

The Evolutionary Nature of Parent–Provider Relationships at Child’s End of Life With Cancer

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Abstract

Relationship strains between families and providers can have intense repercussions on the bereavement experience. Little is known about how to define and differentiate relationships within various interpersonal contexts and how those families manifest their bereavement. Therefore, the purpose of this study was to understand parental experiences about their relationships with providers at their child’s end of life with cancer and describe the manifestations of their grief. In this hermeneutic study, data were collected through interviews with bereaved parents and observation of families and health care providers in the hospital setting. Parents variously experienced complex relationships characterized by support, collaboration, trust, silence, deterioration, hierarchy, and tolerating, which were interchangeable and varied overtime, as new meanings were incorporated into their experiences. Through better understanding of the nature of these relationships, nurses can provide leadership in research and practice for identifying consequences of their care.

Keywords

professional–family relations, family nursing, parents, child care, end-of-life care, grief, bereavement, cancer

Parenting children with life-threatening illnesses entails establishing and maintaining relationships with their children’s health care providers. Parents and providers’ relationships during the illness course can shape parents’ perspectives about the care received, their bereavement, and their perceptions of themselves as parents and caregivers (Contro et al., 2002; Heller & Solomon, 2005). We consider providers to be all the members of the hospital health care team with most emphasis on physicians and nurses.

Parents whose children are treated along the cancer trajectory experience relationships with members of the health care team of varying quality and intensity, which inevitably brings distress (Ljungman et al., 2016). If their child dies, the intensity of those experiences with members of the health care team is magnified within the context of family grief and bereavement and can add to parents’ sense of being overwhelmed (D’Agostino et al., 2008; Davies et al., 2013).

Relationships established during nursing care are central to family-centered care for children with life-threatening illnesses and their families (Baird et al., 2015; Davies et al., 2017). These relationships have been studied in varied contexts such as parenting and bereavement follow-up (Berrett-Abebe et al., 2017; Meert et al., 2015), with most emphasis on

intensive care (Butler et al., 2018a, 2018b), cancer palliative care settings (Ljungman et al., 2016; van der Geest et al., 2013), and providers’ communication (Feudtner, 2007; Meert et al., 2008). Reciprocal social interactions are those in which parents and health care workers engage in back-and-forth communication to build productive relationships that meet the needs of children and their families (Hill et al., 2018). Hence, professional education is needed with respect to parental preferences and children and adolescent developmental status (Smith et al., 2019).

We do know generally that relationship strains between families and providers can have intense repercussions on the bereavement experience (Aschenbrenner et al., 2012;

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Melin-Johansson et al., 2014). For example, judgment and criticism among parents and providers (Butler et al., 2018; Neill & Coyne, 2018) can strain the best of relationships. Little is known, however, about how to define and differentiate relationships within various interpersonal contexts and as a first step in investigating their consequences. Without such knowledge, research and education regarding end of life are severely hampered. The aim of this study was to understand parental experiences of their relationships with providers at their child's end of life with cancer and describe the manifestations of their grief. Therefore, this study sought to answer the following questions: How are provider and parent relationships established at the child's end of life? What are the parents' experiences of their relationships with providers at the child's end of life? How is parental grief manifested?

Research focusing on everyday encounters between parents and providers is necessary (Davies et al., 2017) to address the complexity of providing support and empathy for parents (Kane, 2006; Kane et al., 2004) and to further refine educational programs (End-of-Life Nursing Education Consortium [ELNEC], 2009). Parents experience barriers and facilitators to their relationships with health care providers and acknowledge the impact of the surrounding clinical environment on these relationships (Butler et al., 2018a, 2019; Rosenberg et al., 2018). This study is designed to consider these issues but to move the science toward a more nuanced, multifaceted, and dynamic understanding of family-provider relationships and how they unfold over time.

Method

Design

This qualitative study was guided by philosophical hermeneutics or the interpretation of human understanding (Gadamer, 2015) and the main principles of hermeneutics including prejudices, fusion of horizons, and the hermeneutic circle. These principles underscore the importance of the researcher's background and experiences or prejudices and comprehension (Gadamer, 2015). Researchers strive to be aware of their prejudices or prejudices (Gadamer, 2015) which are not separate from the events they seek to understand because these prejudices are useful in understanding the topic under investigation. Unlike other methods, prejudices are not held in abeyance but are mined as sources of knowledge (Moules et al., 2015). In an interactive process, the interpreter's past and present understandings come together in a fusion of horizons to achieve new understanding (Gadamer, 2015). The hermeneutic circle is "the [circular] movement of existing understanding, or prejudice, into constructive interchange with another" (Moules et al., 2015, p. 44) which constantly expands and interacts between the parts and the whole (Gadamer, 2015).

In this study, we identified our partial knowledge about family, children during the dying process, and palliative care developed in previous research (Santos et al., 2019a;

Mooney-Doyle et al., 2017; Wiegand et al., 2015; Misko et al., 2015). These pre-judgments have not only motivated us to focus on the relationship between families and care providers but are inevitably preconceptions which are modified as new questions arose during the research process in the research team.

