



Are children as relatives our responsibility? – How nurses perceive their role in caring for children as relatives of seriously ill patients



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ARTICLE INFO

Article history:

Received 28 February 2016

Received in revised form

31 August 2016

Accepted 12 September 2016

Keywords:

Children as relatives

Nursing

Parents

Support

Qualitative research

ABSTRACT

Purpose: The purpose of this study was to elucidate how nurses perceive their role in caring for children as relatives to a parent with a serious physical illness.

Method: A qualitative explorative design with focus group interviews was used. In total, 22 nurses working at one neurological, one haematological and two oncological wards were interviewed. The transcripts from the interviews were analysed in steps in accordance with inductive qualitative content analysis.

Results: This study revealed six variations in how nurses perceived their role in the encounter with child relatives, ranging from being convinced that it is not their responsibility to being aware of the children's situation and working systematically to support them.

Conclusion: Nurses should consider whether their patients have children who might be affected by their parent's illness. The nurses' self-confidence when meeting these children must be increased by education in order to strengthen their professional role. Furthermore, guidelines on how to encounter child relatives are required.

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1. Introduction

When caring for adult patients, nurses also have a responsibility to meet the needs of the relatives, irrespective of age. Caring for patients with a serious illness such as cancer and their relatives is a challenging task as a result of the emotional burden involved. This obligation is even more challenging when the relatives are children as it is related to the child's cognitive developmental stage and maturity as it affect the children's possibilities to understand the parent's illness (Turner et al., 2007). Nurses have a central role in supporting the whole family. Wright and Leahey (1999) stated that meetings as short as 15 min can be sufficient for nurses to increase their knowledge and understanding of the family situation in order to support the family members.

Women with breast cancer described their wish to protect their

children and to maintain normality, while at the same time trying to take the child's need for information into account (Asbury et al., 2014). In the study by Helseth and Ulfset (2005), being a "good parent" and focusing on the child's needs through striving for an ordinary everyday family life were considered important by parents. The main intention of parents who receive a diagnosis of cancer is protecting the child and enabling her/him to feel safe. The decision about whether and how to inform the child is based on the parents' own experiences of how a "good parent" should act (Semple and McCance, 2010). The situation is described as a balancing act between telling the child about the illness and maintaining her/his feeling of security (Billhult and Segesten, 2003; Helseth and Ulfset, 2005). When deciding whether and how to talk to their children, parents perceive a lack of knowledge and ability (Semple and McCaughan, 2013) and express a need for support and guidance from nurses (Semple and McCance, 2010).

In contrast to the parents' wish to protect their children by not telling them about the illness, the children themselves describe the need for knowledge in order to feel safe and secure (Davey et al., 2011; Finch and Gibson, 2009; Maynard et al., 2013). Furthermore, children expressed a wish to be able to talk with their parent

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about her/his illness and treatment and how it affects the child and the family. If the parent does not initiate such discussions, the child feels unable to talk about it and keeps the questions and concerns to her/himself in order to protect the parent. However, if the parent indicates an interest in how her/his illness affects the child's everyday life, the child will feel free to talk, which will enable her/him to more easily understand and cope with the new situation (Karlsson et al., 2013; Maynard et al., 2013).

Oncology nurses working with patients who have children describe ambiguity when supporting children as relatives (Turner et al., 2007). They find the situation difficult to handle when they see how the parent's decision not to inform and talk to the child about the illness hinders the child from being close to her/his sick parent. At the same time, the nurses express a fear of discussing the situation with the parent, despite being aware of her/his grief and unhappiness. The nurses' fear is based on their lack of knowledge about how to talk to parents about the child's situation when having a sick parent and to answer parents' questions about how to talk to their children (Turner et al., 2007). Buchwald et al. (2012) point out the importance of providing nurses with education and supervision to accomplish their work and enable them to encounter and support patients and their children. Furthermore, Niemelä et al. (2010) argue for the development and implementation of structured interventions for children whose parent has a serious illness that are easy to use in clinical practice.

