
Article:

Atout, M., Hemingway, P. and Seymour, J. orcid.org/0000-0002-9384-2551 (2019) The practice of mutual protection in the care of children with palliative care needs: A multiple qualitative case study approach from Jordan. Journal of Pediatric Nursing, 45. E9-E18. ISSN 0882-5963

https://doi.org/10.1016/j.pedn.2018.12.004

The Practice of Mutual Protection in the Care of Children with Palliative Care Needs: A Multiple Qualitative Case Study Approach from Jordan

Atout, Maha, Hemingway Pippa and Seymour Jane.

Journal of Pediatric Nursing: Nursing Care of Children and Families, Volume 45, e9 - e18

Short Title: The experience of disclosing information with children with palliative care needs

No. of Pages: 38

No. of Tables: 4

No. of Figures: 0

ABSTRACT

Purpose: This study explores the experience of disclosing critical information in the care of children with palliative care needs, from the perspective of physicians, nurses, and mothers in Jordan.

Design and Methods: This study employed a qualitative case study approach. It was conducted in three paediatric units in a Jordanian hospital. Each case comprised a child aged 1-12 years with a condition eligible for palliative care who received health care in one of these units, and their most involved carers (e.g. mother, physician and nurse). Two data collection methods were employed: participant observation and semi-structured interviews with three categories of participants: mothers, physicians, and nurses. Ethical approval was obtained from the hospital ethical review board. Written consent was obtained from all participants.

Results: Qualitative case studies were developed around 15 children (aged 1-12 years, nine were boys and six were girls, with varying diagnoses: renal disease, neurological conditions, and congenital heart defects). A total of 197 observational hours and 60 interviews were completed (15 mothers, 12 physicians and 21 nurses). The findings demonstrate that the practice of ‘mutual protection’ dominated communication between children, parents and clinical staff. Parents protected their children by disclosing only partial information about their disease, and by avoiding any information they thought would cause the child distress or loss of hope. Similarly, children avoided expression to their parents of their anxieties or fears, in order to protect them. In turn, nurses attempted to ensure observance of professional boundaries with children and mother to avoid a sense of loss when a child died.

Conclusion: The findings of the current study indicate that while open and honest communication between parents and children is generally recommended by literature, not all mothers agree with adopting open communication with their children concerning their illnesses. Therefore, any future intervention planned for them should respect parents' autonomy and decisions in addition to their cultural backgrounds.

Practical implications: The provision of ongoing education and specialised training for professionals to provide them with culturally sensitive skills in communication and provision of emotional support for children and parents is needed to improve clinical practice in healthcare settings with limited access to specialist palliative care such as Jordan.

Keywords: Child; life- limiting; communication; mutual protection; palliative care; Jordan; qualitative.

Introduction

Palliative care for children is defined as “The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease” (World Health Organisation, 1998, p. 8). Communication is a key component in the field of palliative care. It is vital that professionals working with children with life threatening and life limiting illnesses have effective communications skills for a number of reasons. Firstly, the manner in which a diagnosis or prognosis is delivered to a family can have a profound effect on how they are able to cope in the months or years ahead (Blazin, Cecchini, Habashy, Kaye, & Baker, 2018). Secondly, when therapies have failed and the child moves towards the end of life, the ability to have empathetic and honest conversations with family about palliative options can provide comfort (Sisk, Mack, Ashworth, & DuBois, 2018). Furthermore, when good communication helps to form positive relationships, this can give consolation to grieving family when a child sadly dies (Nyborn, Olcese, Nickerson, & Mack, 2016).

Informational exchange is a critical element of communication among health professionals and parents (Hsiao, Evan, & Zeltzer, 2007). Receiving and obtaining adequate information is reported by families to be helpful in ameliorating the fears and uncertainties related to their children’s illness (Blazin et al., 2018; Freeman, O'Dell, & Meola, 2004; Hsiao et al., 2007; Steele, 2006). Parents who are well informed about their children’s illnesses feel safe and secure despite any uncertainty about the prognosis (Ringner, Jansson, & Graneheim, 2011). Further, providing timely accurate information about the child’s condition on a regular basis is perceived to be one of the basic rights of the families of critically-ill children (Bartel et al., 2000).

However, empirical studies show that parents tend to protect their children when they are discussing their illnesses with them, particularly where they have a life-threatening or life-limiting condition. Often, parents do not wish to discuss forthcoming death with children, and find this topic difficult, painful and hard to address (Dangel, Fowler-Kerry, Karwacki, & Bereda, 2000; Van Der Geest, Heuvel Ebrink, Van Vliet, & Pluijm, 2015).

In addition, health professionals report that they have discomfort in speaking with parents. For example, physicians report difficulties in judging how much information should be given to parents (Epstein, 2010), finding it difficult to evaluate how much information each individual family needed. Nurses face several challenges communicating with patients or their families, and in many situations they find themselves being unprepared to act or behave appropriately (Patel, Coad, & Murray, 2012).

Literature Review

Despite the accumulation of evidence that supports the importance and benefits of giving parents detailed information (Freeman et al., 2004; Hsiao et al., 2007; Ringner et al., 2011), there is less evidence to support the notion that providing negative information about a prognosis has a harmful effect on both parents and children (Mack & Joffe, 2014). As highlighted by Stenmarker, Hallberg, Palmerus, and Marky (2010), physicians report that “Being a messenger of life-threatening conditions” (p.483) is a major concern associated with informing patients/families about a recurrent disease and the transition to palliative care. Similarly, a qualitative study conducted with 35 health professionals recruited from a UK children’s hospice reports that health professionals who are involved with treating children with life-limiting diseases find it stressful and difficult to undertake “truth telling” (Price, Jordan, & Prior, 2013, p.75) .

There is evidence that families vary in their needs for amount and style of information about their child's serious illness (Kastel, Enskar, & Bjork, 2011; McGrath, Kail-Buckley, & Phillips, 2007). A longitudinal Australian qualitative study conducted by McGrath et al. (2007) investigated experiences related to the treatment of paediatric acute lymphoblastic leukaemia (ALL). Experiences of 62 families from the perspectives of parents, children, and well siblings over a five year period were sought. The findings of the open-ended interviews show that there was considerable variation in the parents' needs for information. While some parents reported that they found detailed information helpful, other parents in the same study reported that that much of the information they received about the child's condition was very challenging to cope with, and could be a source of anxiety, especially with regard to side effects of treatment. Some parents asked for details about the condition of their children, and then found that they regretted it later (McGrath et al., 2007). Some parents coped with information overload by thinking about the information in part and according to the stage of child's illness instead of being overwhelmed by all the details from the beginning; this significantly increased their acceptance than if they received it early (McGrath et al., 2007).