To gather different interpretative pathways, the study was accompanied/supervised by experts: a psychologist specialized in grief and bereavement, a nurse qualitative researcher with expertise in bereaved populations, and a pediatric physician from an oncology center. The discussions with these experts during the entire process were essential to gaining awareness of hermeneutic concepts, distinguish prejudices, achieve the fusion of horizons, and engage in the hermeneutic circle. The process also facilitated assessment of quality during the data collection and analysis process and reduced potential risks for participants and researchers due to the sensitive topics involved in this study (Butler et al., 2017).

Ethical Approval

The research was conducted in accordance with the standards for human research and was based on ethical considerations for research with bereaved populations (Beck & Konnert, 2007; Nadeau, 1998; Parkes, 1995; Rosenblatt, 1995). Ethical approval was obtained from Human Research Ethics Committee at School of Nursing, University of Sao Paulo, Brazil (Protocol no. 486.204/13) and at Clinical Hospital from Medicine Faculty from University of Sao Paulo (Protocol no. 504.822/14). This study is reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007).

Research Participants

The primary source of data for this investigation were family member interviews, which were conducted in a location chosen by the parents, mostly in their homes. The inclusion criteria for the interviews were as follows: parents whose children had died in the hospital at least 6 months ago; who were over 18 years of age; and who lived locally to make it feasible for the researcher to travel to the homes. As shown in Table 1, the family carers ($n = 24$) were on average 41 years of age and the children who died were on average 9 years of age and were mostly male ($n = 16$). All had cancer, most commonly leukemia ($n = 10$). Most were treated at public institutions in San Paulo ($n = 22$). The median time between diagnosis and the children's death was 3 years. Most deaths occurred in the ward versus the intensive care unit (ICU; $n = 16$). The median time between death and the interview was 4 years.

Data Collection

Family member home interviews. The impact of grief was discussed during the consent process (Parkes, 1995) as an

Table 1. Sociodemographic Data of Children and Family From Interviews and Observations.

Characteristics	N = 24 ^a families
Age, median in years (range)	
Child	9 (1–18)
Family carers	41 (21–52)
Child gender	
Female	8
Male	16
Diagnosis	
Osteosarcoma	3
Leukemia	10
Neuroblastoma	6
Lymphoma	2
Astrocytoma	1
Medulloblastoma	2
Median of the period between diagnosis and death in years (range)	3 (9 months–7 years)
Median of the period between death and interview in years (range)	4 (11 months–10 years)
Institution	
Public hospital	22
Private hospital	2
Place of death	
Ward	16
ICU	8

Note. ICU = intensive care unit.

^aThe observations had a total of 18 families, and seven bereaved parents were interviewed. The number of 24 is due to an overlap, as one father participated in the interview and the family was also included in observation.

individualized journey with intensive grief lasting about 6 months (Nadeau, 1998). For this reason, we limited our invitation to interview bereaved parents whose child died at least 6 months prior to their participation in the study.

Recruitment was conducted using three strategies. The first was the use of social media. Specifically, on the research group's Facebook page, we published information about the study and inclusion criteria for participation. This page gathers an audience interested by the theme that already accompanies the activities of the research group, so it is not necessarily visited by bereaved populations but people who work in the area and have a special knowledge of the population. If a parent met the criteria and agreed to participate in the study, we set a date and place for a face-to-face interview. The second strategy was to enlist the assistance of health care providers from the hospital, whose ethics committee authorized the study, to identify families who had experienced the loss of a child in the respective institution. A list of families was provided, and participants were contacted one by one, through telephone numbers registered in the medical records. In addition, we used the snowball sampling technique in which all

study participants were asked whether they knew of other parents who met the inclusion criteria and may want to participate (Biernacki & Waldorf, 1981).

In research involving vulnerable populations and sensitive topics, such as grief and bereavement, ethical concerns are considered from planning recruitment to data analysis and interpretation (Butler et al., 2017). Strategies to strengthen our ethical approach included planning recruitment procedures carefully in which invitations were individualized to each family and each family member. The first contact was made by a member of the health care staff on behalf of the research team. If the parent agreed to hear more about the research, the principal investigator (PI) made the next contact to discuss the purpose of the study. One to two follow-up phone calls were made to determine whether the family member would like to participate.

Seven parents agreed to participate in the interviews. Fourteen parents declined, stating, "I am not ready to talk about it," "it still hurts too much to talk about it," and "maybe later, but now I don't feel comfortable with it." After informed consent was obtained for the interviews, a genogram was constructed to engage with the participants and to better know the family members. Demographic data (Table 1) were collected followed by a semi-structured, individual interview (Figure 1). All interviews were digitally recorded and transcribed by the main researcher for a continuous analysis. Identifying information was removed. Letters and numbers were used to distinguish participants.

Family and health care provider hospital observations. The meaning of parents' experiences during their children's last days of life is shaped by their interactions with their children, other family members, and with health care Providers (Santos et al., 2019a). Therefore, participant observations of these interactions became a fulcrum point to this study and were the second source of data. That is, critical observations were fundamental to developing our hermeneutic horizons, allowing us to foreshadow how multiple influences in the environment contributed to the perceptions of the parents.

