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Family Management Framework and Its Use With Families Who Have a Child Undergoing Palliative Care at Home

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Abstract

Palliative care settings in many countries acknowledge families as their prime focus of care, but in Brazil, to date, researchers have devoted scant attention to that practice setting. In this article, we report the findings of a study that explored how families define and manage their lives when they have a child or adolescent undergoing palliative care at home. Data included individual semistructured interviews with 14 family members of 11 different families. Interviews were transcribed and the coding procedure featured qualitative content analysis methods. The deductive coding was based on the major components of Family Management Style Framework and the eight dimensions comprising these components. The analysis provides insight into families' daily practices and problems inherent in managing their everyday lives that are encountered when they have a child in palliative care. The article features discussion of implications for the palliative care related development of family nursing practice.

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Keywords

family nursing, Family Management Style Framework, palliative care, family management, end-of-life, Brazil

Palliative care is held to be a “philosophy,” a “way of caring” that the World Health Organization (WHO, 2009) defines as follows:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Parenting a seriously ill child undergoing palliative care requires attending to and balancing responsibility for the “normal” functioning of the family system, the ill child’s treatment and needs, and the family’s financial needs, including health coverage (Brody & Simmons, 2007). At a time of terrible emotional stress, parents often struggle to learn and carry out previously unfamiliar household and parenting roles. The level of available support for these families is often low and the lack of support further increases the stress on parents (Contro, Davies, Larson, & Sourkes, 2010). Because palliative care practitioners view the family as the primary unit of care, those practitioners need a comprehensive understanding of how the family experiences palliative care and manages family life, including care of the ill child throughout the course of palliative care and the terminal stage of the illness. Without such knowledge, their efforts to guide and support individuals through this stage remain limited.

The purpose of this study was to explore how families define and manage their life when they have a child or adolescent undergoing palliative home care. The ultimate goal of the research was therefore to optimize care for children in palliative care and their families by gaining a clearer understanding of their experience.

Background

Palliative care, insofar as the concept, instruments, and methodology are concerned, is still a work in progress. What leads patients to be included in a palliative care program are conditions in which, apart from curative treatment, other symptoms or discomforts compromise their quality of life and require a competent and specialized approach.

In pediatrics, conditions that often are associated with the need for pediatric palliative care are genetic errors of metabolism (inherited metabolic diseases), genetic syndromes, cystic fibrosis, bullous epidermolysis, AIDS, complex heart conditions, and neuromuscular diseases, among others. Thus children who benefit from palliative care are living with pathologies of undetermined duration that can range from a short period, leading to premature death of the child, to a progression that may last for years (Barbosa, 2010).

To this day, medicine in Brazil features a strong paternalistic component associated with a culturally grounded belief that the patient's life must be maintained at all costs. Brazil has no tradition of respect for patient autonomy. End-of-life decisions are ultimately made by the medical team in charge, and are based on the concept of beneficence and influenced by the cultural and moral values of each individual team of health care professionals. Family participation in the decision-making process is still negligible. This occurs because training and practice of health care professionals—especially physicians and nurses—focus on the treatment and cure of disease, not interacting with patients and their families.

Brazil enacts an incipient, unarticulated end-of-life policy, faced with the great challenge of having to incorporate palliative and hospice care in its health care system. In the area of health care, the first palliative care services appeared in the 1980s and despite the increase in the number of units available, the services are still insufficient to meet the country's needs. There are no statistics on the number of patients undergoing this type of care in Brazil but, as is the case in other parts of the world, it is known that, given the advance in therapies for the various chronic illnesses, the number of palliative care services providing care in both outpatient and home settings is growing. At present, the greatest challenge faced in Brazil is the training and qualification of human resources to work in this context (Maciel, 2008).

In Brazil, working with patients' families is an important part of a nurse's job description, a fact that nurses are only now beginning to realize. Family care became increasingly important following the advent of legal regulations that bring families closer to nurses. These include the "Child and Adolescent Law," that ensures children and adolescents the right to have the presence of a family member at all times throughout their stay in hospital (Brazil, 1990).

Researchers have studied the unique needs faced by parents providing palliative care in the home. Looking after such children at home can be a full-time job, placing great strain on the family, and parents often suffer physical and emotional stress and exhaustion (Yantzi, Rosenberg, & Mckeever, 2007). In such situations, parents must assume multiple caregiver roles (Hays et al., 2006; Misko & Bousso, 2007). Other members of the family, including siblings and grandparents, also bear some of the stress and strain of caring for these children and siblings may miss out on a "normal" life (Dumont et al., 2006) as families of children in palliative care struggle with an acute life-altering diagnosis and long-term chronic implications. Family members also suffer physical wear and tear and considerable emotional pain (Dumont et al., 2006; Monterosso, Aoun, Kristjanson, & Phillips, 2007; Wolfe et al., 2000).

In the course of palliative care, parents prefer, whenever possible, to care for their children at home, and for this task they often receive the support of other family members and friends (Monterosso, Kristjanson, & Phillips, 2009). During palliative care, the parents' greatest concern is to diminish the child's suffering (Edwards et al., 2008). In this context, pain control is the key element and prime concern of the families and they invest tremendous effort in assuring that unpleasant symptoms and pain are minimized. (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Hays et al., 2006; Monterosso et al., 2007). Another recurring concern of the families is to ensure that the child receives the necessary care continuously throughout the whole course of the illness and the process of dying. Parents believe that in this way they will be offering the best care for the child and thus fulfilling their role as good parents (Heller & Solomon, 2005).