- The role of culture

Parents' cultural background affects how much information they prefer to share with their children about their serious or terminal illnesses (Papadatou & Bellali, 2002). Conservative cultures demonstrate collusion behaviours in terms of keeping children unaware of their diagnosis, as these cultures often believe that telling the patient the truth will deprive the patient of hope, thereby adding to their distress (Seth, 2010). For example, it is common in Greek culture not to inform children about their diagnosis; rather, information about poor prognoses and the imminent death of children is communicated exclusively between physicians and parents, who usually attempt to adopt a protective approach with their children (Papadatou & Bellali, 2002; Papadatou, Martinson, & Chung, 2001).

In contrast, the cultural milieu of some parents may encourage them to initiate open discussions with their children concerning death. For example, as shown by Gaab, Owens, and MacLeod (2013), in a study among indigenous primary caregivers in New Zealand, caregivers reported that they were encouraged to speak with their children with the aim of preparing them for death. This was partly due to the indigenous (Maori) tradition in New Zealand whereby parents are encouraged to explore concepts related to death with their children.

In the conservative mileu of Jordan it is not the norm to reveal serious and terminal diagnosis to children (Arabiat, ALQaissi, & Hamdan-Mansour, 2011). Jordanian culture is derived from the Arab-Islamic culture. This paper draws on one aspect of a larger study conducted in Jordan to explore the experience of communication in the care of children with palliative care needs **(Reference removed to avoid authors' identifications)**. This paper particularly focuses on the experience of disclosing information between children, mothers and health professionals in Jordan; to identify implications for interdisciplinary palliative care education and practice.

Methods

Study design

In this study, we used a collective qualitative approach of the case study which investigated the phenomena of communication by examining several cases rather than focusing on one case. The collective qualitative approach of the case study is a suitable approach to capture the multifaceted nature of the communications between children, their family carers and the health professionals who were the most involved in their care (Lucka, Jacksonb, & Ushera, 2006; Salminen, Harra, & Lautamo, 2006; Stake, 2006; Yin, 2014). A typical case consisted of a child with palliative care needs, one or more family carers (e.g. mother, grandmother), one physician, and one or more nurses. For more details on the study design, refer to the published paper (Reference removed to avoid authors' identifications).

Setting

This study was conducted at one of the major public hospitals in Jordan located in Amman, which provides health care services for a large and varied proportion of the population. There are three paediatric departments in the hospital: medical floor, surgical floor, paediatric intensive care unit (PICU). In order to ensure that this study comprised the highest variety of children's cases, all three departments were included in its' scope. However, it is important to note that while there is no specialised paediatric palliative care unit in this hospital, the three abovementioned departments admit children with conditions that are suitable for palliative care (Association for Children's Palliative Care, 2009) (Table 1).

[Insert Table 1 here]

Sampling

Sampling strategy

In order to find suitable cases to build the data for the study, a purposeful sampling strategy was employed (Merriam & Tisdell, 2015). The inclusion criteria for the participants of the study were:

- Children aged between 1-12 years old.

- Admitted to the hospital's paediatric units diagnosed with a condition eligible for palliative care.
- Agree to participate in the study and their children give assent for researcher to build up the case around them and to be observed by the researcher where applicable (school age children).

As discussed in detail in the section on ethical issues, in order to eliminate any potential harm, the children were not interviewed for this study, despite being the core of each case. Instead, once an appropriate sample of children had been established, the family carers who had been with them at the point of admission were identified and invited to take part in the study in their place. In this study, the primary family carers were the children's mothers. Subsequently, the participating mothers pointed out the healthcare professionals who had been most involved in their child's case.

Access and Recruitment

In order to actually access the study participants, the initial action was to inform all of the professional gatekeepers about the study. This entailed liaising with the heads of the medical and nursing departments of both floors and placing an announcement on their bulletin boards notifying the healthcare providers about the study. Additionally, an internal memo was issued to the medical and nursing staff on both floors. Finally, leaflets giving a brief description of the study in Arabic were provided to the department heads, which were then distributed to the nurses assigned to the admission rooms in the two departments. The nurses subsequently talked about the study during the routine hospital policy identification sessions usually conducted for all new admissions.

Ethical considerations

Ethical approval for the research was obtained from the hospitals' ethics committee. The participants' informed written consent for the interviews and observations were also secured. In order to ensure that the participants understood exactly what they were consenting to, the forms were provided with an Arabic translation. For the purpose of maintaining anonymity, the names of participants were removed; instead, a number was assigned to each participant. Moreover, to safeguard the data, it was saved on the principal investigators' personal computer, and could only be accessed with a password.

The decision of whether to interview children in the study

The decision of whether or not to interview children in the current study was not straightforward. It is essential to weigh up the risks and benefits of interviewing them (Jokinen, Lappalainen, Merilainen, & Pelkonen, 2002) to protect them from any potential harm (Kennan, Fives, & Canavan, 2012). Although currently there is no consensus on including children in research, concerning their health and wellbeing (Helseth & Slettebø, 2004; Lambert & Glacken, 2011), according to the declaration of Helsinki, research involving children should be limited, with special justification related to their health (World Medical Association, 2000).

In qualitative health studies, participants are usually asked to discuss specific topics, which rarely cause substantial physical harm. However, there is still potential for emotional and psychological risk during the research process (Helseth & Slettebø, 2004; Jokinen et al., 2002; Kankkunen, Vehvilainen-Julkunen, & Pietila, 2002). In the current study, interviewing children would have had the potential to cause them significant emotional harm, as the interviews might force them to recall painful memories and events, or discuss sensitive issues concerning death and end of life issues (Helseth & Slettebø, 2004; Jokinen et al., 2002; Kankkunen et al., 2002). Moreover, the conservative culture of Jordan around care of children with palliative care needs made it imperative that you were not seen to 'interfere' or disrupt the social order by discussing with children their illness or any issues associated with it, but rather took the lead from the children's family carers. Considering all these issues, the research team decided to avoid interviewing children in the current study.

Data collection methods

Two data collection methods were employed: participant observation and semi-structured interviews with three categories of participants: mothers, physicians, and the nurses who cared for the children who are the centre of each case.

- *Participant observation*

Participant observation is usually used to triangulate the information taken in interviews (Merriam & Tisdell, 2015). It is different from the interview, as it presents a first-hand encounter with the phenomenon. This is contrary to the interview, which gives a secondary source of understanding the phenomenon (Merriam & Tisdell, 2015). In this study, participant observation was implemented to observe the communication between family carers, nurses, and physicians with each other as well as with the children within the context of the paediatric departments of the recruited hospital.