The observations took place in a public hospital that specializes in pediatric oncology and hematology in Brazil. Parents were recruited from a 19-bed general ward, a six-bed ICU, and a six-bed allogeneic bone marrow transplant unit by the PI of this study. The inclusion criteria were as follows: Two physicians confirmed that the child would likely die within 6 months. The exclusion criteria were transfer to other units or institutions for end-of-life care and death occurred prior to the initiation of formal observations. Informed consent process involved meeting in the child's room to introduce the parents to the study and researchers' role for parents. We introduced the research team and explained the purposes of the study. Eleven families from the ward plus seven from ICU were observed for a total of 18 parents. Of the seven parents who participated in the

How was your experience of losing a child in the hospital?
 When you realized that (child's name) was dying?
 How was your relationship with the healthcare providers like during the last days you spent with (name of the child) at the hospital?
 Was there any remarkable experience for you in regard your relationship with providers?
 Today, when you think about the people who took care of your child when they were dying at the hospital, what comes to your mind?

Figure 1. Semi-structured interview guide.

interview, one father represented one of the families included in the observation. Due to this overlap, the demographics (shown in Table 1) represent the 24 families who were part of this study.

Once a parent was enrolled in the investigation, the research nurse set up a schedule for the observations, which were done every weekday in the unit and at least one shift per week inside the child's room, except when the child had significant clinical worsening when researchers followed the family closely, for one shift every day. Text messaging was used to communicate and respond to any clinical changes especially during the last 24 to 72 hr of the child's life as well as to recruit families and respond to other study-related issues.

Although we focused on interactions between parents and providers, we also observed which family members remained with the child, who made regular visits, as well as who participated in the child's care. Inside the child's room, we observed which providers entered, dialogues with parents, and the daily care routine provided for the families. While in the unit, we observed the discussions among the providers regarding the families in the transition of the nurse's morning shift and the meetings with doctors. Health care providers observed in conversations with the families included physicians, nurses, physiotherapists, occupational therapists, nutritionists, psychologists, social workers, and pharmacists. Hospital volunteers were also included in the observations. These observations allowed us an opportunity to witness discussions about each family, the decisions made, the perceptions and reactions of different providers facing these decisions, or the disagreements related to the child's care. Observation data were recorded during or right after each hospital visit through field notes.

Parents who participated in the observation also gave consent for the researchers to review and analyze their child's medical record. Data were collected regarding the child's illness trajectory and daily evaluations by health care providers. In these records, we looked for data which would describe the care provided for the families related to the child's end of life (communication and introduction to exclusive palliative care, failure of the cure-oriented treatment, execution of measures to provide comfort, and family's reactions). Notes were extracted from each record in an individually identified document.

Data Analysis

Data from the interviews and observations were analyzed with attention to the hermeneutic circle, that is, we interpreted both the individual parts of the data text and the text as a whole (Moules et al., 2015). Data were chronologically organized by date and observation time and were divided into types (participant observation, documentary analysis, interviews, and analytical "memos"). Similar to other studies guided by hermeneutics (Laing & Moules, 2016; Moules et al., 2018), the transcriptions were numbered line by line. The data for each family were identified by a color. Data matrices were formed with Microsoft® Word Excel software. At the end of each transcribed document, codes with similar meanings were grouped, contributing to the interpretation of a specific topic. The same process was used for observational and medical record data. Units of meaning were identified and grouped into themes and, if pertinent to understanding the topic, were divided into smaller more specific analytical units. Whenever new themes were formed, we looked back to the original transcriptions and wider context to ensure that the narrative meaning was preserved in the themes. In hermeneutics, the analysis is circular and recursive. We returned several times to the original transcriptions to rethink the meaning of interpretations considering the raw data.

The practice of writing allowed us to further deepen interpretations about the relationships (Moules et al., 2016). The participant observation helped us identify concepts considered central to the relationship between parents and health care providers in the dying process of a hospitalized child. An example of the analytic process from raw data is described in Table 2.

The interviews and observations were conducted by a trained investigator. After every interview or observation day, a feedback session was conducted with the study supervisor to improve initial data analysis and to ensure the emotional health of the researcher. This helped guide the interviews, subsequent observations, and early interpretation processes, adding new perspectives, as hermeneutics proposes (Moules et al., 2015). During these meetings, memos were created in an individualized document, which was used as support for the data analysis.

Table 2. Interpretation and Analysis Process.

Interviews and observation	Theme	Sub-theme	Final interpretative phase
And there's that silence . . . that silent suffering. You keep thinking, damn it, is that so? (M.5) I looked around in the ward, and my impressions were that no one wanted to take care of him. Even the doctor that gave him the diagnosis, He looked far away. (M.4) It is abandoned. When you realize that you are abandoned, you, as a father, what do you do? [. . .] (P.7) Focus of the team discussion was about G.'s evaluation (excretion, vital signs and exams request). Different from last meeting, providers did not discuss other possibilities or options for G.'s care, neither about the family as they used to point out. Occupational therapist mentioned: "What more to say?" Compared to previous meetings, less providers raised some issue to discuss about G.'s case. (August, 2015; 4 days before G.'s death) What they [physician] want to tell me, I prefer not listening. What about the whole 'be confident' thing? (March 2016; H.'s mother's speech for the nurse)	Communication	Absence of communication about EoL	Silent relationship

Note. EoL: end of life.

Results

The characteristics of parental relationships with the health care providers were embedded in the bereaved parents' narratives about their coexistence with each other. Based on the parents' conceptions, these characteristics shaped the nature of their interactions that varied over time in strength and intensity. The main definitions, characteristics, and manifestations of their grief formed the components for describing the types of relationships identified in parents' narratives (see Table 3). First, we describe the main characteristics and conceptions involved in every relationship at the hospital. Second, we describe the attributes of those relationships and their defining characteristics. Third, we describe the manifestations of the parents' grief.

