Children's experiences of information, advice, and support from healthcare professionals when their parent has a cancer disease

Experiences from an oncological outpatient department

Abstract

Purpose: This study was carried out in order to evaluate children's experiences after taking part in the pilot clinical intervention "See Me" aimed at supporting children as relatives.

Method: A qualitative explorative design with interviews was chosen, with analyses using an inductive approach. Interviews were conducted with 19 children (9 aged 7-12 years and 10 aged 13-18 years). The younger children were asked to draw a picture of a person in hospital, using the Child Drawing: hospital (CD: H) instrument to measure the child's level of anxiety. The older children completed the Caring Professional Scale (CPS) as a measure of the caring approach in their encounter with the nurse.

Results: The interviews with the children show that: they felt expected and welcome at the hospital; they need knowledge about their parent's situation; they need information and participation based on their individual situation; and they need the nurse to offer them information and support. The results from the pictures showed that one child had above-average levels of anxiety. The older children reported that the nurses were *Competent Practitioners*, but to a lesser degree that they were *Compassionate Healers*.

Conclusions: The results of this pilot study indicate that the structure of "See Me" could be used as a starting point to ensure that children as relatives receive information, advice, and support. Further the results indicate that both CD: H and CPS could be used to evaluate children's experiences of support when a parent has a long-term illness.

Key words: children as relatives, cancer, clinical intervention, support, Sweden

INTRODUCTION

Several studies have found that children of parents suffering from various diseases experience mental ill-health, such as anxiety as well as emotional and behavioural problems, due to their parent's sickness (Appel et al., 2018; Bogosian et al., 2010; Davey et al., 2011; Jakobsen & Christiansen, 2011; Krattenmacher et al., 2013; Kühne et al., 2012; Turner, 2004). Research has shown that the child's knowledge about what is happening to their parent is crucial for the child's mental health, wellbeing, and relationships (Davey et al., 2012). Parents describe a lack of knowledge and ability regarding how to communicate with their children about their cancer disease (Semple & McCaughan, 2013). Research has shown the importance of age-appropriate information and communication with these children, as well as the significant role of professionals in facilitating early interventions (Knutsson et al., 2008; Nilsson et al. 2015; Nolbris et al., 2010; Stinesen-Kollberg, et al., 2013; Turner, 2004). Receiving information about the parent's treatment and its side effects is described as crucial for a child's possibility to understand the parent's situation and why he or she has acted in an unfamiliar way (Maynard et al., 2013). Also, children have stated the need for support, manifested as listening and understanding, encouragement and reassurance, tangible assistance, communication about the disease, and engagement in normal life experiences (Wong et al., 2010), as well as involvement in the patient's and the family's situation (Knutsson et al., 2008).

Even though it has been proven that children of parents with a disease need support, there is no agreed-on programme for offering this support. Earlier studies have shown how healthcare professionals fumble in their attempts to understand how to encounter children as relatives and how to provide support (Golsäter et al., 2016; Karidar et al., 2016; Knutsson et al., 2017). Further, the needs of these children are not clearly recognized and are often forgotten in the clinical setting (Fearnley, 2012). There is, however, agreement regarding the need for a systematic approach (Andersson et al., 2018; Knutsson et al., 2017), for instance based on templates and manual procedures (Dencker et al., 2017). A family support project, including meetings with parents and children and offering age-appropriate information, was found to be helpful by both children (Bugge et al., 2008) and parents (Bugge et al., 2009). A literature review (Järkestig Berggren & Hanson, 2013) based on 11 studies of methods for supporting children whose parents have a serious physical illness demonstrated a lack of research in this area, and none of the studies in the review had been carried out in a Swedish context. The conclusion is that there is a need for further research, especially interventions evaluating the effect of information, advice, and support provided to children (Järkestig Berggren & Hanson, 2013). Niemelä et al., 2010) argue that there is a need of studies using structured child-centred interventions, which are furthermore easy to use in clinical practice.

PURPOSE

To evaluate children's experiences after taking part in the pilot clinical intervention "See Me" aimed at supporting children as relatives.