Families may experience periods of uncertainty that diminish the possibility of foreseeing future life perspectives (Woodgate & Degner, 2003). They recognize the physical symptoms stemming from clinical deterioration by a child in the terminal stage, but only acknowledge the impossibility of a cure and the child's imminent death in the few days preceding that death. In the phase of palliative care, the parents need financial and emotional support and practical assistance that will enable them to care for the children (Monterosso et al., 2007, 2009).

Families often play a key role in palliative care and although there is a large number of instruments already in place to measure family processes in general (communication, decision making, coping, resilience), little is known about how family members define and manage family life in the context of a child undergoing palliative care in the home. Using evidence-based models such as the Family Management Style Framework [FMSF] (Knafl & Deatrick, 2003) may be one way to further the development of interventions aimed at improving end-of-life care.

Family Management Style Framework (FMSF)

Family management has been defined as “the family’s role in actively responding to the illness and different situations of health care” (Knafl & Deatrick, 1990, p. 6). Recently, there has been an increased interest in identifying styles of family management that reflect diverse situations of illness. The term “family management style” is used in literature to refer to a relatively consistent pattern of response on the part of the family unit to some condition or illness, and the term “management” reinforces the focus on the active behavioral ingredient of family response, differentiating it from other family processes such as communication and decision making (Knafl & Deatrick, 2006). Identifying patterns or typologies of family response to health care challenges is increasingly recognized as useful to the precise description of family illness management strategies (Knafl & Deatrick, 2003). The FMSF provides a guide to researchers investigating these patterns or styles of response. FMSF has been used to study situations of chronic illness in children (Deatrick et al., 2006; Gallo, Angst, Knafl, Hadley, & Smith, 2005; Gallo, Hadley, Angst, Knafl, & Smith, 2008; Gallo & Knafl, 1998; Knafl & Grey, 2007; Nelson, Deatrick, Knafl, Alderfer, & Ogle, 2006; Ogle, 2006; Sullivan-Bolyai, Knafl, Deatrick, & Grey, 2003).

In 2006, the Association of Pediatric Oncology Nursing held a conference that highlighted FMSF as a useful framework for understanding and assessing family responses to oncologic illness in children with a view to lending support for the development of interventions aimed at preparing families to manage the challenges of pediatric cancer (Nelson et al., 2006). Deatrick et al. (2006) and Ogle (2006) published similar results, adding specific directions regarding the methodology for application of the model in clinical practice. The authors recommend that we take into account the stage of illness, treatment demands, and the family’s lifestyle and culture. They also point out that families of children with brain tumors potentially face aspects of the situation that may predispose them to less desirable family management but argue that these families are no less capable of successfully managing the situation than other families if they have access to interventions that match their profiles (Deatrick et al., 2006). Other studies emphasized that the FMSF can be used to successfully evaluate families so that personalized interventions can be planned at times of transition in family life (Bernaix, Jamerson, & Smith, 2006), and in the adult population (Wiegand, Deatrick, & Knafl, 2008).

Prior applications of the FMSF to families in Brazil has been limited to studies of families experiencing serious, of life limiting, conditions (Misko &

Bousso, 2007) and pediatric liver transplants (Mendes-Castillo, 2011). The findings of these studies reinforce the usefulness of the framework and the importance of recognizing changes in management style over the course of the illness so that professionals can equip themselves to facilitate development of the required care competencies that support families' efforts to incorporate condition management into everyday family life.

Given this scenario, we see ongoing international growth in the relevance of grounding practice in a sound evidence base and becoming acquainted with how families define their situation and how they manage family life in the various contexts of illness. Taking into account the need for more research in diverse cultures featuring this family focus, the intent of our study was to explore the experience of family management within the context of palliative care and to assess the usefulness of the FMSF in this new cultural and family context.

Method

Design

It is generally agreed that the choice of method in research investigation should be determined by the research question. Qualitative methods are singularly suited to research questions dealing with subjective experience and perceptions, with situational meanings, and with areas where there is little existing knowledge. This qualitative, descriptive study was conducted to achieve a better understanding of the experience of families who have a child undergoing palliative care at home. The design, method, and purpose were descriptive (Sandelowski, 2010). Qualitative description is a standalone method that affords a comprehensive summary of human experience. The goal is to stay close to the surface of data while capturing the elements of that experience, and the inherent scientific rigor is a reflection of a researcher's ability to achieve that goal. Hence descriptions depend on the perceptions, inclinations, sensitivities, and sensibilities of the describer (Milne & Oberle, 2005).

In this study, we defined family broadly as "the persons who experience the care of a child in palliative care at home." The term "family" was thus inclusive of those who were biological, adoptive, foster, single, or legal guardians. We recognized that in Brazil, extended family members often participate in parenting roles.

Sample

All study procedures were completed in accordance with the study protocol approved by the hospital's Institutional Review Board. After receiving approval from the Institutional Review Board the investigators conferred with expert clinicians to identify families meeting the study criteria. To be eligible for participation, the family had to include a child who had a disease, was no longer receiving curative therapies, and was identified by his or her physician as no longer an appropriate recipient of aggressive therapy; who was a patient in the hospital's palliative care program regardless of the pathology, had been in the program for a minimum of 2 weeks, and whose family had been informed that the child was undergoing palliative care; who was judged by clinical personnel and the researchers as someone who would not be significantly burdened by participation in the study—that is, a patient who was not suffering from severe fatigue and/or uncontrolled pain (no such families were approached).

