al., 2016b; Rodgers et al., 2018; Withycombe et al., 2016). The topics were identified by expert panels of nurses and pediatric oncologists (Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Withycombe et al., 2016), but also by parents who have gone through or were currently going through the experience of having a child with cancer (Aburn & Gott, 2014; Rodgers et al., 2016b; Wilson Smith et al., 2018).

While a variety of different topics were identified in the research, the most common topic related to critical teaching points prior to initial discharge was parental actions necessary when the child gets a fever (Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2016b; Rodgers et al., 2018; Withycombe et al., 2016). In a survey of 201 COG affiliated institutions, 99% of participants identified fever as the education topic necessary for primary teaching (Withycombe et al., 2016). In this same survey, 97% identified signs and symptoms of infection, 97% identified how and when to call the health care team, 96% identified home medication regimens, 94% identified the explanation of the child's diagnosis, and 90% identified the need for education pertaining to chemotherapy and radiation side effects as important initial education topics to be addressed prior to discharge (Withycomb et al., 2016). Conversely, parents reported being more interested in learning about the disease, prognosis, and treatment plan as the first education topics received upon diagnosis (Rodgers et al., 2016b).



Haugen et al. (2016) utilized Delphi methodology to gather professional opinion about significant education content among pediatric oncology experts affiliated with the COG. This study had an 80% participation rate and consisted of 100 pediatric oncology experts (Haugen et al., 2016). Questionnaires were distributed, and participants were asked to rank 20 different education topics on a 7-point Likert-like scale (Haugen et al., 2016). Diagnosis information was classified as the highest teaching priority with an average score of 6.91 with a fever following at 6.89 (Haugen et al., 2016). Psychosocial concerns and fertility prevention were ranked as least important with scores of 5.64 and 5.66 (Haugen et al., 2016). Overall, Haugen et al. (2016) presented a strong agreement that fever, diagnosis, and education regarding the child's treatment plan were priority teaching topics. This group of experts also identified that additional education needs to be varied depending on the child's diagnosis (Haugen et al., 2016). For example, a patient with a central nervous system tumor would require specific education about increased intracranial pressure, safety, and post-operative wound care (Haugen et al., 2016).

The experts questioned in the study by Haugen et al. (2016) weren't alone when they recommended that education be adjusted according to patient diagnosis. Landier et al. (2016) also stated that varied diagnoses, treatment protocols, and age should be taken into consideration when determining what education content to present to the parent and child. Along with educational topics recommended by Haugen et al. (2016), this group also mentioned the importance of an appropriate description of the disease and its etiology, including information regarding the treatment plan, possible complications, and the child's prognosis (Landier et al., 2016).

Rodgers et al. (2018) identified primary, secondary, and tertiary education topics for parents of children newly diagnosed with cancer through a panel of 19 nurses, and two patient

advocates. The panel assessed current educational checklists utilized in COG facilities and analyzed expert recommendations. The goal of this panel was to create a standardized checklist that would guide nurses in patient education (Rodgers et al., 2018). The panel's identification of primary, secondary, and tertiary education topics allowed them to create three different checklists for patient education (Rodgers et al., 2018).

Primary topics included evidence-based content to be completed before initial discharge for the parents to safely care for their child at home (Rodgers et al., 2018). These topics consisted of essential things such as (a) the child's diagnosis; (b) when and who to call for help; (c) fever; (d) how to take a temperature; (e) good handwashing; (f) how to prevent infection; (g) important information regarding home medications (Rodgers et al., 2018). Secondary topics were identified as items that parents needed to know within a month after initial diagnosis (Rodgers et al., 2018). These topics included (a) the definition of cancer; (b) treatment side effects; (c) care of the central line; (d) bathing; (e) nutrition; (f) environmental precautions (Rodgers et al., 2018). Then, tertiary topics consisted of information that needed to be presented before the end of treatment (Rodgers et al., 2018). This checklist included information about vaccinations, coping and life skills, sexual activity, and further tests and procedures (Rodgers et al., 2018).

While the large majority of the research findings relative to recommended education topics emerged from pediatric oncology experts, parent participants from Rodgers et al. (2016b) identified a range of desired education topics from their point of view. Topics recommended by parents included (a) duration of treatment; (b) the length of hospitalizations; (c) the likelihood of readmissions; (d) chemotherapy precautions for family members; (e) activity restrictions; (f) clinic routine; (g) how to give their young child oral medications were identified (Rodgers et al.,

2016b). In 12 parent interviews conducted by Aburn & Gott (2014) it was said that a "white education folder" was a common education method that had both good and bad components. This folder was given to all families when their child was diagnosed with cancer and contained information about the child's diagnosis, necessary care at home, symptoms to monitor, and what to do in an emergency situation (Aburn & Gott, 2014). Parents reported that while it was beneficial to have all the information that they needed in one place, others found that too much medical jargon was used, the information was out of date, and it tended to be irrelevant to their situation (Aburn & Gott, 2014). The parent participant group recommended information provided be relevant at the time of diagnosis, use less medical language, and routinely updated content based on the phase of treatment the child was in (Aburn & Gott, 2014).

Another prominent topic in the literature that pertains to educational content is the idea of standardized versus individualized teaching plans (Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2016b). The literature reported different perspectives as to which approach is more effective. Rodgers et al. (2016b) found a distinct need for individualization of education among parents. Tailoring information based on the amount of desired information, child diagnosis, preferred learning needs, and parental preference enables the parents to gain some control and to process the information in the best possible way (Kahn et al., 2017; Rodgers et al., 2016b). When a parent receives information in the most appropriate way, it can facilitate a healthy transition during the critical event such as a new diagnosis of childhood cancer. Porter (personal communication January 15, 2019) confirmed this idea and suggested that giving parents back as much control as possible facilitates a healthy transition from an overwhelmed and scared parent into being one who is fully functioning and well educated to care for their child with complex needs.

On the other hand, Kahn et al. (2017) completed a prospective cohort study that solicited the thoughts of 68 nurse practitioners, physician assistants, and registered nurses to determine the variability of educational methods and materials about oral chemotherapy for parents of children newly diagnosed with ALL. This study found that no standard curriculum for teaching this special population seemed to exist, and only 25% of health care provider participants reported a need for standard teaching materials (Kahn et al., 2017). An expert panel from the COG bridged the two perspectives. This expert panel from the COG's nursing discipline gathered to review the literature and report evidence-based recommendations regarding patient and family education practices for children newly diagnosed with cancer (Landier et al., 2016). The group identified the need to standardize educational content but recommended that an individualized approach to delivering the information would improve the educational outcomes (Landier et al., 2016). In this scenario, important topics pertaining to diagnosis and treatment, as well as coping strategies and safe care of the child would be standardized, but assessments of individual parent needs would be completed to ensure teaching methods were implemented to accomplish effective learning (Haugen et al., 2016; Landier et al., 2016).

### **Role supplementation.**

The final measure of nursing therapeutics is role supplementation (Meleis, 2000). Role supplementation is the actual transfer of information and offers of support that parents need to be able to anticipate the behaviors, feelings, and goals involved in the role of a parent with a child who has cancer. Education may be the key to encouraging parents to successfully adapt and develop positive coping strategies while progressing through the health/illness transition (Gunter & Duke, 2018). Without appropriate and adequate education, parents might not be able to experience a positive health/illness transition, which could ultimately have a negative influence

on the safety of the child. The focus of this sub sub-section is on education interventions that have been created and tested by parents and health care providers (Matutina, 2010; Sigurdardottir et al., 2014; Wilson Smith et al., 2018).

Matutina (2010) created educational information for parents of children newly diagnosed with cancer in an easy to read and readily accessible format. Overall, the education materials consist of laminated wallet cards and refrigerator magnets (Matutina, 2010). The fridge magnet listed vital information such as when to call the doctor and important contact numbers and instructions (Matutina, 2010). This magnet included colorful images, and easy to read bullet points with all the pertinent information (Matutina, 2010). This magnet was also produced as a laminated wallet card to accompany an emergency room card that contained vital information to refer to if their child needs to be seen in an emergency department (Matutina, 2010). This information consists of the child's name, diagnosis, and any special instructions for that child (Matutina, 2010). The parents were given the magnet and two wallet cards and advised to place the magnet in an easy to access location should their child become sick (Matutina, 2010). They were also advised to always carry the wallet cards with them and use them if questions came up, or if they needed to take their child to the emergency room (Matutina, 2010). Parents were taught about these tools using a one-on-one instruction method by the nurses in the pediatric oncology clinic (Matutina, 2010). This one-on-one instruction method was designed to meet cognitive and affective learning objectives by allowing parents to express feelings, and ask questions (Matutina, 2010). This instruction method did have limitations throughout this study as it was more labor intensive for the ambulatory care nurses who may be caring for up to three patients at a time (Matutina, 2010). Matutina (2010) recommended that the nurses needed to be allowed sufficient time to spend with each family during one-on-one teaching. Matutina (2010)

assessed parents' achieved knowledge level with post-tests and questioning and discovered parents had an overall positive response to the teaching intervention. Matutina (2010) concluded that this intervention has the potential to improve patient safety, patient-provider communication, and improve the stress levels in parents.

While the intervention by Matutina (2010) focused on ambulatory care education, the educational intervention developed by Wilson Smith et al. (2018) focused on inpatient education to be completed before the child's first discharge home after diagnosis. Wilson Smith et al. (2018) created this education program with the goal of developing an interactive and engaging education method for patients and caregivers. The *Road to Home* (RTH) program was ultimately created as a standard approach to education to ensure that all families are given the same high level of quality discharge teaching, and for parents to be able to safely take care of their child at home (Wilson Smith et al., 2018). The RTH program consists of a 2 ft x 3 ft wall mounted magnetic board that is hung in the patient's hospital room (Wilson Smith et al., 2018). This interactive board consists of a road, bridges, boats, and trees to help the patient and parents visualize the education progression (Wilson Smith et al., 2018). There was a total of four roads that included educational content needed from diagnosis to discharge: (a) information highway, (b) teach back street, (c) demonstration lane and, (d) ready for home road (Wilson Smith et al., 2018). "Information highway" addressed initial information upon diagnosis, "teach back street" consisted of information that parents need to 'teach back' to the health care provider, "demonstration lane" included information that needed to be demonstrated prior to discharge, and "ready for home road" addressed the discharge planning that needs to be done prior to leaving the facility (Wilson Smith et al., 2018). The teaching progress was tracked with magnetic cars and dry erase markers (Wilson Smith et al., 2018). This visual aid allowed the

patient, parent, and other health care providers to quickly see progress in the education process, and how close the child is to going home (Wilson Smith et al., 2018).

The parents were provided with a tool kit at discharge that was intended to reduce medication issues (Wilson Smith et al., 2018). This tool kit included items that parents needed to safely care for the child at home such as a pill organizer, pill cutter/crusher, oral medication syringes, a thermometer, and a card with the facilities emergency contact information (Wilson Smith et al., 2018). Nurses taught parents about medications and assessed their knowledge about administration before discharge as well as encouraged the parents to bring the kit with all medications to each clinic visit (Wilson Smith et al., 2018). Providers are able to assess for correct medication administration throughout therapy when the parents bring the kit and medications with to appointments (Wilson Smith et al., 2018).

This pilot for the RTH program consisted of 22 families and lasted for six months (Wilson Smith et al., 2018). At the end of the six months, the families were asked standardized questions during post-discharge telephone calls (Wilson Smith et al., 2018). The feedback from the parents was overwhelmingly positive (Wilson Smith et al., 2018). Eighty-two percent stated that the board helped them understand what they needed to learn, 91% took their toolkit with medications to each clinic visit, and 95% could correctly teach back fever guidelines for after discharge (Wilson Smith et al., 2018). The satisfaction of the nursing staff was also assessed using a standardized survey and concluded that the overall satisfaction with discharge education and planning had improved (Wilson Smith et al., 2018). In general, this interactive patient education tool has shown to improve patient, family, and nurse satisfaction with the discharge education process as well as assist parents with understanding how to safely care for their child at home (Wilson Smith et al., 2018). While inpatient and outpatient education is very important,

it's also important that learning doesn't stop after the initial diagnosis and that it continues throughout treatment (Gunter & Duke, 2018; Landier et al., 2016; Rodgers et al., 2018).

