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FAMILIES IN PAEDIATRIC ONCOLOGY NURSING: CRITICAL INCIDENTS FROM THE NURSES' PERSPECTIVE

Original study

ABSTRACT

PURPOSE: Paediatric oncology nurses encounter challenges with families on a daily basis. This study explores how nurses describe significant incidents when encountering families and family members during the child's hospitalisation in the paediatric oncology unit.

DESIGN AND METHODS: A qualitative study with a phenomenological approach in which 17 paediatric oncology nurses from three different hospitals described critical incidents related to families. The participants' written descriptions were analysed using inductive content analysis.

RESULTS: The results indicate three domains where critical incidents occur: 1) Families' capability and resources, 2) parents' behaviour and 3) **emotional labour in paediatric oncology nursing.**

CONCLUSION: The results indicate that paediatric oncology nurses face situations with patients' parents that can cause them stress and uncertainty, as well as burden them emotionally. Some of the incidents dealt with difficult ethical questions. Because of the challenges that families are facing, as described in the study, nurses need to focus more on helping families identify their resources and empower themselves in order to adapt to a new situation in their lives.

IMPLICATIONS: The results provide important information not only for paediatric nursing but also for education and management. Since the quality of family nursing does not only depend on the competence of nurses or available resources, nurses should receive support from management concerning their work with families of severely sick children. In addition, educational interventions need to be developed in order to strengthen the capability of nurses to successfully respond to challenging situations with families.

Keywords: paediatric nursing, paediatric oncology nursing, family nursing, family-centred care, critical incident technique

INTRODUCTION

The relationship with the patient and their family is a primary focus of paediatric nurses' work. Such a relationship is especially poignant in oncology paediatric nursing where one or both parents stay with their severely ill child in the hospital for a long period. Taking care of families is vital, but paediatric oncology nurses face challenges and barriers when attempting to provide high-quality care (Boztepe & Yildiz, 2017; Coyne, O'Neill, Murphy, Costello, & O'Shea, 2011). Thus, it is important to study the significant incidents that are related to families from the oncology paediatric nurses' point of view.

PAEDIATRIC ONCOLOGY NURSING

Discussion regarding the nature of paediatric oncology nurses' work has dominated research in recent years (Bartholdson, af Sandeberg, Lutzen, Blomgren & Pergert, 2016; Beresford, Gibson, Bayliss & Mukherjee, 2018; Boyle & Bush, 2018; Conte, 2014). It is widely accepted that paediatric oncology nursing is a stressful profession, since it involves watching children and their families suffer, taking care of severely ill children, experiencing loss and grief, encountering moral and ethical dilemmas, and caring for dying children (Adwan, 2014). Furthermore, administering complex treatment regimens, managing a heavy workload and high patient acuity have been reported as sources of stress in paediatric nursing. Continuously meeting suffering family members is especially perceived as being both professionally and personally demanding (Altounji, Morgan, Grover, Daldumyan & Secola 2013; Chang, Kicis & Sangha 2007; Meyer, Li, Klaristenfeld, Gold & Jeffrey, 2015). For example, Chang et al. (2007) reported that haematology oncology nurses experience numerous physical and emotional stressors in addition to expressing concerns regarding possible burnout. According to Pyo (2013), paediatric oncology nurses have been documented as experiencing moral distress, which includes feelings of powerlessness, helplessness, frustration and anger. Furthermore, paediatric oncology has become a highly specialised area, and the transition from novice nurse to expert can be complicated (Enskär, 2012).

Prior research generally confirms that families and family members in paediatric oncology nursing can be a source of reward as well as stress for nurses. Citak, Toruner and Gunes (2013) learned that paediatric oncology nurses experience communication difficulties with children and their families during long hospital stays. They posit that communication difficulties increase during crisis periods, such as the time of first diagnosis, relapse and the terminal stage, or on days with special meaning, such as holidays. Nurses experience that communication difficulties lead to feelings of incompetence, exhaustion or difficulties in coping (Citak et al, 2013). Feelings of reward have also been reported: Enzman and Gaughan (2014) indicated that when a paediatric nurse coaches parents and family as a

caregiver, the caring is reflected in the relationship, which can be particularly rewarding to nurses. In addition to stress, paediatric nurses have been stated to experience satisfaction and commitment to their work. Wyatt and Harrison (2010) conducted a survey of paediatric nurses which examined factors affecting satisfaction. Almost 90% of paediatric nurses were satisfied with their job, with their responses ranging from excellent to good. A sense of autonomy at work appears to be one of the largest sources of influence on paediatric nurses' job satisfaction (Roberts-Turner, Hinds, Nelson, Pryor, Robinson & Wang, 2014).

