

# Patterns of Response in Parents of Children With Cancer: An Integrative Review

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**Problem Identification:** To identify patterns of response of parents in relation to taking care of their child with cancer.

**Literature Search:** The search was performed using CINAHL® and Scopus in February 2013.

**Data Evaluation:** The selection process resulted in 18 articles with a wide range of methodologic approaches. The description of the research methods of each study and the relevance of the results in comparison to the purpose of this review were established as assessment criteria.

**Synthesis:** The results of the studies were analyzed using Meleis's Transition Theory, identifying a vast number of patterns of response developed by the parents. These patterns of response were analyzed, compared, and split into four themes.

**Conclusions:** Using this methodology, a wide range of behaviors, attitudes, and competencies associated with the circumstance of parents caring for a child with cancer could be identified.

**Implications for Practice:** Knowledge of the patterns of response will enable nurses to lead parents through a healthy transition process in caring for their children with cancer.

After receiving the diagnosis of a serious illness in a child, parents are faced with the loss of the child's health and the risk of the child dying. Young, Dixon-Woods, and Heney (2002) state that the cancer diagnosis of a child is the beginning of a process that will trigger a major transition in the family. Family members will have to reorganize themselves, and plans and expectations have to be adapted to the circumstances of having a child with cancer (Silva, 2009). The child's condition means that an adult takes on the responsibility for monitoring, managing, and providing the more complex care needed. The mother is usually the main caregiver when a child is diagnosed with cancer (Relvas, 2007; Wegner & Pedro, 2010).

According to Young et al. (2002), becoming the parent of a child with cancer implies a transition process, which involves redefining one's own identity. Parents will undergo experiences that lead to the reconstruction of their identity. Transition Theory provides a framework for understanding this process as a whole (Meleis, 2010; Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Previous studies by the authors of the current article have revealed that parents caring for a child with cancer go through a transition that involves the redefinition of their identities (Cerqueira & Barbieri, 2012; Silva, 2009; Silva & Barbieri-Figueiredo, 2011).

Meleis et al. (2000) state that such a transition can take different paths; therefore, recognizing the signals that mark the direction of a transition is important. Early recognition of whether the parent and patient are undergoing a healthy process or are in a vulnerable state enables preventive action to steer them toward a successful

transition. According to this theory, the progress of a transition can be observed and monitored through a set of expected results called patterns of response. This concept refers to a set of behaviors one would expect to see in a healthy transition (Meleis et al., 2000).

A vast body of scientific research has been published about children with cancer and their families, revealing a deep and extensive knowledge of the topic. The current authors felt it was important to review this literature with the goal of identifying the patterns of response of parents who care for a child with cancer. This integrative review was done following the five stages recommended by Whitemore and Knafl (2005): (a) problem identification, (b) literature search, (c) data evaluation, (d) data analysis, and (e) presentation.

The process was guided by the following initial question: "What are the patterns of response of parents undergoing the experience of taking care of a child with cancer with regard to their daily demands?"

## Literature Search

The goal of this review was to gather as much information as possible from credible and high-quality sources, and empirical studies and theoretical works were included as outlined in an integrative review (Whitemore & Knafl, 2005).

The search terms emerged from the authors' knowledge of the area of study and population involved. These terms were initially identified in Portuguese. Then, the respective descriptors were identified in English using the National Library of Medicine and the Virtual Health Library. Boolean search terms used included ("parental role" OR "pa-

ternal role" OR "maternal role" OR "famil\* role" OR "parental skill\*" OR "paternal skills\*" OR "maternal skill\*" OR "famil\* skill\*" OR "parental competence\*" OR "paternal competence\*" OR "maternal competence\*" OR "parental care" OR "paternal care" OR "maternal care" OR "parental caring" OR "paternal caring" OR "maternal caring") AND (child\* OR minor\* OR infant\* OR adolescen\* OR pediatric\*) AND (cancer OR neoplasm\* OR tumor\* OR oncolog\*) AND (nurse\* OR nursing).

The review question guided the following inclusion criteria: (a) the article deals with the experience of taking care of a child with cancer; (b) the issue is discussed from the perspective of the child's parents, family, or legal guardian; and (c) the research depicts the items of interest are the experiences linked to the active treatment phase. As such, the following exclusion criteria were defined: (a) experiences linked to the palliative or terminal phase of the illness, (b) experiences during the survivor phase, (c) minutes from scientific conferences, (d) editorials, and (e) opinion articles.

The search was carried out using the CINAHL® and Scopus databases. No time limits were established in the search. The search was carried out in February 2013 and included all the results in the databases up to that date. Using the terms selected for the search, a total of 937 sources were found (see Figure 1). All articles written in Portuguese, Spanish, French, or English were considered.

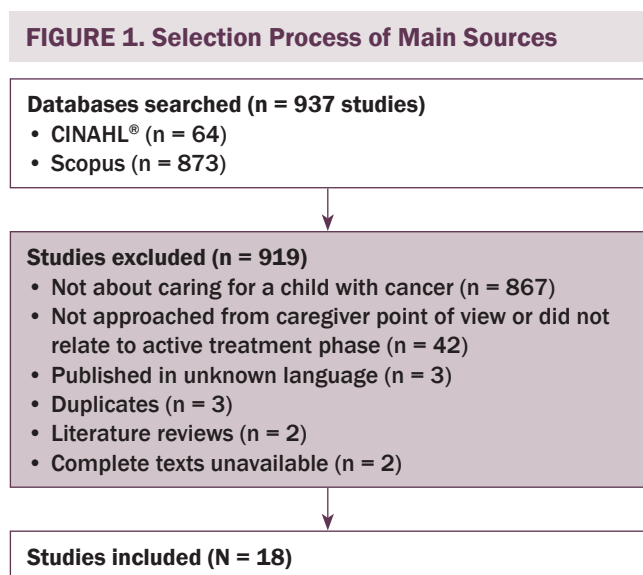
## Data Evaluation

The application of inclusion and exclusion criteria resulted in 18 primary sources in this integrative review. The diversity of sources made it impossible to build an instrument that would allow for the systematic assessment of an array of predefined items. To overcome this issue, the three researchers decided to establish, as assessment criteria, the description of the research methods of each study and the relevance of the results, in accordance with the purpose of this review. Both criteria were evaluated with a two-point scale (1 = low, 2 = high) (Whitemore & Knafl, 2005). The reviewers individually assessed each source and decided, by consensus, to include the 18 sources presented in Table 1.

