



# Parents' perceptions of how nurses care for children as relatives of an ill patient- Experiences from an oncological outpatient department



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## ABSTRACT

**Purpose:** Research has shown that a child's knowledge about what is happening to a parent when he/she has a cancer disease is crucial to the child's health and wellbeing. Therefore the purpose of this study was to explore parents' perceptions of how nurses in clinical practice care for children as relatives when one parent in the family has a cancer disease.

**Method:** A qualitative explorative design with interviews was used. Altogether 28 parents (17 patients and 11 partners) were interviewed. The transcripts from the interviews were subjected to qualitative content analysis.

**Results:** The parents perceive that the nurses make efforts to support the child as well as them as parents, but feel that the care needs to be more tailored to the specific child and his/her situation. The children are initially invited, generally informed and seen by the nurses, but the parents perceive that they themselves need repeated support and advice over time to uphold their parental responsibility for caring for their children during the illness trajectory.

**Conclusion:** The parents argue for the importance of receiving repeated advice and support for how to talk to their children about the disease and treatment. The parents describe how the nurses were helpful by asking after the children and explaining the value of their visiting the hospital.

## 1. Introduction

Research has shown that a child's knowledge about what is happening to a parent when he/she has a cancer disease is crucial to the child's health and wellbeing (Davey et al., 2013; Turner, 2004). To feel secure and safe, children ask for information and knowledge to be able to handle the new situation of illness in the family (Davey et al., 2011; Finch and Gibson, 2009; Maynard et al., 2013). Parents describe a contradiction when trying to protect their child, but also take into account the child's need for information about the parent's situation (Asbury et al., 2014; Billhult and Segesten, 2003; Helseth and Ulfset, 2005). Additionally, the situation of being worried about their children affecting their own wellbeing is reported by mothers (Stinesen-Kollberg et al., 2013). Parents describe a lack of knowledge and ability for communicating with their children about their cancer disease (Semple and McCaughan, 2013). To handle the situation, support and guidance from professionals are desired (Semple and McCance, 2010); and several studies highlight the significant role of professionals in facilitating early interventions for families in which a parent has received a cancer diagnosis (Fearnley, 2012; Turner, 2004). However, nurses in clinical

practice report a lack of routines and guidelines for working with patients who are parents as well as their children as relatives (Knutsson et al., 2016; Turner et al., 2007). Nurses have reported being insecure talking about and meeting children as relatives of patients (Golsäter et al., 2016; Turner et al., 2007). Great variation is shown in nurses' perceptions, from insisting it is not their responsibility to care for children as relatives, to believing they should work systematically to support such children (Golsäter et al., 2016).

These studies show that there is a disparity in what parent's desire in order to be able to support their children and what they actually receive from the healthcare services. This disparity could be due to a lack of understanding of beliefs and knowledge between the parents and the healthcare professionals. To further develop the care, there is a need for more research-based knowledge on how to support families in clinical practice when a parent has a cancer disease. This is especially related to early health-promotive interventions on a basic level for all families.

## 2. Purpose

The purpose of this study was to explore parents' perceptions of how

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nurses in clinical practice care for children as relatives when one parent in the family has a cancer disease.

### 3. Method

#### 3.1. Design

To obtain a detailed understanding of how parents experience the information, advice and support offered to their children, a qualitative explorative design with interviews was used (Polit and Beck, 2012).