Since nurses provide 24-hour care and are usually the first point of contact for families and patients in paediatric oncology nursing units, their perceptions and experiences of family nursing are essential to the study. However, little research has been conducted on the topic from the paediatric oncology nurses' perspective. In order to reveal significant incidents, this study will use a critical incident technique (hereinafter CIT) to capture the voices of paediatric oncology nurses in identifying significant situations when encountering family members of a severely ill child.

PRESENT STUDY

The data were collected in the advanced nursing training of paediatric nurses (n=17) in autumn 2017. Paediatric oncology nurses from three Finnish university hospitals participated in the two-year training (2016–2018) that was arranged to be completed while maintaining an employment relationship. The aim of the training was to reinforce the participants' clinical skills and family counselling and nursing competence. During the training, the participants kept a learning diary where they reflected the content of the training and their own skills. As a part of the learning diary assignment, participants (n=17) were asked to write about a personally significant situation or event that involved one or more members of a child's family. The situation or event in question must have occurred at a paediatric oncology ward at some point of the nurse's career. The given assignment was based on a critical incident technique, which can be defined as a retrospective story generating behaviour, and it is critical if there is a major activity that is sufficient in allowing conclusions and predictions made by the person themselves. CIT, which focuses on real situations influenced by both intellectual and emotional causes, has become an appropriate qualitative method that is suitable for healthcare research (FitzGerald, Seale, Kerins & McElvaney, 2008; Friland, Henricson & Martenson 2017). The technique helps understand and identify the demanding and rewarding nature of looking after the families of children with cancer from the nurse's perspective in a new way.

METHOD

Objective

This paper explores how nurses describe significant incidents when encountering families and family members during a child's hospitalisation in the paediatric oncology unit. The objective was to provide valuable information of the versatile phenomenon of family nursing from the nurses' perspective in order to develop nursing interventions and create educational material for the field of paediatric oncology nursing based on the findings. Furthermore, the study results will benefit nurse managers in the planning and implementation of family nursing interventions by providing a better understanding of the experiences of nurses regarding family members of severely ill children. Our literature review showed that there were no prior studies of significant situations in family nursing from the paediatric oncology nurses' point of view, with or without CIT.

Research design

We applied a qualitative study with a phenomenological approach which describes the common meaning for nurse participants regarding their lived experiences of a phenomenon of family nursing in the paediatric oncology unit. Hence, the focus is on describing what all participants have in common, as they experience taking care of families during a child's hospitalisation. The selected approach was consistent with Creswell and Poth's (2018) statement that the purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence.

Participants

A convenience sample of 17 paediatric oncology nurses was used from three different university hospitals in Finland. All of the respondents participated in advanced nursing studies conducted in 2016–2018. The participants' median age was 39 (range 29-49), and all were female. All of them had a bachelor's degree and they provided direct care to children with cancer. The average experience as a paediatric oncology nurse was 12 years (median 11, range 6-22).

Critical incident technique: study data

Data were based on the CIT in which participants wrote about an incident that has been significant to them and in which the child's family or family members have been involved. CIT is a suitable data collection method for the phenomenological approach because it is significantly participant-driven, meaning that the data collection takes place based on the participant's perspective. Notably, when we used written text as data, the participants had time and enough privacy to meticulously reflect

upon the critical incident from their point of view.

Chipeta, Bradley, Chimwaza-Manda and McAuliffe (2016) describe a series of probing questions that can be used to invite respondents to describe the critical incident. In this study, the oncology paediatric nurses were asked to reply to the following questions, which were consistent with the questions of Chipeta et al. (2016): Describe an incident or a situation from your work as a paediatric oncology nurse that involves the child's family and possibly other health care professionals. Reflect upon the incident; what is it that made it critical from your point of view? Describe also what happened, where and when. Consider all the positive, negative and interesting points about the incident. In addition, recount how the incident had made you feel, and what are your thoughts now. What has changed or developed your thinking? What have you learned in practice from this? Participants were given ten weeks to reflect upon and complete the description of the incident.