METHOD

Setting – the "See Me" intervention

An oncological outpatient department, threatening different kind of cancer diseases, at a county hospital in southern Sweden constitutes the setting for this study. At the department the most

common cancer disease in parents of young children was breast cancer. Based on Swedish law stating that children's needs for information, advice, and support must be considered by the health services when their parent has a physical or mental illness or dies unexpectedly (*The Patient Safety Act 2010: 659 Chapter 6 § 5*, 2010), the department has an ongoing process to develop its work for children as relatives. As part of this process, a pilot version of a clinical intervention "See Me" was developed, aimed at facilitating the identification of children as relatives in order to shed light on a child's situation and to provide opportunities for the child to get information, advice, and support based on their individual situation and needs (Fig 1). The pilot clinical intervention is based on earlier research (Bugge et al., 2008, 2009) and the researchers' experience in the area, and was developed in collaboration with researchers and nurses working at the outpatient department within the framework of the "child dialogue", an arena for developing healthcare for children in the county. The pilot version of "See Me" intervention (Fig 1) consists of three phases: 1. *Early identification*, 2. *Encountering*, and 3. *Referral*.

The "See Me" intervention can be described as a direct form of support for children and an indirect form of support for parents, as a supplement to the information and support the parents give their children. At this outpatient department each patient has a contact nurse who has the main responsibility for the patient, and it is this nurse's responsibility to encounter and include their patients' children.

The evaluation in this pilot study is focused on children's experiences of the pilot version of the intervention. Parents' perceptions of their child's participation in the intervention have been published elsewhere (Golsäter et al., 2019).

Participants

Participants were children of one parent 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. The parents informed their children about the study, and if a child was interested in participating the parent informed the researcher, who then contacted the child.

At the time of the interview, the patient had been receiving treatment at the unit for at least two months. In total the 17 families had 38 children, aged 4-18 years, and in 15 of the families there were children aged seven years or older. Of the 34 children aged 7-18, 19 children from 11 families agreed to participate in the study. Of the participating children, nine were 7-12 years old (4 boys and 5 girls) and ten were 13-18 years old (7 girls and 3 boys). Of the parents in the 11 families 10 had breast cancer.

Data collection and data analysis

All children were interviewed about their experiences of mainly the second part “*Encountering*” of the pilot version of the clinical intervention “See Me” (Fig 1). The younger children (7-12 years) were also asked to draw a picture of a person in hospital to measure their level of anxiety. The older children completed the Caring Professional Scale (CPS) as a measure of the caring approach in their encounter with the nurse.

The interviews

The interviews were conducted by the first author. Thirteen of the interviews were conducted in the children’s home, one at the hospital, one at the researcher’s office, and the remaining four by telephone. Based on earlier research (Golsäter et al., 2016; Golsäter et al., 2017;

Knutsson et al., 2008; Knutsson et al., 2017; Turner, 2004), an interview guide was developed. To facilitate the construction of understandable questions adapted to the age group, the questions were discussed with other researchers with experience of interviewing children and adolescents (Docherty & Sandelowski, 1999; Elo et al., 2014; Wong et al., 2010). The interview started with the question “Can you tell me about your encounters with the nurses caring for your parent? Based on the child’s narratives, further questions were asked about how they had experienced the information, advice, and support they had received. To elaborate on the child’s experiences, probing questions such as “Can you describe further?” were asked based on their descriptions (Docherty & Sandelowski, 1999; Kvale, 2014). The interviews, which were audio-recorded and transcribed, lasted 14-49 minutes (median 25 min).

To **analyse the interviews** a qualitative content analysis according to Krippendorff (2004) was used, and the inductive approach as described by Elo and Kyngas (2008) guided the analysis process. In the first step, the interview transcripts were read by the three researchers independently. During this reading process, notes and headings were written in the text as codes. After reading and coding, the researchers discussed and compared the notes and codes. The codes were first grouped into preliminary categories and then into subcategories based on their similarities and differences. Thereafter, the subcategories were abstracted into four generic categories based on their similarities and differences (Elo & Kyngas, 2008). During the analysis process, the researchers discussed and explored the links between the categories until consensus was reached.