In order to ensure children's rights when their parent has a serious illness, an addition to the healthcare regulations was implemented in Sweden on January 1st., 2010 (Swedish Health and Medical Services Act, 1982:763) setting out the healthcare professionals' responsibilities to take the child's need for information, advice and support into account when her/his parent has a serious illness. Although nurses working in oncological, neurological and haematological wards encounter seriously ill patients who are parents of dependent children, knowledge about how they perceive caring for patients who are parents and their children is limited.

In order to develop interventions to support families with children when a parent is diagnosed with a serious illness, it is necessary to elucidate nurses' perceptions of their role in caring for child relatives in greater depth.

2. Purpose

The purpose of the study was to elucidate how nurses perceive their role in caring for children as relatives to a parent with a serious physical illness.

3. Method

3.1. Design

A qualitative explorative design with focus group interviews was used to obtain a detailed understanding of how nurses perceive their role of caring for child relatives of a parent with a serious illness (Polit and Tantano Beck, 2012).

3.2. Participants

Registered and assistant nurses working in one neurological, one haematological and two oncological wards at a County hospital in Sweden participated. The seriously ill patients at the haematological and neurological wards mostly had oncological diseases and all of the interviewed nurses had experiences of caring for patients with oncological diseases as leukaemia and brain tumours. The nurses were informed about the study by the head nurse at each unit based on information from the researchers and they also

received an information letter. Nurses who were interested to participate in the study and worked on days when the work situation at the unit enabled interviews to be conducted took part in the interviews. About 6–8 nurses were working each shift and the interviews were conducted when nurses from both the morning and evening shift were present in the afternoon. A total of 22 nurses took part in four focus groups with five or six participants in each group. The participants comprised 19 registered nurses and three assistant nurses and all had worked at the respective unit for more than one year.

3.3. Data collection

The focus group interviews as described by Krueger and Casey (2009) were conducted at the nurses' work place by four nursing students under the supervision of the two first authors. The student nurses were trained by their supervisors in conducting focus group interviews through both theoretical and practical training. Two students performed each interview with one acting as the moderator and facilitating the discussion, while the second served as an assistant. The interviews started with an open question "Can you please tell me about your experiences of caring for children whose parent has a serious illness?" Probing questions such as "Can you explain further?" or "Can you tell me more?" were posed to elaborate on the nurses' role in caring for child relatives. At the end of the interviews, the assistant presented a summary to which the participants could respond (Krueger and Casey, 2009). The interviews, which lasted from 45 to 55 min, were audio recorded and transcribed verbatim.

4. Data analysis

Qualitative content analyses is a method of analysing written or verbal communication in a systematic way and it was chosen for the data analysis as it allows the researcher to make valid inference from data to their context (Krippendorff, 2004). Further the inductive approach was chosen as the knowledge in the studied area is fragmented (Elo and Kyngäs, 2008). The transcripts of the interviews were analysed in different steps in accordance with inductive qualitative content analysis (Elo and Kyngäs, 2008). Each interview was read several times by all four authors in order to capture essential features and obtain a sense of the content. In the next step the transcripts were coded based on the aim of the study. Three of the authors (MG, KE, SK) then compared and discussed their written codes in order to reach consensus, before grouping the codes into preliminary categories. By moving back and forth between the descriptions, codes and preliminary categories, these authors identified the subcategories and the links between them based on their similarities and differences. To increase trustworthiness, the remaining author (MH), based on her coding, read the preliminary categories, the subcategories and compared and adjusted to the codes from the transcript. Three of the authors (MG, MH, SK) compared, discussed and adjusted the codes and subcategories before abstracting the subcategories into six generic categories describing how the nurses perceived their role of caring for children whose parent has a serious illness. In Table 1 the subcategories and generic categories are presented (Table 1).

4.1. Ethical considerations

The study was performed in accordance with the guidelines issued by the World Medical Associations (2009). The manager of each of the units gave permission for the study. The participants received both oral and written information about the study, that the data would be treated confidentially in accordance with the

Table 1
Overview of the findings. Generic categories and subcategories.