Data analysis

The data consisted of 65 typed, double-spaced pages of the participants' descriptions of significant incidents. Each participant described one incident. Data were analysed using the inductive content analysis method that is appropriate when examining the multifaceted and sensitive phenomena of nursing (Chresswell & Poth, 2018). In the first stage, one researcher read the transcription several times in order to obtain a sense of the whole content. In the second stage, 729 initial expressions were generated from the data. Next, these expressions were examined, and 156 codes were formed. At this point, the codes were analysed, and 16 preliminary categories were formed. In the final stage, the categories were carefully examined by both authors, and coherent and meaningful patterns were described. We used quotations to confirm the content of categories that emerged from the data.

Data analysis was followed by a systematic procedure that moved from the original expressions to broader units of analysis. Our main aim was to describe what the participants have experienced and how they have experienced it. Creswell and Poth (2018) emphasise that these questions are the culminating aspects of a phenomenological analysis and the essence of experience for individuals.

ETHICAL CONSIDERATIONS

Participants were told to include only necessary information about the incident and were particularly advised not to disclose any personal information about the people involved. As the collected data included information concerning the families and nurses involved, the original data was read only by one of the researchers. The second writer became involved in the third phase of the analysis after

the preliminary categories had been formed. This was a deliberate decision as we wanted to ensure the anonymity of the study subjects and families as well as possible. The descriptions of critical incidents are stored in a closed learning environment and the data are to be erased once the study is completed. In the authentic quotes provided in the results section, “mother” and “father” have been replaced with “parent” or “parents”. This was done to ensure that the families could not be identified. Permission for conducting the study was granted from each hospital. All participants provided their written informed consent for the use of their learning diary as research data.

FINDINGS

PARENTS’ CAPABILITIES AND RESOURCES DURING THEIR CHILD’S HOSPITAL TREATMENT PERIOD

The child’s development and behaviour

According to the respondents, parents do not always have the capability or resources to support the child’s growth and development. Some of the children are under-developed already at the time of their diagnosis. According to the respondents, such cases generally indicate that the parents do not have the sufficient capability to look after the development of their child. For instance, the child’s personal hygiene might not be sufficiently well maintained before the diagnosis. The respondents describe situations where the teeth of a pre-schooler were not brushed or the child was still wearing diapers, even though they could have already been trained to use a potty. The situation might escalate during treatment, because particularly careful attention needs to be paid to the regular brushing of a child’s teeth during chemotherapy. According to the respondents, the skin of pre-schoolers is already sensitive because of the treatment methods and increasingly irritated due to the use of diapers, highlighting the importance of learning to use a potty.

According to the respondents, some of the parents do not have the capability or resources to support their child’s cognitive or psychological development during the hospital treatment period. For instance, some parents did not engage in playing with their children in the hospital, but instead let them play video games for the entire time. One respondent describes how *“the saddest thing was that the child did not know how to play with toys at all.”* (T16) Respondents pondered the extent of their job description and responsibility regarding the child’s development. They also wondered how to become involved in the matter. *“There has been a lot of discussion between the nursing staff regarding what is acceptable and what is not, and in which cases we should become involved. Are we there only to treat the cancer or should we also provide additional treatment to maintain the child’s development on level with the average in their age group as well as possible?”* (T1) However,

parenthood and the child's development are supported in many ways during inpatient care: *"We try to train children to use a potty in the hospital and encourage parents to keep up the training at home as well."* (T1)

Some children present behavioural challenges and problems during the hospital treatment. The respondents feel that it is difficult to become involved in the child's inappropriate behaviour without support from the parents. The child might express uninhibited behaviour and bite, kick or hit a nurse. In such cases, parents lack the capability to control their child's behaviour. One respondent ponders how *"sometimes it feels like being a nurse is also like being an educator of the parents."* (T7) Another respondent describes the feelings arising from such a situation and the related approach:

"I remember the feeling of irritation I had when the parent began to play along according to the child's rules. The child started making rules on how to act in the situation and the parent allowed this instead of setting limits for the child. Such situations where a child begins to boss their parents around and attempts to give orders to the nurse are not uncommon. As a nurse, I never give in to the child's demands, especially not if they are related to procedures that simply must be performed." (T9)

According to the respondents, some parents do not understand how important it is that the child is sufficiently co-operative during the treatment period. Respondents describe that, in spite of several counselling meetings, some parents never understand that the timely administration of medication or measuring the child's body temperature or blood pressure are essential parts of the child's treatment. One respondent ponders the parenthood they have faced in their work: *"It seems that more and more parents do not know how to be a parent. In my work, I meet an increasing number of parents who do not set clear limits for their children."* (T7) However, respondents often talk about parenthood and the significance of setting and maintaining limits with the parents. *"I talk often about parenthood with the parents and say that, in spite of their condition, it is important to maintain the limits set for the child. The limits help the child feel more secure with their condition."* (T7)

