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# Contextualisation of patient-centred care: A comparative qualitative study of healthcare professionals' approaches to communicating with seriously ill patients about their dependent children

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Patients' family relations play an important part in the provision of patient-centred cancer care, not least when healthcare professionals encounter seriously ill patients with dependent children. Little is known about how children are perceived and dealt with in clinical encounters. In this qualitative comparative study, we explore the influence of medical contexts in three Danish hospital wards, haematology, oncological gynaecology and neuro-intensive care, on communication with patients about their children. In exploring the degree to which the inclusion of children in clinical encounters is dependent on context, we took a comparative approach based on fieldwork in wards either exclusively focusing on cancer treatment or partially involved in critical phases of cancer treatment. We conducted 49 semi-structured, in-depth interviews with doctors and nurses, and 27 days of participant observation. The thematic analysis was based on Bateson's conceptualisation of communication. We found that healthcare professionals' approach to children in clinical encounters and the ways in which children were positioned on each ward were influenced by aspects specific to the ward, including the diagnosis and treatments that related specifically to the patient. Our findings suggest the need to explore further the influence of medical contexts on the inclusion of children in patient communication.

## KEYWORDS

cancer, comparative study, families with dependent children, intensive care units, patient-centred care, qualitative research

## 1 | INTRODUCTION

This article uses a qualitative comparative study conducted in two cancer wards and a neuro-intensive care unit in Denmark to focus on patient-centred care and on the issue of encounters between health professionals and seriously ill patients regarding patients' dependent

children aged 0–18. To explore the degree to which the inclusion of children in clinical encounters is dependent on context, we adopted a comparative approach based on fieldwork in wards either exclusively focusing on cancer treatment (haematology, oncological gynaecology) or partially involved in critical phases of cancer treatment (a neuro-intensive care unit).

Patient-centred care has been shown to increase patient satisfaction and their understanding of the medical information imparted, while improving their sense of being able to cope with illness (Ha Fong & Longnecker, 2010; Ortmann, Rösler, & Helbig, 2016; Stewart, 1995; Zachariae et al., 2003). Various models suggest how healthcare professionals' patient-centred care can be conducted, for example by seeking a common understanding regarding information and treatment plan, by building the doctor-patient relationship on empathy and confidence using open questioning, by checking non-verbal conduct, by making summaries and by sharing the patients' worries and expectations (Cronin, 2004; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Kurtz, Silverman, Benson, & Draper, 2003; Stewart et al., 2014). Epstein argues that patients should be seen both as individuals *and* as part of a whole (a family), and that the viewpoints of patients, healthcare professionals and family members should be addressed more relationally than separately in research, in training of healthcare professionals, and in practice (Epstein, 2013). However, to our knowledge children have not previously been systematically included as a focus area in working with patient-centred care, even though, from cancer patient's perspective, dependent children play such a central role.

Studies regarding seriously ill patients and their dependent children indicate that patients feel insecure about how to inform their children about their illness and how to cope with their children's reactions. Furthermore, they tend to underestimate their children's need for information (Buxbaum & Brant, 2001; Gaveras, Kristiansen, Worth, Irshad, & Sheikh, 2014; Helseth & Ulfsæt, 2005; Semple & McCane, 2010; Semple & McCaughan, 2013). This is a problem, because research also shows that patients with dependent children are especially likely to experience worries when it comes to making decisions about treatment and about time spent away from the family (Mack, Cronin, Fasciano, Block, & Keating, 2016; Park et al., 2016). In spite of patients' insecurities and worries, they do not necessarily participate in psychosocial interventions because of barriers such as practical difficulties for the families, perceived lack of need for support and lack of collaboration between institutions (Inhestern, Haller, Włodarczyk, & Bergelt, 2016).

To put this in perspective, about one-third of cancer patients worldwide receive their diagnosis at an age when they could have children aged 0–25 years (Ferlay et al., 2008). In Denmark, approximately 40,000 out of 1.2 million children under 18 experience a parent being hospitalised with a serious illness, including cancer (Statistics Denmark, 2015), whereas in Finland, almost 4,000 children out of 60,069 born in 1987 had a parent suffering from cancer during a 21-year follow-up. Moreover, studies show that maximising time spent with their children and preserving parental functioning are important concerns underlying parents' preferences for advanced cancer care (Check et al., 2016; Zaidler, Salley, Terry, & Davidovits, 2015).

In spite of these evident concerns among parents, very few studies have addressed healthcare professionals' encounters with seriously ill patients who have dependent children are almost non-existent. A few qualitative studies have identified health professionals' barriers to addressing the concerns and uncertainties that

patients experience. These barriers include the lack of professional confidence and/or knowledge in guiding parents in supporting their children and the fear of being emotionally overwhelmed (Dunne, Sullivan, & Kernohan, 2005; Odling, Norberg, & Danielson, 2002; Turner et al., 2007, 2008). In addition, attitudes among nurses range from conviction that children are not their responsibility to awareness that patients' wellbeing can be dependent on feeling that their children are, so to speak, at their side (Golsäter, Henricson, Enskär, & Knutsson, 2016). The paucity of studies is striking given the centrality of the issue to patient-centred care and the potentially pivotal role that healthcare professionals play in helping patients promote communication with their children.

The overall aim of this study was to include children in patient-centred care for the purpose of improving cancer care both for patients and their children. This has led us to conduct a qualitative comparative study focusing on encounters between healthcare professionals and seriously ill patients about patients' dependent children aged 0–18. Using Bateson's theoretical framework, we explored the degree to which the inclusion of children in clinical encounters is dependent on context (Bateson, 1972; Dilley, 1999; Rawlins, 1987).