Criteria sampling techniques were used to recruit the families for this study (Patton, 2002). A sample of 11 families who met the criteria was selected from an outpatient palliative care unit of a public hospital in the City of São Paulo, Brazil. In obtaining the sample, the investigators called on the expertise of clinicians already familiar with the potentially eligible subject families. When a patient/family who met the study criteria was identified, the clinician approached a family member, personally whenever possible, or by telephone. The potential subject families were provided with a written description of the proposed study. If they agreed, the investigators then contacted the family by telephone or in person to set up an appointment to meet with them, explain the study, answer their questions, and obtain their consent to participate. Although all family members were invited to take part in the interview, the mother was the family member most often approached and in most cases was the sole participant. In only two families did more than one member agree to participate and in those two cases the interviews were conducted as a family group.

Fourteen family members from 11 families, including 11 mothers, 1 paternal aunt, 1 grandmother, and 1 father took part in the study. Participants ranged from 25 to 65 years of age. In regard to the marital status of the couples, 10 were married and 1 couple had married only recently. One mother was a widow who lived alone with her sick child. The children in palliative care included 7 females and 4 males ranging from 3 to 16 years of age. Nine children had at least one sibling living in the same household, one child had married siblings who lived separately, and one girl was an only child.

Time in the palliative care service ranged from 2 months to 3 years and 6 months. Six children had different oncological diagnoses (Hodgkin's lymphoma and xeroderma pigmentous, astrocytoma, pleural mesothelioma, primitive neuralectodermal tumor (PNET), osteosarcoma, and biphenotypic leukemia), and 5 had other chronic diseases (myelopathy, fibromyalgia, myelomeningocele and cerebral paralysis, degenerative neuropathy, and dermatopolymiosite).

Procedure

Data were collected at a Pain and Palliative Care Outpatient Center of a pediatric hospital in Brazil featuring a multidisciplinary team. Patients from multiple pediatric medical specialties including oncology, rheumatology, infectious diseases, hematology, and hepatology receive care in the facility. The child's first consultation in this outpatient center is scheduled on referral by the child's attending physician. Follow-up is by prescheduled appointments or on request by the family.

Semistructured interviews were conducted with family members using open-ended questions to elicit their views about (a) how the family was managing the illness situation, (b) the child's care, and (c) the family's perceptions of home care. The eight dimensions that compose the three components of the FMSF were used as a basis for developing an interview guide that would elicit data to better understand families' experiences (see Figure 1). Interviews were tape-recorded and the data transcribed verbatim. Field notes, both descriptive and reflective, were recorded by the interviewer. The interviews lasted 30 to 60 min and were usually held in the family's home or in a reserved room at the outpatient palliative care unit, whichever was more convenient for the family.

Interviewing families with children in palliative care presents many challenges. First, we recognized that participants in the study would be undergoing a period of considerable stress (Contro et al., 2010). Therefore, when they were first approached regarding the study, when they signed the consent form, at the beginning of each interview and in the course of all interviews, the families were reassured that they could choose to stop the interview at any time. In addition, we recognized that it was essential for family members to perceive the researcher as a knowledgeable and caring individual, someone who would respect participants' privacy and ensure that they would be protected

MAJOR COMPONENTS	DIMENSIONS	EXAMPLES OF QUESTIONS
DEFINITION OF THE SITUATION	*Child Identity*	How is your child's everyday life compared to that of other children his/her age?
	Illness View	How did you decide to keep the child in palliative care at home?
	Management Mindset	What is your opinion about your skills to manage palliative care at home? What are the greatest challenges you face in your everyday life to take care of the child? How do you handle that?
	Parental Mutuality	Do you and your partner share similar thoughts regarding your child's condition and the need for palliative care?
MANAGEMENT BEHAVIORS	*Parenting Philosophy*	What are some specific goals that you keep in mind in order to help you manage your child's condition?
	Management Approach	How did you incorporate palliative care into your routine family life?
PERCEIVED CONSEQUENCES	*Family Focus*	Do you believe that palliative care gets in the way of your family routine? Why?
	Future Expectations	How do you see the child's and family life in the future?

Figure 1. Examples of questions based on the FMSF

as far as possible from any adverse consequence of their participation. It was essential that interviewers have the expertise to conduct interviews in this manner. The second author conducted all interviews of this study. She was well qualified to do so, having a solid knowledge base in family systems, a clinical specialization in palliative care, and had the required skills.

Analysis

Data from all sources were analyzed to identify major components of the FMSF and the dimensions comprising these components, as the basis for a thorough description of how families define and manage their life when they have a child or adolescent undergoing palliative care at home. The interview coding procedure followed the methods of qualitative content analysis (Mayring, 2000). A combined model of inductive and deductive coding was used; deductive coding was based on the major components of FMSF and the dimensions comprising these components (Knafl & Deatrick, 2003) were adapted to palliative care. The first major component contained information that described the family's Definition of the Situation, the second major component identified the family's Management Behaviors, and the last major component addressed the family's Perceived Consequences for their family of having a child who was receiving palliative care. The FMSF components and the dimensions comprising the components helped to integrate the critical aspects of the family's experience of having a child in palliative care at home, differentiating the meaning, the management, and the consequences of the experience for each family.

Data from each of the families were reviewed line by line and coded with regard to the dimension they reflected. In addition to coding based on the eight FMSF themes, data-based dimensions helped to further explain each of the major components (Definition of the Situation, Management Behaviors, and Perceived Consequences) of the FMSF (examples of this are exemplified in the results section). The final, across-family analysis of the data helped the researchers identify aspects of the experience that were shared by all of the families and aided the researchers to determine variations in how families defined and managed having a child in palliative care.