There are other resources available to patients and families beyond one on one instruction by the nurse. The literature selected for this review found that other resources such as online webpages have also been found to be beneficial (Sigurdardottir et al., 2014). Sigurdardottir et al. (2014) created a web-based educational and support intervention (Web-ESI) for families of children with cancer. The website consisted of three main topics: (1) cancer, (2) family, and (3) living with cancer (Sigurdardottir et al., 2014). The cancer section focused on presenting information about different types of cancer and its medical treatment, medication, radiation therapy, and surgery whereas the family and living with cancer sections focused more on the patient and family wellbeing, adjustment, and psychosocial symptoms of cancer (Sigurdardottir et al., 2014). The website presented the information among 140 pages of evidence-based text, pictures, and drawings that were explicitly chosen or designed to provide appropriate information (Sigurdardottir et al., 2014). This quasi-experimental intervention study consisted of 38 participants, including 15 mothers, 12 fathers, and 11 children (Sigurdardottir et al., 2014). These participants were given access to use the Web-ESI for four months (Sigurdardottir et al., 2014). After that time, two questionnaires were used to evaluate that effectiveness of the Web-ESI (Sigurdardottir et al., 2014). Overall, the group of participants rated the website to be very useful with an average score of 8.2 on a 10-point scale, ten being the most favorable and zero being the least (Sigurdardottir et al., 2014). While the participants reported that the Web-ESI was beneficial, it's important to mention that this intervention does not replace the face-to-face education and emotional support that's given upon initial diagnosis, and continues through treatment (Sigurdardottir et al., 2014).



## Summary

This review of the literature identified a variety of important concepts about parent education when their child is diagnosed with cancer. In particular, study limitations included small sample sizes and, (Aburn & Gott, 2014; Granek et al., 2012; Kelly & Kelly, 2013; Patterson Kelly et al., 2018; Rodgers et al. 2016b) studies completed only on inpatient units (Rodgers et al., 2016b; Wilson Smith et al., 2018). The levels of evidence were somewhat divided, as they included eight studies that were a level one or a level two on the Melnyks Pyramid and 11 studies that were among the four lowest levels of evidence.

It is clear that upon diagnosis, parents and family members experience a range of emotions that can inhibit self-care, caregiving, coping, and the ability to learn valuable information (Aburn & Gott, 2014; Gage-Bouchard et al., 2018; Gunter & Duke, 2018; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Sigurdardottir et al., 2014; Wilson Smith et al., 2018). Nurses and other health care providers can assess and evaluate the parents' emotional state and ensure that proper actions are taken to help facilitate a healthy transition from health to illness. The literature identified that proper nurse training regarding education (Kahn et al., 2017; Landier et al., 2016; Withycombe et al., 2016), pacing the delivery of education (Gunter & Duke, 2018; Rodgers et al., 2016a; Rodgers et al. 2016b), ensuring one consistent educator (Gunter & Duke, 2018), completing a learning needs assessment prior to teaching (Rodgers et al., 2016b), and standardizing content, but also individualizing methods based on individual family needs (Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2016b) are components that health care providers can utilize to ensure that parents are receiving the best possible education experience.

Further research needs to be completed to determine an appropriate timeframe for educating parents to avoid further emotional distress, and to promote optimal learning. More research about individualized education should also be completed, as well as the creation of structured yet individualized educational interventions.

## **Discussion**

### **Interpretation**

A cancer diagnosis in a child is a life-altering event for both the child and parents and sets a health transition into motion. During this time parents are required to learn new and complex information to safely and effectively care for their child (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone et al., 2013; Wilson Smith et al., 2018; Withycombe et al., 2016). Parents need effective education to care for their child at home safely and the educational modality must fit their specific learning needs (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). Providers need to address a variety of elements before and during education to help facilitate learning and a healthy transition, ultimately ensuring that teaching is effective. The review of the literature helped to identify these crucial elements for health care providers to appropriately assist parents through the transitional process. These components have been divided in order of events based on the transitions theory and include: (a) assessment of parent readiness, (b) preparation for transition and, (c) role supplementation.

**Assessment of parent readiness.**

The time prior to and after a child is diagnosed with cancer is a stressful occasion for both the parent and child (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Gunter & Duke, 2018; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Sigurdardottir et al., 2014; Wilson Smith et al., 2018). Providers need to assess the impact of the emotional toll, the parents' readiness and ability to learn and to ensure that the appropriate approach is utilized based on individual parent needs.

The first thing that the provider needs to be aware of is that parents are experiencing a variety of emotions and face a period of emotional and physiological vulnerability that puts them at risk for poor self-care, caregiving, and general situational awareness (Aburn & Gott, 2014; Gage-Bouchard et al., 2013; Gunter & Duke, 2018; Patterson Kelly et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Sigurdardottir et al., 2014; Wilson Smith et al., 2018). With this lack of situational awareness and engagement after a new diagnosis, the provider needs to understand that parent learning might not appropriately occur, requiring information to be repeated and reinforced multiple times. For this project, the timing of education will be discussed further in the following sub-subsection.

Once providers understand that emotional turmoil can influence parent understanding and learning, the provider needs to complete a learning needs assessment for all caregivers involved in the child's care (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). This assessment is completed to ensure that material will be presented in the most appropriate way for the learner. If education isn't delivered in a way that parents respond to, or understand, it can hinder learning and inhibit a healthy transition (Gunter & Duke, 2018; Haugen

et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). A learning needs assessment should consist of information such as preferred learning style and language. Knowing the preferred learning style can help the provider select teaching materials that best fit with the parent — for example, utilizing informational videos, or discussion for those who learn better by listening or viewing information (Gunter & Duke, 2018; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018; Withycombe et al., 2016). Language is a critical component that requires consideration when assessing parents and constructing an education plan. A language barrier, or when information is presented in a style that the parents don't understand will negatively impact the parents' understanding and put the child's safety at risk (Rodgers et al., 2016a; Slone et al., 2013).

Family dynamics influence the coping ability of members of any family, but even more so during times of extreme stress, such as when a child gets diagnosed with cancer. The family dynamic not only impacts coping among family members but can also affect how parents respond to receiving stressful information and thus, how education would be most successfully delivered (Granek et al., 2012; Patterson Kelly & Ganong, 2011). For example, when a child within a stepfamily gets diagnosed with cancer, it can cause greater conflict that may already be present within the family structure (Patterson Kelly & Ganong, 2011). Stepfamily dynamics can involve multiple adults, households, and existing tension among former partners (Patterson Kelly & Ganong, 2011). Therefore, healthcare providers should assess the family dynamic before beginning any parent teaching. Dynamic components to be evaluated include: (a) who are the caregivers involved, (b) the number of caregivers involved, (c) who is the primary caregiver?

More people need to be included in teaching, and many learning needs are considered when there are more adults involved. The health care providers also should ensure that they are continuously communicating with all members of the parent caregiver team, so everyone involved has consistent, up-to-date information.

**Preparation for the transition.**

Once the provider has completed a comprehensive assessment, the family can be prepared for the education process that will facilitate the transition. The healthcare provider sets the stage attempting to establish optimal conditions that will help support the parent during this time (Meleis, 2010). Optimal conditions include timing of education, staff involved, and communication with all family members (Gunter & Duke, 2018; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone et al., 2013; Withycombe et al., 2016).

Education is most effective when it takes place during transitional periods such as the diagnostic phase and before the first discharge home (Gunter & Duke, 2018). However, timing when information is delivered during these transitional periods is critical, and providers must account for the significant amount of emotional turmoil parents are experiencing immediately after their child is diagnosed (Rodgers et al., 2016b). Providing education when the parents aren't ready to learn can hinder their ability to process this valuable information (Rodgers et al., 2016b). Because parents are experiencing a variety of emotions immediately after diagnosis, one recommendation that emerged from the evidence is that providers give parents time to process the actual diagnosis before teaching about other vital information (Rodgers et al., 2016a; Slone et al., 2013). Unfortunately, evidence for the best timeframe for teaching was not uncovered in this literature review. However, the evidence did support the importance of pacing the delivery of

information slowly during the first few weeks after diagnosis (Rodgers et al., 2016b). Providers can facilitate better parent understanding by setting aside a specific time for teaching and ensuring that material is provided in a non-rushed manner (Gunter & Duke, 2018). Given the parents' emotional state and the complexity of information, providers must remember that information may likely need to be repeated until parents can demonstrate proper understanding.

While the timing of teaching is essential, so is the person who is educating the family. Literature recommended that one individual often a nurse, be held responsible for teaching the family to ensure the consistency of information (Landier et al., 2016). The designation of one person who will conduct family education can promote a trusting parent-provider relationship while also ensuring that all the necessary information is being delivered in the most appropriate way (Gunter & Duke, 2018). On the other hand, when more than one person is involved in presenting information, the parents might receive conflicting information from multiple providers, or they may hear unnecessary details more than once, which inhibit learning (Landier et al., 2016).

There is evidence that a designated individual is most useful for educating families experiencing cancer, but individuals who are responsible for teaching need to be appropriately trained to deliver adequate instruction (Kahn et al., 2017; Landier et al., 2016; Slone et al., 2013; Withycombe et al., 2016). Unfortunately, while the literature recommends formal staff training for those responsible for educating the families, no current recommendations for preparing providers for this role emerged from this review other than primary practice and principles of patient education (Landier et al., 2016).

This stage of preparing the family for learning followed the assessment of the family's emotional state and individual needs. With these first two phases complete, providers and families are ready to proceed to the actual process of role supplementation, or education.

**Role supplementation.**

The provider should consider the necessary content, preferred language, and education methods when teaching a family. Evidence strongly supported the recommendation that instruction contain standardized content, but that teaching methods be adapted to meet the needs of the individual families (Gunter & Duke, 2018; Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016b; Withycombe et al., 2016).

Standardization of content is recommended to ensure that all parents experiencing a new cancer diagnosis are receiving consistent, high quality information (Gunter & Duke, 2018; Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016b; Withycombe et al., 2016). Standardization can also assist providers to effectively coordinate the delivery of information and ensure that critical information is delivered to parents in a way that won't overwhelm them, such as spacing teaching sessions (Gunter & Duke, 2018; Rodgers et al., 2018). Providers and parents have identified topics that are necessary for every patient scenario such as diagnosis, infection prevention, and who to call in an emergency (Aburn & Gott, 2014; Haugen et al., 2016; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016b; Withycombe et al., 2016). However, not all information regarding a child's diagnosis pertains to every scenario (Gunter & Duke, 2018; Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2018; Rodgers et al., 2016b; Withycombe et al., 2016). In most cases, there is information that may need to be tailored based on the child's diagnosis and medical status. For example, if there are two children with ALL, both families

require necessary information about the diagnosis, standard medications, neutropenic precautions, and what to do in an emergency. However, one child may have more severe nausea than the other, requiring a feeding tube to supplement nutrition. This family would need further instruction about the specific feeding tube and how to care for it, whereas this information wouldn't pertain to the family of the child without a feeding tube.

As mentioned in the previous section, when completing a learning needs assessment, the preferred language of the parents needs to be considered. Because of the potential for language barriers, health institutions should have a variety of learning materials in many different languages to best assist the parents (Slone et al., 2013). The need for a variety of learning materials in multiple languages requires the provider to be knowledgeable of all resources available for non-English speaking patients (Slone et al., 2013). For all face to face and phone conversations, the use of medical interpreters is suggested to ensure that accurate information is being relayed and understood by the parents (Rodgers et al., 2016a; Slone et al., 2013). However, not all institutions have access to in-person interpreters, so video and telephone interpreting services should be identified (Slone et al., 2013; Squires, 2017).

It's also important to note the use of a medical interpreter, and not using a family member or friend to interpret sensitive medical information unless there is an immediate threat to life (Squires, 2017). Medical interpreters have the ability and training to deliver technical information with accuracy, as well as with culture-specific terminology (Squires, 2017). They are also held to a professional code of ethics, meaning that they are required to maintain patient confidentiality and convey all sensitive information stated by the provider (Squires, 2017).

Providers should use assessment findings to select teaching methods to fit the parents' learning needs, language, and preferred learning style. The provider can also tailor information



centered on the parents desired content at that particular time. For example, some parents have reported wanting to know more about their child's prognosis and treatment plan initially upon diagnosis (Rodgers et al., 2016b). Conversely, some parents would rather learn about the duration of treatment, or length of hospitalizations upon diagnosis (Rodgers et al., 2016b).