#### 3.2. Setting

The setting in this study is an oncological outpatient department at a county hospital in southern Sweden. The department has an ongoing process in place to develop its work to meet the needs of children as relatives according to the Swedish Health and Medical Services Act (1982:763 cap.5 §7). The Act states that it is the healthcare professional's obligation to take into account children's need for information, advice and support when their parent has a severe illness. When the Act was enacted, the county council, as one of four councils/regions in Sweden, received funding from the National Board of Health and Welfare to enhance its implementation into clinical practice. The work was carried out through the Child Dialogue, which is an arena in the county for development and collaboration in issues concerning children's health and welfare. The nurses in the oncological outpatient department took part in education sessions about children as relatives to further develop their knowledge on the topic. Nurses with special responsibility to care for children as relatives, from the department took part in learning seminars aimed at tailoring the work with children as relatives to the clinical practice at their specific unit. Based on this work, and in collaboration between researchers and the department, a clinical intervention addressing how to care for children as relatives has been developed. The clinical intervention incorporates practices (for the nurses) to identify children as relatives and to talk to the parents (both the ill and the healthy one) about children as relatives and how they can help them handle the situation. The clinical intervention also incorporates inviting the children to the unit and offering them information, advice and support in collaboration with the parents.

#### 3.3. Participants

Participants were parents in families in which one of them was diagnosed with a cancer disease and being treated at the oncological outpatient department. Patients with dependent children (up to 18 years of age) were informed by their contact nurse about the study, based on information from the researcher, and received an information letter. Patients who were interested in participating in the study were then contacted by the researcher and given additional information, and an appointment for an interview was made. This purposive sampling is common in qualitative research Elo et al. (2014). After the interview with the patient the researcher asked if his/her partner was interested in taking part in the study, and if so an information letter for the partner was given to the patient. When the partner had consented, the researcher contacted him/her.

Altogether 17 patients (15 women and two men) and 11 partners (nine men and two women) were interviewed. The most common diagnosis was breast cancer ( $n = 13$ ). At the time of the interview, the patients had been receiving treatment at the unit for at least two months. The patients' ages varied from 36 to 54 years (median 42 years), and the partners' ages varied from 34 to 58 years (median 39 years). The 17 families had altogether 38 children, aged 4–18 years.

#### 3.4. Data collection

The interviews were conducted by the first author, and the

participants decided the time and place for the interviews. All patients except one were interviewed in conjunction with a treatment session at the hospital; the remaining interview was performed at the patient's home. Seven of the interviews with the partners were conducted by telephone and two at their homes, and two partners were present at the interview with the patient and the couple chose to be interviewed together.

Before the interview started, the researcher repeated the information about the study orally. The interview questions were developed from earlier research (Golsäter et al., 2016, 2017; Knutsson et al., 2008, 2016; Turner et al., 2007) and in association with a reference group, consisting of researchers within the research area. This helped in the construction of understandable questions that made better sense of the subject studied (Elo and Kyngäs, 2008; Elo et al., 2014). The interview started with the question "Tell me about how you as a parent and your children have received information, advice and support during your or your partner's cancer disease and treatment?". Based on the parent's narratives, further questions about how information, advice and support were given by the nurses to them as parents as well as to the children were asked.

To elaborate on the participants' experiences, probing questions such as "Can you describe further?" were asked based on their descriptions (Kvale, 2014). The interviews, which were audio-recorded and transcribed, lasted 25–71 min (median 45 min) with the patients and 11–30 min (median 25 min) with the partners. The interviews were performed between December 2015 to December 2016.

#### 3.5. Data analysis

To allow the researchers to make valid inferences from the data to their context, a qualitative content analysis method according to Krippendorff (2004) was used, and the inductive approach as described by Elo and Kyngäs (2008) guided the analysis process.

In the first step of the analysis, the transcripts from the interviews with the patients and partners were read as two separate parts in order to explore similarities and differences in the two data sets. The reading process was performed independently by the three researchers, with notes and headings written in the text as codes. After reading and coding the two data sets, the researchers compared and discussed the coding and agreed that the similarities between the two were comparable. Thereafter, the data sets were handled as one part. In the next step, the codes were transferred to coding sheets. The codes were first grouped into preliminary categories and then into subcategories based on their similarities and differences. The links between them were explored until consensus was reached. In the following step, the subcategories were abstracted into three generic categories. In the last step of the analysis process, the generic categories were abstracted into one main category: "Made efforts to support the child and parents through mainly a generic approach" (Fig. 1).