## 2 | METHODS

### 2.1 | Study design

This study was based on interviews and participant observations. Semi-structured in-depth interviews and participant observations are qualitative research methods well suited for exploring and understanding how people experience and reflect in relation to the world around them (Creswell, 2009; Grimen & Ingstad, 2007). Participant observation in particular promotes the understanding of peoples' contextual conditions as the researcher takes part in people's lives, experiencing what the world looks like from their perspective (Tjørnhøj-Thomsen & Whyte, 2008).

Our methodological approach was informed by a social constructionist worldview (Bryman, 2008), which addresses interactions between individuals by focusing on the specific contexts in which people act and live (Creswell, 2009). To increase transparency, we used Bateson's theoretical framework, including his notion of "context" and the question "what differences make a difference?" to investigate how the medical context influences views on children and related communicative challenges (Hoeyer, 2008).

Semi-structured, in-depth interviews and participant observations on three Danish hospital wards were conducted. To explore the degree to which the inclusion of children in clinical encounters is dependent on context, a comparative approach was taken based on fieldwork on wards either exclusively focusing on cancer treatment (haematology, oncological gynaecology) or partially involved in critical phases of cancer treatment (a neuro-intensive care unit). This allowed comparison across wards of the influence of diagnosis and treatment modalities on views of children and related communicative challenges.

**TABLE 1** Participating doctors and nurses divided between wards

	Doctors	Nurses	Total
Haematology	2	5	7
Gynaecology	4	5	9
Neuro-intensive	3	5	8
Professionals total	9	15	24

## 2.2 | Participants and recruitment

We recruited a total of nine medical doctors and 15 nurses from three different hospital wards, who participated in an educational programme on how to communicate with patients about dependent children, organised by the Knowledge Centre for Patient Support under the Capital Region of Denmark. This included, for example children's age-specific reactions to parental cancer and their perceptions of death. About half of the doctors and nurses were contacted by mail before the programme, whereas the other half was asked personally to participate in our study, either during the training programme or during participant observations. Everyone who was asked to participate accepted the invitation (see Table 1).

The average age of participants was 46; all nurses were women, whereas one-third of doctors were men. The average years of experience were 19. Of the 49 informants, 39 were interviewed more than once to get an in-depth understanding of doctors' and nurses' clinical practice (see Table 2). The last ten informants were interviewed once or twice due to the later recruitment.

## 2.3 | Data collection

Between September 2013 to August 2015 we conducted 49 semi-structured, in-depth interviews and 27 days of participant observations (9 days in each ward spread over three visits consisting of 8 hr a day, giving a total of 216 hr). The prolonged period of data collection was due to the first author having a dual purpose, each with its own focus. On the one hand, data were included in an evaluation of an educational programme designed to investigate effectiveness and guide improvements for healthcare professionals and their communication with seriously ill patients about their children. The other purpose, which forms the basis of this article, followed a research logic exploring the degree to which the inclusion of children in clinical encounters is dependent on context (Fain, 2005; Levin-Rozalis, 2003; Patton, 2008; Scriven, 2004; Stufflebeam, 2001).

The interview method was derived by ethnographic interviewing, which seeks an understanding of "the other," of their experiences and views. Healthcare professionals might be asked what was considered typical for their wards and encouraged to give examples of their communication regarding children, about the last such encounter they had had, and more specifically what that encounter entailed (Kvale, 1997; Spradley, 1979). The interviews explored healthcare professionals' approaches to their working context including the ward's organisation, disease categories, daily practices and routines regarding the involvement

**TABLE 2** Number and frequency of interviews across profession and ward

	Doctors	Nurses	Total
1. Round			
Haematology	2 (2,3) <sup>a</sup>	4 (1,2,3,3)	6
Gynaecology	3 (1,2,3)	4 (1,1,3,3)	7
Neuro-intensive	3 (2,2,3)	4 (2,2,2,3)	7
Total	8	12	20
2. Round			
Haematology	1 (3)	2 (3,3)	3
Gynaecology	1 (3)	2 (3,3)	3
Neuro-intensive	1 (3)	3 (2,2,3)	4
Total	3	7	10
3. Round			
Haematology	2 (2,3)	4 (1,2,3,3)	6
Gynaecology	3 (1,2,3)	3 (1,3,3)	6
Neuro-intensive	3 (2,2,3)	4 (2,2,2,3)	7
Total	8	11	19
Interviews total	19	30	49

<sup>a</sup>2 (2, 3) meaning one health professional was interviewed twice and the other three times.

of dependent children as relatives. Questions were asked about *experiences*, clinical practices for example, about attitudes, and about perceived challenges in communicating with cancer and neuro-intensive patients who had dependent children (see Table 3). Interviews were conducted on the wards after participant observations, which involved shadowing doctors and nurses in their working environment.

Participant observations also focused on doctors' and nurses' multiple tasks, on their actions as regards dependent children, such as when they did and did not address the issue of children with patients, and how they approached their encounters with children.

## 2.4 | Analysis

Interviews were digitally recorded and transcribed verbatim. Interview recordings, transcribed interviews and field notes were read several times and carefully reviewed to obtain both a general and a more in-depth impression of the main themes and the empirical diversity.