Transcripts were initially free-coded by the interviewer according to content and then organized into thematic units. In addition to coding based on FMSF dimensions, the interviewer developed a code system with key categories that was revised by investigators skilled in qualitative analysis. An outside researcher performed an audit trail. The audit trail confirmed the dimensions identified, and the authors and the auditor agreed regarding identified dimensions. We chose this strategy in an attempt to demonstrate trustworthiness, but we do recognize that this outside auditor may not have been totally objective or may even have felt uneasy about disagreeing with some aspects of our analysis. However, our key objective was to show our steadfast commitment to the qualitative spirit of the research (Sandelowski, 1993). More important than the strategy were the reflections and common sense methodological decisions made in the course of the study.

In the following results section, quotations from the interviews are used to illustrate the themes that characterized families' experiences. The quotations are translated from the Portuguese and oriented to approximate their original meaning within the English syntax; expletives and/or repetitions were replaced by ellipses (. . .).

Results

Analysis of the data obtained from interviews revealed that the situational context of having a son or daughter receiving palliative care at home was defined as the family struggling to keep a balance—parents reported developing the necessary skills to manage this new situation in their daily life. Consistent with the definition of "family management" proposed by Knafl and Deatrick (1990) as "the family's role in actively responding to illness and health care situations," for these families, the object of management was to preserve the child's quality of life and avoid physical suffering as far as possible. The FMSF helped to understand how family members defined and managed their situation, dealt with caregiving demands, and devised strategies to maintain a balance between focusing on the demands of the illness, and preserving the everyday life of the family in view of the threatening and unstable situation of having a child undergoing palliative care.

In our study, the family's management style changed over time as the child's clinical condition changed and family members acquired more information and skills for managing the child's palliative care at home. Data driven dimensions described the families' varying Definitions of Situations, Management Behaviors and Perceived Consequences, and the extent to which the experiences of individual family members were similar or discrepant. It is important to note that, as stated by Knafl, Deatrick, and Gallo (2008), although those dimensions are theoretically distinct, they are associated with one another to some degree in the course of the families' experience. We found that to be true in our findings since parents' accounts reflected multiple dimensions of the FMSF. Therefore, we chose a presentation in which the FMSF major components are more evident than the specific dimensions.

In reporting the study findings, we opted to interweave the multiple dimensions, since this allowed us to present the family's experience more faithfully and consistently. We found it conveyed the overall pattern of response more effectively than reporting on each dimension separately. Because of this, the quotes selected to illustrate the findings may reflect multiple dimensions in their representation of the overall experiences of the families.

Major Components

Definition of the Situation. The situation includes information on how parents view their children's abilities, and the extent to which these views focus on illnesses, normalcy, capabilities, or vulnerabilities. It also includes data about the parents' beliefs regarding the condition of the child undergoing palliative care at home, and their self-assessment of their own capability to manage the situation effectively. Information related to parental mutuality concerning partners' perceptions and approach to management of the situation of having a child undergoing palliative care at home was also explored. To define the children and their situations, parents take into consideration the role occupied by the child in family life, which has a symbolic and affective meaning to family members.

To these families, both the children's identity and how they define the illness is variable. The families' stories present different processes stemming from the factual circumstances of what caused the child to be referred to the outpatient palliative care unit, namely, the diagnosis of a rare chronic disease or worsening of an illness that was in the treatment phase to the point of being considered incurable. These aspects of the situation, as well as the length of time the child has been cared for in the outpatient palliative care unit, influenced how the family defined the situation, especially during the initial period of the child undergoing palliative care at home. As the aunt of one child remarked,

> (. . .) then the treatment (for cancer) ended. One month and 15 days after finishing the first treatment, it all came back again—it came back in the knee, in both lungs, and in the ribs . . . (Family 10)

In the beginning of the palliative care experience, information provided to parents related to the child's health and care planning was limited. Receiving information on the child's critical state of health and the news that there is no longer any possibility of a cure led the family to define the child's identity as fragile and/or vulnerable. Given the meaning of the health status that the parents ascribed to the child's condition, they also modified their view of the child.

> She got very weak and debilitated with the treatment and the disease (. . .); she became a very special girl to us. I was very careful with her . . . (Family 6, mother)

Family members described themselves as experiencing emotional shock characterized by feelings of uncertainty, distrust, disbelief, and fear. The family was forced to confront the news that the child's pathology was beyond any hope of a cure, and at the same time they were faced with stressors stemming from the need to keep the child at home, despite his or her unstable condition. In the beginning of their experience in palliative care, family members found it especially difficult to manage unexpected incidents related to their child's care or condition. Initially, family members did not perceive themselves as capable of managing the demands of the illness and felt overwhelmed by the situation. Family members sometimes acknowledged the terminal nature of the illness and the fact the patient would not recover. For mothers especially, this signified that the illness was serious and symptoms were difficult to manage despite their best efforts. One concerned mother stated,

> (. . .) I'm very scared of dealing with A. I think that, because she's my daughter, I'm even afraid to touch her. I don't do any procedure alone; I'm scared; it's as though I don't know how to do anything. (Family 4)

Each member of the family developed his or her own view of the child and of the situation based on their own experiences and interactions with the others. These views shaped their caregiving behaviors. Mothers typically described themselves as being extremely protective of their ill child and lacking confidence to manage the child's care effectively. In the interviews, they described their fear once the death's inevitability was announced, it could occur at any moment. One mother expressed that fear in the following words:

> I'm afraid of having to go to the supermarket, of not being close by if he needs me, if he takes a turn for the worse, if something should happen to him in the house and I'm unable to help him. (Family 5)

Within the context of a highly uncertain situation, parents struggled to address the child's physiological problems, needs for support to maintain quality of life, and the implications of palliative care for the family. For those families who had been managing for more than 1 year, previous experiences with the illness influenced current views and management efforts. Parents incorporated what they had learned from past experiences into their present experiences including the current palliative care and terminal illness. They described not only traumatic events of the past but also enjoyable experiences that the family continued to share with the child. They were able to reconstruct reality and changed their view of the child's identity. Over time, a new view emerged, and parents came to see their child as a person capable of overcoming adversities, as the father of one child related:

> . . . Just like he struggles to overcome, we're always right there struggling by his side, right? And he's strong; this kid is strong . . . but really strong. (Family 7, father)

Parents discovered new meanings in the presence of the sick child in the family at home, and this led them to redefine themselves; they came to see themselves and their family as special and strong. One mother stated,

> (. . .) As a person who's the mother of a special child . . . I feel that I'm special too because I think that God meant for him to be my responsibility, that He chooses people who have patience. (Family 1, mother)

Living with a child undergoing palliative care at home, as well as visits to the outpatient palliative care unit led the families to acknowledge the terminal nature of the illness. Families believed that it would not be easy to have a child in this condition at home but nevertheless they all wanted to keep the child at home, close to the family. Family members believed it was it easier to manage the situation effectively in the home where family members could continue their life together with the child.

During their visits to the outpatient palliative care unit, the parents assessed the interactions with the staff and the efforts of the attending health care professionals to monitor the child's progress. This active engagement was described as making parents feel more confident of their ability to manage the situation. The mother of one child stated,

> Then, with time I got better, learning to deal with some situations and becoming acquainted with the treatment. I learned that immunity drops and I began to look differently at my daughter. The fear remains, but

> when we know what we will have to face, it gets a little easier to deal with the problem. (Family 6)

Parents described how they continued to see their child as unchanged in many ways and to hope that he or she would recover fully. Thus, the parents never defined the situation as tragic, even knowing that there is no cure for the child's illness. Although they were aware that no cure was possible, some parents held on to the hope that some miraculous cure might be discovered that could change the course of history, or the progression of the disease would slow and be accompanied with minimum of after effects.

The reality experienced by the parents up to the time when they were informed that the child's clinical condition precluded any possibility of a cure was that the child played an active role in the family and, although a hard struggle was inherent to the treatment, the child would still have a long life. This new reality engendered by the reality that cure was not possible led to a redefinition of the situation on the part of the parents. Redefining involved a shift in parents' view of what used to be and what was now. This shift was difficult, especially when members' perceptions of the situation differed or when there was no mutuality between the parents. Arriving at a new definition for this new moment within a context of great suffering was not a simple task for parents and evolved over time. Transforming this reality to another, that of being the parents of a child who was dying, required both skill and a context of confidence. When parents identified this context with the health care professionals attending their child, they felt more confident and came to believe in their ability to manage the illness at home. They did not believe that keeping the child at home will overburden their lives. Below is a statement by one family member:

> We've been going to the hospital constantly for years. (. . .) We see what's happening to them and to the other children. We're acquiring information and experience and getting to know more details about this world, and this gives us more peace of mind. (Family 6, mother)

Parental mutuality fluctuated, especially with regard to the need for access to palliative home care services. This sometimes caused tension between family members who recognized the terminal nature of the condition and those who evaded the effects of the progressing illness and behaved as though little has changed. The mother of one child put it as follows:

> I'm always ready to run whenever necessary to care for my daughter. My husband is relaxed. He prefers to leave everything till tomorrow. (. . .) If it depends on him we wait. He thinks it will pass, that giving her some sort of medicine will solve the problem . . . (Family 6)

Sometimes family members had different perceptions of the situation and varying needs. Usually it was the mother who cared for the child full time. When this occurred, the father did not share caring for the child and his opportunity to observe the child's declining status often was limited. In these situations, parents disagreed on how to manage care properly, creating conflicts between them. The fathers rarely or never interacted with the health care team since they seldom accompanied the child on visits to the hospital. One mother said,

> (. . .) whenever anything happens, my husband places the blame on me. He says I didn't take proper care—that I need to question the doctors more. I would like to see him take care of our son 24 hours a day, like me, so he would be better able to integrate the treatment and share the decision making with me more often. (Family 5)

On the other hand, some families acted cooperatively to manage their child's care, seeking resources to help them solve the difficulties. These families involved other people, such as neighbors, in managing care. They turned to physicians they trusted, asked family members and acquaintances in the health care field for information and help, and talked with members of other families they had met during visits to the palliative care outpatient unit to obtain or confirm information that could help them in managing the illness of the child at home. The mother of one child remarked,

> I divide my struggles, see? Yesterday the father was here, today it's me, and tomorrow my sister is coming. So we . . . it's not all up to one person. We manage to share the burden. (Family 7, mother)

Management Behaviors. The Management Behaviors component of the FMSF has to do with the parents' management goals and strategies (Management Philosophy), and their efforts to develop a routine for managing the child's care at home (Management Approach; Knafl & Deatrick, 2003).

With regard to management goals, the families did everything in their power to protect the child by controlling symptoms, minimizing pain, and preserving quality of life. Taken as a whole, parents viewed these efforts as contributing to the preservation of the family's normal everyday life. Following are the words of one father:

> And we just never give up hope. We support and encourage one another and just get on with our life. So, to me . . . we're always struggling . . . Like now, we always have some hope like, that he'll . . . at least . . . go on living with less suffering. That's really what we hope for—to change in any way possible. But we always want what's best for him. We're always here for him, always struggling. (Family 7, father)

In many ways, life continued as usual and the families' focus was on the present, trying to adapt to the adversities confronting them. Parents believed that, at home, they had more control over their environment than in the hospital and more options for including extended family and friends in the child's care.