Generic categories	Subcategories
Being convinced it is not nurses' responsibility	Focus is on the patient Children are not present Do not know the child Should not interfere Have nothing to offer
Assuming that parents have the main responsibility for the child's health	Parents need to take the main responsibility Parents need help to see the child's needs Show that children are welcome A good relationship with the parents is helpful
Believing that others can help the children	Arrange contact The child just needs a fellow human being Society fails to provide adequate support Identify the family's social network Children talk with their friends
Being unable to fulfil one's responsibility to care for children as relatives	Not meeting the child Knowing that tools exist, but not using them There is a fear Lack of knowledge and experience The need to be professional Easy to forget
Acknowledging children as relatives at the unit	Be natural Let children visit Allow them to see the technical equipment Create a child-friendly environment Create a relationship with the child Play down the situation
Working systematically to fulfill the needs of children as relatives and involving them	Document the information in the patient's record Involve children See the individual child Use brochures, literature and pamphlets Need for reflection and feedback to improve the work

Swedish Personal Data Act (1998) and that they had the right to withdraw from the study at any time. According to Swedish law (SFS, 2003:460) the approval of an official research ethics committee is not required for research involving healthcare professionals.

5. Findings

The findings revealed subcategories and generic categories (Table 1) showing variation in how nurses perceive their role in the encounter with children whose parent has a serious illness. The generic categories are presented as a stepwise progression from being convinced that it is not their responsibility to being aware of the children's situation and working systematically to support them (Fig 1).

As nurses can adopt different roles it implies that a unit may have nursing staff who perceive their role in the encounter with children whose parent has a serious illness in various ways. One variation was the belief that child relatives are not their responsibility, as they have to focus on the patient. Nurses in another variation assume that parents have the main responsibility for their children's health and that nurses should make them aware of their obligations. A third variation was the belief that others can help child relatives, making it necessary to arrange contact with such others. Another variation was nurses who want to care for children as next of kin but feel unable to do so due to various obstacles. One variation demonstrates that nurses are aware of their role of caring for child relatives by allowing them to visit and giving them an ice-cream. The final variation represents nurses who describe working systematically by acknowledging the individual child and involving her/him in the care and situation of the ill parent.

5.1. Being convinced it is not nurses' responsibility

The nurses expressed that it is not their responsibility to care for children whose parent has a serious illness. Their *focus is on the patient* and they have no time to care for others, especially children.

“ our duty is to care for the sick person ... ”

They do not encounter them to any great extent as *children are not present* in the unit. According to the nursing staff, children must continue their daily activities and attend school rather than visiting the hospital. It is therefore difficult to establish a relationship with the child, which means that they *do not know the child* and they mean that they do not need to have knowledge about the child/, while some stated that such knowledge was not necessary. Because they perceive that caring for the children is not their responsibility, they do not make any effort. The nurses stated that they *should not interfere* with the family's situation; the family members should be allowed to decide for themselves. They are convinced that they lack the necessary resources to take care of child relatives, believing that they *have nothing to offer* and thus relinquish their responsibility.

5.2. Assuming that parents have the main responsibility for the child's health

Some nurses stated that *parents need to take the main responsibility* for the children's health when one of them is in hospital. However, the nurses also reported that parents themselves may have a great deal of fear and anxiety about the illness, as well as being exhausted and feeling guilty, thus they are not always able to see the child's needs. Despite assuming that parents have the main responsibility, the nurses reported that it was necessary to ask them about the child's knowledge and whether she/he is informed



Fig. 1. Variations in how nurses perceive their role in the encounter with children as relatives.

about and involved in the situation. The nurses stated that *parents need help to see the child's needs* but consider that they cannot overrule parents.

"... it depends on the parents ... if the parents want I do not want to step on their toes"

A way to handle this is to *show that children are welcome*. They need to explain to the parents that it could be beneficial for the child to be involved in the family's situation and receive information about the sick parent, for which *a good relationship with the parents is helpful*. They try to establish a relationship by talking to the parents and explaining about the child's needs but without insisting, as they believe that the parents are the ones who should take care of the children.