The analysis was based on Bateson's conceptualisation of communication as multifunctional, on the notion that every conversational utterance conveys both a digital and an analogical aspect. The digital aspect refers to the "literal" content, whereas the analogical aspect provides cues for interpreting the content (Bateson, 1972). In this case children were variously perceived, depending on the medical context. These contexts seemed to determine the extent to which children could be included in clinical communication, for example if the parent was unconscious or at risk of dying if exposed to minor infections.

We used Bateson's notion of context, acknowledging that context is not something given and stable (Dilley, 1999). Bateson's concepts of "context markers" and "frames" helped us to understand that defining context

**TABLE 3** Topic guide for qualitative interviews

Aim – lines of inquiry	Questions
Context	
Organisation	What is the management set-up? How many employees are there on the ward? Professions? Shifts? How many patients? Rules for visitors? How is the ward organised physically? What are the ward's strengths/weaknesses?
Illnesses and treatments	What illnesses are treated? Treatments? Side-effects for the patients? Prognosis? Survival? Treatment challenges?
Daily tasks and routines	What are the main tasks for your profession? What do you perceive as the most important tasks? What are the main meetings during a working day? What are they about?
Ward expectations regarding actions related to dependent children as relatives	How are your tasks defined regarding dependent children as relatives? If there are no objective descriptions—how do you perceive your tasks?
Experiences relating to dependent children	
Actions	When do you typically talk with patients about their children? How—and by whom—is the subject raised? What are the talks about? How do you experience these talks? Have there been times when you thought about bringing up the subject but decided not to? What were your reflections?
Challenges	Do you remember the last talk you had about dependent children? What was it about? What happened? How did you feel during this talk? What went particularly well? What challenged you? Do you remember a talk about dependent children as relatives that made a special impression on you? What happened? What did you feel/think—and what were your reflections afterwards?
Attitudes	How much time do you think it is ok to spend on dependent children compared to other subjects that preoccupy patients? How much time is available? What other personal topics do you discuss with patients: psychosocial, existential, physical, other? What do you think should be your tasks as a health professional regarding dependent children? What tasks would be you find realistic, taking your other tasks into consideration?

implies that the researcher takes an active stance. This means that context markers will refer to particular “signals whose major function is to classify context,” whereas a frame provides a context within which new messages can be interpreted (Rawlins, 1987; Van Gorp, 2007). Identification of context markers and frames varies from tacit agreement to the identification of “differences that make a difference” (Rawlins, 1987).

We began the coding by searching for medical contexts markers influencing views on children and generating communicative challenges. A comparative perspective between wards promoted an understanding of specific context markers within each ward (Miles & Huberman, 1994). Resulting context markers included risk of infection (haematology), women diagnosed with cancer or discharged to a hospice (oncological gynaecology), and unconsciousness (neuro-intensive care). These gave, for example, the following themes: “infection risk and isolation,” “children as sources of infection” and “ambivalence regarding the presence of children,” indicating how diagnosis and treatment modalities influence views on children and related challenges to communication.

In our study the overall context was medical, and this framework meant that context markers dependent on illness and treatment determined how healthcare professionals would relate to children.

## 2.5 | Ethical aspects

This study was conducted in a setting where professionals encountered people who were seriously ill or relatives to seriously ill patients. Participants were therefore in a very vulnerable situation, where death was either an imminent possibility or a reality, further treatment having been ruled out. Such encounters are particularly difficult when patients have dependent children. Our project required careful ethical consideration to minimise any possible harm or distress (Kumar, 2005).

Our study adhered to the following ethical criteria to protect health professionals and the patients and relatives that they encountered during fieldwork (Richards & Schwartz, 2002):

1. Avoid creating anxiety and mental strain,
2. Ensure that participants participated voluntarily without infringement to their personal limits,
3. Prevent breaches of the participants' sense of autonomy, which meant respecting their perceptions and avoiding stigmatisation in the analysis,
4. Ensure participants' anonymity.

Against this background, we wrote an introductory letter, informing patients and relatives about our project, which stated that:

1. Data collected would be used to improve doctors' and nurses' current efforts.
2. Participation was voluntary and could be terminated at any time.
3. Non-participation would not affect the treatment of patients or relatives or their stay at the hospital in any way.
4. Participants' anonymity was guaranteed. In any subsequent use of interviews, individual identities would be rendered unrecognisable.

After reading the letter, patients and adult relatives gave oral consent to the healthcare professional.

According to the system applied by The Danish Committee on Health Research Ethics, notification is only required in the case of research projects and questionnaire-based surveys in which human biological material is included. Similar regulations apply for interview-based surveys (Kobbernagel, 2016). The project lived up to the Helsinki declaration (World Medical Association, 2013) and was approved by the Danish Data Protection Agency. Registration number: J.nr. 2016-41-4895.

### 3 | RESULTS

Overall, we found that communication between health professionals and patients about their dependent children was influenced by aspects specific to the ward in question, including particulars related to the patient's diagnosis and its treatment modalities. In the following, we will present each ward and its foci as regards patients' treatments. Moreover, we present the categories we found for how children were approached on each ward according to their parent's diagnosis and treatment, and how encounters came to reflect these contextual conditions. Quotes from interviews are referred to with profession and number, for example doctor 4:1, whereas quotes from participant observations are referred to, for example nurse from fieldwork.

In the following, we will present each ward and its foci as regards patients' treatments. Moreover, we present the categories we found for how children were approached on each ward according to their parent's diagnosis and treatment, and how encounters came to reflect these contextual conditions. Quotes from interviews are referred to using profession and number, for example "doctor 4:1," whereas quotes from participant observations are referred to, for example "nurse from fieldwork."

