



# A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology – The perspective of nurses



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## ABSTRACT

**Purpose:** Children who have a parent with incurable cancer are in a vulnerable situation and the Swedish law tries to protect them. This article aims to explore the interactions between nurses and children of patients with incurable cancer from the nurses' perspective.

**Method:** Semi-structured interviews with nine nurses in palliative oncology in Southern Sweden. Latent content analysis was carried out, inspired by Lundmann and Graneheim.

**Results:** Parents are gatekeepers to the children's involvement and meetings with the healthcare professionals. Therefore the nurses were dependent on the parents for contact with their children. Additionally, nurses were subject to the structural frame of their working environment in terms of time, economy, resources and the medical logic ruling the priorities for nursing during their daily working day. The opportunities to pay attention to the children of patients were limited, despite good intentions, willingness and a favourable legal framework. Teenagers were regarded as a challenge, and *per se* they challenged the nurses' opportunities to gain control of the meetings and situations around the families.

**Conclusions:** Often nurses did not see and acknowledge the children of the palliative patient. They knew that the children were there and that it was important that they were there, but they challenged the order in the working environment in relation to time-allocated tasks and working flow. In the working environment patients were prioritised over relatives. From the perspective of nurses, there is a gap between the intentions of the Swedish law and the interactions between nurses and children.

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## 1. Introduction

Every day about nine children lose a parent in Sweden and in 40% of these cases it is because of cancer (Regional Cancer Center in collaboration, 2012). The life situation changes for the entire family when a parent becomes ill (Elmberger and Hedstrom, 2004). A cancer diagnosis in a parent has a major impact on many aspects of the life of both the patient and other family members, especially for children who are still dependent on their parents (Huizinga et al., 2011). Psychological reactions such as anxiety, depression, sleep problems, bad concentration and difficulty in school are seen in the child through all stages of disease and treatment of the parent, and

forced physical separation from a parent can in itself be stressful for a child (Kornreich et al., 2008; Huizinga et al., 2011; Sutter and Reid, 2012; Syse et al., 2012). Teenagers are described as being in a particularly difficult situation when a parent gets cancer because they are in a life situation dominated by secession and at the same time dependence on parents. When a parent has cancer it may mean that the teenagers have nobody to support them during the parent's illness and death. Some teenagers are not even informed about their parent's disease and impending death (Huizinga et al., 2005; Bylund-Grenklo, 2013).

Several studies demonstrate the importance of advice, support and information to children to facilitate their handling of and grief reaction to the parent's illness and death (Lewandowski, 1996; Clarke, 2000; Helseth and Ulfset, 2003; Gabriak et al., 2007; Osborn, 2007; Thastum et al., 2008; Kennedy and Lloyd-Williams, 2009; Syse et al., 2012). Further, studies show that

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some parents may be afraid to inform their children about illness and death, and may not have the strength to be the necessary support for the child in the situation (Elmberger and Hedstrom, 2004; Dyregrov, 2007; Forinder, 2007; Thastum et al., 2008; Kennedy and Lloyd-Williams, 2009; Sutter and Reid, 2012). The dominating professional understanding is that children need to participate in the emotional community that is created in a family or circle of friends through grief and loss. They need to be involved to understand what death means and it is important that their grieving process can begin. Grieving can be more difficult when adults are hiding things and not talking about the circumstances surrounding the death. Embellished descriptions of death can lead to anxiety and confusion in children. Rituals and ceremonies may reduce feelings of unreality, prevent fantasies and help the child to express the loss, and it seems to be important that the child is prepared for what they will see and what is going to happen with their ill parent (Dyregrov, 2007; Forinder, 2007; Dencker, 2009).