Children’s reports of anxiety related to the hospital visits

Data were collected from the younger children (n=9) using the Child Drawing: Hospital instrument (CD:H), to measure anxiety (Clatworthy et al., 1999). The child was given a blank

piece of paper and crayons in eight colours, and was asked to “draw a person in hospital” according to the CD:H. This is an instrument designed and validated for use with children five to 11 years of age for investigating experiences of anxiety in hospital (Clatworthy et al., 1999; Wennström et al., 2011). However, one 12-year-old girl chose to answer the CPS questionnaire like her older brother instead of drawing, resulting in eight drawings.

Adolescents’ reports of caring behaviours by the nurses

Caring behaviour was measured using the Caring Professional Scale (CPS) by Swanson (Kalfoss & Owe, 2015; Swanson, 1991). This questionnaire consists of 15 items measuring the two aspects *Competent Practitioner* (7 items) and *Compassionate Healer* (8 items).

Data on adolescents’ reports of caring behaviours by the nurses were collected from the older children (n=10). One boy chose not to answer the questionnaire, and one of the younger children (girl aged 12 years) chose the questionnaire instead of the drawing, resulting in ten questionnaires.

Ethical consideration

Before each interview, the parents and children 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 parent’s forthcoming care at the unit. The study has been approved by the Ethical Committee at Linköping University: 2014/362-31.

FINDINGS

The interviews with the children show four generic categories: need to feel expected and welcome at the hospital; need knowledge about their parent's situation; need information and participation based on their individual situation; and need the nurse to offer them information and support (Figure 2).

Insert fig. 2 here

Need to feel expected and welcome at the hospital

The children described the nurses as kind and friendly, and as having a focus on them as children as relatives. This positive approach, together with the nurses' attempts to make the environment as child-friendly as possible, contributed to the children's feelings of security when accompanying their parent to the hospital.

Kind and accommodating nurses

The children experienced a positive and optimistic atmosphere when they entered the department. When greeting and welcoming the parent, the nurses also took the children into account, which made the children feel included. When they were greeted in a positive and friendly manner, the children perceived the nurses as kind, fun, and confident. They experienced these actions as reducing their anxiety and fear:

*“That they not only say hello to the mother and father but also see the child.
Saying hello and welcome.” (Child 9)*

The children described the nurses as kind and accommodating.

Child-friendly hospital environment

The children experienced the hospital environment as a positive place. However, situations in which the environment was experienced as a bit unfamiliar were also expressed. Concerns about the physical environment as cold, boring, and scary were more prominent among the younger children, who also explained that it could be hard to have to be still and quiet. Being given something to play with, e.g. a syringe, was experienced as positive. The children also described situations in which the nurses had given them a stuffed animal as a gift, which they appreciated, and this reinforced their feelings of a child-friendly environment. They also described being invited to the nurses' lounge, or offered something to eat like biscuits or a chocolate drink, as part of the child-friendly environment:

“You might get an ice cream or something to be happy. If you're afraid of them or something like that, then you get happy when you get something from them.” (Child 5)

The children experienced the nurse's way of talking with them in a nice and friendly manner as another part of the child-friendly environment, and this helped them take the initiative themselves to start talking to the nurse.

Need knowledge about their parent's situation

Having the opportunity to meet the nurse who was caring for their parent and see that she was competent increased the children's confidence that the parent was being treated well. The children described the value of talking directly to the person responsible for their parent's care, which was possible when they had the opportunity to talk with the parent's contact nurse.

Know that the parent is well taken care of

The children described that they felt confident in knowing that their parent was well taken care of. When they saw that the nurses were kind and gentle towards their parent, they were reassured that they could trust the nurses. They also mentioned getting a picture of the nurses' competence as one way to feel comforted:

“She was kind and seemed to be careful with Mum, so it didn't hurt. I think that's good”. (Child 3)

Older children expressed an overall impression of having trust in the nurses' competence and actions.

Participate and see what is happening in hospital

The children stressed the importance of being invited to visit the hospital and accompany their parent for treatment and care; they wanted to see with their own eyes what was happening to their parent. They mentioned the risk of growing afraid of what was happening to their parent if they were not allowed to accompany them:

“You get scared if you don't get to come.” (Child 9)

“I think it's good to be at the hospital and understand what's going on.” (Child 8)

These feelings were most prominent at the beginning of the parent's cancer trajectory. Some children described feeling forced to be engaged in the parent's illness, and stressed that being involved in the treatment and care should be voluntary.