Child's loneliness

Some parents spend only a little time with their child in the hospital. The parents or only one of them might arrive late in the evening and leave early. According to the respondents, some parents might not necessarily inform the nurses about when they will come and visit their child again. *"The sole parent of a child has taken a lot of free time when the child has been admitted by leaving the hospital*

early or arriving late in the evening. The child keeps asking about their parent and it is heart-braking to keep telling them that their parent is sure to come.” (T13)

The respondents say that they talk with the parents about how important and significant it is for the child that the parents are present. They encourage the parents to spend time and play with their child, for instance. Nevertheless, some children have to spend time alone during their hospital treatment period. In such cases, a nurse is assigned for each child in every work shift to look after them while their parents are away. *“Neither of the parents is very capable of coping with adversity and the support network of the family in terms of relatives is non-existent. The child had to spend a lot of time alone in the hospital.” (T5)* The respondents feel sad for the children and incapable of doing anything to change the situation. According to the respondents, in spite of the constant support and guidance, some parents do not spend enough time with their child in the hospital.

Focusing on the child’s treatment

Some parents are fully focused on the treatment of the child and reviewing available treatment alternatives. In such cases, parents are unable to pay attention to or support the child’s normal growth and development during the treatment. One respondent describes such a situation: *“The parents are easily preoccupied by matters related to the treatment and distracted from the fact that the child’s healthy functions require development and practice. One child was able to practice their motor skills only by playing with a nurse on the floor.” (T12)* For example, the parents might process or ponder various matters related to the treatment for weeks, such as providing the child with formula milk or organic nutrition, the use of diapers or the type of skin lotion to be used. The respondents feel that, in such cases, achieving a level of understanding with the parents is particularly demanding and time-consuming. In addition, the siblings of a sick child might not receive the attention they need from their parents as their time and energy are spent on the sick child’s treatment and the choices and decisions related to it. *“The sick child seems to take all of the parents’ attention ... we’ve highlighted the importance of not separating siblings from each other to the parents.” (T12)*

Parent’s need to protect their dying child

When a decision about providing a child or young person with palliative care is made, parents might forbid telling the child about their imminent death. Some parents forbid telling their child that they will not recover, as one respondent describes: *“The disease has continued to spread and we should now talk about arranging suitable conditions and treatment for the rest of the child’s life. The problem is that the parents forbid telling their child about the circumstances.” (T4)* The parents’

decision makes things especially difficult for nurses when the developmental stage of the child or young person favours that they are truthfully informed about the situation. Nurses respect and observe the parents' decision to not tell the child about their actual condition. On the other hand, because of such a decision, respondents say that they have to be constantly cautious about the topics and manner of discussions held with the parents and the sick child. According to one respondent *"there are parents who will not tell the truth even when their child asks directly if they are going to die."* (T15) Complying with the parents' decision can easily cause tensions between the parents and the staff. There are discussions with the parents about why the child should be made aware of the real circumstances and how this can make communication between the family members easier. Respondents wonder why parents will not let their children know the truth and who they think they are protecting by hiding these facts. *"The matter has been discussed numerous times with the parents, but they are not willing to change their view. On the other hand, the staff cannot overrule the parents' decision. Sometimes, we just have to accept this fact even if we do not think that it is for the best of the child."* (T4)

PARENT'S BEHAVIOUR DURING THEIR CHILD'S HOSPITAL TREATMENT PERIOD

Inappropriate or threatening behaviour

Some parents express inappropriate behaviour towards the nursing staff during their child's hospital treatment period. This behaviour is manifested in various situations involving interaction and communication between the parents and the staff. Respondents describe how parents can make inappropriate remarks to the nurses or constantly monitor the nurse's actions when their child is being treated, for example. One respondent presents an example: *"The parent was rude, particularly towards new and inexperienced nurses. They were doubtful of all treatment procedures and treated and spoke to the nurses very impolitely."* (T3)

Generally speaking, the parents' inappropriate behaviour during the initial phase of their child's sickness is assumed to be naturally caused by the shock of discovering the child's condition. According to the respondents, this is why such behaviour is tolerated and considered normal processing of the child's severe disease on the parents' behalf. However, some parents might express inappropriate behaviour towards nurses for an extended period of time. There are discussions between colleagues about why the parent is behaving in such a way. According to the respondents, parents are actively offered support during their child's hospital treatment. For example, they have the opportunity to review their feelings arising from the child's disease with a psychologist or a priest. Some parents do not want to discuss the situation with anyone outside their family.