## Data Analysis

Taking into account the goals of this integrative review and the diversity of the material gathered, the next step was to organize, codify, and categorize primary sources in accordance with the intended analysis. The strategy was to organize the sources using their methodologic nature as the criterion, which resulted in three subgroups: qualitative, methodologic, and

**FIGURE 1. Selection Process of Main Sources**



**TABLE 1. Data Summary of Studies Included in the Literature Review**

Study and Origin	Participants and Study Goals	Results	Knowledge Translation
<b>Qualitative studies</b>			
Clarke, 2006 Canada	49 mothers participated in this study that describes the different duties that mothers carry out at home when they provide care to their children with cancer, focused on the emotional aspects.	Mothers have to carry out different kinds of emotional work when they stay at home (e.g., having to deal with the moral imperative linked to maternity, managing feelings and a certain isolation and separation from the normal world, managing fear, managing their relationships with their husbands). The main strategy for managing feelings involves keeping a written record of their feelings, medical notes, and related data.	When mothers remain at home, they provide emotional support for the rest of the family members, in addition to the child with cancer. These women also have to deal with their own emotional needs and feelings. Mothers develop personal strategies for dealing with their emotional needs to be able to care for a child with cancer.
Clarke et al., 2005 Canada	49 mothers participated in this study that describes the different activities mothers carry out at home when providing care to their children with cancer.	Mothers carry out activities related to the care provided at home (e.g., giving medicine; providing care to ease pain, suffering, and changes in behavior; substituting the teacher; monitoring the child; undertaking technical procedures). They manage and plan everything related to their child's care (e.g., recording events, managing unexpected events, running the household).	Taking care of a child with cancer is a full-time job for a mother. At home, these women accumulate other concurrent tasks. Mothers have to be supported and the families have to be organized to successfully deal with all the tasks.
Comaru & Monteiro, 2008 Brazil	One female caregiver participated in this study that identified the significance attributed by a family female caregiver to the home care of a child with cancer.	The caregiver provides care, ensures self-care needs, carries out the technical procedures, administers medication, monitors a child's condition, provides a safe environment for the child, and gives affection. The caregiver accepts caring for the child as her main priority in relation to the rest of her life. The act of caring is described as being inspiring and gratifying.	Caring for a child with cancer is a gratifying journey of personal development and accepted as a priority from the beginning.
Evans, 1994 United Kingdom	Five mothers participated in this study that researched the feasibility of parental participation in children's care.	Parents should decide the moment when they take on the child's care. Active participation in the child's health care is a coping strategy because it can provide a feeling of control over events. Mothers state that their involvement in care diminishes the child's anxiety and increases feelings of security.	Parents' initiative is decisive for their involvement in their children's care. Parents' participation in care is desirable and benefits parents and children. Negotiation and clarification of the nature of the parents' involvement is essential for the success of this process.
Holm et al., 2003 United States	45 parents participated in this study that explored the parents' descriptions of their participation in the medical care for their child with cancer.	Looking after the child's interests was the theme that showed how the parents take part in the medical care of their child. The main category is understood through other categories that explore and explain the central theme: being informed about the child's condition, making medical decisions, limiting the action of the health professionals, and supporting the health professionals.	One of the main forms of parental involvement is defending the child's interests. Parents get involved to feel control over the child's situation. Promoting the parents' feeling of control is important for their well-being and successful participation in the process.

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**TABLE 1. Data Summary of Studies Included in the Literature Review (Continued)**

Study and Origin	Participants and Study Goals	Results	Knowledge Translation
<b>Qualitative studies (Continued)</b>			
Huang et al., 2008 Taiwan	Nine single parents participated in this study that explored the essence of the family resources and how to assist a single parent as the caregiver of a child with cancer.	Single parents of children with cancer need to take care of the child, keep working, and take care of the other family members. These parents identify the following resources as necessary for their success: developing the right attitude for facing up to the illness, getting the attention of health professionals, developing their parental abilities to care for the child, and constructing a life for the child. To function as a normal family, single parents need to adapt family relations in a flexible way and modify the family roles and interactions.	Family resources and support are important for the successful abilities of single parents to take care of their child with cancer. The support provided by the rest of the family demands flexible roles for parents to carry out other concurrent tasks.
Jones & Neil-Urban, 2003 United States	10 fathers participated in this study that analyzed the content and sharing process established among the fathers of children with cancer in focus group dynamics.	The participants showed mutual interest in themes, such as cancer and their children, the diagnosis and treatment, medical staff and the effect of the illness on the family, and the male perspective on dealing with the situation. The results of this research suggest that fathers benefit from sharing their experiences with one another. They seem to be consoled by being listened to, understood, and comforted. They seem to appreciate the opportunity to offer support to each other.	Fathers need information and emotional support. Participation in group dynamics with other fathers is a strategy that provides the support they need.
Kelly & Kelly, 2013 United Kingdom	15 parents participated in this study that describes the everyday experience of parents with children with cancer from Bangladesh living in Great Britain.	Parents gradually take on the care of the child in line with the knowledge and experience they have. They constantly monitor the child with cancer and fight for his or her interests. They carry out other tasks linked to caring for the family's needs and strive to keep a sense of balance despite the demands put on them. The parents attempt to manage their difficulties because they are afraid of being considered incapable of looking after their children. Language is a barrier to parenting, as well as an obstacle to better performance and achieving access to available resources.	Non-native families take on the care of the child with cancer in the same way as native families do. They live through their experience in a more isolated manner, relying merely on their internal resources. The fear of being deemed incapable and their lack of command of the language are the main reasons behind this isolation. Understanding the culture of the clients is important for nursing care planning.
Leavitt et al., 1999 United States	18 families participated in this study that identified ethnic influences on accepting treatment, using other healthcare methods, parental perception on the possible results of the illness, the impact on the family, and focusing on the children and their needs.	Native and non-native families show similar results with regard to caring for children with cancer, looking after the families' needs, and accepting treatment. Both groups experience the initial phase in an emotional fashion and gradually evolve toward acceptance of the event. Ethnic differences were obvious in the approach to the emotional care of the child, the provision of and use of social and emotional support and emotional coping, and the expression of distress.	Understanding the clients' culture is important for planning nursing care. Cultural factors, a lack of command of the language, and immigrant status contribute to the isolation of non-native families. Immigrant families experience taking care of a child mainly using internal resources.