#### 3.6. Ethical considerations

Before each interview, the participants received both written and oral information about the purpose of the study and how the interviews would be conducted. The information letter and the interviewer, before the interview began, stated that participation was voluntary and that the choice to participate or not would not influence the forthcoming care at the unit. The study has been approved by the Ethical Committee at Linköping University: 2014/362-31.

### 4. Findings

The main category was labelled 'Made efforts to support the child and parents through mainly a generic approach'. The parents perceive that the nurses are trying to support them in maintaining their parenthood during the illness trajectory. Through highlighting the

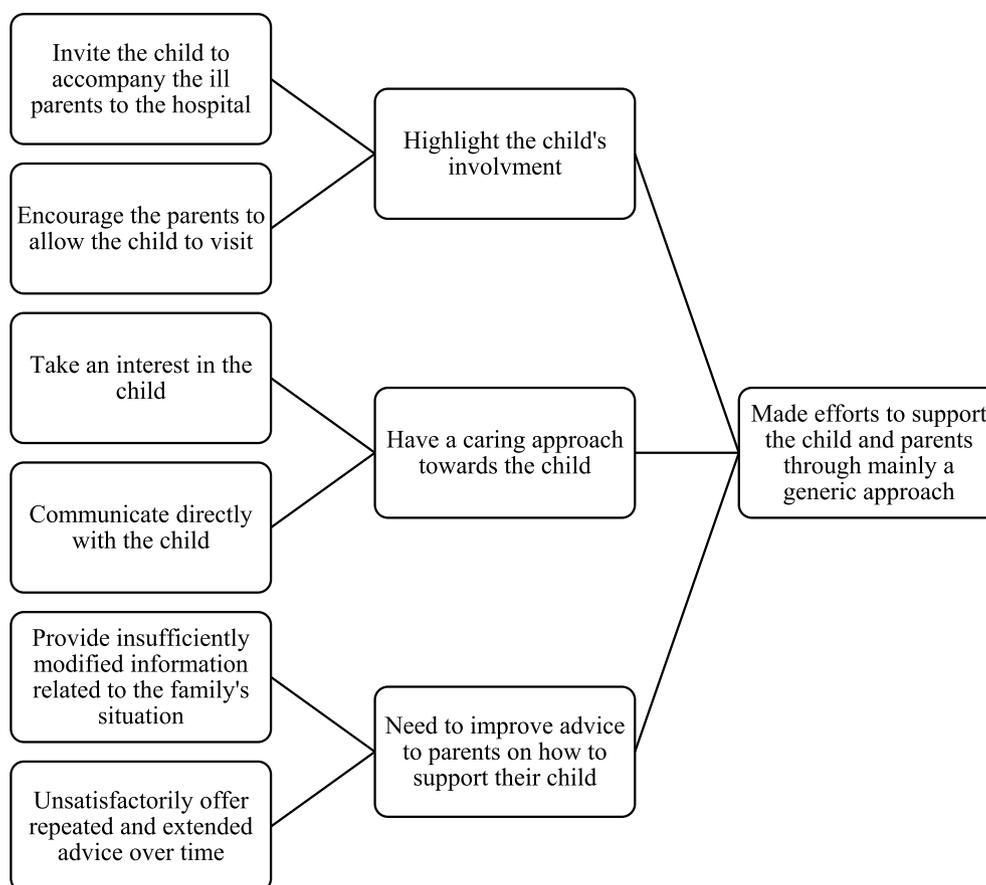


Fig. 1. Overview of parents' perceptions of how nurses in clinical practice care for children as relatives.

children's situation, the nurses try to help the parents understand the need for the child to accompany the parents on hospital visits. When meeting the child, the nurses use a caring approach to enable him/her to feel comforted in the hospital's unfamiliar environment. By making an effort to advise the parents in how to support their children, the nurses try to help them put their children's best interest in focus. However, the parents express a desire for more repeated, extended and in-depth advice over time so that the advice and support can be tailored to the conditions and situation of their own children and family.