If the parent's inappropriate behaviour is not addressed sufficiently quickly, the nursing staff can become tired of the situation and be nervous about or even avoid meeting the parent. Respondents describe how the staff attempts to ensure that the parents are provided with the best possible support through the organisation of their work. For example, their work is arranged so that a single nurse does not treat a specific child for several successive shifts. In addition, the child may have several personal nurses or the child can be treated only by experienced nurses. However, this has proven to be difficult in the respondents' opinion. If a child is treated by several nurses, no one gets to know the family or their habits sufficiently well. *"None of the nurses got close enough with the parent to find out what caused their distrust towards nurses."* (T3)

The child's parent or parents can also behave threateningly towards the staff during the child's hospital treatment. Respondents think that, in general, threatening behaviour is manifested especially when the relationship between the parents is conflicting in itself, the treatment the child has received is not sufficiently effective or when the child is admitted into palliative care. The parent's behaviour can be aggressive, hostile or uninhibited. According to the respondents' experiences, parents behaving threateningly are generally not willing to accept help. Nurses can sense the tense atmosphere while treating the child. One respondent describes such a situation: *"The relationship between the child's parents was very confrontational and one of the parents occasionally behaved in a threatening manner towards the nursing staff as well. I have not encountered physical violence in these situations, but the risk of violence has been present throughout the child's treatment period."* (T10) The atmosphere can be fearsome and nurses have to be prepared for different kinds of situations. Some nurses ask a colleague to accompany them, while others say that they always keep their backs towards the door and carry an alarm device when entering an area with a threateningly behaving parent.

"The most demanding situations arise when both parents are present and conflicts must be resolved. You can never be certain what to expect when entering such a room." (T11)

According to the respondents, their work communities analyse the reasons behind the threatening behaviour and what kind of situations can trigger this behaviour. The respondents felt that it is particularly difficult to try to be cautious about the manner of communication with the parents. Nurses can also easily become nervous about the treatment of the child and the time spent with the parents in the room is kept at a minimum. The possibility of threatening situations takes a lot of the nurses' energy. *"One situation was difficult as I was not familiar with the parent's behaviour and*

predicting their reactions was challenging. I saw myself considering very carefully what to say to the parent and how to word it.” (T10)

Sudden and unforeseen changes in the parent’s behaviour

The parent’s behaviour can change radically in different stages of the child’s sickness. Once the child’s active treatment has been stopped and the palliative care initiated, there is a phase where some parents can express sudden and unforeseen changes in their behaviour. For example, a parent can stop communicating about the child’s condition and treatment with nurses and keep to themselves while the nurses treat the child. *“When the family was told that there was no cure for their child’s disease, their reaction to the stressful news was very powerful. The formerly open, friendly and really talkative parent became silent and sometimes even expressed somewhat inappropriate behaviour towards the nurses.” (T15)*

The behaviour of some parents remains changed until the death of their child, while the behaviour of others returns to normal after some time. Respondents say that, in addition to the decision to perform palliative care, the death of the child is also a situation where the parent’s behaviour can change suddenly. According to the respondents, the parent might attack the nurses verbally, scream, curse or lose control over the situation altogether. *“Nevertheless, it is impossible to predict human behaviour completely accurately, and the anxiety caused by a child’s sickness or palliative care can bring out certain characteristics of otherwise pleasant people.” (T10)*

EMOTIONAL LABOUR IN PAEDIATRIC ONCOLOGY NURSING

Supporting the parents and maintaining their trust

The respondents reflect on whether they have been able to provide the parents with sufficient support in situations where they have been preoccupied with treating and monitoring the child. One respondent describes a situation where they had to focus completely on the treatment of the sick child because of their lack of experience. *“The parent of the child required the support of a more experienced nurse. I was able to concentrate only on the treatment of the child.” (T11)* The respondents feel that they need to be considerably more capable of supporting the parents in these kinds of situations. The respondents also feel that they have not been able to provide parents with the support, care and time they feel the parents require because of too busy work shifts. One respondent describes their work shift: *“A child who was administered palliative care had their parents present and we had agreed that they could spend time with each other and I would check up*

on them every once in a while. However, despite my promise, I did not have the time to visit them even once during the night on my own initiative.” (T6)

The fear of losing the parents’ trust was highlighted in the respondents’ descriptions. A work error in evaluating various samples of the child, for example, may give rise to fear of losing trust. One respondent describes that while administering a medicine, they made a mistake that did not endanger the child and was appropriately reported and of which the parents were immediately informed. The respondent describes that they began to fear that the parents do not trust them anymore. In addition, they describe why it was important to review the situation with the parents.

