Health communication
– when seriously ill patients have dependent children

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- when seriously ill patients have dependent children
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**Front cover:**
Anonymous 8-year-old child’s drawing of her dying mother in the hospital bed
Authorization to use the drawing has been obtained
Thank you to Mette Eland for help in finding the drawing, and to Martin Berge who suggested the color orange as background
Preface
In 1933, an 8-year-old boy was playing around in a school yard in Copenhagen. Some of his schoolmates stopped him.

“So, what’s this about your mother?” they asked.
“She is in hospital,” he replied.
One of the schoolmates looked at him.
“Don’t you know that your mother is dead?” he said.

The boy went home and asked his father if it was true. His father’s face darkened as he answered that his son’s schoolmate was right, that he was very sorry about his mother’s death and for not having had the courage to tell the truth much earlier. It turned out that the boy’s mother had died of breast cancer two years before. During these two years, his father had told him that his mother was in hospital and that hospitals were not for children. He could not bear to tell his son about his mother’s death as he struggled to hold onto being a single father for his son.

This 8-year-old boy was my stepfather for 38 years until April 2017, when he died at the age of 92 after a long, rich and fulfilled life.

This PhD thesis focusses on communication on three different hospital wards between healthcare professionals and seriously ill patients about patients’ dependent children. In conducting this study, I found that the case of my stepfather way back in 1933 remains relevant, since inviting children into hospitals and involving them in their parents’ illness trajectory is still perceived as a challenge by the patients themselves, by the healthy parent and by healthcare professionals.

It was only in 2012 that Denmark developed its first set of national recommendations for healthcare professionals in their encounters with seriously ill patients regarding their children, but, unlike Norway, Sweden and Finland, there is still not sufficient political backing for legislation to assist healthcare professionals in supporting parents in supporting their children during times of serious illness and crisis. Likewise, there is no national standard pre- or post-graduate training for healthcare professionals in this area. Therefore, healthcare professionals must often improvise their actions by themselves, and this, combined with lack of time and other structural deficiencies, sometimes leads them to avoid the subject or to become emotionally overwhelmed. I found that healthcare professionals’ emotional responses tended to become more intense if structural barriers for addressing the issue of the patients’ children were not addressed.

I conducted this PhD thesis in an emotional field in which parents were facing death or had died, leaving behind their dependent children without having had the opportunity to complete their most important mission, to protect their children until they could manage on their own. This posed special demands on the research process. For example, interviews with patients close to death, in pain because of their situation, and in distress about their children required of me a degree of clarity
and control if I was not to be swallowed up in my own emotions on their behalf. In this process, it helped me to be constantly aware of the reason for me being there – and the reason for my research. The aim of this research has been to cast light on patients’ communicative experiences and on the demands made on hospitals in relation to having seriously ill patients with parent responsibility. Moreover, I wanted to contribute new knowledge in order to facilitate development of this particular field of communication. Ongoing sparring with fellow researchers and colleagues at Danish Cancer Society alongside a recognition that the patients’ situations were not mine were also important aspects underpinning this research. Finally, I was conscious of the importance of not missing out other crucial aspects influencing this field of communication, such as the structural conditions at the hospital.

I wish to thank a number of people who have inspired, contributed and supported me throughout this process and helping me to stay focused.

First and foremost, I want to thank my principal supervisor, professor, anthropologist, MSc, PhD Tine Tjørnhøj-Thomsen, National Institute of Public Health, University of Southern Denmark. I could not have wished for a better mentor, neither professionally or personally. I am deeply grateful for all our talk, discussion and laughter. Everyone I know has heard about you. I also want to give a special thanks to my boss and industrial supervisor, the teacher and head of the Bereavement Project Per Bøge, whom I worked with for 12 years and without whom this PhD would not have been possible. Thank you for all your support and for always staying focused on the children. Thanks also to pedagogical consultant Jes Dige, who together with Per Bøge created the Bereavement Project in Danish Cancer Society back in 1995 and appointed me to work with them. You have both been very generous in teaching me about children and bereavement. From Danish Cancer Society, I also want to thank the rest of the Bereavement team, including Andrea Nedergaard Jensen and Adriana Pljevaljic, who transcribed the bulk of my interviews. Also thanks to my other industrial supervisor, head of Development and Documentation Bo Andreassen Rix MD, MSc, PhD, for supporting and encouraging the whole process. Moreover, I want to thank Kræftlinjen, a telephone line for patients and relatives at the Danish Cancer Society, for valuable discussions about this thesis and its perspectives and possible clinical impact in the future, especially to doctor Mogens Munch Nielsen and psychologist Kirsten Heldbjerg for facilitating and contributing to these discussions.