#### 3.1 | The haematological ward

*A common flu infection can be the death of our patients.*  
(doctor 4:1)

##### 3.1.1 | Bone marrow transplantation, infection risk and isolation

In the haematological ward, cancer patients went through bone marrow transplantation. During the transplantation process, patients had no immune system to protect them from infection and could die of even the slightest infection. Therefore, patients were hospitalised in so-called flow-rooms, where the air was constantly changed to avoid bacteria or virus and both adults and children were excluded if they had the least infection.

After transplantation, patients were kept under careful observation in the outpatient clinic and sometimes hospitalised because of life-threatening complications.

*I think the treatment we give here is the harshest treatment you can offer a human being. Often patients die from the treatment and not from their basic illness.*

(doctor 4:1)

We found that this intensive and risky treatment made the health professionals perceive the patient primarily as a unit that had to be isolated from the family.

##### 3.1.2 | Children as "sources of infection"

*The children are a major source of bringing a lot of stuff [infection] in here. So, in that way they become an issue.*

(nurse 4.1)

Prior to receiving the treatment, patients, often with a close adult relative, participated in a so-called pre-consultation session, where the transplantation process was reviewed in detail. The subject of children rarely came up. Their well-being and the issue of how patients could handle the harsh treatment while having dependent children scarcely featured.

However, there were cases when the issue of children did arise, primarily in relation to safety.

*But then, during the pre-consultation, we did actually talk about it [the issue of children], but that was more about practical measures regarding how he [the patient] could avoid being infected. Because children, especially children, are a major source of infection.*

(nurse 6:1)

In the outpatient clinic, the issue of children was also brought up for safety reasons. Patients wanted to know what they should do if their children were ill. Patients also experienced restrictions in their social lives due to risk of infection. Here follows an example from the outpatient clinic of how doctor and patient shared concerns about the necessity of taking precautions. The patient is in his sixties.

Patient: How about me hanging out with other people?

Nurse: Well, that depends on your level [level of infection resistance] and what we call common sense. Of course, you should not hang out with sick people. Now, I know that you have grandchildren, so with them you should be aware of the infection risk.

Patient: Well, they are big now, 16 and 19 years old.

Nurse: Oh, are they that old?

Patient: But one of them works with children, so she could actually bring something [infection] home.

Nurse: Ok, then, be aware! And no big Christmas parties and buffets.

Patient: I have already said no to a big Christmas Eve with my mother-in-law. I told her that I have to spend Christmas Eve in a smaller group

During treatment, patients and their children had to be kept separated for up to 6 weeks. This was especially difficult for the smallest children, who were often in kindergarten or at school. They carry the most infections and at the same time had the greatest need for physical contact.

*It is difficult to explain to children that it is okay for you to see your mom or dad, but you are not allowed to kiss and hug.*

(nurse, fieldwork)

Parents also suffered from the separation.

*Six weeks is a long time, finding out that 'but I can't see my children for six weeks'.*

(nurse 7:3)

### 3.1.3 | Ambivalence regarding the presence of children

Healthcare professionals felt it important that children visited the ward to get a realistic picture of the parent's situation, but they were keenly aware of children as potential sources of infection, as threats to successful treatment and to their parents' lives.

*We cannot have children running around here. Still, I usually say, and I think my colleagues say the same thing, that children are very welcome at this ward; they just have to be healthy. They can't be snotty and have colds because then they are a danger to the patient and to other patients.*

(doctor 4:1)

The physical environment was not inviting for the children either, because of the risk of infection.

*This ward is enormously sterile, because we care a lot about hygiene and bacteria (laughs), so we can't really have anything extra here [for children]. For instance, when I look around this room, it is just uninteresting in itself, right. We do not have many child-friendly things here.*

(nurse 7:1)

### 3.1.4 | Children re-categorised in the face of death

Healthcare professionals considered children "sources of infection" until the patient was dying or had died. As one nurse said:

*We don't talk about their children every day at all. It is more if something happens. If the patient gets worse.*

(nurse 5:1)

Then children shifted position from being sources of infection to regaining their position as loved ones and objects of attention in their own right.

*I think it is important to take care of those kids. If the patient dies or becomes extra fragile.*

(doctor 4:1)

To involve children also meant inviting them in to be close to their dead or dying parent.

*Many would say 'no, a five-year old child should not be placed together with a dead human being... - but if that is what the five-year-old needs, then that is what the five-year old should do.*

(nurse 7:2)

In summary, communicative conditions on the haematological ward were characterised by long-term hospitalisation, risk of infection and patients' isolation, including separation between parent and child for a prolonged period. We found that these conditions made health professionals and patients position children as sources of infection. Health professionals expressed ambivalence regarding children's visits, acknowledging the importance of the parent-child relation but needing to protect the patient from life-threatening infections. In haematology, the core communicative challenge for healthcare professionals was, then, how to care both for the patients' medical treatment and for the affective needs of children and parent. It was not until the parent was dying or had died that children were genuinely invited in, since by then there was no longer any risk of infection.

### 3.2 | The gynaecological oncological ward

*I think it is important that the patient feels that we perceive her as part of a family structure.*

(doctor 8:2)

### 3.2.1 | Female patients, microscopy answers and palliation

Women on the ward were under diagnosis or in treatment for different kinds of lower abdominal cancer, which often caused severe side-effects, such as pain during intercourse because of thin and delicate mucosal, the tendency vaginal walls to adhere, frequent urination and diarrhoea. In rare cases, patients had a stoma or a urostomy. Patients of childbearing age could lose their ability to have children because of the illness and the treatment.