Characteristics and Conceptions About Relationships

Certain characteristics framed all relationships established between parents and providers. The first characteristic of the relationships was their dynamic nature; the connection formed was not rigid but was transitory and could be transformed as new meanings were incorporated into experiences over time. For example, parents may have identified a relationship as unsupportive, but in the days, months, or even years later, this perception could change as they explored their own experience in a different manner: "Today, I recognize that she [the nurse] was trying to help me but at that time I could not look to her as a reference" (M.6).

The second characteristic of the relationships was that they could be shaped by human values. Parents pointed out that the quality of the relationships was permeated by the value accorded to them as humans. That is, caring attitudes

made parents feel valued as being human which then framed each interaction. The presence or absence of caring and valuing the other as a human pervaded all forms of relationship and was embedded throughout the parents' experiences. Such valuing then helped to frame the meaning of their experience and their loss. For example, one parent stressed possible different outcomes according with human values: "If it wasn't for the disregard of Dr. N. [oncologist] everything would be better" (M.1).

The third characteristic was the bond formed with various health care providers along the illness trajectory. As the illness progressed and the child neared death, parents came into contact with many health care providers; some relationships were transient, and some were long-term. Bonds made the relationship a phenomenon beyond the simple interaction between people. Tacit relationships were established and formed over the negotiation of the child's end-of-life care. Tacit relationships mean interactions were continuously established without being clarified directly through verbal communication, which was a crucial issue for bonding, considering providers and parents may have had different views and assigned different meanings for the same person or phenomenon in each the interaction. Parents potentiality formed affective and moral connections as a part of these relationships which reframed the subjective benefits of pivotal encounters. For example, parents referred to immediate memories of a certain provider, differentiating one from other. When health care providers' attitudes and actions were performed in a personalized way, the child's identity was reinforced and became part of special memories: "As I was a usual patient, we had close bonds. She [the daughter] had THE [emphasis to pronounce one particular person] ambulatory nurse, THE ward nurse [. . .]" (M.2).

Table 3. Concepts Involved in Parents–Providers Relationships During the Child’s End of Life With Cancer at the Hospital.

Relationship components	Supportive	Collaborative	Trusting	Indulgent	Silent	Deteriorated	Hierarchized
<i>Definition</i> Attribute that is emphasized at the end-of-life caring moment	To have something or somebody to count on	To share goals for caring	To apply the best expertise to care, recognizing human dimension and limitations	To develop tolerance for and to minimize interactional failures of providers	To occupy a quiet space with providers (more pronounced as death gets closer)	To notice discontinuity in the care provided	To develop patterns of interactions based on abuses arising from power inequality
<i>Defining characteristics</i> Main observable inferences present in the relationship	Authentic presence Availability and competence Compassion Empathy	Effective communication families’ wishes respected/attended Synchrony and harmony to achieve similar goals	Behaviors in accordance with parents’ expectations Transparency, sincerity, and frankness Maintenance of faith and hope Opening space for uncertainties	Exalted intuitions Developed tolerance: good intentions perceived or avoidance of direct confrontation or recognition of suffering	Inadequate patterns of communication Abandonment and neglect	Breaking ties Abandonment and neglect Interruption of bonds	Compromised dialogue Disrespect of parents’ knowledge, values, and world view Imposed decisions
<i>Manifestations of parents’ bereavement</i>	Security Family adjustment Assurance of parents’ roles	Certainty to have protected and advocated for the child Fulfill goals of parenting Established partnerships	Confidence and tranquility that the best was provided	Emotional overload Fragility and unbalance	Emerging need to increase vigilance Sadness Anger Loneliness	Pain Feeling of anticipation of the death	Angry Impotence

The bonds were a point of support for parents because they enabled sensitive and caring interactions at the end of life. Parents did comment that the bonds did not have to be particularly intense: "I do not think we have been like a family—the doctor and the patient" (M.3). Others desired more intense bonds, "We had them [providers] as a part, as an extension of my family" (M.2). If those connections are not available to the parents because of provider behavior, however, the parents could be left without such an anchor and feel isolated or abandoned:

When B. [son's name] wants to speak to the doctor and he sends an assistant who does not know him, this is absolute disrespect. You need to ask something, and an assistant comes in: "You [physician assistant] has nothing to do with this. I want to speak with Dr. U. [physician's name] who told me something that is not" [not true; initially physician said to the mother that her son would recover and go back to his activities]. I want to talk to him, but he never showed up. (M.3)

Types of Relationships

As shown in Table 3, manifestations of characteristics were embodied in certain types of relationships. The types of relationships represented parents' experience of relationships characterized by support, collaboration, trust, silence, deterioration, hierarchy, and tolerance. The characteristics of relationships were not necessarily embodied by a relationship with one health care provider overtime. Rather, they were based on the provider's ability to respond in the moment to their children's emergent demands appropriately.

Supportive relationships. The parents' greatest emphasis was on the importance of supportive relationships; that is, those relationships where they felt "held" and protected by providers. Such relationships intuit the idea of consciously needing something or someone to count on when needed. Knowing people and resources were available was vital for parents in their caregiving role in order that they felt their child had the best resources available for treatment.