Being encountered by the nurse caring for their parent

The children appreciated being encountered by the same nurse who was caring for their parent. They wanted information and answers to their questions from someone who knew their parent, in order to get valid information and be able to ask questions about the individual parent's situation, treatment and care:

“Tell me what they're doing.” (Child 5)

They pointed out a need for guidance in order to understand their parent’s situation, and wanted this information from a nurse with knowledge of the parent’s situation and care whom they knew and had met before. The children stated that they were afraid of meeting with unknown adults, and that they did not feel comfortable talking to an unknown nurse alone.

Need information and participation based on their individual situation

To be able to take advantage of information, the children argued that it needs to be adapted to their individual needs. They described it as important that nurses are trained in how to talk to children of different ages, and skilled enough to know that the child has understood.

Adaptation based on age and experience

In the interviews the children pointed out that everyone is different, and that they experience a need for individualized and age-appropriate approaches. Children with a great deal of hospital experience expressed that they wanted an experience-based approach from the nurses. They expressed a desire for something for them as well, that could distract them from their feelings about waiting and that they could have fun with. For example, there were toys at the hospital, but the older children perceived these to be more suitable for young children:

“Some activities for children, so the kids don’t have to wait, and a playroom for both older and younger children. But there’s mainly baby stuff.” (Child 3)

They wanted the nurses to be able to provide information adjusted to the child’s age and experience, as well as on an individual basis related to their parent’s situation.

An educational approach

Children stated that it was important that the staff use an educational approach when talking with them. They wanted the staff to talk in a teaching manner to help them understand. They also stressed the importance of having a good layout for the information, and of being skilled in explaining in a way the children can understand:

“I understood that she wasn’t so briefed on my mother’s situation // she wasn’t as proficient as the doctor, but I understood that.” (Child 15)

The children also pointed out the need for repeated information related to new aspects in their parent’s disease trajectory.

Need the nurse to offer them information and support

The children described a need to have guidance in finding information that is credible, not only about their parent’s disease but also about how to get further support if needed.

Additionally, they described the need to be offered a well-balanced mix of individual- and family-based support.

Help in finding credible information

In the interviews, the children stated that there is a great deal of information available, but that they experience that they need help in finding information that is credible. They had received brochures, and knew how to find further information on the Internet. However, they experienced that they had not used this source to any great extent and explained that all the information on the web is not valid or useful to them, and that it is hard to sort out the credible information:

“If you have any questions you can google it? But I haven’t done it.” (Child 3)

The children experienced that they relied to a high extent on adults, especially their own parents, to find the right information and support for them. This could involve, for example,

informing the school health services about the child's need for support. They expressed trusting that their parents had received information from the nurse about how to support them:

*“It's the parents who decide to some extent what the children get to know,
that's how it is.” (Child 4)*

Children mentioned worrying that their parents might not have enough knowledge themselves to transfer to them, or that their parents might not want them to know everything and thus held back information.

Well-balanced mix between individual- and family-based support

According to the value of sharing feelings and information among the family members, the children had mixed feelings. On the one hand, they stated that it is good to know how others in the family think. Having family meetings with the nurses could also form a bond in the family and offer a way to understand each other, as well as help them interpret the information provided. On the other hand, the child might not be completely forthcoming in family meetings, as they might not want to speak for themselves, and the conversation might not be the same if the whole family is included:

*“There were several of us in the family who heard the same information.”
(Child 13)*

*“It's a bit awkward when adults start talking because you don't have so much
to do yourself, but if the doctors only speak with Mum then I can't talk to
them.” (Child 3)*

Another difficulty the children mentioned concerned integrity within the family: you might not want everyone to know everything about each other. It seems as if the older children preferred to talk to the staff by themselves, while the younger children preferred to be accompanied by other family members.