Parents are able to process the material in the best possible way when information delivered is customized and allows them to gain some control in the situation (Kahn et al., 2017; Rodgers et al., 2016b). A variety of preferred and valuable teaching methods exist including; (a) written materials, (b) verbal discussions, (c) short videos, (d) structured classes (Aburn & Gott, 2014; Gunter & Duke, 2018; Kahn et al. 2017; Matutina, 2010; Rodgers et al., 2016a; Rodgers et al., 2016b; Sigurdardottir et al., 2014; Wilson Smith et al., 2018).

Parents and providers have recommended written materials in plain, simple language (Aburn & Gott, 2014; Kahn et al., 2017; Matutina, 2010; Rodgers et al., 2016a; Rodgers et al., 2016b). In addition to presenting information in a cultural language that parents understand, it's essential to ensure that educational materials are at a reading level of a typical ten or 11-year-old (Matutina, 2010). The provider also needs to ensure that medical jargon is not being used in educational materials or during face to face instruction (Aburn & Gott, 2014; Matutina, 2010). The progression towards a healthy transition is inhibited if the material is presented at a level that parents can't understand due to native language or the complexity of the vocabulary (Aburn & Gott, 2014; Matutina, 2010).

Written materials are better understood when a one-on-one conversation between the parents and the provider occurs (Matutina, 2010; Rodgers et al., 2016a; Rodgers et al., 2016b). Providers should allow the parents to choose a comfortable, neutral location to ensure that optimal learning can occur when one-on-one instruction is to be completed (Matutina, 2010).

Creating this comfortable learning environment not only promotes deep learning, but it helps foster an atmosphere of trust and social support between the parents and provider (Gunter & Duke, 2018).

Written materials can be used as convenient, interactive tools when combined with visual aids (Matutina, 2010; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018). While some providers have utilized colorful fridge magnets, or easy to access wallet cards containing crucial information, others have used large, interactive display boards to help the parents visualize the education process (Matutina, 2010; Gunter & Duke, 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Wilson Smith et al., 2018). As previously described in the literature review, the Road to Home Program consists of an interactive board hung in the patients' room that creatively monitors the patients' education process (Wilson Smith et al., 2018). This interactive visual aid was created to help the parent, child, and providers better understand the educational advancement, as well as ensure that unnecessary information isn't being repeated (Wilson Smith et al., 2018). Parents can experience further distress when the material is repeated, or when communication regarding what elements were discussed is deficient (Matutina, 2010; Rodgers et al., 2016a; Wilson Smith et al., 2018).

The review of the literature provided a wealth of information regarding the transition that parents experience after their child is diagnosed with cancer. Providers can take a variety of actions to help the parent through the transition from health to illness and back to wellness. Three steps are identified based on the Transitions Theory and the results of the literature review: (a) assessment of parent readiness, (b) preparation for transition and, (c) role supplementation. Providers can best support parents through this period of change by understanding the steps presented and utilizing the evidence-based strategies that have been identified to help parents

during this time of emotional turmoil. Subsequently, by facilitating the most effective parent learning possible, this will give them the tools to safely care for their child at home, ultimately increasing the child's quality of life.

### **Outcome**

The concepts and context associated with the Transitions Theory assisted in the organization and creation of an informational pamphlet intended to educate pediatric oncology nurses and other potential parent educators. The pamphlet content focuses on the transitional phases that parents experience after their child is diagnosed with cancer and how providers can help support parents at each stage. The goal of the informational pamphlet is that providers will be able to identify the transition level and implement the suggested support interventions at each phase.

The educational tool consists of a colorful, two-sided pamphlet (Appendix A) that can be printed or viewed in a portable document format (PDF) to be easily examined on a computer or other electronic device. Side one presents seven concise bullet points that explain the background of a childhood cancer diagnosis and how it affects the parents, as well as information regarding the transition experience and various stages. There is also a highlighted box that allows for quick identification of the three transitional stages that parents progress through. The large font of the title, highlighted box containing the stages, and the concise bullet points allow for providers to quickly scan the document while also providing them with the necessary introductory information before continuing to the second side. The second side consists of a colorful flow chart that identifies each stage of transition, as well as more detailed information regarding steps providers can take at each phase to best support the parents. This flow chart

gives the provider further details about each step as well as identifies interventions that the research showed to assist parents during the different transitional phases.

For this project, the education pamphlet was not evaluated for its effectiveness. However, if evaluation were to be completed, it would be done so by using a five-point Likert scale. Likert scales were developed to measure direct attitudes by asking the person to respond to various statements about the topic (McLeod, 2008). These statements require the person to rate the extent to which they agree with them, giving the reviewer insight into their cognitive and affective attitudes (McLeod, 2008). This scale was chosen to gain better insight into the providers' opinion regarding the pamphlet effectiveness, and because the quantitative data gathered can be easily analyzed (McLeod, 2008). Once it is better understood to what extent providers found the pamphlet to be beneficial, a cohort study could be conducted to determine its effectiveness on parent transitions and an overall understanding of critical diagnostic information.

### **Implications for Nursing**

There are very few standards that describe education to best support the patient and family after a child is diagnosed with cancer (Withycombe, et al., 2016; Haugen et al., 2016; Slone et al., 2013; Rodgers et al., 2018; Rodgers et al., 2016a; Wilson Smith et al., 2018; Landier et al., 2016; Rodgers et al., 2016b). The review of the literature has identified potential actions to help providers assist parents during the health/illness transition. While the evidence was able to identify possible actions, further research is needed regarding the qualities of adequate education, characteristics of formal provider education training, and the timeframe for performing teaching.

Because the deliverable product of the literature review has not been evaluated in the clinical setting, it's recommended that it be further assessed. If the pamphlet is deemed effective, a cohort study should be conducted to determine if it's beneficial for providers who are conducting parent education. Once the pamphlets effectiveness is known, its use could be implemented in the clinical setting.

### **Conclusion**

A cancer diagnosis in a child is a traumatic experience for both the parents and the child (Rodgers et al., 2016b). During this time, families experience a transition from health to illness and hopefully back to a new state of wellness. Successful transition requires a significant amount of education for parents to safely care for their child (Gunter & Duke, 2018; Haugen, Landier, Mandrell, Sullivan, Schwartz, Skeens & Hockenberry, 2016; Landier et al., 2016; Matutina, 2010; Rodgers et al., 2018; Rodgers et al., 2016a; Rodgers et al., 2016b; Slone, Selft, Friedman & Heiman, 2013; Wilson Smith et al., 2018; Withycombe et al., 2016). This project sought to identify standards of education that best support the patient and family because of the need for a vast amount of effective teaching. The transitions theory and a comprehensive literature review allowed for the identification of the transitional process that parents experience after their child gets diagnosed with cancer. Interventions that providers can implement at each stage were also identified based on that information. With this information, providers will be able to identify the transition experience and stages that parents progress through and implement interventions at each stage that can help facilitate the progression towards a successful health/illness transition.

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doi:10.1177/1043454216652857

Appendix A

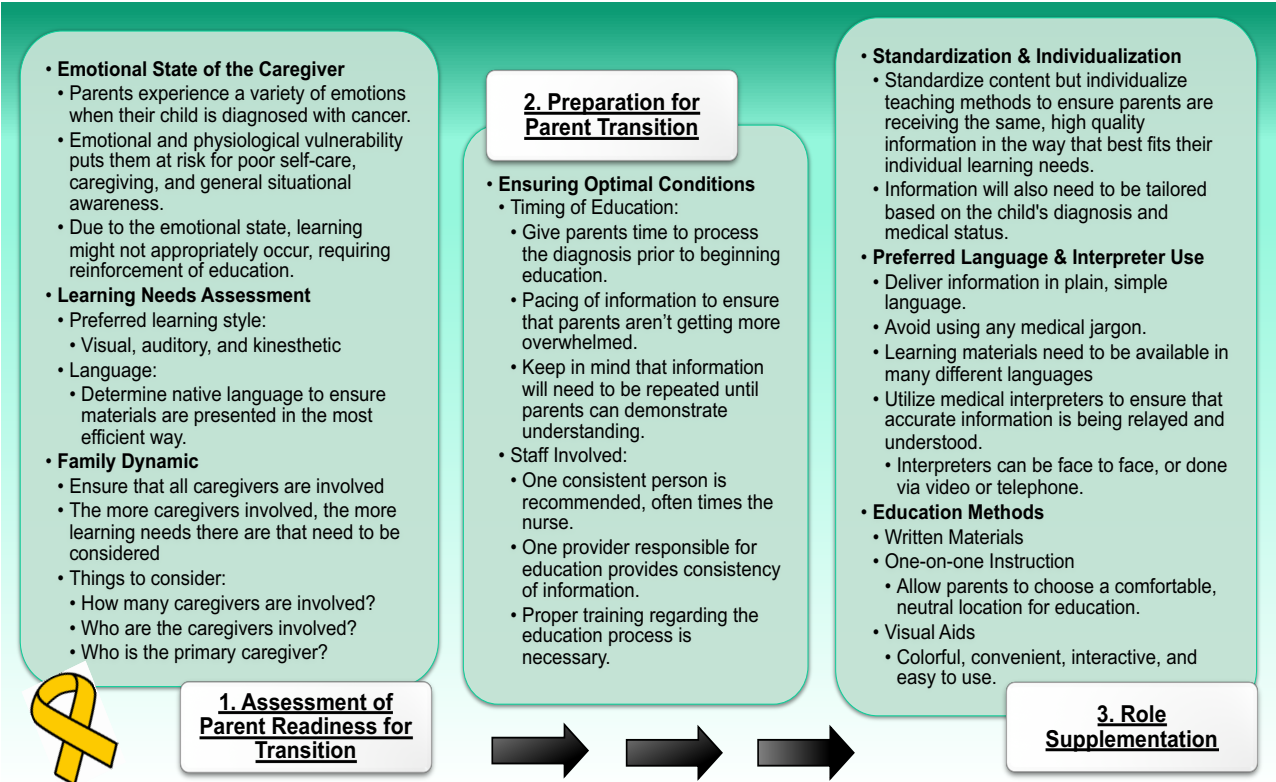
### Facilitating the Best Transition for Parents of Children Newly Diagnosed with Cancer

- A cancer diagnosis in a child is a life-altering event that requires parents to transition from a state of health to illness.
- Parents are required to learn new and complex information to safely care for the child (Gunter & Duke, 2018).
- Effective teaching needs to be performed in a way that fits within the parents individual needs (Haugen et al., 2016; Landier et al., 2016).
- To ensure that teaching is effective, health care providers need to address a variety of elements prior to and during parent education to facilitate learning and a healthy transition.
  - There are three stages of transition identified by Meleis' Transition Theory that each parent passes through that providers need to be aware of: (a) assessment of parent readiness, (b) preparation for transition, (c) role supplementation (Meleis, 2000).
  - Knowing the stages and details to help support parents can ensure that they learn and understand the vital information to safely care for their child, as well as experience a healthy transition.
- The supportive details specific to parents of children with cancer are outlined in further detail on the reverse side of this page.

