



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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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

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