Apart from an in-patient unit, an out-patients' clinic and an operation section, the ward included a palliative unit with so-called open admission for those patients, for whom no further curative treatment could be offered. Patients were hospitalised in this unit when they were very ill or dying, and if they needed pain management or nutrition.

### 3.2.2 | Family focus

Here, the subject of children was addressed more often than in haematology and neuro-intensive care. Those who had worked in other departments with both male and female patients noticed the greater focus on the family.

*I have been working in a urological ward, which has to do with bladder and waterworks, you know, and there you have quite a few men, too. And then when I think back, I realize that there is greater focus on the family when women are lying in bed than when men are.*

(nurse 8:1)

There was concern about the patient as the family's "anchor" and the possible consequences of her being seriously ill.

On medical rounds, healthcare professionals would ask whether patients had children, where they were, what they had been told and who took care of them. They would ask whether schools and kindergarten had been informed about the patient's condition, whether the children had visited the hospital, and when the next visit was planned. And they would sometimes notice if the children had not been to the hospital during the patient's hospitalisation.

*Yesterday, I sat down and talked to her because I wanted to know... I hadn't seen her children... how they are, when they are here, and what they do, and who takes care of them.*

(nurse 11:1)

### 3.2.3 | Children as invisibly present

Healthcare professionals spoke about children in specific situations, but children were seldom physically present, unless the patient was dying.

In gynaecology, doctors always asked about the patient's children because for technical reasons they had to know whether the patient had ever given birth.

*In fact, we investigate if the patients have children because it is relevant for us technically to know whether they have given birth or not.*

(doctor 6:1)

Doctors had to know if the patient wanted surgery that would conserve fertility, and knowledge about previous births was also important for preparing which technique to use during surgery.

If the microscopy results revealed cancer cells, patients often brought their children up as a subject because they were concerned about how to inform their children in the best way. During fieldwork patients asked: "What shall I say to my children?" and "What can I say when my children ask me if I am going to survive this?"

### 3.2.4 | Supporting patients in supporting their children

Healthcare professionals thought that the best person to inform the children about the diagnosis was the patient herself.

*The children should primarily be told by their mum.*

(doctor 7:1)

Nevertheless, healthcare professionals often found that patients did not have the mental resources to think about their children in the diagnostic situation.

*It does happen that they shut down when they get the diagnosis.*

(doctor from fieldwork)

Therefore, some healthcare professionals paid extra attention to addressing children themselves in trying to support patients in supporting their children.

*I think it is very, very common, when we give a diagnosis to someone with children younger than 18, that they haven't really thought about the need to inform those children when they leave here. [] Then it is we who bring it up by saying: 'Do you have any children, and what have you thought about telling them?'*

(doctor 8:1).

### 3.2.5 | Children re-categorised in the face of death

Healthcare professionals particularly addressed children when patients were to be discharged from the hospital to a hospice. In these cases, patients had difficulty telling their children that they were dying and knowing how to say goodbye to them.

*I remember several cases where women have reached that stage where they can no longer get well and where we*

*have them hospitalised in what we call a palliative unit, but where they haven't really reached a clear understanding with their children - meaning that they haven't told them how ill, they are.*

(doctor 7:1)

When patients were hospitalised and waiting for admittance to a hospice, children came to the ward more often.

*It can be quite hard. [...] However, we really try to involve them, especially in the palliative unit where we sometimes have younger patients with children. In those cases, we really try to get the children in here [clears throat]. We try to make them feel comfortable even though they don't feel like that at all.*

(doctor 8.1)

One nurse spoke of an interaction with a 5-year-old girl who followed her to the nurses' area and told her: "I know that my mum is going to die soon". The nurse asked the girl if she had talked to her mum about it, and the girl said: "Yes, I did." The nurse then asked "Do you know what happens when your mum dies?" and the 5-year-old responded: "Yes, then I can't talk to her anymore" (nurse 8:2).

In summary, here there was a greater focus on the patient as part of a family, and children were discussed more often than on the neuro-intensive and the haematological ward. Nevertheless, we found that health professionals and patients mainly positioned children as "invisible present," meaning that the children featured in their discussions even though they were seldom present.

### 3.3 | The neuro-intensive care unit

In contrast to the haematological and the gynaecological oncological ward where treatment processes were longer, the neuro-intensive care unit was characterised by its many acute situations.

*This is not like a longer cancer treatment process where you arrange a meeting to talk about things and to find out what to do. That is not our reality. Our reality is that relatives are called in at some point or another and now they are standing here.*

(doctor 3:1)

#### 3.3.1 | Unconsciousness, high-tech treatment and crisis

On the neuro-intensive care unit, most patients were unconscious because they had a cerebral haemorrhage, spinal cord injury or a so-called traumatic brain injury caused by heavy blows or shocks to the brain tissue. The treatment was highly technological, and the patients were constantly monitored because of their life-threatening condition.

The patient's hospitalisation period was most often only a matter of days, which meant that health professionals rarely got to know the families very well. They met relatives who were in deep crisis, shocked, sorrowing, and oscillating between hope and hopelessness.