1. Assessment of parent readiness
2. Preparation for Transition
3. Role Supplementation



References available upon request: karlier28@gmail.com



Appendix B

**The Transition from Health to Illness: Best Practices for Education of Parents with Children Newly Diagnosed with Childhood Cancer**



Karlie M. R. Wolf, BSN, RN, Master's Candidate  
University of North Dakota  
Grand Forks, North Dakota



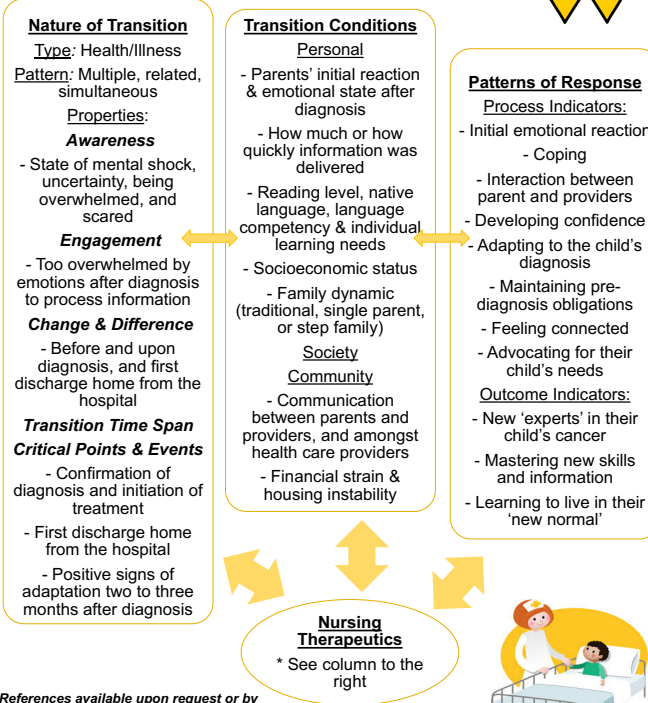
**Introduction**

- Each year in the United States, there are about 13,500 new childhood cancer diagnoses
- A new diagnosis increases the need for education for the patient, and caregivers
- It's imperative to use best practices to teach this special population
- Few standards exist for education to teach this special population
- The goal of this project was to define this problem and develop evidence-based interventions to address the issue at hand

**Literature Search**

- Searched CINAHL, PubMed, and the National Library of Medicine
- Search terms: childhood cancer, cancer education, pediatric, pediatric transitions, and cancer coping
- Inclusion criteria: Publication within the last 8 years, peer-reviewed, and written in English
- Nineteen articles retained

**Conceptual Framework: Transitions Theory**



**Nursing Therapeutics**

- Nurses should be properly trained for effectively educating patients (Kahn et al., 2017; Landier et al., 2016; Withycombe et al., 2016).
- Educate all caregivers involved in the child's life (Granek et al., 2012; Patterson Kelly & Ganong, 2011).
- Education delivery needs to be paced, spread out, and consistently reinforced during treatment (Gunter & Duke, 2018; Rodgers et al., 2016a; Rodgers et al., 2016b).
- One consistent educator is recommended improve comfort of family learning (Gunter & Duke, 2018).
- Deliver consistent, current information (Landier et al., 2016; Withycombe et al., 2016).
- Standardize content, but individualize methods based on the individual family needs (Haugen et al., 2016; Kahn et al., 2017; Landier et al., 2016; Rodgers et al., 2016b).
- Design reading material at a level of a typical 10-11 year old (Matutina, 2010).
- Avoid the use of medical jargon (Aburn & Gott, 2011; Rodgers et al., 2016b; Slone et al., 2013; Matutina, 2010).
- Design education materials in many languages (Matutina, 2010; Rodgers et al., 2016a; Slone, Self, Friedman, & Heiman, 2013).
- Utilization of medical interpreters (Matutina, 2010; Slone et al., 2013).
- Complete learning needs assessments prior to teaching (Rodgers et al., 2016b).



• *References available upon request or by email: karlie.wolf@und.edu*  
• *Advisor: Linda Shanta, PhD, RN, ANEF*

## Appendix C

<b>Citation</b>	Kahn, J. M., Athale, U. H., Clavell, L. A., Cole, P. D., Leclerc, J., Laverdiere, C., ... Kelly K. M. (2017). Delivery of information: Approaches to patient education about oral chemotherapy in the pediatric oncology clinic. <i>Journal of Pediatric Health, 31</i> (1), e1-e6. Retrieved from: <a href="http://dx.doi.org/10.1016/j.pedhc.2016.06.004">http://dx.doi.org/10.1016/j.pedhc.2016.06.004</a>
<b>Purpose</b>	To identify how pediatric oncology providers educate families about oral chemotherapy (how they communicate and reinforce treatment information about oral medications to patients and families during the continuation phase of pediatric ALL therapy).
<b>Design</b>	Cross sectional survey / prospective cohort study
<b>Study Sample</b>	68 health care providers
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Administered a 10-item questionnaire over three months</li> <li>- Administered online via Survey Monkey</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- ALL adherence to oral chemotherapy teaching relies heavily on a parent's understanding of the drugs indication and administration guidelines</li> <li>- Patient info is variable</li> <li>- Can consist of handouts, treatment calendars and discussions</li> <li>- Extent of teaching often varies depending on a providers' subjective assessment of the family needs</li> <li>- 25% of providers suggested standardized teaching</li> <li>- The challenge for providers to how to optimally deliver the critical information to each family</li> <li>- Ensuring adherence is a challenge when you have a highly complex and labor-intensive process</li> <li>- Some kids take up to 10 medications per day</li> <li>- Up to 30% of the study population was nonadherent to oral chemotherapy</li> <li>- Multiple studies highlight the provider-patient teaching to therapy adherence. Without appropriate teaching, safety is at risk.</li> <li>- Accurate and consistent adherence to home meds is influenced by patient, provider and systems related factors</li> <li>- HCPs are responsible for education</li> <li>- 7% stated that they were "unsure" of how well patients and caregivers understood what is being taught about oral chemo</li> <li>- 17% couldn't identify who was primarily responsible for administration at home</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Provides information about deliver of care within the pediatric oncology unit/clinic.</li> <li>- Addresses different provider approaches to patient education of oral chemotherapy.</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- 75% response rate</li> <li>- Only 10 questions on the survey</li> </ul>
<b>Level of Evidence</b>	Four – prospective cohort study

<b>Citation</b>	Matutina, R. (2010). Educating families of children newly diagnosed with cancer. <i>Cancer Nursing Practice, 9</i> (1), 26-29.
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<b>Purpose</b>	To trial a method to simplify information for parents by creating teaching and support materials for the reading level of a ten or 11-year old.
<b>Design</b>	Qualitative pilot – cohort study
<b>Study Sample</b>	Three families of children newly diagnosed with Acute Lymphoblastic Leukemia (ALL)
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Families were given a fridge magnet and laminated wallet cards that contained vital information</li> <li>- Parents were advised to place the magnet on the fridge and carry the two wallet cards with them at all times</li> <li>- Information on the cards and magnet were also taught via a one on one method</li> <li>- Formative evaluation was completed via post-test questions</li> <li>- Only three families were surveyed</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Post-test responses confirm Bastables theory that teaching materials should be at a reading level of typical ten to 11-year-old.</li> <li>- Overall, post-test seems capable of assessing whether or not the content was absorbed</li> <li>- When properly implemented, this intervention has the potential to alleviate stress for parents as well as improve patient-provider communication and patient safety so that pediatric oncology patients can receive optimal home care</li> <li>- If parents are educated and empowered, problems that arise during home care will be addressed promptly, and the number of critically ill children should be decreased</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Positive parent response</li> <li>- Wallet cards and fridge magnets were administered to 200 patients, but only three families were surveyed to determine their effectiveness.</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Small sample size</li> <li>- Post-test questions required multiple revisions</li> <li>- Parent confusion over wording of post-test questions</li> </ul>
<b>Level of Evidence</b>	Level 4

<b><u>Citation</u></b>	Withycombe, J. S., Andam-Mejia, R., Dwyer, A., Slaven, A. & Landier, W. (2016). A comprehensive survey of institutional patient/family educational practices for newly diagnosed pediatric oncology patients: A report from the Children's Oncology Group. <i>The Journal of Pediatric Oncology Nursing</i> , 33(6), 414-421. doi:10.1177/1043454216652857
<b>Purpose</b>	To conduct a comprehensive survey of the COG institutions aimed at determining the current state of practicing regarding the delivery of patient/family education to parents/caregivers of newly diagnosed pediatric oncology parents prior to the child's initial discharge home after receiving chemotherapy in the inpatient setting.
<b>Design</b>	Quantitative / cohort study
<b>Study Sample</b>	201 COG institutions (90.5% participation rate)
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Internet based survey to determine current patient/family education at COG institutions.</li> <li>- One individual from each institution completed the survey</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Information was delivered primarily by an individual, rather than a team (43% of the institutions)</li> <li>- APRNS had primary responsibility for education (32%)</li> </ul>

	<ul style="list-style-type: none"> <li>- Fever was the most frequently reported mandatory topic for new diagnoses</li> <li>- Over 50% of the institutions reported using checklists and or end-of-shift reports to facilitate health care team communication regarding education</li> <li>- 77% reported using the teach back method of assessing readiness for discharge</li> <li>- 37% of institutions reported delays in hospital discharge secondary to the need for additional teaching</li> <li>- 90% reported that there was some sort of training to prepare nurses to provide education, with the most common method of training consisting of a formal class or workshop at 67% of sites. Other types of training were on the job training, learning modules, orientation.</li> <li>- 10% reported no training for education</li> <li>- Delivery of patient education was reported to involve primarily one person (or individuals sharing a common goal) at 43% of the sites, while a team approach was utilized by 24% of the sites and 33% of the sites reported using a combo of team and individual delivery</li> <li>- 70% of sites reported using a clearly delineated protocol or process for providing education, while 30% stated that they used a clearly established process less than half the time</li> <li>- WHAT: Following 6 topics were reported as essential for discharge teaching (fever, s/s of infection, how and when to call, home meds, explanation of diagnosis, chemo side effects)</li> <li>- HOW: variety of communication methods among team members to share what education had been given (checklist, form, discharge plan, end of shift report, informal notes, white boards or similar devices in patient rooms</li> <li>- ASSESSMENT OF LEARNING: teach back, evaluation by the team, use of a test or quiz.../some didn't assess at all</li> <li>- There is significant variability in practices relating to patient education</li> <li>- Responsibility seems to mainly fall on the nursing profession...resulting in significant implications for nursing practice</li> <li>- Not all facilities employ teaching protocols or processes</li> <li>- Inconsistent communication techniques among staff occur (what has been taught and what still needs to be addressed) – this will just lead to decreased quality of care</li> <li>- Checklists have been successfully used in the surgical setting to improve with patient quality of care, so it may also prove useful for this patient population</li> <li>- Reported variability as far as what should be discussed prior to discharge (what was “essential” and what wasn't)</li> <li>- Nurses need formal education/training regarding this specific education – not all nurses are</li> <li>- There is a variation of techniques uses, but the teach back method seems to be effective</li> <li>- Ability of nurses to provide education is of high importance, as effective delivery of education is a strong indicator of a patients readiness for discharge</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- High response rate (90.5%)</li> <li>- Children's Oncology Group (COG) institutions</li> <li>- Large and geographically diverse sample of COG institutions</li> <li>- The first comprehensive report of institutional patient/family education practices of newly diagnosed pediatric oncology patients.</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Each institution was represented by one individual, meaning that there could be biased or inaccurate information relayed.</li> </ul>
<b>Level of Evidence</b>	Level 4

<b>Citation</b>	Haugen M.S., Landier, W., Mandrell, B. N., Sullivan, J., Schwartz, C., Skeens, M. A. & Hockenberry, M. (2016). Educating families of children newly diagnosed with cancer: Insights of a delphi panel of expert clinicians from the Children's Oncology Group. <i>Journal of Pediatric Nursing</i> , 33(6), 405-413. doi:10.1177/1043434216652856
<b>Purpose</b>	Aimed to identify essential informational content for inclusion in parent education at the time of initial diagnosis, and to determine what topics are mandatory to promote safe care at home following the initial hospital discharge.
<b>Design</b>	Delphi Methodology – qualitative meta-analysis
<b>Study Sample</b>	100 health care providers
<b>Data Collection and Measurement</b>	Three questionnaires were delivered to determine group consensus Round 1 – free-text questionnaires after a 2-hour session regarding patient/family education Round 2 and 3 – 60 clinicians were chosen to comprise the expert panel for the Delphi study. Chosen panelists were given two electronic surveys to complete.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Lack of standardization across institutions, resulting in considerable variability in the content included in teaching for newly diagnosed patients</li> <li>- Identified 20 topics of importance for inclusion in initial discharge education for all newly diagnosed peds on patients, as well as additional topics of importance for inclusion in discharge education for pts with leukemia/lymphoma, solid tumors, and CNS tumors</li> <li>- Expert panel rated diagnosis, fever, and treatment plan highest for importance and school and complementary therapy lowest for importance</li> <li>- Clear consensus among the expert panel with regard to the importance of educating newly diagnosed families about the child's diagnosis and treatment plan, as well as fever management</li> <li>- 100% indicated that they considered fever and assessing the treatment team (who/how to call and when/why to call) as mandatory topics for inclusion in education prior to first discharge</li> <li>- Teaching for specific disease groups</li> <li>- Expert panel rated psychosocial issues of lowest importance in educational topic to be addressed prior to discharge</li> <li>- Results from this study support current literature that suggests targeting educational topics by diagnosis</li> <li>- Lack of formal delineation of the information necessary for inclusion in patient/family education for newly diagnosed patients has limited the provision of optimal care for this vulnerable population</li> <li>- parents/caregivers require specialized education in order to care for their child with newly diagnosed cancer</li> </ul> <p>no current evidenced based guidelines exist to ID content essential for inclusion in patient education prior to first discharge home</p>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- results reflect multidisciplinary expert panel consensus</li> <li>- Clear consensus among expert panel</li> <li>- Results from the study support current literature regarding targeted education based on diagnosis</li> <li>- Participants remained anonymous during the study with decreased the risk of bias</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Diverse institutional type and geographical location</li> <li>- Difference in professional disciplines couldn't be evaluated</li> </ul>
<b>Level of Evidence</b>	Level 1