Unstructured observation was employed as this acknowledges the importance of the context in which knowledge is constructed between the researcher and the ‘researched’ (Mulhall, 2003). In the early stages of the research, MA had general ideas of what to observe (communication between the nurses, family carers, and physicians). She tried, therefore, to observe and record as many notes as she could. However, as the study progressed, the observation became more focused (Hammersley & Atkinson, 1995; Schensul & LeCompte, 2013; Spradley, 1980). The physical environment and context of the interaction was considered as well.

To identify MA role during the research, she introduced herself as a researcher who had clinical experience in paediatric settings. Moreover, she clarified that she currently had no formal nursing role and that her main role was as a researcher. This reduced the power imbalance between her and the participants. Observations were undertaken during the morning or afternoon shifts.[1] The night shift was excluded from the study in order to prevent any sleeping disturbances to the patients and their families. The preliminary observation period (around two weeks) was very helpful in terms of getting her known, building rapport, and gaining broad consent from the health care providers. Informal conversations and socialisation were helpful in this regard (Balsiger & Lambelet, 2014). In addition to the preliminary observation period, MA gained permission to attend some consultations with doctors/residents as well as observing and accompanying the assigned nurses during their work with the participants.

MA kept the focus of her observation on the cases that met the study's inclusion criteria and those who agreed to participate in the study and their context. She did not observe any other interactions related to other patients who were not included as cases in the study.

- *Observational period*

In order to achieve the saturation of the data collected for each case, MA budgeted for the observations to take enough time (i.e. not less than one week per case). Moreover, she planned to join the shift from its beginning, to help her to observe the interaction between

---

[1] The hospital morning shift runs from 7 a.m. to 3 p.m.; the afternoon shift runs from 2 p.m. to 11 p.m.

nurses and other participants during the shift handover. However, she found it difficult pragmatically to observe the same case for one complete shift, for several reasons. For example, the nurse she accompanied during the participant observation was assigned to several patients that were not included in her study.[2] Therefore, she often became busy performing procedures for them, or even receiving new admissions. She found it difficult to accompany her for the whole shift, because she needed to protect the confidentiality of the other children and their families, so instead she spent this time with the family carers of the participating children. However, it was not appropriate to stay with family carers for long periods (more than three hours) as they could become busy receiving visitors, making phone calls, going to eat, and other activities. Although they did not disclose this to MA due to cultural sensitivities that venerate the rights of the guest (which was how they regarded me), MA was aware that sometimes they wished her to leave. Therefore, she used to stay around 2-6 hours per shift, except when she worked with more than one child, when she stayed for a longer period. Further details regarding the length of participant observation for each case are shown in Table 2 (supplementary file)

- *Field notes*

Field notes are a fundamental part of observation. Taking notes is an essential part of connecting the researcher and their subjects in the writing of ethnographic reports (Wolfinger, 2002). During her fieldwork, MA recorded field notes that included verbal interactions and conversations with study participants as well as non-verbal elements of the research settings. Moreover, MA was concerned with developing a reflexive analysis of her role in the data collection and interpretation and considering that as a part of the data. With

---

[2] In this hospital, a paediatric nurse is usually assigned to 8-20 patients; the nurse-patient ratio in paediatric ICU is up to 1:4.

regard to the suitable time for taking field notes, it is better for them to be taken as soon as the observable event happens (Emerson, Fretz, & Shaw, 2011; Mulhall, 2003).

Therefore, MA took notes as they occurred in the field. However, sometimes during interactions with patients and health care providers, it was difficult for MA to take notes at the exact time of observation, so this was postponed to the earliest time that she was able to do so. These field notes were preliminary notes that MA expanded at the end of the day (Wolfinger, 2002). Analysis of the observational notes was ongoing, as this helped MA to make sure that the subsequent interviews were used to best effect, as well as giving MA helpful directions related to the next observations. Box 1 (supplementary file) gives an example of one field note written during the fieldwork. The focus of the note is usually narrowed over time (Hammersley & Atkinson, 1995; Spradley, 1980).

Data analysis

The data were analysed following the frameworks of data analysis proposed by Stake (2006). Within-case and cross-case analysis was undertaken in accordance with Stake's (2006) recommendations. The within-case analysis focused on establishing the contextual background for every case. This was significant to protect the uniqueness of each case within its context and to be consistent with the case-study approach. The within-case analysis was presented narratively for every case. Then, cross-case analysis was undertaken to systematically extract the themes and subthemes of each case to identify similarities, differences, and contradictions.

The process of systematic data analysis: step by step process

Once we had amassed all the case data, these documents and data were saved into MA computer and password protected, allowing access to the research team only. Interviews were transcripted by research assistants; this enabled us to make sure that the analysis proceeded parallel to the data collection. In order to avoid any limitation of the analysis that might result from analysing data from a language different to the participants'' own (Arabic), we analysed the data in the same language it was given in (Van Nes, Abma, Jonsson, & Deeg, 2010). The inductive approach indicates that the themes are derived from the data itself (Patton, 1990). With inductive analysis, data are not derived from the researcher's previous theoretical assumptions. In addition to the thematic analysis of every case, we presented every case individually, using the narrative approach (thick description) in order to give a sense of the detail and context of each. MA sent a few examples of case narratives for the other research team for feedback, which in turn helped us to develop subsequent case narratives (Table 3: supplementary file)

Cross-case theme analysis

Cross-case analysis includes collecting and analysing data from the within-case analysis. Cross-case analysis seeks to build assertions across all cases (Merriam & Tisdell, 2015). We initiated the cross-case analysis once we had gained separate findings in all fifteen cases using the QSR NVivo 10 software. We presented the data in a way that shows the reader the validity of our analysis. This was done by providing sufficient evidence of the themes from the data. The information was presented so that rather than merely describing the data, it was instead presented analytically, producing arguments that related to the research questions (Braun & Clarke, 2006).

Study rigour

The trustworthiness of the findings was increased through lengthy interactions with the paediatric department which facilitated MA to closely observe each case for an extended duration. This took place over nine months, totalling approximately 197 hours, as it was necessary in order to comprehensively ascertain the intricacies of communication in a paediatric environment. A peer debriefing strategy was employed to enhance the credibility of the findings (Lincoln & Guba, 1985). This involved MA sending extracts of the interview transcripts and field notes to the other research team members for them to give their input. Member checking was conducted by requesting that the participants' review their interview transcripts to ensure that the text correctly expresses their intentions (Shenton, 2004). Several methods of enhancing confirmability were utilised including: triangulation, audit trail, and fostering reflexivity throughout the research process (Lincoln & Guba, 1985; Merriam & Tisdell, 2015).