5.3. Believing that others can help the children

In this variation the nurses described that professionals other than themselves are in a better position to help children whose parent has a serious illness. If they are aware that a child needs help, they *arrange contact* with other professionals such as a psychologist or counsellor at the child's school or at other healthcare services for children. Sometimes the child is assigned to a counsellor and/or a physician at the unit. Some nurses believe that *the child just needs a fellow human being* to talk to and feel safe with.

"... children are not mentally ill they just need another person to talk to anyone ..."

However, despite arranging contacts and believing that other professionals can help these children, the nurses concluded that *society fails to provide adequate support* for children who are relatives. At present the counsellor is not a part of the team at the units, as it would not be possible to meet the dependent children of all patients. The counsellors are not responsible for caring for the patients' children, as their role is to give advice to the nurses and parents. Nurses also *identify the family's social network* in order to find others who can help and support the child, e.g., grandparents. According to the nurses, *older children talk with their friends* about their sick parent, as well as about their own situation.

5.4. Being unable to fulfil one's responsibility to care for children as relatives

The nurses acknowledged that they have a responsibility to care for children whose parent has a serious illness but considered that they were unable to fulfil this obligation.

"...we are not trained to talk with a child in that way ... and we do not have time ..."

As children do not visit the unit very often, it results in staff members *not meeting the child*. The child is not visible. Despite *knowing that tools exist*, such as a special family questionnaire in order to identify and successfully care for child relatives, the unit is *not using them*. Although a special child representative who is responsible for taking children's needs into account is based in the unit, the nurses expressed that they do not turn to this staff member as much as they would like to. *There is a fear* of caring for children who are relatives. Thinking about this task gives rise to concerns, uncertainty and a feeling of not daring to face these children. In addition, they perceived a *lack of knowledge and experience*, which increases the fear. Furthermore, lack of knowledge results in not knowing how to talk with children in crisis. The nurses do not know what is permitted and what the limits are in the encounter with the child. They require concrete advice from, e.g., the counsellor, as well as clinical guidelines to help them to understand how best to encounter the child. While acknowledging their responsibility to care for the child, they stated that the parents are the ones who make the decision to allow the child to receive information. In order to enter into a closer relationship with the parents, the nurses considered it essential to have something to offer the parent and the child, which they do not have. Nurses reported *the need to be professional* when meeting and talking to the child but are afraid of making a mistake and becoming too close to her/him. It was not considered proper for a nurse to cry. Emotions must be contained, for which they need support from their colleagues in the form of collegial reflection and feedback. However, the nurses described being overworked and not having the necessary time for the children, making it *easy to forget* their responsibility for child relatives.

5.5. Acknowledging children as relatives at the unit

The nurses believed that they acknowledge children whose parent has a serious illness and want the encounter and everything around the child to be *natural*. They *let children visit* and when the child enters the unit and her/his parent's room, the nurses *allow them to see the technical equipment* and try to create a *child-friendly environment*.

"... we try to talk to them and ... offer them ice-cream"

The nurses endeavour to *create a relationship with the child* by being positive to her/his presence, joking and treating them in a

natural and easy-going manner. The relationship often begins with the nurses doing their best to *play down the situation* and giving the child sweets, lemonade or ice-cream. They believe that acknowledging the child's presence is sufficient.

5.6. Working systematically to fulfil the needs of children as relatives and involving them

In this variation, the nurses described providing care in a structured way to fulfil the needs of children whose parent has a serious illness. The first step is to ascertain whether the patient has children and *document the information in the patient's record*. They *involve children* by letting them participate in the parent's care; the child can give the parent lemonade or help position the pillow. The nurses believe that they are flexible and able to *see the individual child* at her/his level of maturity. They sit down and talk with children, giving them time, trying to be honest and to answer their questions as best they can.

“... we always see and talk to them tell them about the disease ...”

When talking with children they use brochures, literature and pamphlets. In order to gain the necessary strength and improve their work with child relatives, the nurses stated that there is a *need for reflection and feedback*.

6. Discussion

The result elucidate variations in how nurses perceive their role in the encounter with children whose parent has a serious illness ranging from being convinced that it is not their responsibility to awareness of the child's situation and working systematically to support them.