> . . . In my home . . . everyone plays a small part in our daily life. There is the father who helps, the two younger sisters, this nephew of mine who is being an Angel to me. Sometimes he says: You're tired out; go lie down on the couch and I'll fix his supper. We're preparing syringes like every five minutes. So everybody shares, even my daughters' boyfriends help so it's not a very great problem for us. Everyone gets involved—everyone helps take care of him. He peed, who's going to change his diaper? See? (Family 7, mother)

The parents' Management Philosophy entailed balancing the multiple goals of minimizing the pain and suffering imposed by the child's situation, sustaining the child's better quality, and maintaining usual family routines. In their attempt to adapt to this new situation, parents considered their goals to be protecting the child; being able to express love for the child on a daily basis; keeping hope alive; upholding usual family routines; and managing symptoms.

> You only think about him. He has to be well. All you want to do is take care of him, lend support, treat him kindly, give him love, give whatever is necessary . . . (Family 2, mother)

Parents' Management Philosophy was to keep the child's life as close to normal as possible. Achieving this goal came to be increasingly difficult as the child's condition progressed. The mother in the following quote was especially proactive in planning activities that could ensure the child's care at home.

> . . . He has to take medicine on an hourly basis. So you just have to live like this, dedicating your life to him. But that doesn't stop you from doing other things. You manage to clean the house, take care of him, aspirate him, apply inhalation . . . You just have to get a grip on everything and carry on. (Family 2)

For the most part, palliative care services were incorporated into the family's routine whenever parents were unable to control their child's symptoms. The mother usually has a plan of action to address the emergency situations that had become an expectable aspect of family life. In such situations, parents were not always capable of agreeing on the best solution, as was explained by one parent:

> I always have suitcases ready because anyone going through this experience knows that nothing is scheduled. They're like little boxes full of surprises and they may need medical attention at any time. (Family 3)

In most cases, it was the mother who assumed primary responsibility for making decisions regarding care. Mothers in this sample described how making and carrying out these decisions was easier when the whole family was in agreement. In cases of disagreement, the mother became the decision maker at times not even consulting the others. Mothers assumed multiple roles as they managed the care of the child at home: sometimes the protector, sometimes adapting to the situation, but always seeking to ensure the child's comfort and safety as shown by the following comment:

> It's always me who decides when it's time to take her to the doctor, what to do at home, because I'm the one who takes care of her. (. . .) I know everything about the treatment (. . .) how to proceed in every situation (. . .) I already know all the reactions and I don't like to allow anyone else to take her to the doctor for me. (Family 2)

The parents redefined the priorities of family life according to the child's needs. They took advantage of the constant contact with the child to reassert their unconditional love of that child. They believed that in this manner they were promoting a better quality of life for the child and for the family.

> I've always led a very intense life with her. I always live each day as though it were the last. . . because I always said: She's only going to die when her time comes because it won't be due to lack of care or someone's negligence, it just won't be because I won't allow it. (Family 6)

Parents wanted the child alive, but as healthy as prior to the illness. They were willing to provide care but expressed anguish over their child' suffering. They sometimes thought that it would be better for the child to die. In this context of "struggling with paradoxes" they were unable to foresee the demands of caregiving, and this made management more difficult.

> I'm afraid of losing her and that in the end they will have to sedate her and she won't be able to talk to me. I pray to God not to let that happen, that her death be quick and painless, if I should have that right. (Family 6, mother)

Perceived Consequence. This dimension is defined as the actual or expected family, child, and illness perceived outcomes that shape Management Behaviors and affected the subsequent Definition of the Situation. It includes Family Focus and Future Expectations (Knafl & Deatrick, 2003).

For families in this study, satisfaction with family life at present was variable. Families experienced several paradoxes related to the complexities of caregiving, continuing with the ongoing requirements of daily life while fulfilling other responsibilities both within and outside the home.

At times, family members felt overwhelmed by the responsibility of having to manage pain and other symptoms. Even so, they worked to keep the child at home. They pointed to the normality of the home environment as a factor that helped in the management of family life. Parents stated that management was easier at home because they could count on the support of family members. Family members' appreciation of each other's contributions provided a sense of support and togetherness and allowed them to allocate household chores and the child's care in a flexible manner. They were able to integrate roles and responsibilities, giving caregivers much needed respite time, and opportunities to meet the needs of siblings.

> It was hard, because when she was in the hospital and had a fever, the health care team took charge. At home that's not the case. I'm the one who has to decide everything—decide if she should go to the doctor, if I should give her that medicine . . . So at home, I was the doctor. It's an enormous responsibility, but as time passes we learn to deal with it,

> we learn how to give care and it begins to get easier . . . (Family 3, mother)

Sometimes painful experiences in the past helped prepare family members for future adversity. The family revisited their life since the child fell ill, evaluating the experience and its consequences for family life. However, they rarely talked about what their lives would be like after the child died. Family members reminisced about the role the child played in the family when healthy and acknowledged how much they missed the child being able to fulfill this usual role. The family tried both morally and emotionally to find some meaning in the ordeal they were experiencing, as the aunt of one child explained:

> . . . He's a child who played with everyone, made friends very easily. When he had the crutches he would walk to school. Now, after amputation of his leg, he doesn't want to even hear about going to school . . . I think it really weakens all aspects of family life. You simply cannot live a normal life—there just is no such thing. (Family 10)

As death approached, parents' focused on upholding of familiar routines and minimizing invasions into the home environment. The child's condition was a daily concern for the family and focused on symptom management, and slowing disease progression. By anticipating demand, families were able to identify care priorities.