Findings

Participant characteristics

This study was comprised of 15 cases (Table 4) and therefore 15 children (Table 5). The demographic breakdown was that eleven of the children were school-aged, one child was preschool-aged, three of the children were toddlers, nine of the children were male, six of the children were female. There were a range of conditions across the children; however the most prevalent was renal disease, followed by neurological conditions, and one child with a congenital heart defect (see Table 5 for further details).

Table 6 depicts the characteristics of the participants' groups. As mentioned, the sample was comprised of 15 mothers as the family carers (n=15), however there were three other relatives that helped the mothers care for the children and participated in the joint interview with them. They were a father, maternal grandmother, and sister-in-law. Of the mothers, 12 were stay-at-home parents, two were school teachers, and one was a university student. Most of them had completed their education to primary or secondary school level, leaving to care for their children, whilst three were graduates and two had a higher diploma. Thirty three (33) healthcare providers also took part in the study, 21 of which were nurses (n=21) and 12 were physicians (n=12). With regards to the nurses, they came from a wide variety of work areas, and the group was comprised of one head nurse, two first charge nurses, 17 registered nurses, and one practical nurse. In terms of the group of physicians sampled, seven were specialists and five were residents. Additionally, 17 of the nurses held a bachelor’s degree in nursing and three held master’s degrees, while one nurse held a two-year higher education diploma.

Themes

Data analysis resulted in one major theme; which is mutual protection with three subthemes; first, protection by children, second, protection by parents and health professionals, finally, maintain professional boundaries.

Mutual protection

The study participants adopted a protective approach when they communicated with each other about their children’s care. The children protected their parents from sadness by not discussing their anxieties, and likewise, the parents sought to protect their children by only disclosing partial information to them. Furthermore, they sometimes tried to isolate their children from any environment where sensitive illness-related topics might be discussed. The nurses tried to keep within professional boundaries when they nursed children and parents in order to protect themselves from emotionally demanding situations.

- Protection by children

The majority of children tried to protect their parents from emotional suffering due to their disease. They used several techniques to do this. For example, child #15’s mother told MA that he tried to protect her from being sad, especially when she talked negatively about the progression of his condition to her relatives and friends. She said that he became sad and cried when he saw her crying and screaming when she initially found out about his diagnosis. Likewise, child #12's mother mentioned that in spite of being a very nervous child, child #12 was demonstrably affectionate towards his mother. She mentioned that one time when she was crying after being informed about the possibility of him needing dialysis, he sat in a corner and started crying as he always did when he felt that she was suffering because of him. Child # 6, child # 8, and child # 9 protected their parents, especially their mothers, by avoiding discussions about their conditions and diseases. Child #8's mother described how her daughter tried to protect her from knowing her suffering. Child # 8's mother reported that when she asked her daughter some questions about her friends with the same disease, Child # 8 refused to answer her mother, pretending that she did not know:

> *Child # 8's* mother told me that she asked her daughter (child # 8) about the progression of her friends with the same condition. Child # 8 refused to answer her mother and pretended that she did not know [I knew that from her mother, who told me that child # 8 did not like to show her awareness as she described her as a secretive person]. I realised that she was trying to protect her mother and to decrease her suffering by avoiding discussing these issues with her (Child #8, a 12 years old female child with nephrotic syndrome, Fieldnote 16).

- Protection by parents and professionals

The families played a significant role in terms of controlling how much the children knew about their conditions. The health care providers took the families' wishes into consideration when they initiated discussions with the children about their diseases. During the study, almost all of the participants agreed that their children only needed to know partial information that was appropriate to their age and their cognitive ability. Furthermore the information provided was only to be sufficient to ensure their cooperation with treatment, such as medication compliance and undergoing investigations, as well as ensuring good adaptation to symptoms in terms of life and school. Almost all participants refused to give the children any information that would give them pain about their disease:

> You know child # 13 h*as cerebral palsy* ... [3]but if the child is at an age and a health status that enables him to understand, we might inform him with as much *information as he needs to reduce pain or complications ... Because we need sometimes patient's cooperation ... whether in t*erms of medication administration, lab investigation, or the adaptation of the symptoms in life or *school ... however, we never give him any painful or hopeless information* (Doctor 1, child # 13, a 9 years old male child with cerebral palsy).

As reported by both mothers and staff, there were several reasons behind their avoidance of deep discussions with the children. The first reason was to protect them from the expected emotional suffering that might result from them being informed in comprehensive detail about their conditions. N2C4, for example, did not discuss Child # 4's future expectations in order to avoid increasing her fears:

> MA: do you think that she could get this information from other resources?

> N2C4*: yes, she might know from other resources such as friends ... TV ... the internet ... but she is still not sure that this will happen to her specifically ... it is not like when you told her honestly and ensure and support her fears ... if you*

---

[3] Pauses are presented by three dots (…).

> support her fears, she *will have a great fear and she will lose trust in herself … by doing this, you've killed her slowly … it is something like putting poison for her in* order to die slowly (Nurse 2, child # 4: , a 6 years old female child with ESRD).

Likewise, D1C6 did not involve child # 6 in discussions of sensitive information with her parents. She accepted the need for family approval to involve children in these kinds of conversations. She mentioned that she preferred not to inform children or even teenagers about end of life issues unless they asked about it themselves. From her experience, no child had ever asked for that before, and she thought that this might be related to the protective culture:

> *Now … how much children should know about their condition … it* depends on the *child himself … now some clever children know and you know that they know …* child # 6 is a good example; however, I do not make any type of confrontation to go to tell her or to talk with her about death (Doctor 1, child # 6).

> *child # 6's* mother: when one of her friends was dying, I asked the doctors and *students to hide this from her … however she knew, she knew by herself … she was coming and sitting down in the room … I was telling her "*my daughter , go *out the room go out the room" … never … she refused, I tried to prohibit her from observing this … but she was sitting on the bed … after the dying child was transferred, by around two hours, her temperature rose to 40°C … her blood* pressure was elevated as well (Child # 6 *'s mother*,: a 10 years old female child with ESRD).

The mothers of child # 6, child # 8, child # 9, child #11, and child #12 reported that they were unprepared to answer difficult questions from their children. For example, child # 9's mother mentioned that when he had general oedema in his body, he asked his parents several difficult questions:

> *He usually had fears about it ... he feels when he sees himself oedematous, he fears very very much he says "until when will I stay [like this]? When will I be* cured? Until *when will this disease be with me ... um ...Why me but not my friends?"... this means he asks questions like this*.