Supportive relationships were established with particular providers or with the staff in general if parents had been treated by the same staff throughout the child's illness. A different level of presence and compassion, however, was necessary near the end of the child's life. Being authentically present regarding expressions of compassion and empathy was essential to supportive relationships established in the end-of-life context. At times, physical presence was evident, but a supportive relationship went beyond simply sharing the same space and included demonstrating competence to help, support, and shelter in accordance with the child and parents' needs. This physical or nonphysical presence was crucial for parents to be secure during the last moments of their child's life. Supportive relationships provided security and protective factors for parents' bereavement. "They [providers] did

not open their mouth . . . they were there with me [pause] and . . . and they did not come out until I left the room" (M.2). Another mother felt nurses' nonphysical presence which helped her feel secure in the private last moments of her child's life:

I knew nurses were around, but I did not want anyone there. It is a sad moment, I wanted to feel free to say anything for him [the child], to pray, say goodbye. In this moment, the provider could disturb more than help. (M.5)

Collaborative relationships. Health care systems were charged with responding with synchrony and harmony to the family's needs as well as helping parents feel confident as parental caregivers. Health care providers were charged with forming trusting relationships with children, parents, and other family members. Collaborative relationships enabled these processes and helped parents fulfill their parenting roles through shared goals and responsibilities for their children's care as explained by this mother:

My husband and I, we are big fans of H. [name of the hospital]. We had everything there. We wanted to give him [the child] security, that we felt it was important and nothing would get in the way of achieving it. (M.5)

Collaborative relationships involved communicating effectively and establishing partnerships, which demanded knowing others' roles and goals when caring for children at end of life, including accepting their imminent death. As these parents explained, decisions needed to be shared, preserving each one's roles and competence: "I've always asked doctors to do their best and everyone wants to do their best but they [doctors] are not clear where they want to go" (F.7). For instance, the certainty of having advocated for their children within the context of a collaborative relationship seemed to facilitate grieving after loss, as it is common for parents to reassess their own role during the child's illness trajectory:

If I did not point things out, a lot of things would go unnoticed. [. . .] Nothing bad happened with G.'s [child's name] care because I was taking care of everything, but I realized [later] that it could have been better. (F.7)

Trusting relationships. Trusting relationships between parents and health care providers at the child's end of life were based on valuing human connections and recognizing human limitations. Confidence was the result of trusting relationships, which could change over time, as parents' expectations were not only satisfied but also exceeded. Developing trust in health care providers was possible through authenticity, genuineness, maintenance of faith and hope, and especially, even if it seemed contradictory, through the openness for uncertainties. Bereaved parents' narratives about trusting relationships indicated they were confident in the care provided for the child:

At first, I wanted to know if they [physicians] were telling the truth, so I searched and studied a lot. [. . .] I thought they were hiding something. Along the treatment, I studied things that could help them. (M.4)

Trusting was challenged over the course of the illness. Children at end of life may or may not respond consistently to aggressive treatment or experience side effects. In addition, parents learned at the beginning of treatment that challenging the “cure” goal could threaten trust and raise contradictories. Therefore, parents waited for their child’s improvement and their hope sometimes lasted until the very last minute: “There is no decision greater than God’s. Doctors cannot decide whether and when someone goes or stay” (observation notes). “No one knows if someone will survive. [. . .] So just say: ‘trust me!’ This is ridiculous!” (M.3).

Transparency in relationships was encouraged by proactively sincerely and frankly explaining changes in the child’s condition but was rarer as the death approached because the information was clinically difficult to predict and communicate. Parents’ trust could then be shattered as they may have felt their children’s care being controlled by issues they did not understand: “In hard times, when he [son] was not well, it is very rare when people are willing to respond with frankness and an open heart” (observation notes).

Indulgent relationships. An indulgent relationship indicated a tendency to minimize interactional failures of the providers. Parents “looked past” the potentially offensive behaviors and acts to avoid distress. They valued their own intuitive knowledge to do so and/or to call attention to whatever was offensive to “protect” their child from any repercussions of calling attention to the distressing behaviors and acts. In doing so, they sometimes became authentic in a paradoxical way: “You notice that the person is trying hard. The truth is that they want to do a good thing and you realize when a person is authentic with you, don’t you?” (F.7).

Tolerance was developed in an indulgent relationship, but it could take time and the bereavement process allowed parents time to modify their beliefs related to interacting with providers’ attitudes during the child’s end of life. For instance, by recognizing providers’ suffering, parent’s redefined health care provider’s distancing at the child’s end of life. In these parental narratives, an intense effort was directed at comprehending health care providers’ attitudes and behaviors and avoiding direct confrontation; first the parent talked about verbal distancing and later reflected about providers physically not being present:

The doctor sometimes gave me some hope that I knew would not happen. [. . .] I remember looking at him and thinking that he was telling me those things just to comfort me. So, I’d not give up, right? (M.4)

Later the same mother said,

The impression I had is that everyone has disappeared. [. . .] they were not abandoning because of gravity, but for their own protection; to protect themselves, you understand? from that pain, I guess. It was not negligence. (M.4)

Tolerance was challenged and resulted in a fragile and unbalanced relationship filled with latent disagreements: “Nurses enter the room and it seems they can’t do anything else. We feel that all the small things we do only worsens the suffering because the reaction of the people is the worst possible” (M.5).