<b>Citation</b>	Gunter, M. D. & Duke, G. (2018). Reducing uncertainty in families dealing with childhood cancers: An integrative literature review.  <i>Pediatric Nursing, 44(1), 21-37.</i>
<b>Purpose</b>	<ul style="list-style-type: none"> <li>- An integrative review was completed to summarize the evidence on parental and familial uncertainty in childhood cancer, and to provide recommendations for psychosocial and educational interventions.</li> <li>- The goal of this article was to review research relating uncertainty to stress, anxiety and adaptation</li> </ul>
<b>Design</b>	Systematic literature review
<b>Study Sample</b>	29 articles
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Thirty-six articles were originally identified and then sorted according to topics (uncertainty during diagnosis, adapting and living with chronic childhood illness, and education and supportive care).</li> <li>- Ultimately, 29 articles were included in the review.</li> <li>- Seventy-three percent of the articles were published in or after the year 2000</li> <li>- 15 were qualitative</li> <li>- 14 were quantitative</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Remember uncertainty related to the diagnosis of cancer exists, and parents will experience it differently. Nurses must take care to make interventions individualized as needed. High levels of anxiety are one of concern as well.</li> <li>- Allow for earlier support and education, as well as opportunities to share or express feelings regarding the disease and its consequences both individually and in small groups or family sessions</li> <li>- Provide early intervention to guide families while fathers are available before returning to work in support networking, information sharing, and external support</li> <li>- Suggest a more structured format for education delivery. Large healthcare teams should coordinate information delivery to optimize retention and integration of parents into the child's care. Continuation of information sharing after the original diagnosis is difficult, and new models should be tried. Working on communication styles and coordination of care models will help improve family centered care and make it more of a reality</li> <li>- Recommend one coordinating person to help deliver information to patients and families</li> <li>- Communication between team members should be improved</li> <li>- Easier access for contact to healthcare providers should be addressed</li> <li>- Creation of an assessment checklist during the diagnostic phase to help ID areas of concerns related to psychosocial support and distress</li> <li>- Help parents prepare for the first transition from inpatient to home life. Offer supportive interventions aimed at providing a list of expectations and things to do prior to discharge to help reduce the uncertainty and fear parents face. Coordinate support between new families and families who have experienced this prior. Include this specifically in the education plan several days ahead of discharge so parents have time to adjust care needs prior to being immersed in it at home</li> <li>- Promote an atmosphere of trust, and share information related to the treatment and its side effects. Promote an environment of social support</li> </ul>

	<ul style="list-style-type: none"> <li>- Use more standardized and structured formats for information delivery to avoid overwhelming families and insuring the maximum amount of information is received. Use individualized pathways to help guide parents through initial interactions with the healthcare system</li> <li>- Promote early identification, early intervention, continued follow up, more longitudinal studies on this topic, and gender differences vs primary caregiver differences in uncertainty</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Large article sample size, appropriate inclusion/exclusion criteria</li> <li>- Similar amounts of quantitative and qualitative articles were chosen</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Lack of available interventional studies</li> <li>- Most articles were descriptive or qualitative design</li> <li>- Lack of diversity in sample populations (most samples included Caucasian mothers)</li> </ul>
<b>Level of Evidence</b>	Level 1

<b><u>Citation</u></b>	Slone, J. S., Self, E., Friedman, D. & Heiman, H. (2013). Disparities in pediatric oncology patient education and linguistic resources: Results of a national survey of pediatric oncologists. <i>Pediatric Blood Cancer</i> , 2014(61), 333-336. doi:10.1002/pbc.24831
<b>Purpose</b>	To determine pediatric Oncologists assessment of institutional resources for new cancer diagnosis education and the availability of linguistically appropriate education (availability of language services, document translation and certified interpreters)
<b>Design</b>	Quantitative cohort Study
<b>Study Sample</b>	423 pediatric oncologists were surveyed
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Survey was constructed and delivered using REDCap (secure, web-based application for building and managing online surveys and databases).</li> <li>- Survey was developed by pediatric oncologists with the help of education and cultural experts</li> <li>- Two pilot surveys were administered at a single institution to gather feedback for item clarification</li> <li>- Final survey consisted of 17 multiple choice questions and two scale bar questions and three free-text boxes</li> <li>- Responses to multiple choice questions were reported as percentages</li> <li>- Chi-squared analysis was used to evaluate independent category responses</li> <li>- Responses to scale bar questions were reports as means with standard deviations</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- There is little data on the methods and availability of education for childhood cancer patients and parents</li> <li>- Found significant differences between academic and non-academic institutions and smaller vs larger volume institutions, with the larger academic institutions having the greatest number of resources</li> <li>- Patterns of provision of education also varied, with larger academic institutions using more protocol driven education delivered by non-MD and smaller institutions using more web-based resources</li> <li>- The availability of resources for non-English speaking patients/families was more robust at larger institutions where certified translators appear to be more commonly used</li> <li>- Families want less medical jargon, more time with HCPs and an up to date and reliable list of websites</li> <li>- Greater than half of the parents reported internet use for education about their child's cancer</li> </ul>

	<ul style="list-style-type: none"> <li>- Smaller volume institutions reported utilizing web-based resources more than larger volume ones, perhaps due to a lack of dedicated staff to provide one on one teaching and established printed teaching materials</li> <li>- COG handbook, American Cancer Society and Leukemia/Lymphoma society websites</li> <li>- Multiple methods can be utilized by the medical team to aid the family in making important treatment related decisions and caring for their child with cancer</li> <li>- Language barrier negatively impacted the parents understanding of their child's care and limited their integration into the appropriate medical services</li> <li>- Resources for non-English speaking patients and parents appear less available in smaller volume and non-academic institutions, as compared with larger volume and academic institutions,</li> <li>- Telephone interpretation services are available for those unable to employ full time interpreters and offer a broad range of language services</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Surveyed American Society of Pediatric Hematology/Oncology (ASPHO) members</li> <li>- 429 of the 573 that responded met eligibility criteria</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Data were collected from providers who may not be entirely aware of the resources available at their facility</li> <li>- Only perspectives of pediatric oncologists were assessed</li> <li>- Inability to validate resources available</li> <li>- Inability to examine differences in educational resources across geographical locations</li> </ul>
<b>Level of Evidence</b>	Level 4

<b><u>Citation</u></b>	Rodgers, C., Bertini, V., Conway, M. A., Filice, A., Herring, R. A., Isbell, J., ... Landier, W. (2018). A standardized education checklist for parents of children newly diagnosed with cancer: A report from the Children's Oncology Group. <i>Journal of Pediatric Oncology Nursing</i> , 35(4), 235-246. doi:10.1177/1043454218764889
<b>Purpose</b>	Goal was to develop a standardized checklist that can be used by nurses across COG institutions to guide the initial education provided to parents of children newly diagnosed with cancer before the initial hospital discharge.
<b>Design</b>	Systematic review of evidence based guidelines – gathered and used current hospital education checklists, expert recommendations, and completed a series of interactive activities and discussions to develop a standardized checklist for parent education.
<b>Study Sample</b>	21 members (19 nurses and 2 parent advocates)
<b>Data Collection and Measurement</b>	Gathered and used current hospital education checklists, expert recommendations, and completed a series of interactive activities and discussions to develop a standardized checklist for parent education.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Primary topics – essential to address prior to initial hospital discharge in order that the parent has information needed to safely care for the child at home</li> <li>- Secondary Topics – should be presented within the first month of diagnosis</li> <li>- Tertiary topics – should be addressed prior to treatment completion</li> </ul>

	<ul style="list-style-type: none"> <li>- Teaching primary topics prior to first discharge and expanding to secondary topics if feasible is a rational approach that can facilitate parental processing and retention of essential information, while minimizing information overload</li> <li>- Use of this checklist provides the nurse with a clear outline of educational topics to be presented and those that can be safely deferred until later</li> <li>- Peds onc nurses tailored education to meet the needs of their patients and families...it might be necessary to customize topics within the checklist to enhance the applicability of the tool in addressing specific clinical scenarios (medications, specific chemotherapy protocols, etc)</li> <li>- Incorporating expert recommendations into nursing practice is imperative</li> <li>- Checklists are a common method used to promote process improvement and foster consistent practice and can provide a method to ensure that information delivered is accurate and complete</li> <li>- A standardized educational checklist can be used to ensure that essential information is delivered consistently to parents and patients, without overwhelming them with information that could be delivered after the initial hospital discharge.</li> <li>- The checklist can enhance communication between interdisciplinary team members and can be employed across various settings (inpatient to outpatient, and potentially between institutions)</li> <li>- Learning needs (teaching methods, amount of information desired, preferred language) should be identified early in the encounter and incorporated into the teaching plan in order to enhance parents ability to optimally process the information</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Multiple methods were used to come to an expert recommendation</li> <li>- Take into consideration standard and individualized patient needs pertaining to diagnosis and medical needs (medications, central lines, etc.)</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Final checklist was designed based on pediatric oncology nurses, current evidence, and feedback from patient advocates. However, information and input directly from parents could have been of benefit.</li> </ul>
<b>Level of Evidence</b>	Level 1

<b><u>Citation</u></b>	Rodgers, C. C., Laing, C. M., Herring, R. A., Tena, N., Leonardelli, A., Hockenberry, & M. Hendricks-Ferguson, V. (2016a). Understanding effective delivery of patient and family education in pediatric oncology: A systematic review from the Children's Oncology Group. <i>Journal of Pediatric Oncology Nursing</i> , 33(6), 432-446. doi:10.1177/1043454216659449
<b>Purpose</b>	Goal was to evaluate the existing body of evidence to determine the current state of knowledge regarding the delivery of education to newly diagnosed pediatric oncology patients and families
<b>Design</b>	Systematic literature review
<b>Study Sample</b>	83 articles chosen for literature review. <ul style="list-style-type: none"> <li>- 80 research studies (randomized control trials, cross-sectional studies, pilot studies, pretest/posttest studies, post intervention studies, descriptive studies, retrospective chart reviews, case studies, qualitative studies, and mixed methods studies), 2 systematic reviews, and 1 unpublished dissertation.</li> </ul>

<b>Data Collection and Measurement</b>	The team developed 6 clinical questions to focus their review. These questions were created in PICOT format. Searches of MEDLINE, CINAHL, and the Cochrane Library were completed.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- PICO Questions</li> <li>- <u>What educational methods are most effective and preferred</u> → written materials, verbal discussions, audio recordings and the internet. Written information “was very helpful at the initial diagnosis and during discharge teaching because it provided information they were afraid to ask.”</li> <li>- Parents of kids with several different diagnoses reported written information as helpful when it was simple, in plain language, brief, well organized, and in large font and included visuals such as pictures and graphs</li> <li>- AYAs prefer discussion with a HCP as their first choice for the delivery of education, while discussion with others and written materials were preferred additional methods</li> <li>- Parents also reported verbal discussions with HCPs as supportive, but these discussions were also described as overwhelming and exhausting</li> <li>- Desire for an informal meeting with other parents but didn’t want this to occur until the initial shock of diagnosis wore off</li> <li>- Audio recording of diagnosis talk was helpful to parents; this allowed them to replay and recall information that they initially could not absorb or understand</li> <li>- Simple videos were effective</li> <li>- Process of learning, as well as delivery should be considered</li> <li>- experiential learning such as acquiring specific skills and managing day to day care before hospital discharge</li> <li>- Individualizing information</li> <li>- <u>What time frame after initial diagnosis is most effective and preferred</u> → AYA’s sought out maximum disease information at diagnosis as a way to gain control of the situation. However, professionals reported educating AYA patients later in treatment was more important than providing information at diagnosis</li> <li>- Important to remember that we all deal with stressful situations differently</li> <li>- Emotional strain after the immediate diagnosis that affected their ability to absorb information</li> <li>- Expression of a sense of being overwhelmed immediately after diagnosis and needing time to process (no specific time period is provided)</li> <li>- <u>What location is most effective to receive education</u> → no evidence</li> <li>- <u>What educational content is important and preferred</u> → there is a range from cancer specific to psychosocial topics</li> <li>- for new diagnoses, most important information about their diagnosis was knowing what was going to happen to them and understanding the etiology and prognosis</li> <li>- <b>AYAs</b> newly diagnosed ranked dealing with procedures as the most important topic followed by relationships with friends and getting back to school as the second and third most important</li> <li>- Studies noted that <b>kids and teens</b> wanted to know more information but were unaware of what questions to ask</li> <li>- <b>Parents</b> desired disease specific as well as psychosocial information. Also wanted information related to practical or day to day management of their child’s cancer</li> <li>- high priority information identified by parents at this time of diagnosis includes diagnosis, prognosis, further testing and treatment plan</li> <li>- medium information needs include understanding of disease, side effects, emotional impact on the child</li> <li>- low information needs include coping with painful procedures, and impact of the diagnosis on the family</li> <li>- <b>Siblings</b> wanted to be at the hospital, talk to staff and other patients and be involved in the patient’s care</li> </ul>