> *I told him "you are not alone ... there are a l*ot of children *like you ... thank God your condition is still better than others ..." What to tell him?* (Child #9's mother: a 12 years old male child with nephrotic syndrome).

The mother preferred to protect Child #9 rather than talking to him in any depth about his disease. Child # 8's mother also reported difficulties answering her daughter's difficult questions, especially when she compared herself to her sisters and peers:

> *One day she noticed that her [younger] sister is significantly taller than her ...* you feel that *child # 8's* clothes would not fit *her sister's size ... so she usually* asks me ..."mum, why is my sister *growing and gaining weight but I'm not? ... I feel that I'm like a boy" ... When I help her during bathing ... she tells me ... "mum look at my body ... why do all of my sisters have white skin but I have yellow?" ... she keeps asking and asking ... I swear sometimes I cry ... I left her ... yesterday she asked D*1C8 ... *"Doctor ... I do not feel that I become older like other girls ... this means tha*t my sister*... I feel that she is older than me although I'm older" ... D*1C8 *told her "I told you* child # 8 ... *tha*t your status is different *... your disease is systematic ... multiple things will be changed with you ... as you have kidney disease" ... she was very honest with her.*

> MA*: So ... what was child # 8's* reaction?

> *child # 8's mother: She cried excessively … then I knew* that her blood pressure *became very high … although it was not like this in D*1C8*'s clinic … when* child # 8 *feels annoyed … her face becomes red and you feel that she is very despondent … I felt that she suffered (child # 8's* mother: a 12 years old female child with nephrotic syndrome).

- Maintaining professional boundaries

One of the most important techniques the health care providers used to protect themselves from suffering was the creation of emotional boundaries. For instance, a few nurses tried to keep themselves from building close relationships with those children they felt had a high probability of dying, in order to minimise the grief and suffering that would result from their deaths.

According to some nurses, the majority of them decided to avoid friendly relationships with children after having painful experiences. N1C8, N1C10a, and N1C11 went through several stages until they became able to prevent themselves from building strong relationships with the children:

> Nurse N1C10: I had one experience where I liked one child … *I liked her too much and she connected to me emotionally … day by day I saw her wilt in front of my eyes … my psyche was extremely tired from that day … I prohibited myself* from emotionally connecting with any pat*ient … she came to me at the counter and said "good morning, how are you?"… One time she wrote me memorable words on a piece of paper … and she asked me to share gifts for memory … I protected her memorable words after her death for several years … when I* read *her memorable words … I had extreme pain … I had extreme emotional suffering*

> *… I spent several years after her death in order to forget her … now I find myself far away from any patient who I know is going to die … I cannot tolerate this suffering … there may be some people stronger than me … but I cannot tolerate … I try to keep myself far away from these issues* (Nurse 1, child # 10: a 15 months old male child with cerebral palsy).

Discussion

The findings of the current study suggest that the study participants adopted a protective approach when they communicated with each other. Children protected their parents from sadness by avoiding discussing their anxieties and concerns and likewise parents did not fully inform their children about illnesses. Sometimes they tried to isolate their children from any environment where sensitive illness-related topics might be discussed to avoid upsetting them. Physicians protected children from discussing sensitive topics regarding the progress of their diseases. Nurses learnt to maintain strict professional boundaries with children to avoid any emotional harm at the time of a child's death.

This study demonstrates some issues that have a significant effect in promoting the protective approach for children. For example, the mothers of child #8 and child #9 felt themselves to be lacking the skills to discuss such sensitive issues with their children. Additionally, the mothers of child #6, child #8, child #9, child #11, and child #12 reported that they found themselves unprepared to answer their children's difficult questions. This chimes with a study by Van Der Geest et al. (2015) that showed that parents felt a lack of confidence in their ability to convey the message that their child had a terminal illness.

In addition to lacking the skills and abilities to discuss sensitive issues with the children, the current study confirmed previous work (Dangel et al., 2000; Gaab et al., 2013; Van Der Geest et al., 2015; Zelcer, D., Cairney, & Bannister, 2010), which found that parents aimed to protect their children from the emotional suffering they might undergo if they were given comprehensive details about their conditions. This was especially so when they thought that the children were not aware of their prognosis. The majority of health care professionals agreed with those mothers, believing that as long as the children were not aware of the possible complications of their illnesses, there would be no need to expose them to the extreme emotional suffering they might experience from knowing the nature and prognosis of their diseases. For instance, D1C6 preferred not to inform children or even teenagers about end of life issues unless they asked for it themselves.

Moreover, the findings of the current study have shown that some mothers (e.g. child #6, child #8, child #9, and child #12's) mothers avoided open discussion with their children, as they perceive the children themselves did not want it. Similarly to previous work (Dangel et al., 2000; Gaab et al., 2013; Van Der Geest et al., 2015), parents and caregivers in the current study avoided discussion with their children about death, as they percive the children themselves refused to talk about it. The present study added the finding that children used several techniques to express their refusal; some of them became angry and denied having anxieties or concerns (such as child #6, child #8, and child #12's), or felt guilty, as evidenced by crying and isolation (such as child # 9 and child # 12). Although a few mothers tried to initiate such discussions, the children's reactions prevented their parents from talking about such painful topics. Van Der Geest et al. (2015) likewise affirm the children's reluctance to consider matters related to death despite using different approaches. For instance, one child in Van Der Geest et al. (2015) study clearly mentioned his/her preferences to discuss positive things in their life, while another refused to answer their parents' sensitive questions.

Moreover, this study has shown that almost all participants, including staff, supported the notion that children only need to know partial information, which is appropriate to their age and their cognitive ability. Information should also be sufficient to ensure their cooperation with treatment, such as medication compliance and the performance of investigations, as well as ensuring good adaptation to symptoms in regard to life and school. The current study adds a new insight, finding that the majority of staff agreed with parents that discussing sensitive issues with children could be harmful to them, but that it could also result in negative psychological complications. However, this is contradictory to recent qualitative studies conducted in the UK and France, which showed that health professionals think that telling children the truth was the most appropriate strategy, as it helped them to alleviate any worries (Price et al., 2013; Sastre, Sorum, & Mullet, 2012). Similarly, as alluded to by Price et al. (2013), there was disagreement between health professionals and parents.