*Our relatives are almost implicitly in crisis when they arrive at the unit, because the occurrence that brought them here did not give them any time whatsoever to defend or prepare themselves for the situation.*

(doctor 3:1)

Although the adult relatives were in crisis, they became involved as spokesperson for the patient, whose unconscious state made communication impossible.

#### 3.3.2 | Children as spectators

When children were present at a parent's bedside, the healthcare professional would communicate mostly with the healthy parent, whereas children became spectators and were excluded from the conversation.

Healthcare professionals did not perceive children as their primary responsibility but saw the patient and any adult relative as the most important people.

*I think that children are always kept a little in the background, because the patients are so critically ill.*

(nurse 3:1)

However, healthcare professionals were aware of the reactions of relatives, including those of children. One nurse wondered:

*How do we give children information without ending up in this adult-to-adult conversation [laughs a bit] that we so easily fall into as medical professionals?*

(nurse 2:1)

Acute situations seemed to reinforce this adult perspective and the children's role as spectators. During the fieldwork, for example an unconscious female patient had her husband and their 13-year-old son visiting her. They were standing by the bed, when the doctor addressed them, informing the husband in some detail about the patient's condition, looking at him constantly. After providing information about the patient's condition and the treatment plans, the doctor looked at the son and said: "It must be very difficult for you to have your mum lying there." The boy nodded, and the doctor left. In the subsequent interview with the doctor, he commented that parents themselves are best placed to inform their children.

#### 3.3.3 | Involving children through a parent in crisis

Healthcare professionals found it hard to support children by communicating with the other parent.

*The adults we meet here are very affected by the situation, they are hit by crisis and don't seem to be able to make head or tail of anything. They need to get the same information repeatedly. You need to be very patient with them.*  
(nurse 3:1)

The need to respond quickly to the critical needs of the patient sometimes made it particularly hard for healthcare professionals to establish contact with relatives.

*The situation is fatal. Death and mutilation. And time is short to make contact.*  
(nurse from fieldwork)

Parents were often so affected by the situation that they could hardly provide their children with the care they needed.

*How is this mother, who is completely wooden almost made of stone in her way of moving and speaking – how is she going to manage the three children? She does not have the resources, and we have nothing to offer but a pamphlet.*  
(doctor 1:1)

During fieldwork, it became apparent that children remained spectators when healthcare professionals left the responsibility for informing them to their parents or to some other close relatives instead of proactively asking if they needed help to handle the situation.

*If they have not asked about it, then it must be because they have a grip on things.*  
(nurse 3:1)

Adult relatives, however, seldom asked for help, even though it was obvious that they were having a very hard time. For their part, healthcare professionals explained that they lacked referral opportunities and felt insecure as to how to support the parents in supporting their children.

*Children float around in intensive care. Nobody knows what to do with them.*  
(nurse from fieldwork)

Health professionals also found it challenging to communicate uncertainties regarding patients' future condition.

*It is not, like, when the ventilator is removed from her throat, then mum comes home. We know that mum will never be the same. How then do we prepare children for the fact that mum will never be the same person; that 'normal' mum is not coming back. We do not know what she will become. We have nothing concrete to say.*  
(doctor from fieldwork)

Communicating with children about organ donation was a particular challenge on the neuro-intensive ward. Patients look as though they are alive but sleeping, because they are warm, dry and their heart beats when they leave the unit. *"And then they [the parents] are driven away from the hospital bedroom and come back dead"* (doctor 3:1).

### 3.3.4 | Limits of "children as spectators"

Healthcare professionals involved adult relatives in assessing how much children at different ages should participate, their aim being to avoid the children's limits being transgressed.

*The natural fear is that you land the child in a situation where they experience something that is scary and that we cannot subsequently explain or that is traumatising for them. I think that makes us take a conservative line.*  
(doctor 3:1)

Health professionals explained that they would rather prevent children from participating than run the risk of traumatising them.

Children's position was therefore restricted to that of spectator.

On the neuro-intensive care unit increased attention had been paid to opportunities for parents to witness the resuscitation of their child. The idea was to help parents cope afterwards if their child did not survive, because they would have seen health professionals do everything possible to save their child. Nevertheless, we found that there were limitations to children as spectators in similar situations.

*If I think the other way around and think that children might benefit from seeing with their own eyes that we did everything we could to resuscitate their parent, I find that we have not reached a point where we think like that.*  
(doctor 2:1)

### 3.3.5 | Children re-categorised in the face of death

However, children ceased to be spectators when the patient died or was dying, because they were informed and invited in to see the deceased or dying parent. When the patient died, the focus of healthcare professionals changed as regards the communicational challenges. From discussing the degree to which children were or should be spectators, they now considered ways in which children could be involved.

*In neuro-intensive care there is no habituation. At four o'clock, the phone rings. At eight o'clock father is dead. The challenge is to involve the children even though it is dramatic.*  
(nurse 1, fieldwork)

*I wonder how children experience being woken up at four o'clock in the morning and then have to go to the*

*hospital and say goodbye to daddy who has become a star in heaven.*

*(nurse 2, fieldwork)*

In summary, communicative conditions on the neuro-intensive care unit were characterised by acute situations, constant surveillance of patients because they were in danger of death, and relatives in crisis. These conditions during treatment apparently made health professionals position children as spectators. This position changed, however, when the patient died, and focus shifted from treatment to saying farewell.