	<ul style="list-style-type: none"> <li>- Worried about developing cancer like their sibling and wanted info on diagnosis, etiology and prognosis</li> <li>- Useful educational booklet – described the book as useful especially the content regarding curing cancer, learning about cancer, feelings related to cancer, and the glossary of terms.</li> <li>- <b>Peds Onc Nurses</b> reported treatment and disease information as important topics at time of diagnosis, and coping, symptoms management and treatment as important topics after the first week</li> <li>- <b>Oncologists</b> think that additional content should include dispelling the risk of contagion of the disease, parents not being responsible for the diagnosis, normal parent reactions to diagnosis, what to tell the sick child, and who is the attending MD, while parents didn't think these topics were important</li> <li>- <u>What are the demographic factors and/or clinical factors that influence the initial educational information delivered and received</u> → only two were identified, age and educational level</li> <li>- Using words they could understand, receiving non-contradictory information and feeling that the HCPs had time to answer their questions</li> <li>- Factors influencing education delivered and rec'd included delivery of information, emotions, language barriers, relationships with the HCPs, the child's condition and social issues</li> <li>- Emotional reactions and previous negative experiences with cancer made it hard for parents to hear and comprehend information</li> <li>- Despite the use of interpreters, language barriers may still be an issue d/t the interpreters inability to accurately translate complex medical information related to the care or failure to incorporate cultural issues for peds patients</li> <li>- Parents also felt overwhelmed when multiple HCP's simultaneously entered the room, or when the HCP was too busy to answer questions</li> <li>- Parents wanted information without the child being present</li> <li>- <u>What interventions have been developed to improve the comprehension of information</u> →</li> <li>- Web based programs, structured teaching tools, videos and interactive education</li> <li>- Children of parents who participated in a structured discharge program had fewer symptoms, central line problems, unplanned clinic visits, and unplanned admissions when compared to a routine care group</li> <li>- Use of a novel teaching support (fridge magnet and wallet card) enhanced retention of important information among parents children newly diagnosed</li> <li>- Standardized teaching plans or checklists significantly improved knowledge among caregivers of hospitalized newborns</li> <li>- Use of videos as an educational strategy has not been evaluated among children with cancer and their families, but other studies among other pediatric populations have had good results</li> <li>- Siblings benefitted from age appropriate interactive education. Sibs who participated in these sessions with a clinical psychologist or reflective journaling and personal diaries reported increased knowledge about their siblings treatment and side effects with decreased stress and anxiety</li> <li>- Sibs of hospitalized patients who participated in a program to explore medical equipment and receive information regarding illness, treatment, and daily routine of the hospitalized sib had significantly less anxiety than those who did not participate in the program.</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- No concerns noted with inconsistency, precision, or publication bias</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Overall quality of evidence was low</li> <li>- Quantitative study flaws included small sample size and utilization of non-validated tools to measure outcomes, lack of disclosure of rigor of interview questions.</li> <li>- Two systematic reviews lacked details of methodology</li> <li>- Many RCTs did not report their randomization method</li> </ul>

<b>Level of Evidence</b>	Level 1
<b>Citation</b>	Wilson Smith, M. G., Sachse, K., & Perry, M. T. (2018). Road to home program: A performance improvement initiative to increase family and nurse satisfaction with the discharge education process for newly diagnosed pediatric oncology patients. <i>Journal of Pediatric Oncology Nursing</i> , 35(5), 368-374. doi:10.1177/1043454218767872
<b>Purpose</b>	To increase family and nurse satisfaction with new diagnosis education and discharge. Using standard improvement techniques, family and nursing stakeholder satisfaction with current processes was assessed. Working from established best practice and literature review, the Road to Home was designed and implemented. Goal of the road to home program was to develop interactive patient education methods to engage nurses, clinical team members, parents and patients in the new diagnosis cancer education process.
<b>Design</b>	Qualitative – literature search, caregivers of five children were interviewed, pre/post surveys
<b>Study Sample</b>	22 participating families
<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- Literature search, current education reviewed by Nursing Education Committee members of this specific pilot facility.</li> <li>- Caregivers of five children newly diagnosed with hematologic malignancies were interviewed regarding hospital discharge experience</li> <li>- A Nursing Satisfaction with Discharge survey was developed and validated – pre and post survey</li> <li>- Education committee designed the Road to Home board, created scripts for nurses, and all direct care nurses received training on the new program.</li> <li>- Implemented the Teaching board, education station, and the parent tool kit/bags</li> <li>- Post experience – nursing and parent satisfaction surveys were distributed</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Effective nurse-led teaching and discharge planning begun at diagnosis can prepare families to safely care for their child following discharge and be a source of satisfaction</li> <li>- The Road to Home – comprehensive program includes a visual interactive display of required education based on the COG group family handbook and hospital specific discharge materials; standardized teaching, tools and documentation for nursing; and caregiver discharge tool kits. This is established for all families of newly diagnosed oncology patients and is meeting goals of increased family and nurse satisfaction with discharge education</li> <li>- Aim was to develop interactive patient education methods to engage nurses, clinical team members, parents, and patients in the new cancer diagnosis education process ... improve patient/family readiness for the transition to home and outpatient care and improve satisfaction with the discharge process</li> <li>- Lack of complete discharge preparation affects patient safety</li> <li>- Caregivers expressed increased stress related to not feeling prepared to care for their child at home after initial discharge</li> <li>- Nursing survey revealed high dissatisfaction especially regarding lack of protected time to provide effective discharge teaching</li> <li>- <b>RESULTS:</b></li> </ul>

- Post discharge parent satisfaction phone calls – 82% stated the board helped them understand what they needed to learn; 95% could accurately teach back fever guidelines; 91% consistently brought their toolkit with meds to clinic visits
- Nursing feedback – satisfaction improved across all questions asked. Highest gains were seen in questions related to discharge education and planning being an organized, multidisciplinary process with adequate resources available. Overall nursing satisfaction with discharge education and planning increased from 2.4 to 2.9 on a 5 point scale after 6 months of pilot
- Expressed that they felt communication about discharge education needs were much appreciated but that they continue to struggle to find time to teach during their busy shift
- Weekly family class called “cookies, counts, and central lines” – addresses basic discharge concerns – allows RNs to focus on teaching rather than patient care assignments as well
- 100% of participants found the class helpful (measured over 2 years), appreciated the material and would recommend the class to other families
- The education committee however, felt that the classroom setting didn’t meet the needs of all families...some families were not comfortable in a class setting, had extra learning needs that fell outside the scope of the class, needed extra hands on time or one on one reinforcement, or had unique interpreter needs
- Proposed the creation of a Patient/Family Education Advocate and Resources (PEARS) Role
- Effective nurse-led teaching and discharge planning begun at diagnosis can prepare families to safely care for their child following discharge and be a source of satisfaction
- Effective teaching and discharge planning begun at admission, facilitates safe care following discharge
- Need for improved transition to outpatient and follow up care
- Scripts were created outlining the education content, resources, sample teach back questions and tips for each section...
- **Road to Home Program** → magnetic wall mounted board in the patients room...four roads encompass education needs from admission to discharge. Family centered visual aid used jointly by families and clinicians that quickly conveys to all who enter the hospital room the family’s advancement towards discharge. Progress is tracked with magnetic cars and or dry markers
- “Information Highway” – initial information included at diagnosis
- “Teach Back Street” – knowledge that the parents need to “teach back” to clinicians
- “Demonstration lane” – care requiring hands on return demonstrations
- “Ready for Home Road” – addresses the discharge planning arrangements that need to be in place prior to leaving the hospital
- Education Station → centralized location for written teaching materials, the COG family handbook and other teaching tools. A portable rolling cart contains hands on supplies and central line mannequins used for demonstrations. Binders of teaching scripts and tips for nurses that linked to the steps on the RTH and the COG handbook are included
- Tool kit/bag → in an effort to address medication issues, each family was given a tool kit at discharge. This included the insulated tote bag, and other items necessary to safely care for their child in the home: thermometer, pill organizer, pill crusher, oral med syringes, business cards with the centers emergency phone numbers. Families are encouraged to bring the tool kit with all medications to all clinic visits...this practice allowed the clinician to review the correct med administration with the caregivers and make any changes
- Nurses need adequate knowledge, resources, time, and support to provide effective teaching that will help caregivers understand therapies, side effects, and care of their child at a time when they are often overwhelmed and anxious



	<ul style="list-style-type: none"> <li>- The RTH program is meeting the goals for increased family and nurse satisfaction with discharge education and helps assure that families are better prepared to safely care for their child at home. This program has proven to affect sustained improvements in nursing and family satisfaction with the discharge education process</li> <li>- Recommendation to create an RTH app for phones</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Conducted pre and posttests of both nurses and caregivers</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Limited detail regarding sample sizes</li> <li>- Small sample size</li> </ul>
<b>Level of Evidence</b>	Level 4

<b>Citation</b>	Landier, W., Ahern, J., Barakat, L. P., Bhatia, S., Bingen, K. M., Bondurant, P. G., ... Hockenberry, M. (2016). Patient/family education for newly diagnosed pediatric oncology patients: Consensus recommendations from a Children's Oncology Group expert panel. <i>Journal of Pediatric Oncology Nursing</i> , 33(6), 422-431. doi:10.1177/1043454216655983
<b>Purpose</b>	To review available and emerging evidence and develop expert consensus recommendations regarding harmonization of patient/family education practices for newly diagnosed pediatric oncology patients across institutions
<b>Design</b>	Expert panel – qualitative
<b>Study Sample</b>	No sample size noted – pediatric oncology nurses, and patient advocates
<b>Data Collection and Measurement</b>	Conference that presented studies in which parents and patient/family education experts were interviewed and studies addressing current literature were reviewed. Following presentations, the panel reviewed and critiqued the evidence presented at the conference, with the goal of developing best-practice recommendations. They then utilized current evidence with expert consensus to develop principles and recommendations for “potentially near better practices” for education.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- <u>Five Key principles and recommendations:</u> <ol style="list-style-type: none"> <li>1. In pediatric oncology, education is family centered</li> <li>2. A diagnosis of cancer in a child is overwhelming for the family</li> <li>3. Quality of teaching determines family readiness to care for their child at home</li> <li>4. Patient/family education occurs across the continuum of care</li> <li>5. A supportive environment is required to optimize learning</li> </ol> </li> <li>- <u>Identified 3 key focus for the education process of new diagnoses</u> <ul style="list-style-type: none"> <li>- Understanding the child's diagnosis, treatment and prognosis</li> <li>- Considering how the family can contend with the diagnosis (coping and management of ongoing life demands)</li> <li>- Recognizing what the family need to know to provide safe care for the child at home</li> </ul> </li> <li>- Patient family education needs to be done on a continuum (across care transitions) and recognized that not all teaching must be completed immediately following diagnosis</li> </ul>