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**TABLE 1. Data Summary of Studies Included in the Literature Review (Continued)**

Study and Origin	Participants and Study Goals	Results	Knowledge Translation
<b>Qualitative studies (Continued)</b>			
Martinson & Yee, 2003 Hong Kong	93 families participated in this study that explored the dimensions of recovering the health of a child with cancer.	Recovering the health of a child with cancer involves providing the right nutrition, using alternative treatments, planning rehabilitation activities, and preventing infections.	The recovering health concept involves providing the child with the best conditions so that the treatment can be successful. Providing the child with the best conditions also affords a feeling of control.
Misko & Bouso, 2007 Brazil	Six mothers participated in this study that aimed to understand how the child's family manages the illness and its consequences at home and how the family makes the decision to take the child to the emergency department.	The data obtained were analyzed using the Family Management Style Framework. The mothers develop a daily monitoring routine of their child. They look for signs that may indicate a new complication and try to prepare themselves to act at any moment. Taking the child to the emergency department is seen as a loss of control of the illness. As the treatment progresses, parents become more and more comfortable making decisions when faced with potential events.	Managing the signs and symptoms and complications of the illness at home is a challenge for mothers and requires knowledge and continuous monitoring. Mothers seek to solve situations at home by using all the resources and skills they have. Preparing mothers to manage the child's condition is essential.
Moore & Beckwitt, 2006 United States	18 parents and 9 children participated in this study that assessed the self-care actions and dependent care that parents and children use to satisfy the self-care requirements of the child and identified the actions of nurses who foster self-care.	Three kinds of actions that parents and children perform can satisfy the self-care requirements of the child: estimative (requirements deriving from the child's lack of health), transitional (related to the self-care requirements and development or requirements deriving from lack of health), and productive (related to the universal requirements of self-care with needs deriving from lack of health and development). Nurses' actions include transmitting and providing information; discussing alternatives and recommending other resources or services; helping to identify resources; and providing motivation.	To respond to self-care needs, the parents and children mention and carry out several actions to satisfy the child's self-care requirements. Nurses should seek to encourage the actions identified.
Souza Andrade et al., 2012 Brazil	10 nursing assistants and 3 nurses participated in this study that aimed to understand the nursing team's perception of the families' participation in caring for a child with cancer.	The nursing team considers parents' participation in the child's care indispensable for successful treatment. Partnership means the parents are able to carry out the care that professionals teach them and are able to report the events experienced by the child. Nurses are responsible for the technical treatment and the family for emotional care.	The nursing team considers parents' participation in the child's care an indispensable condition for successful treatment. Parents' participation is seen as having been delegated by the nurses.
<b>Quantitative studies</b>			
González-Arratia et al., 2011 Mexico	30 mothers and 30 children participated in this study that aimed to identify the mothers' and children's levels of resilience and to understand the strength of the relationship between the two.	Two instruments were used in this study, the Cuestionário de Resiliencia and Escala de Resiliencia (Fuerza y seguridad personal) Para Adultos. The children have high levels of resilience, and factors, such as gender or age, do not influence resilience. Mothers have a moderate level of resilience overall and particularly high resilience in relation to their perceptions about their ability to help others. Limitations included low number of participants and limited time between diagnosis and treatment.	The results suggest that children have a high level of resilience. Cancer may influence the children's resilience level. Mothers present a moderate overall resilience. Promoting mothers' resilience levels should be a focus of nurses' therapeutic efforts.

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**TABLE 1. Data Summary of Studies Included in the Literature Review (Continued)**

Study and Origin	Participants and Study Goals	Results	Knowledge Translation
<b>Quantitative studies (Continued)</b>			
Pyke-Grimm et al., 1999 United States	58 parents participated in this study that aimed to identify parents' preferences in the decision-making process and their information needs.	Data were gathered using two instruments, the Control Preferences Scale for Pediatrics and the Information Needs Questionnaire. The results show that the parents have systematic preferences about their decision-making role in dealing with the child's illness, and they may be collaborative, active, or passive. Parents prefer to share with the healthcare team the responsibility for making decisions about what the best treatment is for their child. The information needs relate to treatment and medical tests, likelihood of cure, care of their child, the emotional impact of cancer on the child, the possible side effects of the treatment, the physical impact of cancer on the child, dealing with painful procedures, and the impact of cancer on the family.	Parents' needs are related to the prognosis, treatment, and consequences of the treatment. Most parents show a shared decision-making profile. The process is shared with the health professionals.
Williams et al., 2006 United States	10 mothers, 1 grandmother, and 1 father participated in this study that assessed the ability of parents and caregivers to monitor the symptoms using the Therapy-Related Symptom Checklist (child version). The study aimed to identify the measures that have to be implemented to alleviate or control these symptoms.	Results show that the parents and caregivers are able to observe the child promptly and identify symptoms using the checklist, as well as state the care strategies to control the symptoms. Results of this study are limited because of the small sample size.	Parents are able to take on the responsibility of identifying and managing the signs and symptoms of the illness. Preparing the parents for this task and transmitting the skills needed should be the main foci of the nurses' therapeutic efforts.
<b>Methodologic studies</b>			
Kuan, 2000 Hong Kong	30 parents participated in the first phase and 255 family caregivers participated in the second phase of this study that aimed to describe the needs and concerns of the family caregivers of a child with cancer.	In the first phase, parents' needs included obtaining information, monitoring the child, negotiating with healthcare professionals, facilitating the continuous growth and development of the child, maintaining strength, dealing with family responsibilities, and mobilizing community resources. In the second phase, data were gathered using the Chinese Childhood Cancer Family Caregiver Needs Survey. The need perceived as the most important was that of obtaining information, followed by monitoring the child and negotiating with health professionals. As the child goes through the different phases of the illness, needs tend to diminish, and satisfaction levels rise in relation to the various dimensions of the needs. The survey has a good internal consistency with a Cronbach alpha of 0.941.	Parents' information needs are perceived as the most important. Parents feel a need to be actively involved in their child's care. Throughout the evolution of the treatment, parents' needs tend to diminish.