### 3.4 | Comparisons across wards

Across wards we found a close link between the patients' diagnosis and treatment and perceptions of both children and patients. In haematology, children were seen as potential sources of infection, while the patient was primarily seen as a unit to be isolated from the family during the treatment, which included an isolation period. In gynaecological oncology, children took on an invisible presence, and patients were seen more as part of a family than on the other two wards. The latter could indicate that, regardless of the medical diagnosis, gender was an important context marker in gynaecology when compared to haematology and neuro-intensive care, where there was a mixed gender distribution. Finally, in neuro-intensive care, children mostly became spectators while an adult relative was included as a communicative substitute for the patient.

The more patients were perceived as units as a consequence of the demands of their treatment or due to unconsciousness, the more children seemed to be absent from encounters. Across wards, the prospect of death seemed to dissolve all categories of "children as," because healthcare professionals became genuinely concerned to include children both psychologically and physically (see Table 4 for an overview of our results).

## 4 | DISCUSSION

We encountered two problems in former research concerning patient-centred care. One was the lack of studies addressing dependent children. Another was that medical contexts were not addressed systematically when it came to investigating encounters between healthcare professionals and patients. Our study embraced both problems by, (1) focusing on the inclusion of dependent children in clinical communication, and (2) contextualising such communication in terms of views of children and communicative challenges.

To our knowledge, this is the first qualitative comparative study to highlight how children are positioned differently according to the medical context and how this influences encounters, including communicative challenges.

In haematology, healthcare professionals were ambivalent about the presence of children, making it clear that they were welcome while at the same time worrying about infections. This expression of ambivalence could be understood with reference to the digital and analogical communication of Bateson's analysis. Thus, health professionals said that children were welcome (digital) while worrying (analogic), which proposed the interpretation that children should stay away.

In oncological gynaecology, the challenges were to enable parent-child communication, revealing a cancer diagnosis and/or explaining that there was no more treatment. In this ward, all patients and most healthcare professionals were women. With reference to Bateson, gender could, as mentioned, have been an important context marker promoting the view of the patient as part of a family underlining the necessity to address children as relatives.

Finally, in neuro-intensive care where acute situations seemed to strengthen an adult perspective with one parent unconscious and the other in acute crisis we found that children often became spectators. With reference to Bateson, time and suddenness could be important context markers here calling for further investigation. Thus, the communicative challenges in neuro-intensive care became to involve

**TABLE 4** Result overview

	Haematology	Gynaecology	Neuro-intensive
Medical context	Risk of infection with bone marrow transplantation, isolation, long-treatment processes	Female patients, microscopy answers and palliation, long-treatment processes	Unconsciousness, high-tech treatment and crises, acute treatment
Children	"Children as sources of infection," ambivalence regarding children's presence	"Children as invisibly present," children are more talked about medically and socially than present	"Children as spectators," children fade into the background with one parent unconscious and the other in acute crisis
Patient	Patient focus. Patient as a unit, to be isolated from the family	Family focus. Patient as part of a family	Adult relative focus. Adult relative as substitute for the unconscious patient
Communication challenges	To support the parent-child relationship during the patient's treatment and isolation	To enable parent-child communication when patient reveals a cancer diagnosis and/or explains that there is no more treatment to offer other than palliation	Involving children through a parent in crisis. Communicating with both adults and children at the same time in acute situations

Children re-categorised in the face of death; children resumed their role as family members

children through a parent in crisis and to communicate with both adults and children at the same time within the narrow timeframe. Using Bateson's terminology, this would imply including children both verbally (digitally) and non-verbally (analogically). We did find examples of encounters in neuro-intensive care where children were not included in any of these ways. This corroborates previous literature, suggesting that healthcare professionals do not systematically involve children in intensive care due to, e.g. the severity of the patient's injury, the business of the unit, or the fear of not being able to cope with children's questions or with their own emotions (Knutsson & Bergbom, 2007a, 2007b, 2016).

#### 4.1 | Contextualising patient-centred care

Although focusing on psychosocial needs and resources, including involvement of relatives, has been articulated as a key element in the provision of patient-centred cancer care, our findings highlight both the challenges in reaching this goal and the context-dependency of communication in clinical encounters. Our contextualisation of patient-centred care may provide impetus for future research and training programmes to enable a more informed and systematic approach to improving encounters between cancer patients, their relatives, especially their children, and healthcare professionals in cancer care. A number of communication training programmes have been conducted over the last 15–20 years with the aim of improving healthcare professionals' communicative skills in cancer care, and thereby promoting and integrating a patient-centred perspective. A few of these programmes have been evaluated as randomised trials and have indicated a variety of communication skills mainly aimed at improving (1) healthcare professionals' medical interviewing skills (with more use of open focus and open questions and less use of closed questions), (2) ways to establish a therapeutic relationship with patients that can reveal their concerns and worries (more expressions of empathy and appropriate response to patient cues) and (3) the ability to give patients information (summarising information and checking understanding) (Delvaux et al., 2004; Fallowfield, Jenkins, Farewell, & Solis-Trapala, 2002, 2003; Razavi et al., 1993, 2002).

Evaluation of the above-mentioned training programmes has given varying results. Some communication skills, such as expressions of empathy, improved in some programmes, while they did not change significantly or decreased in other programmes (Fallowfield et al., 2003; Jenkins & Fallowfield, 2002). As regards these studies, there seems to be some unpredictability as to which skills are transferred from training to the workplace environment. This may be as a result of communication skills being dealt with primarily as immutable and not context-dependent and not as situated activities taking place in an interaction between individual agents and the social world (Lave, 2009). To promote transfer of skills, attention must be paid to the contextual and organisational characteristics of the environment that frames clinical encounters with patients and their relatives (Riiskjær, 2014; Uitterhoeve, Bensing, Grol, Demulder, & Van Achterberg, 2010). Our study is an example of how focussing on contextual aspects can reveal communicative challenges that invite healthcare professionals

to anticipate important focal points in encounters taking place in particular settings, which, we suggest, promote transference from training to practice.