6.1. Being convinced that it is not nurses' responsibility

In the first variation, the nurses stated that the parents have the main responsibility for the child, but according to the [Health and Medical Services Act \(1982:763 § 2 g\)](#) “The Health and Medical Services should also consider the child's needs for information, counselling and support if the parent of the child, or another adult with whom the child lives permanently, has a serious illness or injury”. Nevertheless, the nurses were of the opinion that their role did not involve interfering with the family of a patient and thus did not devote any effort to it. Child relatives were labelled as particularly challenging by the nurses in this study and for that reason they stated that they required expert guidance from other professionals such as a counsellor and/or psychologist, who should assume responsibility for helping the children. [Fearnley \(2010\)](#) agrees with the nurses but also raises the point that these professionals (nurses, counsellors, psychologists) should not work in isolation within their own sectors.

Even when the nurses are willing to meet the children, a problem described in one of the variations is that they do not encounter children on a regular basis, because the children are at school and therefore their issues are not discussed nor do they receive any information or support. In other contexts, such as intensive care, the children's visits are restricted by the nurses ([Knutsson and Bergbom, 2007](#)). Although the nurses in the present study wanted to support families with children, they experienced fear, uncertainty and a sense of not daring to face the patient and treat her/his children as relatives, which could be interpreted as a competent nurse who lacks adaptability ([Benner, 2001](#)). [Turner et al. \(2007\)](#) and [Fearnley \(2010\)](#) described nursing staff members

who do not discuss family circumstances with their patients for fear of upsetting them, despite observing that the parents were worried about their child and expressed a need for support. The nurses requested more education about communication theories, how to care for children in crisis, as well as about children's behaviour and development, in order to increase their self-confidence and strengthen their professional role when caring for child relatives.

Being unable to provide help and support to children whose parent has a serious illness could be interpreted as feelings of powerlessness. The barrier most frequently cited by nurses is that many of them lack the skills, qualifications and experience to support the child, which leads to reluctance to communicate and interact with her/him. According to [Benner \(2001\)](#), a competent nurse has a long-range goal or plan for the patient based on considerable conscious, abstract, analytic contemplation of the problem but she/he lacks the speed and adaptability of a proficient nurse.

6.2. Being aware of the children's situation

Being professional and supporting the family as a whole could be a strength. Both the proficient and the expert nurse in the theory by [Benner \(2001\)](#) had an experience-based ability to take account of the whole situation when caring for child relatives. Lack of exposure to child relatives leads to difficulties for novice nurses and advanced beginners because they are unable to gain experience and confidence in supporting them. In the present study, the proficient nurse is positive to the children's presence, allowing them to see the technical equipment and attempting to create a child-friendly environment. Communicating and sharing information with children is widely acknowledged as an important support factor when a parent has cancer or another serious illness ([Christ, 2000](#); [Fearnley, 2010](#); [Knutsson and Bergbom, 2007](#); [Knutsson et al., 2004](#); [Thastum et al., 2008](#)). It is essential that children understand what has happened and become aware of the reality rather than being left to their own imagination ([Knutsson and Bergbom, 2007](#)). Furthermore, the children in the study by [Kristjanson et al. \(2004\)](#) highlighted the absence of support from the family's social network, which was mentioned as important by the nurses in the present study. The children in the study by [Kristjanson et al. \(2004\)](#) clearly reported fears, uncertainties and feelings of isolation and did not perceive that their family members, neighbours and community networks offered them support because they seemed more concerned with the needs of the parent. Nurses can play an important role in maintaining and strengthening the vital support system in and around the family ([Fearnley, 2012](#); [Kristjanson et al., 2004](#); [Wright and Bell, 2004](#)). To make that possible, a family interview in the form of a short (15 min) meeting can be fruitful ([Wright and Leahey, 1999](#)). By seeing the patient in her/his family context and observing family interactions, a greater understanding of the patient, the potential for treating child relatives and the impact of illness on the family will be gained.