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**TABLE 1. Data Summary of Studies Included in the Literature Review (Continued)**

Study and Origin	Participants and Study Goals	Results	Knowledge Translation
<b>Methodologic studies (Continued)</b>			
Wells et al., 2002 United States	153 caregivers participated in this study that aimed to describe the development and initial assessment of the Care of My Child With Cancer instrument.	The instrument contains 34 tasks carried out by parents who have taken care of a child with cancer and is linked to five domains: physical care of the child, identifying the emotional needs of the child, the caregivers and family members, maintaining daily activities, additional financial responsibilities, and managing information and communication. The instrument has a high internal consistency (Cronbach alpha = 0.93 for 28 items). The correlation between the test and re-test was 0.9, indicating that the test was very stable. The limitations of the results are related to the various institutions and the number of null responses.	The instrument is robust in terms of internal consistency. It can usefully identify and monitor caregivers' responsibilities related to (a) family's emotional needs, (b) information and communication needs, (c) maintaining a functional family, and (d) those needs arising from the medical care of the child.

quantitative studies. This strategy facilitated the analysis of the sources and the extraction of data.

To ensure methodologic rigor in data extraction, a set of variables were defined (i.e., methodologic nature of the sources, context of care, subjects involved, main results, knowledge translation, and patterns of response) to guide the selection of content to be drawn from each source. The theoretical and operational definition of each of the variables were followed to facilitate extraction and agreement among the reviewers (Brown, Upchurch, & Acton, 2003).

Data were extracted from each source and reduced to a single-page matrix, highlighting the data under analysis (Whittemore & Knafl, 2005). Then, the sources and variables under analysis were placed together into one table according to their methodologic nature, aggregating data for ease of analysis. This allowed for the quick and easy viewing of the sources, the variables under analysis, the methodology used, the results, and conclusions with nursing implications.

The results, extracted from each source, were reviewed and analyzed. This procedure was undertaken using the Transition Theory as the framework for identifying patterns of response of the parents of a child with cancer (Meleis, 2010; Meleis et al., 2000). An extensive list of behaviors, competencies, and attitudes was identified, which can be considered patterns of response. These were then compared to seek out relationships among them. Four thematic groups emerged through this process: (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 (see Figure 2).

## Findings

### Caring for One's Child With Cancer

The theme of caring for one's child with cancer was underpinned by data from 14 primary sources and reflected the highest number of responses by parents. In the context of the normal growth and development of a child, parents look after the different needs of the child. Previous knowledge of the child can be used to their advantage upon diagnosis because it allows the child's needs, as well as the resources required to satisfy them, to be identified. The new circumstances after a cancer diagnosis may make it necessary to learn and develop new techniques and skills to carry out self-care activities (Comaru & Monteiro, 2008; Moore & Beckwith, 2006). The illness and its treatment will become part of the child's life for an indefinite period of time. Parents develop behaviors to help with the child's acceptance of the new condition; seek emotional balance, socialization, and integration at school; and develop personal resources (Clarke, Fletcher, & Schneider, 2005; Comaru & Monteiro, 2008; Huang, Mu, & Chiou, 2008; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Souza Andrade et al., 2012; Wells et al., 2002).

In the context of symptom management, care takes on great importance because changes in the child's condition may put his or her life at risk. Several behaviors developed by the parents to manage symptoms were identified in the literature, such as identifying changes in the physical condition of the child, making decisions related to care, implementing a broad array of care techniques, monitoring signs resulting from the

## CARING FOR ONE'S CHILD WITH CANCER

- Providing the care needed for self-care
- Assessing the impact of self-care activities
- Identifying the resources needed to enable self-care
- Promoting the emotional balance of the child
- Promoting the socialization of the child
- Helping the child accept the illness
- Promoting the child's development and discipline
- Promoting the child's reintegration into school life
- Identifying changes in the child's physical condition
- Obtaining information about the child's condition and needs
- Making decisions in relation to care (symptom management)
- Making decisions about the course of treatment
- Promoting care related to the illness and treatment
- Accompanying the child during procedures
- Monitoring aspects of the illness and the treatment
- Providing a diet in accordance with the child's condition and needs
- Ensuring the continuity of the therapeutic measures
- Keeping a record of events
- Keeping in contact with the healthcare team
- Monitoring healthcare professionals' efforts
- Controlling healthcare professionals' efforts
- Gathering the information needed to defend the child's interests
- Negotiating with healthcare professionals
- Facing up to opposition of healthcare professionals to defend the child
- Encouraging the child to trust the healthcare team
- Finding out about the available community resources
- Using the resources available
- Protecting the child by preventing exposure to infections
- Protecting the child from physical harm
- Building a safe school environment for the child

## BECOMING A PARTNER IN CARING FOR ONE'S CHILD

- Accepting one's role in the healthcare team
- Defining one's role in the healthcare team
- Searching for knowledge about the illness and treatment

- Sharing the care provision with the healthcare team
- Ensuring continuous care in different contexts
- Establishing a trusting relationship with the healthcare team

## CARING FOR THE FAMILY

- Preparing the family to integrate the child into a new situation
- Managing the information to be transmitted to the family
- Maintaining the everyday nuclear family
- Giving emotional support to the family
- Restoring the family balance
- Identifying the needs of the spouse
- Identifying the implications of the child's illness on marriage
- Managing the well-being of other family members
- Identifying changes for siblings
- Keeping track of the developmental needs of siblings
- Managing the reactions of siblings
- Obtaining care for siblings
- Managing family finances
- Identifying the needs of the extended family
- Identifying potential resources among family and friends
- Requesting help from family members