Entering the field of science has been a prolonged process for me. Here, I want to thank Professor Christoffer Johansen, the Oncology Clinic, Rigshospitalet & Life after Cancer, Danish Cancer Society Research Center for encouraging me to be a scientist and showing me the way to Tine Tjørnhøj-Thomsen, when I realised that I was never going to be an epidemiologist. Being part of the Research Unit for Health, Social Relations and Structural Conditions at the National Institute of Public Health, University of Southern Denmark with fellow researchers has been to great inspiration. Among the supportive and inspiring colleagues on the road to this PhD I count especially Nanna Ahlmark, Marie Broholm Jørgensen, Susan Andersen, Katrine B.H. Johansen, Maria Holst Algren, Ditte Heering Holt, Anne Sidenius and Liselotte Ingholt. Thank you all for
good discussions, support and for more informal chats. I also want to thank my editor, John Mason, for valuable feedback and great flexibility and Stig Krøger Andersen for helping with the layout of the thesis.

During the research process, I had the privilege to work together with Associate professor Maria Kristiansen MSc, PhD, Department of Public Health, University of Copenhagen, Denmark on my second paper. Thank you for your contribution, kindness and sharpness. Moreover, working on my third paper, I had the privilege to meet and discuss with St Columba’s Hospice Chair, Scott Murray DCH, DRCOG, MD, DFFP, FRCGP, FRCP, and Research Fellow Bruce Mason MA, PhD, Primary Palliative Care Research Group, the Usher Institute of Population Health Sciences and Informatics, the University of Edinburgh, Medical School, Edinburgh, UK. Thank you very much for receiving me so kindly at your Institute during my six-week stay and for valuable and engaged contributions to my third paper.

I also want to thank my friends and family for always being there with their support, wisdom and very nice meals: Kamilla Frimodt Madsen who moved to Greenland but is still close, Mette Ginman, Tina Gudrun Jensen, John Meyer Lassen, Anne-Mette Andresen, Olaf Tehrani, Camilla Torp Olsen, Anders Priemé, Martin Berge, Susanne Tøttenborg, Hanne Hansen, Marianne Søby, Inge Dencker and Charlotte Dencker. And to the amazing women’s club: ‘K-Gruppen’ with Sofie Kempf, Trine Demant and Eva Smedegaard. Without my tennis playmates and my yoga teacher, Lena B. Jørgensen, this work would not have been done. Finally, I want to thank my gifts of life, my daughter Paula and her Sebastian for laughter and discussion of all kinds during the whole PhD process, and Flemming for making sure that I did not fall asleep neither physically, mentally or spiritually.

Last but not least, I owe heartfelt thanks to the participating patients and healthcare professionals for their honest, vulnerable and important contributions. Some of the patients interviewed are no longer with us. May you rest in peace, and may your children find all the love and care they need. I hope this thesis will help to provide for future generations the support you sought for you and your children.

This PhD is for you.

Annemarie Dencker, Copenhagen, December 2017.
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English summary

Objective
The overall topic of this thesis is health communication. It focuses on how healthcare professionals (HPs) communicate with seriously ill patients about their dependent children (CSIP). Research indicates that HPs caring for seriously ill patients with dependent children aged 0-18 often avoid discussing with them the challenges of being a family with a parent in treatment. Children of seriously ill patients risk serious trauma and emotional difficulty later in life and depend on adult support to minimize these consequences. Patients suffer anxiety about supporting their children during their illness.

This thesis includes HPs’ and patients’ perspectives: 1) HPs’ barriers to addressing CSIP, 2) contextualisation and comparison of CSIP across three hospital wards, and 3) patients’ experiences of communicating with the HPs about their children. The thesis discusses the answers to these three questions and relate them to the concept of patient-centredness.

Methods
The thesis is based on an ethnographic study within: neuro-intensive care, haematology and gynaecological oncology conducted from September 2013 to June 2015. The study included 64 semi-structured, in-depth interviews (N=19 doctors, N=30 nurses and N=15 patients) with 39 interviewees (N=9 doctors, N=15 nurses and N=15 patients) and 27 days of participant observations (9 days at each ward). Data was analysed using a social constructionist worldview and addressed encounters between HPs and patients and how specific contexts influenced CSIP. Specific areas were analysed drawing on Maturana’s theory of domains (HPs’ barriers), Bateson’s concept of context (contextualization of CSIP), and Bury’s and Jenkin’s theories of (respectively) biographical disruption and social identities (patients’ perspectives).