This contradictory finding could be explained by the tendency of the majority of staff in this study to distance themselves from children during work, which resulted in less contact with children apart from routine tasks. Although the children became familiar to the staff as a result of being admitted to the same department several times during the period of their illnesses, this study shows that the interaction between children and staff was almost limited to routine tasks, or other general issues far removed from any sensitive topics related to their illnesses. It was clear that staff were very cautious about discussing such matters with the children so as to avoid conflicts with their families, especially if the child had an emotional crisis as a result of discussing such difficult topics. Reduced interaction between children and staff could greatly reduce the potential for staff to understand how the children think, what they know about their diseases, their awareness of their illness, and their worries and concerns. This could contribute to supporting the traditional view of the child as not being able to understand issues related to death. Therefore, the staff were more inclined towards agreement with the parents to encourage the protective approach for their children.

The findings of this study have several implications for clinical practice, education, and future research. First, investigating the reasoning behind parents' decisions to talk (or not) to their children about illness or death is a substantial issue. Although open and honest communication between parents and children is recommended by literature, not all mothers agree with open communication about illness with their children (especially death with those with advanced stage of disease). Therefore, any future intervention planned for them should take their autonomy and decisions into consideration. However, the role of health professionals could be essential, especially for parents who do not realise their children's level of awareness. Hence, increasing the parents' awareness of their children's protective approach and its consequences on their mental and psychological health could be one of the most important interventions to improve mutual communication between parents and children.

Second, the findings have significant implications for education. As several of the health professionals in this study underestimated the children's ability to understand death, they supported the parents' avoidance of such discussions with their children. This increased the parents' tendency to avoid initiating open discussions with their children. The findings of the current study can inform the education of health professionals about the ability of children to understand death even if they prefer not to show it to their parents.

The findings suggest further research on the following key areas would be beneficial: (1) the issue of children's awareness of death; (2) involving the fathers' experiences. The issue of children's awareness of death requires further investigation. Although the previous discussion about children's awareness of disease and end of life issues gives background information that explains the ways parents and health care providers communicate with the children, this knowledge was gained from secondary sources (mothers and HCPs). Interviewing the children themselves was beyond the scope of this study; we were unable to interview the children for several reasons, such as reducing the expected harm to them, especially if we were to discuss sensitive issues with them. We recommend research where the children are the primary resource, to collect more credible information on their awareness of death.

Moreover, the current study explored the communication phenomena from the perspectives of the mothers and health care providers. This was because of the mothers' availability as they were the ones that mainly accompanied their children in hospital. According to hospital policy, fathers are prohibited from accompanying their children in the hospital to protect the other mothers' privacy. Nevertheless, the fathers' experiences of communication with their children would triangulate the findings, and could provide other dimensions that expand on what is already known from this study. Hence, other studies that involve fathers could enrich the analysis of communication and complement the findings of this study.

This study has several strengths. Although it was conducted in one hospital, it is one of Jordan's major referral centres, and covers a wide area, even outside the capital city where it is located. Therefore, the children recruited in the study came from different geographical regions in Jordan. This improves the transferability of the findings to another setting.

While other studies addressed the experiences of parents at certain stages of their children's illness, they did not address parental insight into their children's experiences in the long run. This study recruited children who were at different stages of their illnesses, as highlighted in the methodology section. Therefore, the study participants' experiences varied according to the different stages of the children's illnesses. Moreover, this study captured the different experiences of mothers in the long run as it recruited mothers with more than one child with the same illness. This gives further depth to their experiences and how their perceptions change over time.

This study had several limitations that should be acknowledged. The period of observation varied significantly for each case study. MA spent several weeks performing data collection for some cases (e.g. child # 1, child # 5, child # 6, child # 8, child # 14, and child # 15), which enabled her to collect rich information. However, in other case studies (e.g. child # 2, child # 3, and child # 4), MA spent a relatively short period observing them (a few hours) because of the difficulty of predicting the exact time of discharge, as well as some unexpected events, such as the death of child # 3. Therefore, more attention was given to some case studies (e.g. child # 6, child # 8, and child # 15) than others, which might result in shedding more light on some issues while neglecting others.

In addition, as participation in the study was voluntary, some participants may have contributed more than others due to their greater interest in it. Of the 20 mothers who were recruited, five refused to participate, and they could have different perspectives, which were not depicted in the study.

Another limitation was that the observational data and interview data were sometimes contradictory. While the analysis stage was difficult for MA because her interpretation and observations differed from the participants' experience, the research team attempted to solve this problem by prioritising the participants themselves, as the aim of this study is to explore their experiences. However, we tried to acknowledge the contradictory findings by referring to the evidence and leaving the reader to accept whatever they think is more credible. Another problem was the differing perspectives between mothers and professionals on certain issues. Again, we acknowledge both perspectives leaving the reader to accept the interpretation they think is more comprehensive. This is congruent with the philosophical approach of interpretative constructivism we adopted for the current study, which acknowledges the presence of more than one reality based on different views and perspectives.

The participants, especially the doctors and the head nurse significantly changed some of their behaviours because they were being observed. Despite using several techniques to reduce the effect of MA presence on the findings, this influence could not be completely eliminated. However, we felt that it did not significantly affect the findings, as MA felt that the participants (especially the nurses and carers) behaved in a very natural way, particularly during the middle and end of the study, which indicates that trust had been built up with them.

Finally, the study adopted a multiple case-study approach, aiming to provide a thorough understanding of profound experiences (Merriam, 1998; Stake, 1995, 2006; Yin, 2014). Consequently, the experiences gained from this study were not generalisable beyond the group of study participants from which the information was collected. However, greater insights and understanding were derived from the multimethod approach: allows the findings to be transferred to other mothers and professionals who care for ill children in the same context

Conclusion

This study demonstrates that the parents and health care providers adopted a protective approach when they communicated with each other about the children's care. The parents avoided disclosing information to the children about the severity of their illness to protect their feelings. The health professionals maintained some professional boundaries when they cared for children to protect themselves any from emotionally demanding situations. The mothers described their children as feeling guilty and considering themselves responsible for their parents suffering. Health professionals could play a significant role in supporting parents during the process of communicating sensitive issues to their children. The findings of the current study can inform the education of health professionals who reported a lack of supporting skills for parents during difficult situations, such as when they receive difficult questions from their children.

Acknowledgments

The authors wish to express their profound gratitude to the children, mothers and staff who participated in this study who so willingly gave their time and were crucial to the data collection process. This study would not have been possible without their cooperation.

Conflict of interest

The authors have no conflicts of interests

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Table Footnotes

1	The hospital morning shift runs from 7 a.m. to 3 p.m.; the afternoon shift runs from 2 p.m. to 11 p.m.
2	Pauses are presented by three dots (…).