#### 4.1. Highlight the child's involvement

The nurses ask after the children and encourage the parents to bring them to the hospital. This approach allows the parents to receive advice from the nurses in how to demystify the children's concerns about their parent's disease and treatment. Further, it helps the parents feel secure about bringing their children to the hospital.

##### 4.1.1. Invite the child to accompany the ill parent to the hospital

In one of their first contacts with the staff, the parents had been asked if they had children. Further, they had been given information that the children were welcome at the hospital and that it is valuable for children to attend treatment sessions. The nurses are explicit about inviting the children to the treatment sessions and this usually makes the parents bring them.

*"They said I was welcome to bring her" (Family 6)*

However, there is variation in the extent to which the parents express that they have received necessary information about how it would be helpful for the children to accompany their parent to a treatment session. When they do not fully understand or receive a clear

description about the value of the children visiting, uncertainty arises about whether or not they should bring them. This uncertainty can make the parents hesitate to motivate the children to come, especially if the child has expressed that he/she do not want to.

##### 4.1.2. Encourage the parents to allow the child to visit

When the parents feel encouraged and safe, they allow their children to be present during a treatment session. They perceive that the children experience it in a positive way. Through this visit, the children obtain a more concrete picture of what is happening to their parent during a treatment session and see that it is not as frightening as they may have imagined. This is more prominent among the younger children.

*"It is good that they get a picture of it so they know where mother goes when she's away" (Family 16)*

When the parents feel encouraged and reassured by the nurses that it is acceptable to bring their children to the hospital, it enables them to continue demystifying the children's concerns about the parent's treatment. Getting a picture of who is caring for the parent when he/she is at the hospital is experienced as useful to both the children and the parents. Attending the treatment sessions also gives the nurses the opportunity to meet the children and thus catch up on how they experience their parent's situation. This is perceived as one way in which the nurses can get help in tailoring information and advice for a specific child, especially if the nurse follows up with him/her at the next treatment session.

For the parents, obstacles to taking their children to the hospital can include the desire to balance it against their perception of the importance of maintaining the children's everyday life, e.g. attending school as usual. However, if the children seldom accompany the parent

to the hospital, it is impossible for the nurses to get to know them and thus support both them and their parents.

#### 4.2. Have a caring approach towards the child

By using a caring approach, the nurses enable the children to feel secure and welcome. When the nurses describe the parent's treatment, and at the same time show interest in the children and try to be flexible towards them, a positive atmosphere is created despite the unfamiliar medical environment.

##### 4.2.1. Take an interest in the child

The nurses recognize the children by being welcoming them, as well as showing that they are happy to see them and feel it is positive that they have come. They talk to the children about their everyday life, for instance their leisure activities, as a way to make them feel welcome.

*"I think the staff are very good-natured and kind and always happy – in some way feels like that – so it spreads in some way" (Family 4)*

The parents describe a permissive atmosphere when the children are present during a treatment session, whereby the nurses try to make them feel comfortable and safe. For example, the nurses might give the children something to do while the parent receives treatment, and this makes them feel comforted in the medical environment.

The nurses ask to be notified before a child's visit so they would be able to have the time to approach him/her in a caring manner.

##### 4.2.2. Communicate directly with the child

The nurses approach the children with openness and flexibility. This approach is valuable not only for the children but also for the parents, as it reinforces the sense that the children are important to the nurses as well.

*"They showed them toys and so on and paid attention to them and played ball with them, a soft ball, inside the ward and joked and kidded with them – yes, exactly, and they sat and played games with them" (Family 2)*

During the children's visits the nurses talk to them about the different treatments and equipment, and the parents experience this as a way to facilitate the children's understanding of their parent's illness and treatment.

#### 4.3. Need to improve advice to parents on how to support their child

The parents experience that the initial information they had received was too generic, and feel it needs to be adjusted to individual, richer and deeper information based on each family's situation. To further improve and elaborate the advice and support provided, the parents describe prearranged meetings and repeated dialogues over time as one way to enable support to children during their parent's illness trajectory.