## LIVING WITH ONE'S CHILD WITH CANCER

- Maintaining a positive outlook throughout the process
- Developing spiritual practice
- Having a positive appraisal about one's abilities
- Showing confidence in one's abilities
- Expressing acceptance and appreciation of oneself
- Managing one's emotions
- Managing one's needs
- Learning to live with the illness
- Identifying changes in one's life
- Encouraging healthy habits
- Achieving a healthy balance
- Reformulating values and priorities
- Showing feelings of belonging
- Accepting the responsibility of being a caregiver
- Identifying everyday difficulties

### FIGURE 2. Identified Patterns of Response of Parents Caring for a Child With Cancer

illness or treatment, accompanying the child during medical procedures, keeping a record of events, and interacting with the healthcare team (Clarke, 2006; Clarke et al., 2005; Comaru & Monteiro, 2008; Holm, Patterson, & Gurney, 2003; Huang et al., 2008; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Misko & Bouso, 2007; Souza Andrade et al., 2012; Wells et al., 2002).

The child's condition and treatment must be managed during hospital visits and at home. Parents ensure that the child receives continuous care, allowing them to remain at home as long as possible and receive all necessary attention (Leavitt et al., 1999). To provide the child with access to the necessary resources, parents seek out and use available community resources (Huang et al., 2008; Kuan, 2000; Leavitt et al., 1999; Moore & Beckwitt, 2006; Wells et al., 2002).

Many of the cytotoxic drugs used in the treatment of cancer have toxic effects on hematopoietic progenitor cells, which may result in immunosuppression and blood clotting disorders (Biagi, Bollard, Rousseau, & Brenner, 2003). These are causes of concern and receive close attention from the parent. Parents seek to protect the child from contracting infections. They reduce the child's exposure to crowded places, keep the home environment clean, control the child's visitors, and protect the child from infection (Comaru & Monteiro, 2008; Kuan, 2000; Leavitt et al., 1999; Martinson & Yee, 2003).

During cancer treatment, a child may experience symptoms like nausea, vomiting, diarrhea, mucositis, pain, fatigue, sleep disturbance, and frequent mood changes (Hockenberry et al., 2010). These conditions can lead to changes in the child's appetite and, as a consequence, changes in nutritional intake, which



may result in weight loss and nutritional deficits (Montgomery et al., 2013). A decrease in the energy intake may contribute to an energy deficit with increased metabolic rate and altered physical activity (Brinksma et al., 2012).

Planning a child's diet and encouraging him or her to eat the food he or she needs is a responsibility of the parents. Providing a diet in accordance with a child's energy needs becomes an extremely important issue for parents because they understand that restoring and maintaining a child's physical health is essential. Involving the parents in a child's care makes them feel useful and more confident in their abilities (Comaru & Monteiro, 2008; Huang et al., 2008; Kelly & Kelly, 2013; Kuan, 2000; Martinson & Yee, 2003).

The restoration and maintenance of the child's physical condition is important to parents because they understand that the continuity of treatment and well-being of the child is essential. They feel a need to do more for the child's health, and some do so by using complementary therapies in association with conventional medical treatment. These measures are often closely linked to diet and include supplementary ingredients (e.g., vitamins), certain medicinal foods, and plants (Comaru & Monteiro, 2008; Huang et al., 2008; Kuan, 2000; Leavitt et al., 1999; Martinson & Yee, 2003; Williams, Schmideskamp, Ridder, & Williams, 2006).

Parents make it their mission to defend a child's rights and interests. This results from the emotional relationship between them and from the clear perception that the child is vulnerable, exposed to risks, and unable to defend him or herself alone. Parents defend a child's interests and protect him or her from any harm that might result from the action of the healthcare professionals by seeking the best care for the child and selecting what they believe to be the best resources available (Holm et al., 2003; Huang et al., 2008; Kelly & Kelly, 2013; Kuan, 2000; Souza Andrade et al., 2012).

Despite the parents' involvement in providing the complex care arising from the illness and treatment, healthcare professionals become a constant presence in the child's life. The relationships established between these professionals and the child should make the process easier and promote positive feelings for the child. The parents try to make the child feels comfortable in the presence of professionals by establishing a relationship of trust with them (Martinson & Yee, 2003).

### **Becoming a Partner in Caring for One's Child**

The theme of becoming a partner in caring for one's child was supported by data from 10 primary sources. The parents who take responsibility for caring for their children accompany them at the hospital and

at home. This results in close and constant contact with the healthcare professionals and with a child's treatment and needs. At the beginning, the parents may not know much about the illness and its treatment. Progressive involvement in the child's care, involvement with healthcare professionals, and the need for more knowledge about the illness and its treatment promote the search for information. The knowledge gained helps the parents feel like they are somewhat in control of the situation because they are able to interpret and predict events, giving them firmer ground to make decisions and allowing them to believe they can provide the best possible care (Holm et al., 2003; Jones & Neil-Urban, 2003; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Misko & Bouso, 2007; Moore & Beckwitt, 2006; Souza Andrade et al., 2012; Wells et al., 2002).

As the illness and its treatment advance, the parents become more and more aware of their children's needs and prepare to take over care. In the hospital, parents and healthcare professionals may share responsibilities for decisions about treatment and care. When the child returns home, parents have to make decisions and provide the care based on their knowledge and experience. They become conscious of their role in the caregiving team and gradually adapt their position and functions in relation to the rest of the team (Evans, 1994; Holm et al., 2003; Jones & Neil-Urban, 2003; Kuan, 2000; Leavitt et al., 1999; Misko & Bouso, 2007; Souza Andrade et al., 2012). Sharing the provision of health care and making sure of continuity of care across the different settings are two behaviors associated with the care partnership between parents and healthcare professionals (Clarke et al., 2005; Misko & Bouso, 2007; Souza Andrade et al., 2012). Trust is essential for a successful relationship between parents and healthcare providers. Behaviors expressed by parents include trusting the care team, recognizing the competence of these professionals, and fostering relationships with the care team (Holm et al., 2003; Kuan, 2000; Pyke-Grimm, Degner, Small, & Mueller, 1999).