	<ul style="list-style-type: none"> <li>- Childhood cancer requires frequent planned readmissions or sequential outpatient appointments, thus there are multiple teaching opportunities for continued education</li> <li>- Focusing initial information to be essential only, to avoid information overload</li> <li>- Importance of developing core information content, while individualizing methods of providing education to families</li> <li>- Individualized methods of providing education and tailoring core content based on current evidence, such as consideration of literacy/health literacy and cultural congruence</li> <li>- Importance of family centered education by recommending inclusion of all individuals in the educational process who are central to the child's care</li> <li>- Importance of consistency of messaging across disciplines, establishing a supportive environment for learning, and training of healthcare providers in the provision of education</li> <li>- Recommended development standards regarding the provision of patient/family education, as well as training for HCPs involved in caring for these patients with a focus on developing the skills required for effective patient/family education</li> <li>- Recognized that collaboration across institutions will be necessary to develop high quality evidence in order to inform best practices, ultimately to establish the standard of care for effective patient/family education</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Diverse amount of research was presented to the panel at the conference</li> <li>- Providers were given copies of presentations to review prior to the conference</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Poor identification of sample size</li> </ul>
<b>Level of Evidence</b>	Level 7

<b>Citation</b>	Rodgers, C. C., Stegenga, K., Withycome, J. S., Sachse, K., & Patterson Kelly, K. (2016b). Processing information after a child's cancer diagnosis- how parents learn: A report from the Children's Oncology Group. <i>Journal of Pediatric Oncology Nursing</i> , 33(6), 447-459. doi:10.1177/1043454216668825
<b>Purpose</b>	<ul style="list-style-type: none"> <li>- Descriptive study used to describe actual and preferred educational content, timing, and methods among parents of children with cancer prior to the first hospital discharge</li> <li>- Explored educational experiences of parents after their child is diagnosed and described actual and desired educational experiences</li> </ul>
<b>Design</b>	Qualitative, descriptive study
<b>Study Sample</b>	20 parents
<b>Data Collection and Measurement</b>	Parent interviews
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Parents expressed a variety of preferred learning styles but noted that preferences were rarely assessed by HCPs</li> <li>- Findings suggest that nursing practices should include assessing for influencing factors, providing anticipatory guidance, and incorporating parents preferred learning style into the educational plan</li> <li>- Diagnosis and treatment is very stressful for parents</li> </ul>

- **Parents reported:** an extensive amount of information about their child’s diagnosis and treatment plan. This information was mainly TOLD and not TAUGHT. Parents began to process information as it was delivered but parental knowledge level was usually minimal at the time. Some parents described shutting down immediately after hearing the word “cancer” and not hearing anything else.
- During the initial inpatient stay, the TELLING transformed into TEACHING (a reciprocal information exchange between providers and parents).
- Found several different **teaching methods useful during this time** (learning by doing, learning together, engaging with other parents, using the internet, using helpful approaches and helpful tools such as notebook, calendar, etc).
- Reported **Preferred and actual approaches by HCPs that helped them learn** such as discussion, written information, emphasizing important information, describing current events, repeating information, opportunities for questions, structured teaching, layman’s terms, consistent information, practice, compassion while teaching, anticipatory guidance.
- Reported having a particular learning style, but most parents didn’t recall being asked what that style was.
- TELLING returned at time of discharge – perceived information was conveyed to them prior to discharge with little disregard as to how they were processing it
- Rate of processing information at discharge was individualized based on medical experience and the duration of the hospital stay. One mom who had been there longer was ready to listen and able to understand, but one who had been there one week reported “blinking out” during discharge teaching.
- 11 parents reported that their education was adequate
- All parents reported feeling nervous or scared about caring for their child at home
- Major concerns – med schedules, care of central lines
- Expressed preference for concise discharge information such as magnet or one sheet of paper listing s/s that they needed to watch for at home
- As parents began to process information, they began to seek out information and ask questions
- Parents reported that they identified nurses as they key informants (preferred) because they educated in an informal and formal manner though the day, and that this helped process the information
- Some parents reported that they purposefully avoided information that might make them upset
- Parents recognized their need for ongoing education after the initial discharge home – they called HCPs for additional information once they were home
- Parents reported the time frame for which they felt they understood the cancer information they were presented – 3-10 weeks after diagnosis
- 4/20 parents felt prepared and comfortable to take care of their child after discharge
- 6/20 reported feeling unprepared after discharge and described concerns regarding med admin, neutropenic precautions, and care for the central line
- **FACTORS THAT INFLUENCED LEARNING:** several factors affected parents’ ability to process information
- Initial report of intense feelings of shock, sadness, stress when hearing diagnosis – these reactions interfered with the parents ability to process information delivered to them
- Parents valued HCPs who displayed care and support during their interactions (empathetic, gentile, calm, being attentive to questions, repeating information)
- Ability to process information was affected by parental perception of how much and how quickly information was delivered (too much up front, backed off during stay, too much again prior to discharge)

	<ul style="list-style-type: none"> <li>- Reported the pacing of information during inpatient stay allowed them to process more information and more proficiently</li> <li>- Providing consistent information was important to parents (same provider, uniformity of information provided). Parents felt it was important that the providers were familiar with the written content that the family was given to ensure consistency</li> <li>- Following diagnosis, many parents described feelings of uncertainty about what the diagnosis meant for their family</li> <li>- Parents reported “needing to figure out their life” after the diagnosis and make necessary adjustments (job, home, school, etc). some of these adjustments needed to be addressed prior to them being able to adequately process the diagnosis itself</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Sample size</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Parent only sample</li> <li>- Only parents of children diagnosed on an inpatient unit</li> <li>- Educational experiences and needs weren’t taken into consideration</li> </ul>
<b>Level of Evidence</b>	Level 6

<b><u>Citation</u></b>	Sigurdardottir, A. O., Svavarsdottir, E. K., & Gokun, Y. (2014). The impact of a web-based educational and support intervention on parents’ perception of their children’s cancer quality of life: An exploratory study. <i>Journal of Pediatric Oncology Nursing</i> , 21(3), 154-165. doi:10.1177/1043454213515334
<b>Purpose</b>	To describe the development of an evidence-based web educational and support intervention for families of children with cancer and to assess the favorability of the website, and whether there was any impact on the cancer communication aspect of the quality of life instrument.
<b>Design</b>	Quasi-experimental intervention study Pre/postdesign
<b>Study Sample</b>	38 people, 15 families (15 moms, 12 fathers, 11 children)
<b>Data Collection and Measurement</b>	<p>A literature review was completed</p> <ol style="list-style-type: none"> <li>1. Effects of pediatric cancer on family life</li> <li>2. Informational needs</li> <li>3. Online resources</li> <li>4. Health-related quality of life (HRQoL)</li> </ol> <p>Based on the literature review, two research questions were identified. Developed a cancer Web-based Educational and Support Intervention (Web-ESI) and then granted access to the 38 individuals. The individuals were to access the website independently, at their own convenience. Two questionnaires were used to evaluate the effectiveness of the Cancer Web-ESI.</p>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Lit Review findings →</li> <li>- <u>Nature of health/illness</u> – having a child diagnosed with cancer is one of the most difficult and painful life experiences for parents</li> <li>- Parents have been found to be initially shocked after the diagnosis as well as frightened, scared, in despair, upset and overwhelmed</li> <li>- Parents have experienced emotional pain when seeing their child lose his or her hair or a limb, developing decreased functional ability including experiencing their child become weaker, infected and or fatigued after chemo or radiation</li> </ul>

	<ul style="list-style-type: none"> <li>- Cancer can lead to changes in role functioning including loss of control.</li> <li>- Interventions should address the parents participation in the childs care, professional support, and informational needs to maintain a sense of control and functioning in the parental role</li> <li>- Important to keep in mind that interventions directed at a change in the cognitive domain of family functioning usually offers new ideas, beliefs, opinions, information or education on a particular health problem or risk behavior</li> <li>- <u>Information needs</u> – HCPs may have a hard time judging the amount of information that parents need, which can lead to a complicated situation, because informational needs develop and change as the cancer evolved over time</li> <li>- Parents have different experiences concerning how much information was absorbed when it was provided. If the parents needs were fulfilled, they were better equipped to handle the illness of the child. Families needed better support and more explicit instructions to be able to cope with the cancer situation.</li> <li>- Nurses as well as other personnel play an important role in education and supporting the child and parents to make decisions related to the child’s care</li> <li>- Study Findings → cancer website was developed and assessed</li> <li>- As a group, the website was rated favorably (average of 8.2 on a 4-10 scale, 10 being the most favorable). However, it was small sample size</li> <li>- Evidence based websites are an innovate approach to educate families about cancer treatment, living with the disease, as well as offering families social support.</li> <li>- Since health care information on the internet is on the rise, APRNs in peds onc are in a great place to design specific educational and social support web -based interventions that can be used at the time of the users convenience, through smart phones, tablets, computers, and ca at the same time be of benefit families adjusting to their life situation</li> <li>- This online cancer intervention shows potential to positively affect cancer quality of life as it relates to communication</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Larger sample size</li> <li>- Adequate time frame for participants to utilize website</li> <li>- Ability to access it on their own time</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Sample consisted of parents, children, and siblings</li> </ul>
<b>Level of Evidence</b>	Level 3

<b>Citation</b>	Patterson Kelly, K., & Ganong, L. H. (2011). “Shifting family boundaries” after the diagnosis of childhood cancer in stepfamilies. <i>Journal of Family Nursing</i> , 17(1), 105-132. doi: 10.1177/107484710397365
<b>Purpose</b>	To describe the impact of diagnosis on parental relationships in stepfamilies.
<b>Design</b>	Qualitative secondary analysis (interview)
<b>Study Sample</b>	13 parents
<b>Data Collection and Measurement</b>	Three telephone, and 12 face-to-face interviews that lasted 45-90 min and recorded for later transcription. Interviews were divided into information about the following: <ol style="list-style-type: none"> <li>1. Circumstances of separation/divorce (facilitated by construction a family genogram)</li> </ol>

	<ol style="list-style-type: none"> <li>2. The child's disease and treatment</li> <li>3. Recent treatment decision making experiences</li> </ol>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- 13 parents of six stepfamilies described – the crisis of childhood cancer immediately changed family dynamics. Parental relationships changed, which shifted family boundaries, creating instability in families who were trying to cope with a very stressful life experience</li> <li>- Stepfamilies, compared to first marriage families, include the potential for more adults to be involved in decision making, the possibility of heightened tension between former partners and or their subsequent partners, and the challenges of communicating between two households</li> <li>- Two families increased the demand on problem solving and communications.</li> <li>- The intensive diagnostic and treatment regimens required to treat a child with cancer fractures the familys life</li> <li>- Facing profound emotional distress and often physical separation, parents must make critical treatment decisions that are further complicated with relationship strain</li> <li>- The stress of a child's illness, coupled with lingering hostility from the dissolution of prior unions, and the added demands of a new partner could adversely affect co-parent's ability to work together to care for their child with cancer</li> <li>- Combining old spouses and their new counterparts add fuel to the fire and make for further stress.</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Focused on non-traditional family dynamics</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Original participants not available to validate new findings</li> <li>- Secondary analysis</li> <li>- Primarily mothers were involved in study</li> </ul>
<b>Level of Evidence</b>	Level 4

<b><u>Citation</u></b>	Gage-Bouchard, E. A., Devine, K. A., & Heckler, C. E. (2013). The relationship between socio-demographic characteristics, family environment, and caregiver coping in families of children with cancer. <i>Journal of Clinical Psychology in Medical Settings</i> , 20(2013), 478-487. doi:10.1007/s10880-013-9362-3
<b>Purpose</b>	This study examines the relationship between caregiver's socio-demographic characteristics and the coping strategies they use to adapt to childhood cancer
<b>Design</b>	Meta-analysis
<b>Study Sample</b>	76 caregivers (45 mothers, 28 fathers, 3 aunts)
<b>Data Collection and Measurement</b>	Survey and qualitative interview 93% response rate
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Caregiver education was associated with three dimensions of coping (active, planning, and substance us coping)</li> <li>- Caregivers with a bachelor's degree or more reported higher use of active coping</li> </ul>