##### 4.3.1. Provide insufficiently modified information related to the child's/family's situation

The parents describe that the nurses provide pamphlets on how to talk to children when a parent has a cancer disease, which gives the parents something to use as a starting point. Receiving pamphlets is experienced as helpful in the beginning, but they are largely seen as too generic.

The parents perceive that they can partially find additional information and knowledge online, but this information is more general and is not adapted to their specific situation, for example their children's age or the parent's specific cancer disease. They expressed uncertainty concerning which websites might be helpful, both those for the parents themselves and those they could recommend to their teenagers.

The parents value receiving direct and clear advice about how to talk to their children. They try to demystify the disease and treatment, but at the same time are as honest with their children as they think they can handle; they do this by being attentive to each child's need. For further help in tailoring the information to fit the specific child and family, the parents desired more and deeper dialogues with the nurses. A need was also expressed for the nurses to further explore families' thought processes about how to involve and support the children.

*"It's so difficult, it's so individual from child to child, how to notice when talking to T, it's like the questions don't come right away, but maybe when she's going to sleep; then her questions come, you don't think she's taken it in then but you notice later in the evening when she's going to sleep. It's then that all the questions come and it's that's when it's sunk in" (Family 5)*

The parents appreciate that the nurses continue to ask after the children at the treatment sessions, as they often do. However, they tend to do it in a more overall manner and need to be more explorative in order to enable advice tailored to the specific child and his/her family.

##### 4.3.2. Unsatisfactorily offer repeated and extended advice over time

A desire for more opportunities to talk about the children's situation and advice on how to support them emerged in the interviews. The parents describe how the nurses offer them further advice and support in a more overall manner, and through this transfer the decision to the parents. Instead offering the parents or the family a prearranged meeting could be one way to assist them.

*"Then they say you can call whenever you want and ask us, and there are no stupid questions and all that, but I think for a lot of people that call is never made; instead, you search on your own without talking to anybody, so I think it would be good to 'force' that conversation" (Family 10)*

Parents describe that they initially declined the offer of further support, both for themselves and for their children, but further on realized that it might have helped. They express a desire for both repeated offers over time as well as a more in-depth explanation of how the support can be carried out and how it can affect the situation in a constructive and positive direction. The children's teachers and healthcare personnel in school or preschool can be one part of those supporting them.

*"Mhm; it came up a bit later that she'd been afraid to bring up certain things, so she'd seen a school psychologist or counsellor, so it turned out well when it all came out, so to say" (Family 3)*

The parents feel that the nurses should ensure that information about the parent's situation is provided to school and preschool personnel and they should also offer help in doing this.

According to the parents, having a family meeting in combination with repeated advice and support to the parents about how to talk to and involve their children may contribute to giving the parents what they need in order to support their children.

## 5. Discussion

The findings show that the parents perceive that the nurses make efforts to support the child as well as them as parents. The children are initially invited, generally informed and seen by the nurses, but the parents perceive that they themselves need repeated support and advice over time to uphold their parental responsibility for caring for their children during the illness trajectory.

The parents describe it as helpful to receive advice from the nurse on how to guide and support their children as relatives and say that this can encourage and reassure them about bringing the children to the hospital. A desire for discussions and advice from nurses on how to talk to and involve their children in the illness trajectory has been described

previously (Fearnley and Boland, 2017; Semple and McCance, 2010). Further previous research (Fearnley and Boland, 2017) reveals a divergence between the support parents wanted and what they actually received. This is in line with the results in the present study, in which the parents desired repeated advice and support during the illness trajectory. One way to further develop the care for families when a parent has a cancer disease could be a closer partnership between nurse and family, in what Batalden et al. (2015) argue for as a co-productive approach. In a respectful interaction between families and nurses, a mutual understanding of each other's beliefs and knowledge can arise (Batalden et al., 2015). This mutual understanding can serve as guidance in how to design the care with an aim to give children the best possible support during their parent's illness trajectory.