Nurses may also need to assist parents to assess and recognize their children's psychological distress ([Knutsson and Bergbom, 2007](#); [Kristjanson et al., 2004](#); [Visser et al., 2005](#)). The parents sometimes believe that the children are not aware of what is happening within the family and, in addition, their own emotional distress can impact on their ability to respond to their children. It may be appropriate for nurses to devote a great deal of effort into supporting and advising parents about how to meet the needs of their children ([Helseth and Ulfsaet, 2003](#); [Turner et al., 2007](#)). In order to recognize the family's needs and provide support, an expert nurse could act as an instructor or mentor for novice nurses and advanced beginners by formulating guidelines for action. Education could comprise, e.g., decision-making games and

simulation that enable nurses to practise planning and coordinating multiple, complex care demands. Such games and simulation can, together with time for reflection with colleagues and expert nurses as mentors, increase nurses' self-confidence, strength and experience, thus reducing their insecurity and fear when encountering children whose parent has a serious illness.

6.3. Working systematically to support child relatives

The expert nurses goes "all out" and involves the children by letting them participate in the parent's care, working in a structured way to fulfil the needs of children who are relatives. According to Enskär (2012), an expert nurse has confidence in her/his knowledge and can provide high-quality care. She/He also makes time for reflection, which leads to deeper insight into and empathy for the family situation (Enskär, 2012). The nurses in the present study tried to be honest and answer the children's questions, which Zahlis Hooper (2001) have highlighted as important for the children's health and wellbeing.

On the other hand, novice nurses need to follow rules to guide their work, but doing so can reduce the chance of a successful outcome, as no rules can tell a novice which tasks are the most important when meeting a child as a relative. Leaning on other professionals or the child's parent could be a defence mechanism for novice nurses or advanced beginners who have no experience of situations in which they are expected to perform tasks (Benner, 2001).

6.4. Discussion of the method

To improve trustworthiness the checklist presented by Elo et al. (2014) was used. In order to establish *credibility*, the authors (two paediatric nurses, two ICU nurses) dealt with their pre-understanding in the preparation phase by writing it down, peer debriefing and communicating with colleagues and researchers who had no experience of the research topic. Perceptions about the topic were based on the authors' experience of caring for children as relatives and seriously ill patients. The authors had no relationship with the four wards or the participants in the study. Objectivity was also achieved by audio taping interviews and transcribing them verbatim, taking a critical stance during the analysis and presenting quotations from the participants. Purposive sampling can also be related to credibility. As the head nurse informed the staff about the study and it was also advertised by written information in the ward, participants who had a special interest in and greater knowledge of the topic might have volunteered, which can be considered both a strength and a weakness of the credibility. The fact that no pilot interviews were performed and that four students conducted the focus group interviews might have weakened trustworthiness. However, the two first authors read the interviews and supervised the students during the whole process in order to strengthen trustworthiness.

The purpose of content analysis is to include as many variations as possible. The participants represent four different wards and are nurses and assistant nurses with varying degrees of work experience who meet patients and relatives every day, which enhances the credibility of the content analysis. The context, selection and characteristics of participants, data collection and analysis process have been described, which strengthens *transferability*. By including participants from four different wards, the findings might be relevant to other wards caring for children as relatives. Auditing was undertaken to ensure the accuracy of the data, which were then used to validate the emerging generic categories and sub-categories (Elo et al., 2014).

7. Conclusion

This study revealed variations in how nurses perceived their role in the encounter with children whose parent has a serious illness ranging from being convinced that it is not nurses' responsibility to being aware of the children's situation and working systematically to support them. In conclusion, nurses must establish whether their patients have children who might be affected by their illness in order to support them. The nurses' self-confidence when meeting children also needs to be increased as a means of strengthening their professional role. To achieve this, the nurses requested more education on the subject of communication theories, how to care for children in crisis, as well as children's behaviour and development. Furthermore, guidelines on how to meet children who are relatives are needed to provide family-centred care for sick adults with children. Although an experienced nurse might be able to involve and support such children, less experienced nurses need to follow rules and guidelines in their strive to deliver high quality care.

Conflicts of interest

None.

Acknowledgement

We would like to express our warm and sincere gratitude to the nurses who kindly participated in our interviews and Johanna Lundell, Maria Arnesson, Charlotte Bostig and Evelina Wik who conducted the interviews.

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