Three comprehensive reviews focusing on improving patient-centred care are in line with our results, stressing that future studies should assess communication more holistically and take the clinical context more into consideration, for example complex treatment protocols and the inclusion of spouses and other family members (Gysels, Richardson, & Higginson, 2004; Kruijver, Kerkstra, Francke, Bensing, & van de Wiel, 2000; Moore, Rivera Mercado, Grez Artigues, & Lawrie, 2013).

#### 4.2 | Strengths and limitations

Our study builds on a large number of qualitative, semi-structured, in-depth interviews and participant observations. Combining multiple interviews of healthcare professionals with repeated participant observations on wards was felt to be important for deepening our understanding of healthcare professionals' views about children and of the influence of contextual aspects on these views. Shadowing participants during their clinical practice strengthened our understanding of the context within which healthcare professionals were operating, including their working tasks and challenges. Participant observations also created a common frame of reference for the interviewer and the healthcare professionals, which meant that the interviewer could ask about some of the situations occurring during the participant observations.

Following healthcare professionals in a neutral, though appreciative way also seemed to strengthen their relationship with the interviewer in the sense that they were more open in expressing their experiences, including those they found difficult. It was made clear during participant observations that the ongoing evaluation focused on the intervention group responsible for the training programme, not on healthcare professionals. This approach promoted trust and openness between interviewer and informants.

However, our study also had a number of limitations. First, participants were mainly experienced, middle-aged women engaged in an educational programme. This, together with the continual participant observations, contributed to increasing their awareness of patients' dependent children over time. This inevitably led to the healthcare professionals asking more frequently about patients' children, and it reinforces calls for further studies among less experienced professionals, including men and healthcare professionals unaffected by prior or personal interest.

Second, although our study focused mostly on ward differences rather than on similarities, our findings regarding one ward's views and challenges could provide relevant input for others. For instance, acute situations did arise in haematology and in gynaecological oncology with the risk of children becoming spectators, though not as often. Children could also represent sources of infection in neuro-intensive care and in gynaecological oncology, or be invisibly present in haematology and in neuro-intensive care. Furthermore, patients and relatives on all three wards were often in crisis. Finally, even though healthcare

professionals generally stated that addressing children was an important issue, it was often impeded by very tight timeframes and by the lack of perceived room for manoeuvre, which often left children in the background. So, while healthcare professionals did experience similar challenges across wards, we stressed the differences between wards to explore the degree to which the inclusion of children in clinical encounters is dependent on the medical context.

Third, our analysis was informed by Bateson's theoretical framework, within which we coded the medical context markers influencing views on children and related communicative challenges. This increased transparency but left out other potentially important context markers, such as the patient him or herself, the role of doctor or nurse, gender issues, time, family characteristics among patients or the health professionals' work climate. Apart from considering context as an important aspect in encounters, health professionals also must remember to ask patients about their needs (Zucca, Sanson-Fisher, Waller, Carey, & Boadle, 2017). Moreover, the categorisations of children were our constructions, which, though empirical based, were still our interpretations of the interaction between contexts that we framed and the content of encounters and interactions within this frame. The categories should not be understood as definitive or static.

Fourth, although some insights came from patients, particularly in the haematology ward, our study primarily addressed the views of healthcare professionals'. Future studies should include the viewpoints of patients and their relatives, of their spouses and children, for example through case-based, serial qualitative interviews and observations across the treatment trajectory of cancer patients. Finally, there is a paucity of knowledge regarding gender aspects influencing communication during parental illness, which future studies might also address, for example what fathers' experiences and needs are (O'Neill, McCaughan, Semple, and Ryan (2016).

## 5 | CONCLUSION

Using original empirical research on encounters in three medical contexts, we found that each ward's diagnosis and treatment played a pivotal role for the shaping of children as categories and the challenges that health professionals experienced in addressing patients' dependent children as an issue. In future research, and in training programmes for patient-centred care, including the care of children, it would be important to pay greater attention to the significance of context to understand, target and prepare healthcare professionals to facilitate parent-child communication. This implies further research that would include other context markers than those we defined in our study.

While the focus of this article has been on the inclusion of dependent children in clinical communication as a feature of patient-centred cancer care, it would be wrong to underestimate the complex needs of children here. Focusing on the general support of seriously ill patients in regard to their children may ensure that children are involved before the parent dies. We found across wards that children were not genuinely involved until after the patient died or after the acknowledgement that there was

no more curative treatment to offer. Since earlier studies have shown that children have a need to be involved earlier in the illness process, the field would benefit from investigating barriers to early involvement and methods to overcome them (Bylund-Grenklo et al., 2014; Kennedy & Lloyd-Williams, 2009; Tillquist, Bäckrud, & Rosengren, 2016).

National guidelines regarding patient-centred care in general could also benefit from differentiating between patients as well as between wards and families, so that patients are seen both in their medical context and as part of a family. We conclude that there is no one single solution to an issue that encompasses such a range of interests and involves such emotional complexity for patients, children and professionals alike. Moreover, we find it important to perceive patients, not as isolated entities but as part of a relational fabric—in which children are usually paramount.

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