List of Tables:

Table 1: Conditions eligible for paediatric palliative care (ACT, 2009, p. 8).

Category 1:
Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. For example: cancer, irreversible organ failures of heart, liver, kidney;

Category 2:
Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: Cystic Fibrosis, Duchenne Muscular Dystrophy;

Category 3:
Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. examples: Batten disease, Mucopolysaccharidoses;

Category 4:
Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities e.g. following brain or spinal cord injury, complex health care needs, and a high risk of an unpredictable life-threatening event or episode”

Table 4: Participants involved in every case yielded in the study

(Child #)	**Participants**	**Child (#)**	**Participants**
Child # 1	Child # 1's mother Child # 1's grandmother D1C1 N1C1 N2C1	Child # 9	Child # 9's mother D1C9 N1C9
Child # 2	Child # 2's mother D1C2 N1C2	Child # 10	Child # 10's mother N1C10 N2C10
Child # 3	Child # 3's father Child # 3's mother D1C3 N1C3	Child # 11	Child # 11's mother D1C11 N1C11
Child # 4	Child # 4's mother D1C4 N1C4 N2C4	Child # 12	Child # 12's mother D1C12 N1C12
Child # 5	Child # 5's mother D1C5 N1C5 N2C5 N3C5	Child # 13	Child # 13's mother D1C13 N1C13
Child # 6	Child # 6's mother Child # 6's sister in-law D1C6 N1C6	Child # 14	Child # 14's mother D1C14 N1C14
Child # 7	Child 7's mother D1C7 N1C7	Child # 15	Child 15 's mother D1C15 N1C15
Child # 8	Child 7's mother D1C8 N1C8		N2C15

Table 5: Children details (the centres of each case study)

Case no.	**Child #**	**Gender**	**Age**	**Diagnosis**	**Consent taken From**
1.	Child # 1	Female	**13 Months**	**Meaningomyelocele hydrocephalus**	**Mother**
2.	Child # 2	Male	**10 yrs.**	**Nephrotic syndrome**	**Mother**
3.	Child # 3	Female	**7 yrs.**	**ESRD**	**Mother**
4.	Child # 4	Female	**6 yrs.**	**ESRD**	**Mother**
5.	Child # 5	Male	**2 yrs.**	**Hydrocephalus**	**Mother**
6.	Child # 6	Female	**10 yrs.**	**ESRD**	**Mother**
7.	Child # 7	Male	**9 yrs.**	**TOF, ICA, Seizure**	**Mother**
8.	Child # 8	Female	**12 yrs.**	**Nephrotic syndrome**	**Mother**
9.	Child # 9	Male	**12 yrs.**	**Nephrotic syndrome**	**Mother**
10.	Child # 10	Male	**15 months**	**Cerebral Palsy**	**Mother**
11.	Child # 11	Male	**10 yrs.**	**Nephrotic syndrome**	**Mother**
12.	Child # 12	Male	**11 yrs.**	**Nephrotic syndrome**	**Mother**
13.	Child # 13	Male	**9 yrs.**	**Cerebral Palsy**	**Mother**
14.	Child # 14	Female	**12 Months**	**Cerebral Palsy**	**Mother**
15.	Child # 15	Male	**3 yrs.**	**ESRD**	**Mother**

Table 6: Characteristics of study participants groups

Category of participants	Characteristics	Number
Family carers	**Age group (years)**	
	20- 30	3
	31-40	3
	More than 40	9
	Relationship to child	
	Mother	15
	Marital status	
	Married	15
	Widow	
	Divorce	
	Literacy level	
	Primary level	4
	Secondary level	5
	Diploma (2 years)	2
	University student	1
	BS.C	3
	Occupation	
	Housewife	12
	Teacher	2
	Student	1
Physicians	**Speciality**	
	Specialist	7
	Resident	5
Nurses	**Level of occupation**	
	Head nurse	1
	Charge nurse	2
	Registered Nurse	17
	Practical nurse	1
	Level of education	
	MS.C	2
	BS.C	18
	High diploma	1

References

Arabiat, D. H., ALQaissi, N. M., & Hamdan-Mansour, A. M. (2011). Children's knowledge of cancer diagnosis and treatment: Jordanian mothers' perceptions and satisfaction with the process. *International Nursing Review, 58*, 443–449.

Association for Children's Palliative Care. (2009). *A Guide to the Development of Children's Palliative Care Services* (3rd ed.). Bristol: ACT.

Balsiger, P., & Lambelet, A. (2014). Participant Observation. In D. D. Porta (Ed.), *Methodological Practices in Social Movement Research*. Oxford: Oxford Scholarship Online.

Bartel, D. A., Engler, A. J., Natale, J. E., Misra, V., Lewin, A. B., & Joseph, J. G. (2000). Working with Families of Suddenly and Critically Ill Children. *Archives of Pediatrics and Adolescent Medicine Journal, 154*, 1227- 1233.

Blazin, L. J., Cecchini, C., Habashy, C., Kaye, E. C., & Baker, J. N. (2018). Communicating Effectively in Pediatric Cancer Care: Translating Evidence into Practice. *Children (Basel), 5*(3). doi:10.3390/children5030040

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology, 3*(2), 77- 101.

Dangel, T., Fowler-Kerry, S., Karwacki, M., & Bereda, J. (2000). An evaluation of a home palliative care programme for children. *Ambulatory Child Health, 6*, 101- 114.

Emerson, R., Fretz, R., & Shaw, L. (2011). *Writing Ethnographic Fieldnotes*. Chicago: University of Chicago Press.

Epstein, E. G. (2010). Moral obligations of nurses and physicians in neonatal end-of-life care. *Nursing Ethics, 17*(5), 577- 589.

Freeman, K., O'Dell, C., & Meola, C. (2004). Childhood Brain Tumors: Parental Concerns and Stressors by Phase of Illness. *Association of Pediatric Oncology Nurses, 21*(2), 87- 97. doi:10.1177/1043454203262691

Gaab, E. M., Owens, R. G., & MacLeod, R. D. (2013). Primary Caregivers' Decisions Around Communicating About Death With Children Involved in Pediatric Palliative Care. *Journal of Hospice & Palliative Nursing, 15*(6), 322-329. doi:10.1097/NJH.0b013e318293dc20

Hammersley, M., & Atkinson, A. (1995). *Ethnography: principles and practice*. London: Routledge.

Helseth, S., & Slettebø, A. (2004). Research involving children: some ethical issues. *Nursing Ethics, 11*(3), 298-308.

Hsiao, J. L., Evan, E. E., & Zeltzer, L. K. (2007). Parent and child perspectives on physician communication in paediatric palliative care. *Palliative and Supportive Care, 5*, 355–365.