Results
The thesis provides three overall results:

1. Focusing on HP’s emotional barriers as the main explanation for avoiding CSIP leads to structural barriers being overseen while emotional barriers tend to grow when structural barriers are not addressed.

2. HPs’ approach to CSIP in clinical encounters and the ways in which children are positioned are influenced by aspects specific to the ward, including diagnosis and treatment modalities.

3. Patients have two overall dynamic and competing identities: ‘patient identity’ and ‘parent identity’. As patients, patients are ambivalent about relating to their children; while patients as parents want HPs to ask them more about their children.
**Conclusions**

The thesis contributes to the part of the research field of ‘health communication’ that deals with ‘patient-centeredness’. It stresses that for HPs to be genuinely patient-centred as regards CSIP, there are various aspects to consider.

Firstly, there are a number of needs to be addressed: a) the need to use templates and manual procedures to gather and process information about children in medical records, b) the need for management backing for CSIP and for time allocated to it, c) the need for future HP training programmes to include how to implement procedures and how to address all barriers.

Secondly, communication skills promoting patient-centeredness are context dependent (e.g. skills needed in acute situations may be different from skills acquired during longer illness trajectories). Therefore, patient-centeredness might be addressed more locally taking ward characteristics into account and how these influence communication, including patients’ and children’s needs.

Thirdly, patients are not isolated entities but form part of relationships, including with their children. To be patient-centred, it is important to acknowledge that patients might have competing perspectives and identities, which surface at various times and situations throughout their illness trajectories. Thus, it cannot be taken for granted that patients always want to talk about their children, since they sometimes feel too exhausted.

Hence, the thesis suggests a situational and individualized approach where patient-centred communication skills are seen as context-dependent. The idea of manuals and standardization as a unilateral solution is hereby challenged, which is illustrated and discussed in a new model for communication regarding CSIP, called the BACIC model (Barriers, Contexts and Identities in Communication). The model is based on the thesis’ results. Finally, legislation and resources for implementation are recommended to secure future focus, action and quality when HPs address CSIP.
Resumé (Danish summary)

Formål
Denne afhandlings overordnede emne er sundhedskommunikation. Afhandlingen fokuserer på, hvordan sundhedspersonale (SP) kommunikerer med alvorligt syge patienter om deres hjemmeboende børn (KASP). Tidligere forskning peger på, at SP ofte undgår at tale med alvorligt syge patienter om det at være alvorlig syg og have forældresansvar for børn under 18 år. Det er vist, at børn med alvorligt syge forældre har øget risiko for at udvikle traumer og psykiske problemer senere i livet, og at de er afhængige af voksnes støtte for at mindske disse konsekvenser. Patienterne er ofte usikre på, hvordan de skal støtte deres børn i sygdomsforløbet.

Afhandlingen inkluderer sundhedspersonalets og patienternes perspektiver angående: 1) Hvilke barrierer sundhedspersonalet har for at adressere emnet børn som pårørende 2) Hvordan den medicinske kontext påvirker opfattelser af børn som pårørende og udfordringer i kommunikationen om børn 3) Hvilke erfaringer patienterne har med at tale med SP om deres børn. Afhandlingen diskuterer de tre spørgsmål i forhold til hinanden, og resultaterne relateres til begrebet om patientcentrering.

Metoder

Resultater
Afhandlingen præsenterer tre overordnede resultater:

1. SPs følelsesmæssige barrierer medfører, at de undgår KASP, og at strukturelle barrierer bliver overset. De følelsesmæssige barrierer bliver større, når strukturelle barrierer ikke adresseres

2. Den måde SP forholder sig til KASP på, og den måde børn bliver positioneret på i hospitalssammenheng, hænger sammen med afdelingsspecifikke forhold såsom diagnoser og behandlingsmetoder

**Konklusioner**

For det første må der indføres: a) skemaer og manauler, som sikrer indsamling og opfølgning på oplysninger om børn som pårørende, særligt i patientens journaler b) ledelsesmæssig opbakning og tid til KASP c) undervisning der adresserer implementering af procedurer og barrierer relateret til KASP.