	<ul style="list-style-type: none"> <li>- Associations between degree earned and planning and substance use coping depended on gender; men with lower educational attainment reported lower use of planning coping and higher substance use coping than men with higher education than women (regardless of womens education)</li> <li>- men with lower education are a particularly vulnerable group who may benefit from additional coping resources</li> <li>- Income was not associated with caregivers use of problem focused coping strategies. Findings suggest that there are important differences in the cultural capital attained from education and the financial resources derived from income. Relative importance of financial and educational resources likely vary through the disease process, with financial assets</li> <li>- being especially important in shaping some aspects of illness experiences, and educational capital being an important influence for other aspects of the illness experience.</li> <li>- Educational resources play an important role in shaping caregiver coping after a diagnosis</li> <li>- Educational attainment may influence health related knowledge, interpersonal skills, problem solving ability, social networks, social clout and the characteristics of their occupations</li> <li>- Women are more likely than men to use instrumental support, religious coping and emotional support</li> <li>- Mothers have been found to report more frequent and more effective coping compared to fathers</li> <li>- Mothers use of a passive reaction pattern and support seeking placed them at increased risk for psychological distress in the first year after diagnosis, while father were at increased risk for distress when their coping styles included avoidance, passive reaction pattern, expression of emotions, and decreased active problem focusing</li> <li>- Did not find any significant difference by income or education for family cohesion or conflict</li> <li>- It might be that after the crisis of a childs initial diagnosis passes, caregivers take more time to make decisions or act in a manner consistent with restraint coping, but the effect was quite small in the sample and the clinical significance is uncertain</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- High response rate</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- More women than men participants</li> <li>- Data were collected in the same city – may not represent experiences of families in other geographical areas</li> <li>- Design does not allow comparison of this sample of caregivers to the general population of caregivers</li> <li>- Small sample size</li> </ul>
<b>Level of Evidence</b>	Level 4

<b><u>Citation</u></b>	Cerqueira, C., Pereira, F., & Barbieri Figueiredo, M. C. (2016). Patterns of response in parents of children with cancer: An integrative review.  <i>Oncology Nursing Forum</i> , 43(2), e43-e54.
<b>Purpose</b>	To identify patterns of response of parents in relation to taking care of their child with cancer
<b>Design</b>	Integrative literature review
<b>Study Sample</b>	18 articles (primary sources) <ul style="list-style-type: none"> <li>- Qualitative, methodologic, and quantitative studies</li> </ul>

<b>Data Collection and Measurement</b>	<ul style="list-style-type: none"> <li>- CINAHL and Scopus were searched, resulting in 937 original studies</li> <li>- 919 studies were excluded, 18 articles included</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- <b>Patterns of response of parents of a child with cancer:</b> a list of behaviors, competencies, and attitudes were identified. They were then compared and four themes were found → (a) caring for ones child with cancer, (b) becoming a partner in caring for ones child, (c) caring for the family, and (d) living with ones child with cancer</li> <li>- The diagnosis of a serious childhood illness is an unexpected event that can change one’s plans and aspiration.</li> <li>- (A) Parents fear for the child’s life because they recognize the uncertainties of disease course and treatment.</li> <li>- Parents and the child learn to love under new conditions and develop strategies to carry on with their lives. Parents state that immersing themselves in the childs care can help this process</li> <li>- Parents report that the experience of taking care of a child with cancer leads to the mobilization of capacities that they did not know they possessed and the development of new skills</li> <li>- Data shows that parents need to feel they have control over the events related to their child and need to feel confident about the success of the treatment</li> <li>- Findings suggest that caring for a child with cancer is a process that involves instrumental, cognitive, relational, and emotional responses</li> <li>- Conclusion – knowledge of these patterns of response can help nurses monitor parents transition process when they are responsible for their child with cancer. Monitoring this process allows nurses to quickly identify vulnerable or at-risk parents and act accordingly to guide them toward a healthy transition.</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Inclusion and exclusion criteria</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Wide variety of diverse sources</li> </ul>
<b>Level of Evidence</b>	Level 1

<b>Citation</b>	Patterson Kelly, K., Withycombe, J., Stegenga, K., & Rodgers, C. (2018). The why behind the questions: Question-asking in parents of children newly diagnosed with cancer- a report from the Children’s Oncology Group. <i>Journal of Pediatric Nursing</i> , 43(2018), 22-28.
<b>Purpose</b>	To describe parent question-asking during the new childhood cancer diagnosis timeframe
<b>Design</b>	Interpretive descriptive method (focused analysis)
<b>Study Sample</b>	20 parents (16 mothers, 4 fathers) from 4 pediatric oncology treatment centers
<b>Data Collection and Measurement</b>	<p>Focused analysis – lead author was identified and entered data assigned to the first level of coding selected (as developed from question answers).</p> <ul style="list-style-type: none"> <li>- Data entered into an excel spread sheet and was compared with a constant comparative analysis to expand initial coding</li> <li>- Each researcher independently examined and coded or discarded every unit</li> <li>- From this, a question asking data sheet was developed</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>- <u>What affects parent question-asking</u> → feeling comfortable asking questions, not knowing enough to ask, too overwhelmed or distraught to ask, family members asking questions</li> </ul>



	<ul style="list-style-type: none"> <li>- Parents described feeling inundated with information or being too affected by their emotions after diagnosis to ask questions.</li> <li>- One parent described being overwhelmed after receiving information from multiple providers making it hard to know what questions to ask</li> <li>- One parent reported feeling shocked after the diagnosis and not knowing what questions to ask</li> <li>- <u>Clinician question- asking</u>→ asking questions to understand my understanding, available to answer questions, encouraging questions</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Geographical area</li> <li>- Inclusion of mothers and fathers</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Small sample size</li> <li>- More mothers than fathers</li> <li>- Limited variability in race/ethnicity</li> </ul>
<b>Level of Evidence</b>	Level 6

<b><u>Citation</u></b>	Granek, L., Rosenberg-Yunger, Z. R. S., Dix, D., Klaassen, R. J., Sung, L., Cairney, J. & Klassen, A. F. (2012). Caregiving, single parents and cumulative stresses when caring for a child with cancer. <i>Child: care, health and development</i> , 40(2), 184-194.  doi:10.1111/cch.12008
<b>Purpose</b>	To explore how single parents of children with cancer care for their children as opposed to children with a traditional, two parent household.
<b>Design</b>	Constructivist grounded theory method – qualitative interviews
<b>Study Sample</b>	29 single parents in Canada
<b>Data Collection and Measurement</b>	Interviews were conducted by qualitative researchers. Informed consent was obtained, and the interview was audio-recorded. A semi-structured interview guide was used with questions that were designed to encourage parents to discuss their feelings and experiences in-depth. The interviews were the recorded and transcribed. Data collection and analysis included assessment to determine specific categories and themes. Analysis involved line-by-line coding and was inductive, with codes and categories emerging from participants descriptions.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- The treatment trajectory and its aftermath can be emotionally and physically intensive for patients and their families</li> <li>- reported acting as the “emotional barometer” for their families, communities and for their child. Described this experience as needing to put on a façade that everything is under control in order to assuage the fears of their family and people within the community and dealing with other people’s distress in response to the cancer diagnosis and treatment</li> <li>- described feeling fearful of losing their home, or being unable to pay rent (financial strain)</li> <li>- parents experienced both mental and physical health problems prior to, and during their child’s diagnosis.</li> <li>- Many described disturbances related to sleep, diet and exercise habits, and reported instances of anxiety, depression, and generally feeling down while their child was on active treatment or in recovery</li> <li>- Family history – uncertainty pertaining to their ex-partners</li> <li>- Financial strain, housing instability</li> </ul>

	<ul style="list-style-type: none"> <li>- Geographical shifts – negative impact on families as siblings happened to change schools or in some cases separated them from their parent. Having to move to more suitable living conditions or move closer to the hospital.</li> <li>- Because of lower socioeconomic status of some of the parents, the neighborhoods they were living in were removed from the downtown area where the majority of the hospitals were located, meaning long commutes for parents, especially if they didn't own cars</li> <li>- Administrative duties such as coordinating and scheduling healthcare appointments, filling out forms and managing cancer related financial issues (reimbursement forms, employment insurance), and information/educational seeking tasks such as learning about childhood cancer and its treatment, and seeking information about available resources.</li> <li>- Attending to the educational needs of their children who may be missing school for extended periods of time</li> <li>- Transporting to appointments and procedures, arranging for childcare for the child and their siblings, taking care of their child at home which could include duties such as carrying their weak child around the home or outdoors, bathig and feeding their child, and ensuring their child was properly nourished</li> <li>- Maintaining their home –</li> <li>- meeting the day to day needs of their other children such as feeding, getting them to school and ensuring they were fed and clothed</li> <li>-</li> </ul>
<b>Strengths</b>	- Study that focused on a special, at risk population (single parent caregivers)
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Did not look at the child or their health status</li> <li>- Small sample size</li> <li>- Primarily mother participants</li> </ul>
<b>Level of Evidence</b>	Level 6

<b>Citation</b>	Kelly, P., & Kelly, D. (2013). Childhood cancer-parenting work for British Bangladeshi families during treatment: An ethnographic study. <i>International Journal of Nursing Studies</i> , 20(2013), 933-944.
<b>Purpose</b>	Elicit a detailed picture of the social and cultural aspects of cancer treatment for this group of children and their parents
<b>Design</b>	Ethnographic study design – qualitative
<b>Study Sample</b>	Eight families were followed over a 22-month period
<b>Data Collection and Measurement</b>	Eight families were followed over a 22-month period. Focused interviews with seven parents were conducted. Data were analyzed concurrently during fieldwork with themes identified, defined and refined, maintaining context while comparing within and across data sets.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Parents undertook and spoke about these activities as a specific set of obligations in order to care for the child</li> <li>- managing competing forms of knowledge – monitoring the child and predicting future events.</li> <li>- In addition to acquiring a complex cancer vocabulary and understanding of cancer treatment effects, parents also had to develop practical skills in order to undertake treatment work, such as caring for the child's central line</li> </ul>

	<ul style="list-style-type: none"> <li>- Vigilance – constant watchfulness of parents, both at home and in the hospital. The vigilance was characterized by parents keeping children in close proximity, undertaking checks of the body and repeatedly questioning the child</li> <li>- Monitoring for fever.</li> <li>- Advocacy- advocating for child safety needs</li> <li>- Balancing parental work</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>- Specific to parents of children in Bangladesh</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>- Most information was collected from mothers</li> <li>- Parenting experiences of caring for an adolescent with cancer were limited to only two</li> <li>- Small sample size overall</li> </ul>
<b>Level of Evidence</b>	Level 6

<b>Citation</b>	Aburn, G. & Gott, M. (2014). Education given to parents of children newly diagnosed with Acute Lymphoblastic Leukemia: The parent's perspective. <i>Journal of Pediatric Nursing</i> , 40(5), 243-248.
<b>Purpose</b>	To investigate the perceptions and experiences of parents caring for children newly diagnosed with acute lymphoblastic leukemia (ALL) in relation to education given prior to their first discharge home from the hospital.
<b>Design</b>	Grounded theory - qualitative interview
<b>Study Sample</b>	12 parents
<b>Data Collection and Measurement</b>	Twelve parents of 25 give consent to participate in the study. Eight participants were interviewed in person, others were conducted via phone interviews. All interviews were recorded. When transcribing interviews, codes were given to identify pauses between conversations and non-linguistic cues such as sighs and laughter. Next, the analysis focused on identifying thematic categories (codes). These codes were developed from the data collected and included small and large concepts, as well as personal experiences, and emotions felt during the initial education period.
<b>Findings</b>	<ul style="list-style-type: none"> <li>- Overwhelming nature of the experience</li> <li>- Having to learn very quickly about the disease and how to care for the child</li> <li>- Discussion with the HCP at the time of admission was reported to be vital because it dispelled fears about their child dying and meant parents could move forward and begin to understand the diagnosis and treatment.</li> <li>- Medical play – play therapist told what they were doing</li> <li>- “White medical folder”</li> <li>- - mixed opinions to the value of this folder – some parents found it really beneficial and found comfort in the fact that the information about their child's treatment was located in one place, while other parents didn't find it as valuable. Comments of there being too much irrelevant information, out of date information, and too much medical jargon were reported</li> <li>- - useful things they suggested – layman's terms, more information relevant at the time of diagnosis, information in there needed to be updated on a regular basis based on the treatment phase the child was in</li> <li>- Conversations with other parents are reported to be beneficial</li> <li>- “learning a different language”</li> </ul>

	- “there were two nurses who had a big impact” – the role of the health professional
<b>Strengths</b>	- Variety of patient ages (ages 2-14) - Adds new knowledge and understanding to issues that haven’t been addressed in great detail prior to this study
<b>Limitations</b>	- Small sample size, however relatively ok with a grounded theory study - Poor response rate - Mostly mothers responded (nine of the twelve were mothers). - Not all children are diagnosed in the hospital, so this limited sample size - Due to time constraints, data were not verified through feedback to participants
<b>Level of Evidence</b>	Level 4