> . . . Every day there is something new! Sometimes you go to the doctor today and there's nothing and then the very next day something turns up, it's really maddening (laughter). But we, in my case, we phone the outpatient unit and request guidance . . . This week I noticed that when I placed him on his side he had trouble breathing, and that's why he doesn't want to lie on his side. We have to find alternatives for him to improve. (Family 10, aunt)

Worsening of the child's clinical condition engendered discouragement, despair, and realization that the child's death was imminent. Family members understood the severity of the child's illness and had no hope of recovery. As the disease progressed to the terminal phase, family members usually had the same view of the outcome—the death of the child. One of the mothers said,

> . . . In terminal cases, like my daughter's is already considered to be, pain begins to set in. The tendency of the pains is to do harm and leave the child even weaker according to what we hear and what we see in the other children. (Family 1)

Some families described their ambivalence about what is going to happen. Members acknowledged their vulnerabilities concerning the child's ongoing decline but they could see the potential for improvement in their family life. They sometimes expressed great ambivalence about their situation. One mother said,

> I go on fighting [. . .] I don't want to see him suffering, no, no I don't want that [. . .] No one is going to live forever. I think that I'm learning to live with the word death . . I even frighten myself when I think about this, talk about it: how can a mother wish for her child's death? But it's not that we want him to die, I just don't want to go on seeing him suffer—it's very hard . . . (Family 5)

Although difficult, acknowledgement that the child would not recover enabled family members to face the challenges that lay ahead in the course of the illness. Even so, the family talked about the difficulties that arise in caring for the child, but not about death. Although these families did not plan their child's funeral, they wondered about what life would be like after the death of their child. One distraught mother said,

> That's why I [. . .] ask that mine (a daughter) stay like she is for as long as God wants. For me it will be a pleasure to care for her just like she is (crying) because to me she's the best thing I have at the moment and I'm not prepared to live without her! (Family 3)

In the more advanced stage of the illness, some families found it more difficult to maintain usual routines and control the child's symptoms. Family members expressed negative views of the future. Mothers, in particular, imagined an unfavorable course of the illness. Uncertainty regarding the future and the unusual circumstances of the child's condition constituted the context of this stressful family experience as death became more imminent. One mother expressed her dread of the future and reluctance to talk about it stating,

> . . . It's just that we see that it's hard now . . . over the last few months instead of him getting better we're only seeing him get worse . . . So it gets very difficult . . . I don't want to talk about it anymore . . . (Family 10)

Parents acknowledged their foreboding about the child's ongoing decline and sometimes expected the child's illness to get worse and their own future to be less happy. Some of them described their fears regarding what family life would be life following the death of the child. At the same time they tried to hold on to prior dreams for future and emotions of the past. On the other hand, to seemingly prolong the presence of the child in the family's life, the path some family members followed was to avoid speaking about expectations for the future. They refused to allow themselves to imagine life without the child.

Discussion

This research supports the usefulness of the FMSF in pediatric palliative care. It was possible to identify how family members defined and managed their situation, as well as what consequences they perceived for family life when they had a child in palliative care in the home. The FMSF as a theoretical model made it possible to reflect on the continuum of difficulties that families experienced in managing palliative care of a child in the home.

One of the greatest challenges faced throughout the research process was to find families who met the inclusion criteria and were willing to take part in the study. In some situations, the mother was willing to participate but the spouse wished to "protect" the child, and therefore refused. Even when families were recruited and had consented to take part in the study, we encountered other problems. One family, for example, agreed to participate, but the child's condition became so serious they withdrew before being interviewed. Another family agreed to participate, but the child died before it was possible to conduct the interview.

Brazilian culture is very diverse due to the country's various ethnic groups and to immigration from a great variety of countries. There is therefore no homogeneous Brazilian culture per se, but rather a mosaic of different cultural elements that together form the Brazilian people. In the practice of research and in the everyday life of clinics, we find that the multiplicity of families and family life in Brazil makes it difficult to talk in global terms about the Brazilian family though, as noted below, there are some usual culturally beliefs related to family roles. Changes have come about in both structure and in the different forms of family organization regardless of the name we may attribute to the group: nuclear family, single-parent family, homoparental family, recomposed family.

Whatever their constitution and organization, however, the families in this study sought to provide constructive space for carrying their responsibilities related to protecting their children, maintaining basic care, and above all, teaching the child about life in the broadest sense of what the word "education" means. Using the FMSF within the context of palliative care provided evidence that these functions occur more easily and with less suffering when the couple's relationship features intersubjective functioning, where "being together" makes sense, a space for mutuality.

The FMSF has eight dimensions. All the dimensions proved relevant to understanding the life of families when they have a child undergoing palliative care. The Parental Mutuality dimension, however, was the most difficult to analyze. In Brazil, the mother is always the caregiver of all family members, whether in situations of health or of illness. Although parental mutuality may be present, the lack of sharing in the work of caregiving is a cultural characteristic. People outside the family and family members themselves tended to take it for granted that the mother would find a way to cope with the situation. As a result, mothers usually feel more overwhelmed by management of the situation of having a child in palliative care than other family members. The view that the mother's predominant responsibility was to take primary care of the child still prevails in Brazilian society. Research done in Brazil with families in which women are primarily responsible for the family's financial support show that they still take almost full responsibility for domestic tasks (Wagner, Predebon, Mosmann, & Verza, 2005). The level of responsibility of mothers in the experience of a chronic illness in childhood has been well documented by studies in different cultures (Mendes & Bousso, 2009; Sullivan-Bolyai et al., 2003; Vrijmoet-Wiersma et al., 2008). The need for partnership between parents, other family members, the health care team, and other sources of social support is evident in the context of chronic diseases and its absence means that many mothers who take up full responsibility for the care feel overwhelmed, alone, and unable to adopt a less rigid and vigilant approach in caring for the child (Fisher, 2001).