Jokinen, P., Lappalainen, M., Merilainen, P., & Pelkonen, M. (2002). Ethical issues in ethnographic nursing research with children and elderly people. *Scand J Caring Sci., 16*, 165–170.

Kankkunen, P., Vehvilainen-Julkunen, K., & Pietila, A. M. (2002). Ethical issues in paediatric nontherapeutic pain research. *Nurs Ethics, 9*, 80–91.

Kastel, A., Enskar, K., & Bjork, O. (2011). Parents' views on information in childhood cancer care. *Eur J Oncol Nurs, 15*(4), 290-295. doi:10.1016/j.ejon.2010.10.007

Kennan, D., Fives, A., & Canavan, J. (2012). Accessing a hard to reach population: reflections on research with young carers in Ireland. *Child & Family Social Work, 17*(3), 275-283. doi:10.1111/j.1365-2206.2011.00778.x

Lambert, V., & Glacken, M. (2011). Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. *Nursing Ethics, 18*(6), 781–801.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Beverly Hills: SAGE.

Lucka, L., Jacksonb, D., & Ushera, K. (2006). Case study: a bridge across the paradigms. *Nursing Inquiry, 13*(2), 103–109.

Mack, J. W., & Joffe, S. (2014). Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics, 133* (1), 24-30. doi:10.1542/peds.2013-3608E

McGrath, P., Kail-Buckley, S., & Phillips, E. (2007). Learning a New Language: Informational Issues for Parents of Children Treated for Acute Lymphoblastic Leukaemia. *Asian Journal of Cancer, 6*(4), 205-212.

Merriam, S. B. (1998). *Qualitative Research and Case Study Applications in Education*. San Francisco: Jossey- Bass.

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research :a guide to design and implementation* Retrieved from http://www.myilibrary.com?ID=812235

Mulhall, A. (2003). In the field: notes on onservation in qualitative research. *Journal of Advanced Nursing,, 41*(3), 306-313.

Nyborn, J. A., Olcese, M., Nickerson, T., & Mack, J. W. (2016). "Don't Try to Cover the Sky with Your Hands": Parents' Experiences with Prognosis Communication About Their Children with Advanced Cancer. *J Palliat Med, 19*(6), 626-631. doi:10.1089/jpm.2015.0472

Papadatou, D., & Bellali, T. (2002). Greek Nurse and Physician Grief as a Result of Caring for Children Dying of Cancer. *Pediatric Nursing, 28*(4), 345-353.

Papadatou, D., Martinson, I. M., & Chung, P. M. (2001). Caring for Dying Children: A Comparative Study of Nurses’ Experiences in Greece and Hong Kong. *Cancer Nursing, 24*(5), 402-412.

Patel, R., Coad, J., & Murray, S. (2012). Communication barriers experienced by paediatric palliative care staff when interacting with children, young people and families: a literature review. *BMJ Supportive & Palliative Care, 2*(Suppl 1), A21-A21. doi:10.1136/bmjspcare-2012-000196.62

Patton, M. (1990). *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.

Price, J., Jordan, J., & Prior, L. (2013). A Consensus for Change : Parents and Professionals Perspectives on Care for Children at the End- of- Life. *Issues in Comprehensive Pediatric Nursing, 36*(1-2), 70- 87. doi:10.3109/01460862.2013.779765

Ringner, A., Jansson, L., & Graneheim, U. H. (2011). Parental experiences of information within pediatric oncology. *J Pediatr Oncol Nurs, 28*(4), 244-251. doi:10.1177/1043454211409587

Salminen, A.-L., Harra, T., & Lautamo, T. (2006). Conducting case study research in occupational therapy. *Australian Occupational Therapy Journal, 53*(1), 3-8. doi:10.1111/j.1440-1630.2006.00540.x

Sastre, M., Sorum, P. C., & Mullet, E. (2012). Lay people’s and health professionals’ views about breaking bad news to children. *Child Care, Health and Development, 40*(1), 106-114. doi:10.1111/j.1365-2214.2012.01420.x

Schensul, J. J., & LeCompte, M. D. (2013). *Essential ethnographic methods: A mixed methods approach. Ethnographer’s toolkit, book 3* (2nd ed.). Lanham, MD: AltaMira Press.

Seth, T. (2010). Communication to Pediatric Cancer Patients and their Families: A Cultural Perspective. *Indian Journal of Palliative Care, 16*(1), 26-29. doi:10.4103/0973-1075.63131

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63–75.

Sisk, B. A., Mack, J. W., Ashworth, R., & DuBois, J. (2018). Communication in pediatric oncology: State of the field and research agenda. *Pediatr Blood Cancer, 65*(1). doi:10.1002/pbc.26727

Spradley, J. (1980). *Participant Observation*. Belmont, CA: Wadsworth Cengage Learning.

Stake, R. (1995). *The art of Case Study Research*. Thousand Oaks, CA: SAGE Publications, Inc.

Stake, R. (2006). *Multiple Case Sudy Analysis*. London: The Guildford Press.

Steele, R. G. (2006). Experiences of families in which a child has a prolonged terminal illness: modifying factors. *International Journal of Palliative Nursing, 8*(9), 418- 434.

Stenmarker, M., Hallberg, U., Palmerus, K., & Marky, I. (2010). Being a messenger of life-threatening conditions: experiences of pediatric oncologists. *Pediatr Blood Cancer, 55*(3), 478-484. doi:10.1002/pbc.22558

Van Der Geest, I. M., Heuvel Ebrink, M. M., Van Vliet, L. M., & Pluijm, S. M. (2015). Talking about Death with Children with Incurable Cancer: Perspectives from Parents. *The Journal of Pediatrics, 167*(6), 1320-1326. doi:10.1016/j.jpeds.2015.08.066

Van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing, 7*(4), 313-316. doi:10.1007/s10433-010-0168-y

Wolfinger, N. (2002). On writing fieldnotes: collection strategies and background expectancies. *Qualitative Research in Psychology, 2*(1), 85-95.

World Medical Association. (2000). Declaration of Helsinki: ethical principles for medical research involving human subjects. .   Retrieved from http://www.wma.net/en/30publications/10policies/b3/

Yin, R. (2014). *Case Study Research Design and Methods*. Thousand Oaks, California: SAGE Publication, Inc.

Zelcer, S., D., C., Cairney, A., & Bannister, S. L. (2010). Palliative Care of Children With Brain Tumor: Parental perspectives. *Archives of Pediatrics and Adolescent Medicine Journal, 164*, 225-230.