### **Caring for the Family**

The theme of caring for the family was based on data from nine primary sources. A diagnosis of cancer in a child disrupts the family's functional balance. The needs of each of its members have to be looked after, particularly if other children are involved. The social and financial commitments also have to be safeguarded. Parents, in addition to having to take care of a child with cancer, have to maintain a balanced family and care for their other children. Restoring the balance means being able to identify changes that the child's illness has caused in each of the

family members and in the family unit. To promote the family's equilibrium, parents develop behaviors, such as identifying the needs of the different members, carrying out everyday chores, giving emotional support to those in need, managing the family finances, establishing new routines, redefining roles, and adjusting short- and long-term family plans (Clarke, 2006; Clarke et al., 2005; Huang et al., 2008; Jones & Neil-Urban, 2003; Kelly & Kelly, 2013; Leavitt et al., 1999; Martinson & Yee, 2003; Wells et al., 2002).

When the family has other children, those children are an added source of worry for the parents (Kuan, 2000). The parents try to maintain their role with the other children despite the circumstances giving rise to frequent physical separations (Leavitt et al., 1999).

They seek to identify the needs of their children as they always did, seeing what has changed for the children, monitoring their reactions to the events, and obtaining the resources that the children need (Jones & Neil-Urban, 2003; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Wells et al., 2002).

In some cases, the extended family and friends are considered resources to help overcome the parents' difficulties. The physical distance that separates family members and cultural traditions can be obstacles blocking this collaboration and support. Taking care of a child with cancer, maintaining family balance, and taking care of the other children are demanding tasks that are tiring and often difficult to manage. The support received from extended family members may alleviate the parents' workload and make it easier for the caregiver, spouse, and children to restore equilibrium. Parents are the people who best know the needs of each family member and know the routines and tasks that have to be carried out, and they are able to identify what they need from the extended family and friends (Huang et al., 2008; Kelly & Kelly, 2013; Kuan, 2000).

### **Living With One's Child With Cancer**

The theme of living with one's child with cancer emerged from the data produced by 13 primary sources. The diagnosis of a serious childhood illness is an unexpected event that can change one's plans and aspirations. The future of the child, as well as his or her physical, cognitive, emotional, and social development, is potentially compromised. Parents fear for the child's life because they recognize the uncertainties of disease course and treatment (Misko & Bouso, 2007). The treatment is lengthy and involves side effects that have to be controlled. Parents and the child learn to live under these new conditions and develop strategies to carry on with their lives. Parents state that immersing themselves in the child's care can help this process (Evans, 1994; Huang et al., 2008).

As soon as the parents become aware of the child's diagnosis and the treatment needed, one of them usually takes on the responsibility of remaining by his or her child's side and providing the care needed. Accepting responsibility to be the child's caregiver is associated not only with the affective bond between the two, but also to parental accountability (Evans, 1994; Huang et al., 2008; Jones & Neil-Urban, 2003; Kuan, 2000; Leavitt et al., 1999; Souza Andrade et al., 2012). Parents' knowledge and experience in taking care of the child helps them in this task. However, difficulties arise from a combination of factors related to the child, the caregiver, and the context surrounding the illness. In data analyzed in this integrative review, parents mention difficulties related to the child and the care they need and the variability of everyday tasks (Evans, 1994; Jones & Neil-Urban, 2003).

Knowledge about the disease and its treatment, the experience that is acquired throughout this process, and the success of the treatment are conditions that gradually help restore equilibrium. Analysis of the primary sources highlighted behaviors and attitudes (e.g., identifying changes in their lives, accepting the illness, integrating the unpredictability of the illness into daily life, integrating one's needs, adopting healthy lifestyles, managing one's emotions, reformulating one's values, communicating feelings of belonging) that can be linked to this process (Clarke, 2006; Evans, 1994; González-Arratia, Nieto, & Valdez, 2011; Huang et al., 2008; Jones & Neil-Urban, 2003; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Misko & Bouso, 2007; Wells et al., 2002).

Confidence in their own performance is essential for parents' well-being and for them to continue performing their role. According to the literature reviewed, confidence is a feeling that results from a combination of factors, such as experience in caring, the ability to make decisions in unexpected situations, the ability to act in defense of the child, and the ability to readily take on responsibility for caring for their child (Holm et al., 2003; Leavitt et al., 1999; Misko & Bouso, 2007).

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. These circumstances lead to a positive appraisal of themselves and their abilities (Clarke, 2006; González-Arratia et al., 2011).

Data show 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. These feelings are important to help them face their everyday difficulties and to transmit confidence to the child. The coping strategies linked to this issue involve keeping a positive attitude and implementing

spiritual practices and habits that boost confidence (Huang et al., 2008; Kuan, 2000; Leavitt et al., 1999).

## Discussion

Childhood cancer is a reality that has long been the focus of research by healthcare professionals. Numerous studies have been published on the subject, and the results of different methodologic and theoretical approaches have been disseminated, highlighting a complex reality. The goal of this integrative review was to identify patterns of response presented by parents who care for a child with cancer. The decision to undertake an integrative review of the literature was because of the vast number of studies available and because this approach provided a method that would allow the authors to bring together different kinds of data selected in line with predefined criteria. Using this methodology, identifying a vast range of behaviors, attitudes, and competencies associated with the circumstance of a parent caring for a child with cancer was possible. Parents' responses were analyzed in terms of their meaning.

The theme of caring for one's child with cancer was the category with the highest number of patterns of response identified. This finding results from the fact that a substantial part of the studies are centered on the child with cancer, his or her needs, and the care provided to him or her, which results from the centrality that the child with cancer and the related treatment acquires at diagnosis. The child becomes more vulnerable and dependent on others to satisfy his or her needs. This condition gives rise to the need for an adult to take responsibility for being the child's caregiver, which includes monitoring, managing, and providing the necessary care (Silva & Barbieri-Figueiredo, 2011).