According to Batalden et al. (2015), one principle is that, in every healthcare system, the care is in some way a co-productive service based on a partnership between nurse and patient. However, the healthcare system includes both barriers and facilitators to enable a partnership. According to Batalden et al. (2015), at the basic clinical level co-productive care entails three basic requirements: “civil discourse”, “co-planning”, and “co-execution”.

### 5.1. Civil discourse

In the model of co-productive care, the basic level involves the concept of civil discourse, incorporating a caring approach whereby the communication is based on a mutual understanding (Batalden et al., 2015). Looking at the parents' descriptions in this study, already in their first contact with the parents the nurses try to shed light on the children's situation as relatives, by asking about the children and inviting them to accompany their parent to a treatment session. This approach can be understood as the first step towards achieving mutual understanding about how to care for the children. Earlier research has shown a lack of routines for identifying children as relatives (Knutsson et al., 2016) and a lack of routines and structural frames for promoting children's involvement (Golsäter et al., 2016; Karidar et al., 2016; Turner et al., 2007), but the result in this study show a contrary promising situation in which the nurses have a clear focus on children as relatives. When the nurses, already at the first meeting with the ill parent, call attention to the children this can help the parents start thinking about how to involve their children in the new situation of illness in the family. However, not all the parents describe having been fully informed about how it would be helpful for their children to accompany on a visit to the hospital. This result argues for the need of a more mutual understanding between the nurses and parents about why the children should be involved. Earlier research has shown that parents are uncertain about the extent to which they should involve the children (Helseth and Ulfset, 2005; Semple and McCance, 2010; Semple and McCaughan, 2013). According to the parents in the present study, continuing to ask after the children and how the parents are coping with the situation in order to support their children could be one way to further develop the care for children as relatives based on a mutual understanding between the nurses and the parents.

The parents describe how the nurses, through their caring approach when encountering the children, show a positive attitude as a way to affect them in a positive manner and to make them feel welcome. The nurses' caring approach in the interaction with the children made them feel secure in how the nurses encounter the children. Further, the parents describe a permissive atmosphere when their children meet with the nurses. Parents have been described as the gatekeepers who give nurses access to their child (Karidar et al., 2016). The caring approach and the permissive atmosphere might facilitate for parents in letting their children have access to nurses on their own, which children want to do, according to Fearnley and Boland (2017).

### 5.2. Co-planning

Creating a deeper understanding of each other's beliefs and knowledge is what Batalden et al. (2015) call co-planning. The conversations they had with the nurses about their children helped the parents gain a deeper understanding of, and feel secure about, taking their children to the hospital. According to the parents, when accompanying their ill parent to a treatment session, the children gained knowledge and formed a more concrete picture about what was happening to their parent. Further, they had the possibility to meet the nurse caring for their parent, which children have stated is important for them to feel secure (Bugge et al., 2008).

However, according to the parents in the present study, the nurses need to further explore the parents' thoughts about how to further involve the children based on the parents' wishes and needs. This is in line with what Batalden et al. (2015) describe as co-planning in a partnership. The parents describe a need of knowledge and tools for accomplishing the assignment of caring for and protecting their children in this new situation of illness in the family. Knowledge of each child's personality, age and needs affected how parents chose to talk to him/her, according to the parents in Asbury et al. (2014). Parents also describe a need of extensive assistance from the nurses in initiating and accomplishing conversations with their children about their disease (Forrest et al., 2009). The descriptions in the present study argue for more follow-ups and prearranged meetings for parents and children, as well as for the family in a more directed way instead of an overall manner, as the parents describe. According to the parents in the present study, are the nurses acting vague when offering additional support during the parent's illness trajectory and this could have different reasons. In situations in which the nurses feel emotionally stunned, earlier research shows that they can act in a way that makes the patient feel as if talking about the children's situation was too excruciating even for the nurses, which leaves the parents on their own (Turner et al., 2007). Further, parents have described how nurses often avoid discussions with parents about their children's situation, and how the parents talk to the children about treatment and diagnosis (Fearnley and Boland, 2017). Results from both the present study and earlier research argue for the need to elaborate the care in line with a co-planning approach.