Silent relationships. At the child’s end of life, health care providers could become soundless protagonists. Silent relationships were created as quiet spaces, sometimes desired by parents during the dying process as they need certain reflexivity to this moment:

It depends on each one. Speaking for myself I did not want anyone to stay with me, neither my mother nor my sister. I called a friend, who I know would not bother me. I know the way she is, because at very moment I did not want to talk to anyone. [. . .] I was afraid, only fearing, the fear you have of arriving the time [. . .] and there’s that silence, that silent suffering. You keep thinking, damn it, is that so? (M.4)

Although silence could be protective and healing, silent relationships (based on lack of verbal or nonverbal communication on the part of health care providers) intensified parental vigilance, and parental physical and emotional suffering. Parents thought silent relationships were rooted in providers’ inability to talk about death, dying, and grief and the self-protective mechanisms served to avoid engaging in difficult conversations. Parents felt abandoned and thought their children were neglected, which then reverberated in their bereavement. They recalled their sadness, anger, and the loneliness and unfairness because of the silent relationships they experienced:

You need a support to see that although he is leaving; someone is taking care of him [cries]. I felt abandoned. I looked around in the ward, and my impressions were that no one wanted to take care of him. Even the doctor that gave him the diagnosis, he was there looking at us from far away. (M.4)

Deteriorated relationships. Deteriorated relationships with a health care provider focused on changes to quality of the provider’s care, attitudes, and behaviors. Bonds were interrupted and sometimes broken by the health care provider which was extremely painful because parents simultaneously were anticipating their child’s death: “Relationships deteriorated because as fast as he [the child] got worse, the faster the doctors disappeared” (M.3).

Parents focused on signs of clinical improvement and discontinuity of medical care, such as reduced frequency of physicians and nurses' visits and more spaced or limited procedures and therapies. The perceived negligence meant broken moral bonds and denial of their child's humanness:

Why when it's coming to the end and the possibilities are running out, you realize that no one cares about your levels anymore? How your platelets are like? How's your hemoglobin? It's clear. This comes to be a cruel feeling. (F.7)

After death, relationships built at the hospital throughout the treatment were interrupted. Relationships with health care providers, however, were important for immediate care after the child's death. At the time of the child's death, parents experienced immeasurable physical and emotional exhaustion. As soon as the child died, parents commonly became destabilized, tending to exhibit physical symptoms related to post-traumatic stress disorders and needed assistance: "I had no support after he passed away. [. . .] they cut off that link. Everything was over [. . .] It was like all of us did not exist anymore. They failed to assist this grief." (M.4)

Hierarchical relationships. Hierarchical relationships involved patterns of interactions based on abuses arising from power inequalities. These relationships compromised dialogue and respect, which were fundamental to forming relationships of trust. Thus, hierarchical relationships represented a threat to the integrity and establishment of relationships at the child's end of life. Parents explained they felt unrecognized or belittled when providers did not validate their knowledge about the child, their values, and worldview as the starting point for the conversation. This included the need for sensitive acknowledgment of and attention to parents' wishes and priorities for their child. In hierarchal relationships, however, the parents felt limited or oppressed by providers, "He was prohibited to go home at Christmas. He wanted to punch the doctor. Not by the fact of prohibiting, but by the arrogance in the talk. It's aggressive" (F.7). Another mother stated, "I will not listen to them anymore. What they think it will happen, I already know but I don't need to listen to it all the time" (observation notes).

Discussion

In this study, we sought to understand parental perspectives of relationships with providers at the end of a child's life. The relationships helped shape the meaning of parents' loss and their place in the child's death, which influenced parents' anticipatory and post-death grief. The data interpretation process led to an understanding that these relationships are broad phenomena with defining characteristics and consequences that are involved in each interaction at end of life.

In this study, we described the dynamic nature of relationships through interviews with parents in their homes and observations within the hospital. The changing nature of parents and

providers' interactions has previously been reported with children dying in ICU across illness trajectories (Butler et al., 2017). Dynamicality has previously been described as involving beliefs, resilience, coping, and relationships embedded in anticipatory grief of mothers' lived experience when losing a child with cancer (Lou et al., 2015). This study advances our understanding of dynamicality in that it is central to relationships and is governed by families' needs and demands that vary according to meanings attributed to the multiple losses experienced during the child's illness.

The "types" of relationships are consistent with an evolutionary perspective, capturing the breadth and impermanence presumed in the diversity of subjectivities encountered when suffering the death of a child in the hospital. Parents experienced support, collaboration, trust, silence, deterioration, hierarchy, and tolerance, which were interchangeable and varied overtime because they incorporated new meanings into their ongoing experiences, not only with the loss of their child, but through their role and status as a parent and member of the health care team. These characteristics were not necessarily embodied by a relationship with one health care provider overtime; rather they were characteristics that became evident to the parents as the provider responded to the emergent demands of their child and their family. Parents perceived that the actions of health care providers were most meaningful, therefore, when their practices matched to the singularities of the situation in the moment and led to positive outcomes for parents and providers (Davies et al., 2017).