For det andet må man fremme en kommunikationstilgang, der er baseret på: a) at kommunikationsfærdigheder er kontekstrelaterede (fx can de kommunikationsfærdigheder, der kræves i akutte situationer, adskille sig fra færdigheder, der er relevante i længerevarende sygdomsforløb). Som konsekvens bør arbejdet med patientcentrering være mere fokuseret på de særlige kommunikative forhold, der er influeret af den sygdom og behandling, som foregår på den pågældende afdeling, i dette tilfælde relateret til KASP.

For det tredje må det i patient-centreret kommunikation indtænkes, at patienterne ikke er isolerede enheder men en del af personlige relationer, herunder med deres børn. For at agere patient-centreret i denne sammenhæng er det således nødvendigt at være opmærksom på, at patienter kan have konkurrerende perspektiver og identiteter på forskellige tidspunkter og i forskellige situationer gennem deres sygdomsforløb. Det kan for eksempel ikke tages for givet, at patienter altid er parate til at tale om deres børn, fordi de til tider kan være for umattede pga. sygdommen og behandlingen.


Endelig foreslås lovgivning fulgt op af ressourcer til implementering for at sikre fremtidig fokus, handling og kvalitet i samtaler om børn som pårørende.
PhD thesis: idea and purpose
The overall topic of this thesis is health communication. It focuses on how Healthcare Professionals (HPs) communicate with seriously ill patients about their dependent children (CSIP). The thesis provides insight into how HPs encounter families in which one parent is seriously ill and where there are dependent children, and it comprises three studies, each covering a different aspect of HPs’ communication with seriously ill patients about their dependent children:

1) HPs’ experiences of CSIP
2) The relationship between three different medical contexts and CSIP
3) Patients’ experiences of communicating with HPs about their children.

The three studies present three central elements in promoting communication about dependent children focusing on:

1) HP barriers to addressing the issue of the patients’ dependent children
2) The influence of medical contexts on views of children and related communicative challenges
3) Patients’ identities as parent and patient when communicating with HP about their serious illness.

The three dimensions are presented in a new model for communication when seriously ill patients have dependent children. The model is called the BACIC model: BA for Barriers, C for Contexts and IC for Identities in Communication.

The PhD project is an Industrial PhD which means that I am employed in a company, Danish Cancer Society, and enrolled at a university, The University of Southern Denmark. As an industrial PhD student, my research project allows me the opportunity to apply results to counselling practice within the Danish Cancer Society as well as outside in relevant hospital and educational settings, such as on pre- and postgraduate courses for doctors and nurses. Thus, presenting the BACIC model in the discussion section of this thesis, I reflect on how the models’ three dimensions can be used to develop and strengthen CSIP. I also argue that the model can contribute to communicative practise for HPs in general because barriers, contexts and patient identities in communication may be an ongoing theme in all health communication, especially in situations with a high degree of medical, psychosocial and existential complexity.


1. Introduction

There are three overall perspectives involved when addressing CSIP: that of the children, that of the parents (either the patient or the healthy parent), that of HPs. This thesis focuses on perspective of HPs and of patients, which leaves that relating to children and the healthy partner to future studies to get a full understanding of all the perspectives and interactions involved. Nonetheless, in order to create a complete understanding of the issues involved, I give here an overview of all perspectives involved based on former research, which includes the consequences for children of seriously ill parents and for healthy partners.

Serious parental illness and the family

In 2013, 39,390 children (0-17 years) experienced a parent being hospitalized with critical illness in Denmark. By ‘critical illness’ I mean a patient who is five days in hospital, two times at hospital with a diagnosis within the same diagnosis group or death within 8 days following discharge. In 2004, the number was 42,054 children. Thus, there has been a decrease from 2013 to 2004. At the same time, there has been an increase in hospitalization for non-critical illness from 104,526 in 2004 to 110,672 in 2013. Number of days per hospitalization has decreased since 2004, which means that the estimate of nearly 40,000 children who may be living with a seriously ill parent might be too low (Data are tabulated by Statistics Denmark in 2015 on behalf of Danish Cancer Society).

Children living with a seriously ill parent are exposed to an increased level of psychosocial stress and develop greater behavioural and emotional difficulties than peers with healthy parents (Grabiak et al. 2007; Sieh et al 2010; Huizinga et al. 2011). For instance, children living with parental cancer alternate between despair and hope in the different disease periods. This negatively affects their sleep, memory, concentration and school performance (Dyregrov & Dyregrov 2011). Another study has shown that children living with parental cancer report higher anxiety and lower health-related quality of life than controls (Hauken et. al 2017). In addition, it has been shown that children who have been exposed to the death of a parent are at higher risk of depression and of using antidepressants in adult life, especially if bereaved by suicide (Appel 2013 et al.; Appel et al. 2016). These results indicate that the consequences experienced by children are related to the parent’s specific illness or cause of death.