### 5.3. Co-execution

To fulfil the requirements in creating a co-productive care the next step, described as co-execution, requires the enhancement of shared goals and mutual responsibility in how to carry out the care (Batalden et al., 2015). The parents' perceptions highlight that the nurses need to take into account that information and advice need to be both generic and tailored to parents' and children's needs, which is in line with a co-productive approach (Batalden et al., 2015).

As a way to demystify the situation and through this help the children understand parents in Turner et al. (2007) wished to receive more practical support. This is in line with results from this study, as parents describing the importance of the nurses helping them to tailor the information to the child, if they were given the opportunity to meet and talk to the child during the parent's treatment session.

The parents in the present study experience that when the school or preschool knows about the parent's disease, they can support the children and thus also be facilitated in the assignment of caring for them. For their part, school nurses have described how they can support children with a parent who is seriously ill and contribute to making the school a safe place for them during their parent's illness (Golsäter et al., 2017). However, a main problem in carrying out this assignment is that the school nurse is not always aware of the parent's illness; thus, in line with the parents in the present study, school nurses argue for closer collaboration with the nurses caring for the parent in order to be able to better support the children (Golsäter et al., 2017). These results support the argument for the need of shared goals and mutual responsibilities to

a greater extent between parents and their nurses, as well as between nurses caring for parents and, for instance, the children's school nurse to ensure that the children receive the best possible support.

Looking at the results of this study with a focus on the model of co-productive care (Batalden et al., 2015) sheds light on the need to further develop the care, especially to ensure its co-execution through shared goals and mutual responsibilities between parents and nurses. This could be one way for the parents to maintain their responsibility as parents during the illness trajectory, which they describe as essential, through support from the nurses.

#### 5.4. Discussion of the method

The study had a qualitative design based on interviews. It was found that the research question matched the method, which matched both the data and analytic procedure, and thus methodological coherence was obtained.

One limitation of the study is the question about how representative the participants are. The majority of the participants were woman with breast cancer and their partners. Another limitation of the study is that we don't know if each of the patient with children has been invited to participate or not. It is possible that parents with other cancer diagnoses or those who were not invited or chose not to participate had other experiences than the participants in the present study. These circumstances need to be considered in relation to trustworthiness of this study (Polit and Beck, 2012).

To ensure trustworthiness, the analysis is described thoroughly (Elo et al., 2014). The data were rich and sufficient for all aspects of the phenomenon. The analysis and categorization were performed by all three researchers individually to increase comprehension, a sound interpretation of the data, and conformability (Polit and Beck, 2012). All researchers met and discussed any divergent opinions concerning the categorization and representativeness of the data as a whole (Elo et al., 2014).

The findings reflect the participants' voices and have been included to show connections between the data and results, which indicates trustworthiness of the results (Polit and Beck, 2012).

#### 6. Conclusions

This study showed how parents experience a responsibility to care for their children during the illness trajectory but need professional support to fulfil this assignment. By asking after the children and explaining the value of their visiting the hospital, the nurses highlighted the children's situation; the parents described this as helpful. Further, the parents argue for the importance of receiving repeated advice and support for how to talk to their children about the disease and treatment. Providing families with a prearranged meeting with the nurse and/or social worker could be one way to elaborate the care, according to the parents in this study. To ensure that the children get the best possible support in their everyday life, the parents and nurses need to have a mutual understanding of how the children's school or preschool should receive information about the family's situation.

The fact that information, advice, care, and support need to be both generic and tailored to parents and children argues for the need to elaborate the care in line with a co-productive approach.

#### Conflicts of interest

None declared.

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