Nurses’ emotional challenges

Facing the parents can evoke different feelings in the respondents from time to time, as one respondent says: *“I have felt bad about a situation, and the worst thing was probably the feeling of inadequacy and that I could not provide the time that was required at that point.” (T6)* The respondents say that it is essential to review the emotions and feelings related to working with parents regularly in the work community. One respondent assesses the matter:

“We are not machines whose work is unaffected by their well-being, and our own emotions cannot be completely ignored. However, it is important to maintain an honest treatment relationship and to discuss even the most difficult matters with the family. Mutual understanding helps build and maintain trust during the treatment. You should not fret over difficult situations by yourself, because when such situations begin to accumulate, it becomes impossible to perform your job as a nurse.” (T9)

However, in addition to various emotions, the coping of parents can also sometimes cause concern in the nursing staff. *“We were really concerned of a parent as their child spent long periods of time, up to several weeks, in the hospital. The parent also looked ill, pale and like they had lost a lot of weight.” (T17)* In addition, the respondents reflected on their own professional growth and how the work performed with the families teaches various ways of approaching the families, as one respondent says: *“This experience evoked irritation, anger, frustration, sadness and a wide range of other negative emotions. However, I believe that it helped me develop as a nurse and improved my appreciation towards my work and colleagues.” (T6)* On the other hand, the respondents also describe how they felt successful in maintaining their own emotions while working with the parents. *“In the end, I felt it was good that I managed to control myself and behave appropriately in spite of my irritation and that I could rationally explain to the parent why things had to be done quickly and*

why neglecting the schedules would not be ideal.” (T2) Some families remain in the respondents’ thoughts, and working with them is reflected on even after long periods of time: “I had a lot of thoughts about the family both at that time as well as long after it.” (T14)

STUDY LIMITATIONS

The study was conducted in three paediatric oncology units in Finland with a small number of critical incident cases, which limits the generalisability of the data. On the other hand, using written descriptions instead of interviews or observations gave nurse respondents the opportunity to openly express and evaluate the experiences that they have had with families during the child’s hospitalisation. Furthermore, participants had a quite long period, ten weeks, to reflect upon the critical incident. This may have had a positive impact on their engagement in the description. Our examination of the written data revealed detailed and rich descriptions with valuable and important aspects of family nursing in respondents’ everyday practice.

DISCUSSION

In this study, the parents’ capability and resources to support the growth and development of children with cancer vary a lot, and some parents are almost completely incapable of supporting the normal development of the child during long treatment periods. As earlier studies indicate, a child’s cancer diagnosis consumes the family’s resources and changes the family’s dynamics (Hopia, Paavilainen & Åstedt-Kurki, 2005; Kazak & Noll, 2015; Nam et al., 2016). This is exactly why nursing needs to be comprehensive and nurses have to support the sick child’s growth and development along with other professionals, for example. Whenever a family’s situation seems worrying, it is important to address the issues at hand courageously.

According to the results, child’s behaviour in hospital can be uninhibited and parents might not necessarily intervene with the child’s negative actions. Some parents do not spend enough time with their child in the hospital and, according to the respondents, these children feel lonely. On the other hand, some parents are so strongly focused on the child’s treatment that supporting the development of the sick child and paying attention to other family members, such as siblings, is neglected. Nevertheless, the child’s problematic behaviour during hospital treatment must be addressed. A study by McCarthy (2016) indicates that parents notice their children to have a lot of behavioural, sleeping and eating problems after their cancer diagnoses. It is recommended that the nursing staff should guide the parents to apply various strategies of parenthood, as, according to McCarthy (2016), those might have a long-term positive effect on the well-being of the child and the entire family. **In line with our findings, the study of McCarthy (2016) shows** that nurses tend to

worry about parents who were so preoccupied with the sick child's treatment that they did not pay enough attention to other children in their family. The nursing staff should improve their efforts in helping parents understand why their other children are also vulnerable in the situation and require their parents' support. Earlier studies indicate similar results (e.g., Gerhardt, Lehman, Long & Alderfer 2015; Prahal & Landolt, 2012).

According to the results, some children feel lonely because the parents are not sufficiently present during their hospital treatment. This is a serious matter that needs to be addressed actively. However, parents must not be made to feel guilty. The focus should be on resolving the matter. A child's serious sickness can paralyse the entire family, making them unable to act in the best interest of the child. In such cases, what little resources the family might have may be depleted, and arranging crisis support for the family might be necessary.