Not having to ask for support themselves

The children in this study stressed the importance of having someone to talk to, especially at the beginning of the parent's disease trajectory. The children's experience was that their parents needed to focus on the parent who was sick, and therefore tended to forget the child. The children experienced a need for support from someone not involved in the parent's illness, treatment, and care. Children who had experience of support and comfort from the school health services, such as the school nurse, social worker, or psychologist appreciated this. However, the children stated that someone, such as their parents or the hospital nurse, has to make their needs known to the school health services. The children experienced that the nurses at the hospital had not offered any strategies for support; instead, they had to ask for support themselves:

They've never asked me or my sister directly if we need help or to talk to someone. (Child 11)

The children experienced that they were forced to take the initiative themselves and ask for help; otherwise, they received none.

Children's reports of anxiety related to the hospital visits

The anxiety score, measured using the Child Drawing: Hospital instrument (CD:H), ranged from 34 to 159. The analysis in this study showed that the eight children aged 7-12 years scored 38-135 (md 61). Seven of the children experienced low levels of anxiety (fig 3.), and one child had above-average levels.

Insert fig 3 here

Adolescents' reports of caring behaviours by the nurses

In their answers to the CPS, the adolescents (n=10) acknowledged that the nurses were (absolutely=median 1) *Caring, Clinically competent, Respectful, and Technically skilled*, the aspects of a Competent Practitioner. However, the adolescents did not find the nurses to be (not at all/sometimes=median 4-5) *Centred on you, Visibly touched by your experience, Aware of your feelings, or Able to offer hope*, the aspects of a Compassionate Healer.

DISCUSSION

The findings show that the children felt expected and welcome at the hospital, and that they needed knowledge about their parent's situation based on their individual situation. They also needed the nurse to offer them information and support. The results of the drawings showed that only one child had above-average levels of anxiety related to hospital visits. The older children's answers to the CPS reflected that they perceived the nurses as *Competent Practitioners* but to a lesser degree as *Compassionate Healers*.

When looking at the findings of the present study in relation to the structure of the pilot version of the clinical intervention "See Me", some parts suggest that the nurses are largely working according to the intervention and that it also corresponds to what the children describe as helpful to them. For example, the children described feeling welcome and safe when accompanying their parent to the department, and that the nurses showed an interest in meeting them. On the other hand, there are parts in which the children described that they needed more information and support than they experienced that they received. They also gave clear descriptions of how the intervention can be elaborated and of how the nurses could act to better meet the children's needs. To further elaborate and refine this pilot intervention, to better meet the needs of children as relatives, the discussion are based on an attempt to

combine the children's descriptions of their needs with the structure of the present version of the clinical intervention "See Me". This attempt is described in figure 4, and the results will be discussed based on this figure.

Insert fig. 4 here

Need to feel expected and welcome at the hospital

The nurses were experienced as kind and friendly, and together with their attempts to make the environment as child-friendly as possible, this contributed to the children's feelings of security. Looking at the drawings, only one child reported an above-average level of anxiety. Also, in the older children's ratings on the CPS, the nurses were shown to be experienced as caring and understanding. Despite the small sample, the results from the drawings and questionnaires together with the children's descriptions could be understood as reflections of their feeling welcome and safe when accompanying their parents to the hospital. These results indicate that the nurses have managed to develop their clinical practice when encountering children as relatives, in contrast to earlier studies showing how nurses fumble in their attempts to encounter children as relatives (Golsäter et al., 2016; Karidar et al., 2016; Knutsson et al., 2017; Tafjord, 2019). Also, children in Finch and Gibson (2009) described experiencing anxiety when going to the hospital and perceived that they, as children as relatives, had no place at the hospital, in contrast to the children in the present study. Inviting the children to come to the hospital could be seen as the first step in gaining access to them and through this, in collaboration with their parents, having the possibility to give the children further information and support based on their own situation, in line with the intention of the law on children as relatives (*The Patient Safety Act 2010: 659 Chapter 6 § 5*, 2010).