The suffering and loneliness experienced by parents created an indelible impermanence in relationships with providers, as parents often shift and contradict their previous evaluations of these relationships. The bereaved, especially those who experience disenfranchised grief, may face particular mental health risks (Doka, 2002). Social isolation is an important risk factor, as it does not provide space for the bereaved to share anxieties, frustrations, and ambivalence related to loss (Parkes & Prigerson, 2010). In this study, we learned that the child's end of life in the hospital is as silent as the relationships established. For parents immersed in pain and fear of losing their child, guilt and frustration can emerge from loneliness and abandonment. Thus, these relationships can affect bereavement, reinforcing social isolation and transforming anticipatory mourning into disenfranchised grief.

As parents prepare for their child's death, their anticipatory mourning may be hidden through their efforts to ensure the best for their child. Indeed, parents can "carry on" through their caregiving role but experience physical and emotional overload while their anticipatory mourning is unrecognized (Raffin Bouchal et al., 2015). Health care providers must pay attention to anticipatory mourning expressions and behaviors, demonstrate respect for their experience, and identify more serious reactions, such as depression (Moon, 2016).

Even in a chronic illness, like cancer, while parents and providers form a close bond along the treatment trajectory, relationships must adapt into new realities, as needs change.

In this perspective, the illness process is full of new encounters with providers. Hermeneutics helped us to comprehend the evolutionary nature of “relationships.” Relationships must be examined contextually, as families’ needs vary based not only on the disease prognosis but also on the meanings that parents assign to their children’s actions and reactions. Parents tried to read verbal and nonverbal signs from their encounters with providers, based on their present assumptions. Parents lived their child’s final days and described physician and nurse reactions in detail. Provider distancing, restless looks, and vague answers turned collaborative relationships into silent, deteriorated, or indulgent relationships from the perspectives of parents. Therefore, establishing a relationship depends on effective communication. In the course of life-threatening illness, inability to provide sensitive communication, focused on emotions and needs related to the multiple losses lived by parents, invites deteriorated or silent relationships.

In this study, we observed that communication permeates the quality of relationships. This finding is supported by both clinical and theoretical research (Santos et al., 2019b; Davies et al., 2017; Snaman et al., 2017; Weaver et al., 2016). Reciprocal communication is the basis for establishing caring relationships among nurses, patients, and families. Dialogue with providers has a significant impact on parents’ perceptions of illness and their long-term relationship with the providers (Neilson et al., 2015; Snaman et al., 2016a, 2016b). Communication about loss is complex and requires a high level of preparedness. Emotional aspects beyond information about death and dying are crucial for families (Korsvold et al., 2016). Advanced care planning can be a unique opportunity to help engage in communication about death and dying, as well as in more collaborative relationships. Nevertheless, the challenge of maintaining hope while awaiting the worst requires valuing subjectivity with a gradual and sensitive approach (Lotz et al., 2017). After death, addressing relationships within new boundaries and format allows parents to emotionally distance themselves from the hospital and providers in their own time. Bereavement programs can provide support and attention to parents’ evolving communication needs (Berrett-Abebe et al., 2017; Snaman et al., 2017).

The types of relationships described in this study imply that more nuanced understanding of relationship, beyond communication competencies, is needed in end-of-life care, education, and research (Dahlin, 2015; Ferrell et al., 2018). For example, gaps in understanding culturally diverse experiences of patients and families were identified (Rosenberg et al., 2019). We believe that the characteristics of these relationships can help health care professionals recognize what is needed, beyond universal skills, to adequately respond to families’ needs. Teaching this deepened, contextualized perspective is important, as behaviors and characteristics are developed every moment providers interact with families. Psychosocial needs in palliative care are difficult to assess

due to few existing tools (Barrera et al., 2016). Identifying interactional patterns within the context of the manifestations of parents’ bereavement may be a useful beginning point for further research to assess possible disparities arising from cultural differences, beliefs, or meanings while coping with illness, death, grief, and bereavement. For example, inadequate patterns of communication have been shown in this study to be related to silent relationships, which are characterized by sense of abandonment and neglect, often as the child nears death. Therefore, family interventions could focus deliberately on creating appropriate opportunities for verbal and nonverbal communication with parents as their child nears death.

Anticipatory mourning is generally defined as the coping responses related to an impending death or past, present, or future loss experiences (Rando, 1986). Caregivers can experience intense anticipatory mourning reactions, particularly parents of children with life-threatening illness (Delalibera et al., 2015; Nielsen et al., 2016). For cancer-bereaved parents, however, the multiple relational processes occurring during and after hospital treatment have not yet been fully addressed in the literature to capture the dynamicity of caring relationships and grief reactions before or after loss. Thus, our study provides an illustrative foundation for providers to better understand how families may perceive their actions and relationships.

Limitations of the Study

The following might be considered study limitations. The study population was mostly female and Caucasian. In addition, findings were restricted to parents of children with cancer and it cannot be assumed that the findings would be relevant to families with diagnoses other than cancer, that is, families who do not experience such longitudinal relationships with their health care providers. Although the focus was oncology, however, we believe potential transferability could be investigated for parents dealing with a chronic illness or any life-threatening illness of a child, who might die at the hospital. Long-term treatment and frequent hospitalizations require multiple relationships over time, in which parental needs and demands may change and interactions may present in a similar evolutionary nature as those showed by the parents on this study. Another limitation is that the local culture and context affect the findings and therefore the findings may not be transferable across cultures. The prolonged time frame between the child’s death and the parental interviews is a factor to consider. Although the passage of time allowed the parents to develop an in-depth perspective, their accounts most likely changed over time.