According to the Swedish Society of Nursing, a nurse should take the initiative and conduct difficult conversations with patients and their families and be able to communicate about life, dying and death (Sektionen Sjuksköterskor för palliativ omvårdnad (SFPO) & Swedish Society of Nursing, 2008). It seems to be important that nurses can identify the individual child's needs for support and information (Clarke, 2000). Studies show that some nurses are unaware of the children of the patients in their meetings in clinical practice (Helseth and Ulfsaet, 2003; Dencker, 2009; Huizinga et al., 2011; Syse et al., 2012). This is in contrast to the intention of Swedish law. In 2009, it was established by law that healthcare professionals should consider the needs of children for information, advice and support when a parent or another adult with whom the child lives becomes seriously ill or dies (Hälso-och sjukvårdslag, 1982; SFS, 2009). In order to understand how the intention of the law is put into clinical practice, this study aims to explore what happens in the physical meetings and interactions between nurses and children of patients in the field of palliative oncology, from the perspective of nurses.

## 2. Method

This was a descriptive qualitative study using semi-structured interviews (Kvale and Brinkmann, 2009). The interviews are analysed by latent content analysis inspired by Graneheim and Lundman's (2004) model of analysis.

### 2.1. Recruitment of participants

Nine nurses, who worked at specialised palliative care units in Southern Sweden, were interviewed. Three of the nurses worked at a palliative care inpatient ward and six of them worked with advanced medical homecare. Inclusion criteria were that the nurses would have at least two years working experience in specialist palliative care and experience of meeting with children of patients in oncological palliative care. There were not any exclusion criteria.

Contact with the informants was through two head managers and their unit managers. The unit managers informed the nurses at the working places about the research and interested nurses left their names, phone numbers and email addresses. The researchers then called up the nurse informants with verbal information about the study, and went on to mail information and consent form to the informants. The consent forms were signed before interviews took place. All the nurses who expressed an interest and received the written information agreed to participate in the study; it is not known how many other nurses in these institutions met the inclusion criteria.

### 2.2. The interview process

The interviews were supported by an interview guide consisting of themes for the interview, tested by pilot interviews. The themes were: professional background and palliative experiences; description of a typical working day; description of experiences of meeting children of patients in the working day; challenges in meeting children of patients in the working day. The nurses seemed comfortable with the interview situation where the interviewer pursued their narratives and used follow-up probing, specifying, structuring and interpretive questions to clarify what the informant said (Kvale and Brinkmann, 2009). The interviews were recorded and saved on a USB stick. The interviews lasted 28–71 min and took place at the nurses' working places in undisturbed rooms.

### 2.3. Ethical consideration

All participation was voluntary. Interviewees were informed about the aim of the project both orally and in writing and they gave informed consent. All data was anonymised and kept inaccessible to anyone other than the research team. In publication, the study seeks to maximize anonymity and names, person-specific job names and toponyms have been removed (The World Medical Association, 2013). The study has been approved by the Advisory Committee for Research Ethics in Health Education (VEN) at Medical Faculty, Lunds Universitet (J.no. VEN 92-13) and obeys Swedish Legislation.

### 2.4. Analysis strategy

The interviews were transcribed verbatim (Kvale and Brinkmann, 2009). First, empirical data was read through in its entirety several times by all researchers to get an idea of its contents and to get an overall picture of all the interviews. Secondly, the interviews, first one by one and then across the entire empirical material, were analysed by two of the researcher through constructing meaning units, condensed meaning units with description close to the text and condensed meaning units with interpretation of the underlying meaning, inspired by (Graneheim and Lundman, 2004). This was discussed and challenged by the third researcher. Thirdly, in view of this all three researchers constructed two themes with each two sub-themes (see Fig. 1), within the analysis as it unfolded. The analysis presented quotes from informants to underpin the analysis and clarify the content of the text.

## 3. Findings

It was immediately clear that, from the nurses' point of view, parents related in different ways to children as relatives in the palliative oncological field. Some parents excluded their children from being involved in matters related to the illness and forthcoming death and the physical meeting with healthcare professionals, some parents included their children from the beginning to the end of the illness, and some parents included their children after the healthcare professionals had persuaded them to do so.

*"If we just get permission to talk to the children then it is easy, but sometimes parents can make it very difficult".*

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