A child with cancer has normal developmental needs, but the circumstance of growing up within the context of a chronic illness adds a set of specific needs. The data revealed that caring for a child with cancer requires parents to develop technical, relational, and emotional skills (Comaru & Monteiro, 2008; Holm et al., 2003; Huang et al., 2008; Kelly & Kelly, 2013; Kuan, 2000; Leavitt et al., 1999; Souza Andrade et al., 2012; Wells et al., 2002).

The theme of becoming a partner in caring for one's child identified behaviors related to parents taking on the role of the child's caregiver. They seek the knowledge that allows them to share decisions about the course and treatment options and to carry out most of the care. The parents' role in caring for a sick child is a consequence of (a) reduced time of hospitalization, (b) implementation of care models centered on the family, and (c) the child's needs (Smith, Coleman,

## Knowledge Translation

- Competencies and attitudes were identified that can be considered patterns of response of parents of a child with cancer.
- Knowledge of patterns of response can help nurses monitor parents' transition process when they are responsible for a child with cancer.
- Nurses are able to lead parents through a healthy transition process in caring for a child with cancer.

& Bradshaw, 2006). Studies carried out about the parents' involvement in taking care of a child with cancer show that adopting this attitude benefits the child and the parents (Mendes & Martins, 2012). The child feels safer and less anxious when care is administered by his or her parent (Kuan, 2000). Parents feel useful and more secure when they are the ones to care for their ill child (Martinson & Yee, 2003; Mendes & Martins, 2012).

The theme of caring for the family resulted from the circumstances of the family caregiver being a parent. The issue was approached from the perspective of illness's effect on the family as a unit and how the different members dealt with their different needs and roles. Several parental patterns of response were identified in terms of keeping the family functioning smoothly and performing the parental role with other children. Qualitative studies made a major contribution to this dimension, owing to the detailed and wide-ranging description of the results, which revealed a variety of patterns of response. Studies of this topic showed that women are the main caregiver of the child with cancer and seek to continue performing other roles related to maintaining the family (James et al., 2002; Moreira, 2007; Wegner & Pedro, 2010).

The theme of living with one's child with cancer results from the condition of becoming the caregiver of a son or daughter with cancer. Parents seek to integrate this circumstance gradually into their daily lives and individual needs. They are exposed to daily challenges that test their skills and competencies. Some of the parents' responses fit in with the findings of the authors' previous study (Silva, 2009), particularly related to the fact that having a child with cancer can stretch parents to their limits, leading to the discovery of new capacities and weaknesses. Learning new skills and gaining mastery of the new situation increase self-esteem and lead to a positive self-image. Data also reveal that parents feel a need to have control over the illness and, as such, develop responses that allow them to maintain this feeling.

Silva (2009) stated that, in an adverse context marked by unpredictability and the possibility of losing a child, parents develop skills that allow them to manage the situation in their daily lives with a degree of optimism and confidence.

One issue to highlight is the fact that, despite the cultural diversity that the review included, patterns of response of parents of a child with cancer present striking similarities predominantly in the theme of caring for a child with cancer.

The findings suggest that caring for a child with cancer is a process that involves instrumental, cognitive, relational, and emotional responses. Additional research is needed to determine which patterns lend themselves to the development of indicators, allowing the monitoring of the transition experienced by parents of a child with cancer.

## Implications for Practice and Conclusion

An extensive list of behaviors, competencies, and attitudes was identified in this integrative review, which can be considered patterns of response of parents of a child with cancer. 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. Developing additional knowledge about the patterns of response is still necessary for nursing therapeutics to be developed, implemented, and evaluated (Meleis, 2010).