The dimension, Parenting Philosophy, was fundamental to understanding the protective process lived by the family trying to manage the situation and preserve the child's quality of life day by day. The family wants to manage the pain and symptoms of the child in the home and is capable of doing so. It is possible to achieve the goal of keeping the child on palliative care in the home with good management of symptoms and of family life.

An important aspect in the palliative care context, one that differs from situations of families who have a child with a chronic disease already, was noted in the literature (Deatrick et al., 2006; Gallo et al., 2005, 2008; Gallo & Knafl, 1998; Knafl & Grey, 2007; Nelson et al., 2006; Ogle, 2006; Sullivan-Bolyai et al., 2003). When parents have a child with a chronic condition the emphasis is on raising a child who will be an independent, well functioning member of society and this no longer is the emphasis when the child is dying (Davies, Reimer, Brown, & Martens, 1995). On examining this difference, the importance of incorporating the concept of transition becomes clear. Parkes (1988) proposed the concept of psychological transition, which he defined as a change that necessitates the abandonment of one set of assumptions and the development of a fresh set to enable the individual to cope with a new altered life space. The results of Parkes' study focused on family transitions during the course of caring for a dying child. The families knew that they are experiencing a process of transition between having a child alive and with the symptoms under control and no longer having the child physically present in the family. In many cases, the healthy child begins to "disappear" little by little within this context of palliative care. With each passing day, the child's clinical condition may worsen and, consequently, the child also comes to be defined differently. The family adapts their routine or not to the variations of the child's clinical condition, influenced as well as other aspects of their situation.

The imminent possibility of the child's death is troubling for the whole family. The grief due to anticipated mourning makes it hard to visualize the future, and the family therefore is always focused on the present, which is difficult to manage. Stroebe, Schut, and Stroebe (2007), based on the dual process model of bereavement, found that many families fall into a process of "avoiding thinking about the loss by means of doing"—into an inhibited mourning. The families in this study became totally absorbed in everyday activities and talked little about the loss. These authors stated that such a process can lead to complicated mourning following the child's death. According to the authors, the family must be encouraged to switch back and forth between loss-oriented and task-restoration strategies.

There is a limited evidence base regarding the needs of the family and of the child as far as the psychosocial aspects of grief are concerned. Components that address this concept should be included in care. When we face death rather than hide from it, we develop the courage to accomplish anything. Preparing for death referred to the family's ability to consider plans for death and after death.

Although the FMSF proved useful in providing a clearer understanding of how families manage the situation of having a child in palliative care at home, certain questions regarding the period of terminality still remain unanswered: What are the family's fears and anxieties in regard to management in the end-of-life phase? To what extent does the family wish to take part in care of the child that is dying? What interventions will be necessary to prevent complicated mourning if we fail to care for these families in the course of the child's illness?

Thus, the use of FMSF in the context of palliative care should include a new conceptual component related to "Preparing for death"—referring to the family's ability to consider plans for death and after death. In this case, other dimensions and/or components must be studied such as, for example, transition and grief. This would allow nurses to provide effective intervention strategies for grieving family members, using the FMSF.

Implications of Results for FMSF

There is a broad consensus on issues related to including the family in the practice of palliative care. According to Pastrana, Jünger, Ostgathe, Elsner, and Radbruch (2008), there is a striking agreement in the literature that quality of life and relief of suffering are considered central objectives of palliative care. We have no knowledge of empiric data on the influence of Brazilian cultural aspects in family management in situations where the family has a child undergoing palliative care, nor do we have family assessment or intervention tools created specifically for our culture. Palliative care claims a holistic and family centered view, and, as Jensen (2004) argues, we can extend and intensify our quality of care by challenging assumptions based on our own culture. Many professionals, including those in Brazil, continue to look more at the purely medical/biological situation and find it difficult to assess family relationships and intervene in them if necessary. To advance in the training of health professionals for work in family care in palliative care situations, we must adjust or approximate the family assessment tools to the Brazilian reality of the health care professionals involved. The FMSF proved to be a facilitator to understanding of the experience within this context of multiplicity of diverse Brazilian families.

We authors are well aware that we used a framework developed within another culture. However, the assumption and evidence underpinning this discussion is to innovate, to discover ideas capable of enriching the provision of local services.

Limitations

There are two limitations that need to be acknowledged and addressed regarding the present study. The first limitation concerns the small sample. We recognize that the number of participants is too limited for broad generalizations. However, the solid evidence gathered through the in-depth interviews allowed us to describe the overall experiences of these families, so that clinical and research professionals can benefit from the findings. Further empirical evaluations, however, are needed to replicate the findings in different contexts and surroundings. The second limitation has to do with the impossibility of the interviewer to assess more than one parent in the majority of the families. Even though the interviews were designed to obtain a family perspective of the experience, we are aware that different family members, mainly the fathers, could share aspects and dimensions of the experiences that were not shared or emphasized by one family member alone.

Conclusion

In Brazil, nurses and other health care professionals are finding themselves increasingly involved in providing palliative care. Despite the fact that the literature on care of the dying is growing, caring for the family continues to be described in a general way. The study supported the usefulness of the FMSF for specifying unique areas of family strength and difficulty in the management of a child in palliative care at home. Recurring themes covering social, emotional, and physical aspects in the family interviews suggest useful issues to consider in the development of a palliative care program and point to the importance of addressing family grief as part of pediatric palliative care at home.

More research must be carried out taking into account the specificities of this context such as health beliefs, communication beliefs, religious practice, and diversity in family structure. In so doing, we can develop knowledge and remain open minded about what is new or different within service provision approaches of different cultures. From the perspective of use of the FMSF in the palliative care context in Brazil, our most important learning experience was the possibility of gaining greater insight into the experiences of families within a context that features so much diversity.

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