Respondents of this study described how some parents have a strong need to protect their dying child by refusing to tell them the truth about the situation. This puts nurses in challenging positions in terms of communication with the child and his/her family. This is consistent with Pearson's (2013) study where oncology nurses revealed that communication was the hardest skill to master when providing palliative care to children and their families. Nurses acknowledged that they felt inept in knowing what to say, how to say it, and determining what the family needed in terms of psychosocial support. This is in line with our findings where nurses say that supporting the parents and maintaining their trust towards the staff is vitally important during the child's hospitalization but, at the same time, nurses felt emotional burden and stress when working with families in challenging situations. Curco (2017) states that caring for dying paediatric patients involves not only the dying child, but the family and other healthcare providers. When nurses are facing demanding situations during child's dying process, strategies for minimizing conflict in situations of disagreement between children and families are needed to be identified and developed. Actually, researchers (Kline and Thom, 2011; Mullen, Reynold & Larson, 2015) strongly recommend to create effective strategies to minimize distress and relieve the burden of cancer on paediatric oncology nurses. For example, Snaman, Torres, Duffy, Levine, Deborah, Gibson and Baker (2016) have developed a tool for communication between families and nursing staff that can be used when discussing the possibility of providing the sick child with palliative care. Tools and strategies may enable nurses to confidently communicate with child's family during the process of dying and after their child's death, while providing a profound and meaningful experience for the family.

A parent might express inappropriate or threatening behaviour towards nurses. According to the respondents, such situations can cause anxiety, nervousness and feelings of insecurity. The parents' behaviour may change quickly and suddenly, and these changes seem to follow changes in the child's condition. Our results share similarities with those of Coats et al. (2018), in which paediatric nurses reported that they were worried about their own safety when they were alone with family members who were upset, hostile or behaving inappropriately. Since nurses were alone, they felt they had no choice but to stay in the room and handle whatever came their way, even if they felt threatened. If a parent continues to behave threateningly or inappropriately towards the nursing staff, it is vitally important to address their behaviour quickly. First, it is important to think about what might be causing the behaviour and what might have triggered it. Secondly, parents must be instructed more actively than before about the process in the hospital, the parents' and professionals' role in supporting the child's well-being and how parents can participate in the treatment of their child. It is also essential that nurses support each other and act in a coherent manner when a parent behaves inappropriately or threateningly. In addition, professionals should agree on common operating methods in such situations, because these would likely help the professionals cope better and decrease the parents' threatening behaviour towards the staff. In their study, Zander and Hutton (2009) confirm this: the organisation and the work community have a significant effect on how a paediatric oncology nurse processes the stress caused by their job and what resources to manage demanding situations are available to them.

Although the inappropriate or threatening behaviour of parents is quite rare during the child's hospital treatment period, it nevertheless increases the nurses' load of emotional stress if these situations are not addressed quickly enough. Such experiences can also affect professional self-esteem. According to Taubman-Ben-Arian and Wintroub (2008), good professional self-esteem is the most valuable resource for paediatric nurses and physicians when facing difficult situations. In addition to intervention, it is also important to train and educate the staff in how to act in threatening situations, how to prevent them from happening and how to process them afterwards. The importance of constant training for paediatric oncology nurses is also highlighted by Zander and Hutton (2009). In addition, assigning a specific nurse for the family and providing new nurses with good orientation training and work instructions are important factors in maintaining work capacity. These can also help nurses to offer sufficient support to the families during the child's hospital treatment period. According to Sacco, Ciurzynski and Harvey (2015), particular attention must be paid to young and inexperienced paediatric nurses, because their risk of experiencing compassion fatigue is more significant than that of older and more experienced nurses.