## References

- Biagi, E., Bollard, C., Rousseau, R., & Brenner, M. (2003). Gene therapy for pediatric cancer: State of the art and future perspectives. *Journal of Biomedicine and Biotechnology*, 2003(1), 13–24. doi:10.1155/S1110724303209025
- Brinksma, A., Huizinga, G., Sulkers, E., Kamps, W., Roodbol, P., & Tissing, W. (2012). Malnutrition in childhood cancer patients: A review on its prevalence and possible causes. *Critical Reviews in Oncology/Hematology*, 83, 249–275. doi:10.1016/j.critrevonc.2011.12.003
- Brown, S.A., Upchurch, S.L., & Acton, G.J. (2003). A framework for developing a coding scheme for meta-analysis. *Western Journal of Nursing Research*, 25, 205–222. doi:10.1177/0193945902250038
- Cerqueira, C., & Barbieri, M.C. (2012). La Teoría de las Transiciones de Meleis en el análisis de la “experiencia de cuidar un niño con cáncer” [Abstract]. Retrieved from <http://bit.ly/1Tlq1Go>
- Clarke, J.N. (2006). Mother's home healthcare: Emotion work when a child has cancer. *Cancer Nursing*, 29, 58–65.
- Clarke, J.N., Fletcher, P.C., & Schneider, M.A. (2005). Mothers' home health care work when their children have cancer. *Journal of Pediatric Oncology Nursing*, 22, 365–373. doi:10.1177/1043454205281834
- Comaru, N.R., & Monteiro, A.R. (2008). O cuidado domiciliar à criança em quimioterapia na perspectiva do cuidador familiar. *Revista Gaucha de Enfermagem*, 29, 423–430.
- Evans, M.A. (1994). An investigation into the feasibility of parental participation in the nursing care of their children. *Journal of Advanced Nursing*, 20, 477–482. doi:10.1111/j.1365-2648.1994.tb02384.x
- González-Arratia, N.I., Nieto, D., & Valdez, J.L. (2011). Resiliencia en madres e hijos con cáncer. *Psicooncología*, 8, 113–123. doi:10.5209/rev\_PSIC.2011.v8.n1.9
- Hockenberry, M.J., Hooke, M.C., Gregurich, M., McCarthy, K., Sambuco, G., & Krull, K. (2010). Symptom clusters in children and adolescents receiving cisplatin, doxorubicin, or ifosfamide [Online exclusive]. *Oncology Nursing Forum*, 37, E16–E27. doi:10.1188/10.ONFE.E16-E27
- Holm, K.E., Patterson, J.M., & Gurney, J.G. (2003). Parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer: Results from a qualitative study. *Journal of Pediatric Oncology Nursing*, 20, 301–313. doi:10.1177/1043454203254984
- Huang, I., Mu, P., & Chiou, T. (2008). Parental experience of family resources in single-parent families having a child with cancer. *Journal of Clinical Nursing*, 17, 2741–2749. doi:10.1111/j.1365-2702.2008.02447.x
- James, K., Keegan-Wells, D., Hinds, P.S., Kelly, K.P., Bond, D., Hall, B., . . . Speckart, B. (2002). The care of my child with cancer: Parents' perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing*, 19, 218–228. doi:10.1177/104345420201900606
- Jones, J.B., & Neil-Urban, S. (2003). Father to father: Focus groups of fathers of children with cancer. *Social Work in Health Care*, 37, 41–61. doi:10.1300/J010v37n01\_03
- Kelly, P., & Kelly, D. (2013). Childhood cancer-parenting work for British Bangladeshi families during treatment: An ethnographic study. *International Journal of Nursing Studies*, 50, 933–944. doi:10.1016/j.ijnurstu.2012.11.004
- Kuan, H.Y. (2000). *Identifying the needs of Chinese family caregivers of children with cancer in Hong Kong* (Unpublished doctoral dissertation). Hong Kong Polytechnic University, China.
- Leavitt, M., Martinson, I.M., Liu, C., Armstrong, V., Hornberger, L., Zhang, J., & Han, X. (1999). Common themes and ethnic differences in family caregiving the first year after diagnosis of childhood cancer: Part II. *Journal of Pediatric Nursing*, 14, 110–122.
- Martinson, I.M., & Yee, K.H. (2003). Parental involvement in restoring the health of a child with cancer in Hong Kong. *Journal of Pediatric Oncology Nursing*, 20, 233–244. doi:10.1177/1043454203254037
- Meleis, A.I. (Ed.). (2010). *Transitions theory*. New York, NY: Springer.
- Meleis, A.I., Sawyer, L., Im, E.O., Messias, D.H., & Schumacher, K. (2000). Experiencing transitions: An emerging middle range theory. *Advances in Nursing Science*, 23, 12–28.
- Mendes, M.G.R.S., & Martins, M.M.F.P.S. (2012). Parceria nos cuidados de enfermagem em pediatria; do discurso à ação dos enfermeiros. *Revista de Enfermagem Referência*, 6, 113–121. doi:10.12707/R111144
- Misko, M.D., & Bousso, R.S. (2007). Manejando o câncer e suas intercorrências: A família decidindo pela busca ao atendimento de emergências para o filho. *Revista Latino-Americana de Enfermagem*, 15, 48–54.
- Montgomery, K., Belongia, M., Mulberry, M.H., Schulta, C., Phillips, S., Simpson, P.M., & Nugent, M.L. (2013). Perceptions of nutrition support in pediatric oncology patients and parents. *Journal of Pediatric Oncology Nursing*, 30, 90–98. doi:10.1177/1043454212471726
- Moore, J.B., & Beckwith, A.E. (2006). Self-care operations and nursing interventions for children with cancer and their parents. *Nursing Science Quarterly*, 19, 147–156. doi:10.1177/0894318406286594
- Moreira, P.L. (2007). *Tornar-se mãe de criança com câncer: Construindo a parentalidade* (Unpublished master's thesis), Universidade de São Paulo, São Paulo, Brazil.
- Pye-Grimm, K.A., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision making and information needs of parents of children with cancer: A

- pilot study. *Journal of Pediatric Oncology Nursing*, 16, 13–24. doi:10.1177/104345429901600103
- Relvas, A.P. (2007). A mulher na família: Em torno dela. In A.P. Relvas & M. Alarcão (Eds.), *Novas formas de famílias* (pp. 229–337). Coimbra, Portugal: Quarteto.
- Silva, C.C., & Barbieri-Figueiredo, M.C. (2011). A Pessoa que vive a experiência de cuidar de um filho com cancro. *Revista da Sociedade Brasileira de Enfermeiros Pediátras*, 11, 25–32.
- Silva, C.M.C. (2009). *A pessoa que cuida da criança com cancro* (Unpublished master's thesis). Universidade do Porto, Portugal.
- Smith, L., Coleman, V., & Bradshaw, M. (2006). Family-centred care. In A. Glasper & J. Richardson (Eds.), *A textbook of children's and young people's nursing* (pp. 77–88). London, England: Churchill Livingstone.
- Souza Andrade, N.K., Valença, C.N., Lima, G.A.F., Cavalcante, R.D., Scales, L.K.O., & Germano, R.M. (2012). The perception of nursing staff about the participation of family in care for child with cancer. *Revista de Enfermagem da Universidade Federal de Pernambuco*, 6, 1790–1797. doi:10.5205/reuol.2931-23598-1-LE.0608201207
- Wegner, W., & Pedro, E.N.R. (2010). Os múltiplos papéis sociais de mulheres cuidadoras-leigas de crianças hospitalizadas. *Revista Gaúcha de Enfermagem*, 31, 335–342. doi:10.1590/S1983-14472010000200019
- Wells, D.K., James, K., Stewart, J.L., Moore, I.M., Kelly, K.P., Moore, B., . . . Speckhart, B. (2002). The care of my child with cancer: A new instrument to measure caregiving demand in parents of children with cancer. *Journal of Pediatric Nursing*, 17, 201–210. doi:10.1053/jpdn.2002.124114
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52, 546–553. doi:10.1111/j.1365-2648.2005.03621.x
- Williams, P.D., Schmideskamp, J., Ridder, E.L., & Williams, A.R. (2006). Symptom monitoring and dependent care during cancer treatment in children: A pilot study. *Cancer Nursing*, 29, 188–197.
- Young, B., Dixon-Woods, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science and Medicine*, 55, 1835–1847. doi:10.1016/S0277-9536(01)00318-5