The sample size might be considered a limitation; however, the number of participants in this study is consistent with hermeneutic inquiries and its focus on richness (Moules et al., 2018). Unlike other methods, hermeneutics is not in search of data redundancy, repetition, exhaustion,

or saturation as explained by Sandelowski (1986). Rather, hermeneutics is attuned to looking for particulars that expand our understanding of the topic (Moules et al., 2015).

We want to acknowledge high rate of parent refusals to participate. This can be explained two ways. First, high refusals represent a challenge faced in obtaining parents for the interview. Researchers have described that refusals in vulnerable populations, such as bereaved, are often high and participant's grief reaction may be closely related to the decision to take part in a research (Stroebe et al., 2003). Second, high refusal also conveys that parents "are able to discern when participation in an end-of-life study is not in their best interest and to decline" (Hinds et al., 2007, p. 454). The refusals were thus interpreted as grief responses and served only to reassure us that those who volunteered to participate were at a place in their grief where such conversations could be conducted and may in fact be therapeutic to the participants.

Due to previous experience and specific training for this study, the interviewer was well prepared to conduct the interviews with bereaved populations and generated in-depth and high-quality data. Our interviews generated very powerful experiences from the participants which allowed richness and depth for interpretations. Reflexivity and collaborative exchange with other researchers during data collection were important to ensure the quality of the data in terms of its depth and richness.

Implications for Practice and Research

A key research and clinical implication of our findings is that relationships are factors that can influence how we recognize and assess anticipatory mourning and ultimately bereavement. Recognizing the defining characteristics of each interaction established in child's end of life is foundational for family-focused interventions to enhance family nursing at the child's end of life. Interventions can be tailored identifying relationships' characteristics to assess anticipatory mourning in health care providers' approach when caring for seriously ill patients and families. Nurses can focus more attention on factors that promote and inhibit collaborative relationship with families that have a critically ill child. Education for bedside nurses and clinicians aiming to enhance their interactions with families can include collaborative relationships, to advance already established effective communication in palliative care approaches (ELNEC, 2009; International Family Nursing Association [IFNA], 2015, 2017).

Future research should investigate and clarify core elements of relationships and their outcomes as a foundation for developing sensitive reciprocal connections that support families across illness, grief, and bereavement. Parents of children with cancer live an intense loneliness facing an immeasurable suffering, which is reinforced by silent and deteriorated relationships. Indulgent relationships showed

that parents are affected by high distress. Promoting better connections requires better boundary management and emotional management skills to establish human reciprocity. Skills need to be part of a comprehensive plan to teach students from all disciplines how to address families' particularities, in each present moment (Davies et al., 2017).

Conclusion

In this study, we significantly extended what is known about parent's relationships with providers at the end of a child's life. We were able to describe not only that the relationships helped shape the meaning of parents' loss and their place in the child's death but also that these relationships are broad phenomena with defining characteristics and consequences that are involved in each interaction at end of life.

The changing nature and dynamicity of parents and providers' interactions have previously been reported (Butler et al., 2017; Lou et al., 2015). We not only confirmed that dynamicity is central to relationships but also that dynamicity is governed by the multiple losses they experienced as parents and caregivers during the child's illness. The "types" of relationships (support, collaboration, trust, silence, deterioration, hierarchy, and tolerance) changed overtime because parents incorporated new meanings into their ongoing experiences. Thus, these relationship types were not necessarily embodied in singular health care provider-parent relationships because they were necessarily context driven (Davies et al., 2017). Future research and end-of-life education should address the core elements of relationships, their contexts, and their outcomes as a foundation for developing sensitive reciprocal connections that support families across illness, grief, and bereavement.

Authors' Note

D.L.W. died during the authors' preparation of this manuscript. The authors offer this manuscript as a living memory of her support of doctoral students across the globe who now will carry on her legacy of conducting research with families of seriously ill adults and children.

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Janet A. Deatrck, PhD, FAAN, is a professor emerita, School of Nursing, University of Pennsylvania, USA. She retired from the University after 28 years of service including various leadership roles in the Center for Health Equity Research. She held the Shearer Endowed Term Chair in Healthy Community Practice and is active in community-based research. She collaborates with the Survivorship and Psychosocial Oncology teams at The Children’s

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Kim Mooney-Doyle, PhD, RN, CPNP-AC, is an assistant professor at the University of Maryland School of Nursing, USA. Her research focuses on promoting family health in the context of pediatric palliative and end-of-life care. Her program of research includes elucidating the experience of parenting ill children and their siblings, examining the impact of family-level factors on siblings of children with serious illnesses, and examining social and community contextual influences on family caregiving of children with medical complexity. Research and clinical interests include pediatric palliative care, family research, pediatric Oncology, Pediatric, and Family Ethics. Her recent publications include the following: "Family and Child Characteristics Associated With Caregiver Challenges for Medically Complex Children" in *Family & Community Health* (2020, with L. C. Lindley), "The Association Between Poverty and Family Financial Challenges of Caring for Medically Complex Children" in *Nursing Economics* (2019, with

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