Need knowledge about their parent's situation

When they had the possibility to see that their parent was well taken care of by competent and kind nurses, the children felt comforted. Having knowledge of what is happening to their parent during treatment is crucial for the child's mental health, wellbeing and relations (Davey et al., 2012; Maynard et al., 2013). Children have described that their need for information during a parent's illness trajectory varies over time, but in the initial stage they mainly want to have information about the treatment and examinations (Kennedy & Lloyd-Williams, 2009). This is in line with the children in the present study experiencing that being present at the hospital was most prominent in the beginning. Via the CPS, the older children in the present study described that they to a large extent found the nurses to be clinically competent and technically skilled, and this could be understood as the nurses having fulfilled the children's need for information about the treatment and examinations in the initial phase of their parent's illness trajectory. Having access to a nurse with knowledge about their parents' specific situation was described as prerequisite for getting the information they wanted, and is in line with children's experiences in Kennedy and Lloyd-Williams (2009). Adolescents in Bartfai Jansson and Anderzén-Carlsson (2017) describe the ability to see how their parent's treatment was carried out and to get more knowledge about the cancer as useful.

Need information and participation based on their individual situation

The children argue for individual-based information and support based on what they as an individual child want, in line with the children in Kristjanson et al., (2004). In order to fulfil this wish, according to the children in the present study, nurses need to have knowledge in encountering children and be skilled at being aware of whether and how a child has understood the information and the situation involving a sick parent. Drawings have shown to be a useful approach when conducting interviews with children (Søndergaard & Reventlow,

2019), and the Child Drawing: Hospital instrument might also be useful in clinical practice in order to further explore children's feelings in the situation but also as a way to ease the conversation with younger children.

The nurses in Tafford (2019) describe a need for more knowledge about children's development in order to talk to and inform them about a parent's disease. When they lack knowledge, this can hinder them in approaching the children, causing the children to be left alone. The children in the present study described sometimes needing to ask for support themselves, which could also be based on the nurses sometimes being hesitant in approaching them. Earlier research has shown that children, particularly adolescents, sometimes want to protect their parents and therefore do not tell them about their feelings (Bugge et al., 2008), which highlights the need to offer children meetings with the nurses on their own. Children taking part in a support programme for children with a parent with cancer describe first having felt a bit frightened to talk on their own with professionals, as they did not know them, but afterwards feeling boosted and appreciating the opportunity to talk to someone outside the family (Bugge et al., 2008). The children in the present study also described insecurity in talking to an unknown nurse on their own. According to these children, as well as the children in Kennedy and Lloyd-Williams (2009), it is important to get information about the disease and treatment from a nurse with knowledge about the parent's specific situation. However, if there is a need for further support there might be other healthcare professionals the children can talk to.

Need the nurse to offer them further support if required

It could be asked to what extent the nurses working at the hospital should be the only ones caring for children as relatives. However, the nurses caring for the parent must, in cooperation

with the parents, try to explore whether the child needs further support in handling the situation of illness in the family. One way to manage this (explore the need of further support), according to the children's descriptions in the present study, is to offer family meetings at which the whole family together can talk with a nurse. On the other hand, family meetings might hinder especially adolescents from talking about their feelings in order to protect their parents. These contradictory descriptions shed light on the need to try to explore the individual needs of each child in order to offer referral for appropriate support.

The results from the present study highlight the need to create structures through which children can be referred for further support if needed. In Sweden, school nurses are situated in the schools, and can be one healthcare professional to whom children have access. School nurses have described that they can be one part in supporting children with illness in the family; however, to be able to do this, they need to collaborate with the nurses caring for the parent at the hospital in order to recognize these children (Golsäter et al., 2017). In such a collaboration the school nurse, who has the opportunity for a more long-lasting and trustful relationship with the child, could further explore the child's needs of support. Further, this more long-lasting relationship could enable the school nurse, to a greater extent than the nurse caring for the parent, to provide care based on the aspects of a Compassionate Healer (*Centred on you, Visibly touched by your experience, Aware of your feelings, and Able to offer hope*) (Kalfoss & Owe, 2015; Wei et al., 2017). However, to be able to meet the child's needs, the nurses caring for the sick parent must improve their caring competences. Based on the findings of the present study, in which the older children reported the nurses as being *Competent Practitioners* but to a lesser degree, *Compassionate Healers*, especially the aspects of the *Compassionate Healer* need to be elaborated. To be able to care for children as relatives, as well as all patients and their relatives, regardless of which healthcare settings they are working in nurses need to continuously develop their caring approach.