As nurses work with parents all the time during the child's hospital treatment, they have to face several kinds of challenges concerning the family in their work, as indicated by the results of this study. Some of the problems are related to practical processes and can most likely be solved by an intervention by a supervisor or a multidisciplinary team, agreeing upon common operating methods in the unit or supporting the nurses' occupational well-being by arranging equal work loads and strengthening their autonomy, for example (cf. Roberts-Turner et al, 2014). However, the fact remains that some problems are ethical in nature and cannot perhaps be solved at all. How to act when a child is lonely in the hospital and, despite guidance and instructions, the parents do not spend enough time with their child? How can you help a threatening parent whose child has just been admitted to palliative care? How can you help parents identify their resources if they have only little of it? Or what to answer to a 12-year-old asking if they are going to die and the parents have prohibited telling the child about their imminent death? Paediatric oncology nursing involves these kinds of ethical-related situations that cannot always be resolved by simply increasing support or guidance or focusing on multidisciplinary work (Bartholdson et al., 2014). Nevertheless, although nurses are the ones who spend the most time with the parents, supporting the families is not only the nurses' responsibility. Making it clear what one's basic duties are and using the expertise of the multidisciplinary team are particularly important when facing ethical problems in family counselling and nursing. However, Bartholdson et al. (2014) emphasise that particularly nursing staff have described experiencing a lack of interprofessional collaboration and having no forum for reflection in terms of paediatric oncology nursing and its ethical challenges. Both these things were sources of frustration, as they were a hindrance to the ability to share experiences among health professionals. In addition, researchers (e.g. Johnson, Church, Metzger & Baker, 2015; Boyle & Bush, 2018) suggest that professionals who work in paediatric nursing should have the opportunity to regularly access ethical consultation.

It is clear that nurses cannot and should not be required to solve the families' problems on their own. However, their role should change to reflect the coaching nature of the work more clearly, where parents are aided in finding their own resources and participating actively in the treatment of their child. (Heino-Tolonen, 2017; Landier et al., 2016; Pearson, 2013). According to the results of this study, this is how nurses perceive themselves to be already working, at least to a certain degree. They consider extending the treatment relationship to the entire family to be important and discuss matters that affect the child's well-being with the parents. They are proactive in offering support and guidance to parents with limited resources. The results are in line with earlier studies (Boyle & Bush,

2018; Nadeau, Pinner, Murphy & Belderson, 2017). Nadeau et al. (2017), for example, found out that patients, families and nurses value care continuity and meaningful nurse–patient relationships in a paediatric oncology inpatient unit. After all, these are fundamentals in primary nursing.

IMPLICATIONS FOR PAEDIATRIC NURSING

Efficient family counselling and nursing methods based on evidence must be studied, evaluated and deployed actively in order to help families in vulnerable positions and, in particular, their children (Robertson, 2013). Boyle and Bush (2018) use the concept “difficult family scenario” when referring to high-risk families in paediatric cancer nursing who need more than the basic provision of emotional support provided by nurses. For example, parents with pre-existing mental health problems or those with poor parenting skills pose unique needs that require specialised support during the child’s hospitalisation (Boyle & Bush, 2018). The descriptions provided by paediatric oncology nurses about critical circumstances included exactly these kinds of families. It is worth considering what the decision-making process in nursing is based on and why we act or fail to act in a certain way when working with families who are clearly experiencing a difficult family scenario (cf. Robertson, 2013). The need for support varies not only between families but also within a family over time. Thus, it is essential to identify those families who can benefit the most from nursing and the work performed by a multidisciplinary team. Not all families necessarily require all the support available. Some can cope well with their own resources. If nurses have the opportunity to access ethical consultation with regard to challenging families, it might strengthen the paediatric oncology nurses’ resilience. According to Boyle and Bush (2018), resilience in nursing practice has not been sufficiently studied; hence, strengthening it should be more actively studied. Boyle and Bush (2018) argue that resilience has the potential to become an important element of the paediatric oncology nurses’ stress reducing toolkit.

We encourage nursing managers to find ways to support paediatric oncology nurses in providing high-quality care and being advocates for children and their parents. The results in this research prove that family nursing should be one of the core subjects in paediatric nursing education because challenging situations with families will probably increase in the future. Consequently, more nurses will encounter these situations in their daily work.

The nurses described their experiences of working with families elaborately. The CIT proved to be a successful method of collecting material concerning this kind of phenomenon. As McAteer, Hallett,

Murtagh and Turnbull (2010, p.107) suggest, a 'critical incident is one that challenges your own assumptions or makes you think differently.' This is exactly what happened. Several respondents included a statement at the end of their descriptions of a meaningful event that writing about the situation helped them process it and opened up new perspectives regarding the situations with families.

FUTURE RESEARCH

Finally, there are numerous opportunities for future research based on the findings here. First, the critical incident technique could be used to study nurses' experiences of how they have solved problems, issues and challenges regarding families in paediatric nursing. Second, it would be important to explore the experiences of oncology paediatric nurses and families regarding the same incident by using the critical incident interview. In addition, more research is needed from the interdisciplinary team's perspective in taking care of families in paediatric oncology units.

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