Discussion of the method

Research involving children and adolescents is not without its methodological challenges, one of them involving the different worlds of adult- and childhood (Kirk, 2007). The interviewer in this study is a paediatric nurse with long experience of encountering children and has previously performed several individual and group interviews with children, which was helpful when conducting the interviews. Researchers are discussing the value of parents' participation during interviews with younger children (Gardner & Randall, 2012), and Gardner and Randall (2012) suggest that the interviewer should be flexible and adapt to the situation based on the child's wishes. This was applied in the present study in order to make the children feel as safe as possible. In some of the interviews the parent was present or in a room nearby, or siblings chose to be interviewed together; additionally, four of the adolescents chose to be interviewed by telephone. As the interviewer experienced it, there were no differences regarding the data collected using the different ways of conducting the interviews.

The study was designed as heterogenic to include children with a parent who had any cancer diagnosis, so that the findings could be transferable to all children as relatives (Polit & Beck, 2012). However, it is with one exception the voices of children of mothers with breast cancer that are heard in this study, which is a significant limitation and has to be considered when transferring the results to other groups of children with parents with other cancer diagnoses or a long-term illness in the family.

The data analysis was performed through ongoing discussion between the three researchers, in order to ensure trustworthiness of the findings (Elo et al., 2014). To further support the analytic results, quotations from the interviews are presented (Polit & Beck, 2012).

The CD: H instrument was used to measure the children's level of anxiety, previously to the best of our knowledge only used in situations where the child were the patient at hospital, which could be seen as an limitation. However, the results showing one child with an above-average level of anxiety are in line with the results of the interviews. This may indicate that the CD: H instrument could also be used in clinical practice with children as relatives and in further studies to evaluate the effect of clinical interventions for children as relatives. But as the sample in this pilot study was small it is not possible to draw valid conclusions. Also according to the CPS, the scale was not earlier used in this context, which could be seen as a limitation. The results from the CPS are in line with the results from the interviews, which could also be interpreted as suggesting that the instrument can be used in larger studies to evaluate adolescents' experiences of caring interventions. Further assessment-tools have their limitations when it comes to validation of the tool, to explore and understand people's experiences in more detail and who's actually answering the tool (Polit & Beck, 2012). To more in-depth explore and understand children's experiences of information, advice, and support when their parents have a cancer disease observations of encounters between children and health care professionals could be used in future studies (Polit & Beck, 2012).

Conclusions

The findings show that the children felt expected and welcome at the hospital. The results of this pilot study indicate that the structure of "See Me" could be used as a starting point to ensure that children as relatives receive information, advice, and support in accordance with the law, in a way that is possible to implement in clinical practice. However, through the interviews, suggestions and recommendations emerged, regarding how to further elaborate and refine this intervention of "See Me" to even better meet the needs of children as relatives in the encounter with healthcare professionals. Further improvements to the nurses' caring competences – especially the aspects of the *Compassionate Healer* – are needed to enable for

the nurses to encountering children as relatives and at the same time care for their patients, the parent. Also structures for collaboration with and referral to other healthcare professionals need to be elaborated to facilitate for the nurse's possibility to care for both their patients and the patients' children. Results from this study can be used in a future full scale intervention study and also in educational interventions for health care professionals as well as in supporting organizational structures to care for children as relatives in different parts of the health care system.

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1. Early identification; As soon as possible after parent has been enrolled

- Early identification of children as relatives
- Information about child's situation when a parent has a cancer disease
- Invitation to bring the child to the hospital and offer information

2. Encountering; When parent gives permission for child to visit department

- The child visits the department
- A first meeting with the child together with the parent for information about the parent's illness and situation
- Offer the child an individual meeting with the nurse
- Follow-up conversation with child and parents

3. Referral; Children who need further support

- One or two additional meetings with the child at which the nurse provides information and advice
- Referral for further support if needed

Figure 1 Overview of the pilot version of the clinical intervention See Me

Figure 2 Presentation of the categories and the sub-categories

Fig 3 An example of a drawing representing a child with low level of anxiety

Figure 4. Suggestions for how to carry out clinical practice to support children as relatives in oncology care, based on the children's statements.