Parental illness affects the whole family because daily routines are disrupted, parents and children are separated during hospitalization and the seriously ill parents suffer from lack of energy because of the illness, the treatment and the side-effects (Grabiak et al. 2007; Lewandowski 1996; Osborn 2007). It has been shown that the parent’s psychological condition, e.g. depression and family functioning (adaptation in the marriage, the parent-child relationship and coping strategies in the family) influence how children of seriously ill parents manage behaviourally and emotionally (Bogosian et al. 2010; Diareme et al. 2006; Pakenham & Cox 2012; Sieh et al. 2012). Moreover, studies suggest that parental depression negatively affects children’s coping (Watson et al. 2006; Lewis et al. 1993). This also applies when the healthy parent gets a depression. Thus, earlier studies
have shown that partners of seriously ill patients also more frequently meet criteria for major depressive disorder and generalized anxiety disorder than spousal caregivers without children (Nilsson et al. 2009; Yopp & Rosenstein 2012).

The serious illness challenges the family’s communication. Research has shown that children of seriously ill parents want to be informed about the illness as early as possible and that they prefer honest information about the parents’ condition and treatment (Kennedy & Lloyd-Williams 2009a; Bylund-Grenklo et al. 2015; Tillquist et al. 2016). Research has also shown that parents lack knowledge regarding how to inform their children about their illness and how to follow up on the information in the best possible way (Barnes et al. 2000; Buxbaum & Brant 2001; Helseth & Ulfsaet 2005). For instance, parents are uncertain how they can best handle children’s reactions when informing them about their illness without scaring them or taking hope away from them. Often parents avoid informing their children because of this doubt (ibid). Finally, studies have shown that parents tend to underestimate their children’s need for information and the degree to which their illness negatively affects their children’s well-being (Kennedy & Lloyd-Williams 2009b; Forrest et al. 2009; Huizinga et al. 2010; Watson et al. 2006).

HPs therefore play a potential pivotal role in supporting patients in dealing with those insecurities and doubts they experience during treatment that concern not only themselves but also their close family members, including their children. However, HPs do not practise this support systematically which indicates that they need help and better conditions to provide patients with relevant support (Dencker 2009a; Dencker 2009b).

**HPs addressing CSIP issues**

Research on HPs who meet families during hospitalization and treatment has shown that HPs do not feel competent to provide the support that the families request – which means addressing the challenges and the doubts described above (Dencker et al. 2017a; Dunne et al. 2005; Odling et al. 2002; Turner et al. 2007; Turner et al. 2008). Thus, HPs have been shown to find the emotional burden of the supportive role a key challenge, which results in emotional distancing from patients and avoidance of CSIP (ibid). In addition, being confronted with suffering and working with people facing life threatening illness, especially those who are young and have parental responsibility, can result in stress and ‘burn-out’ among HPs (Turner 2011).

For their part, family members of inpatients hospitalized with advanced cancer have been shown to experience unmet needs when it comes to the support of hope (73%), and the provision of information (65%) (Bužgová et al. 2016). This study suggests that the importance of psychosocial and spiritual needs is not uncommonly neglected by HPs addressing the needs of patients and their family members.

Balancing patients’ medical and psychosocial needs is a central dimension in health communication when HPs communicate with patients. Nevertheless, this is only one part of a bigger whole within the field of health communication. In the following I shall describe the broad dimensions of health communication as a research field and show where my focus is viewed in relation to this whole.
2. State of the art: Health communication

This thesis lies within the research field of ‘health communication’. Health communication has been defined as “any type of human communication whose content is concerned with health” (Rogers, 1996, p. 15). That is, where the focus is on health-related interactions and the factors that influence these.

The word ‘communication’ comes from the Latin: ‘communicare’ which means ‘to make common’ or ‘to share’ (Online Etymology Dictionary, 07.08.2017). Hence, an important dimension in health communication is to create some shared understanding of health and health information between HPs, politicians, researchers and laymen. The construction of meaning is, it is suggested, a more complex process moving beyond the simple roles of sender and receiver of information, being instead a “continuous interplay of perception and action in a co-regulated social context” (Brown et.al 2006, p. 43). From this perspective, health communication is seen as “a dynamic process where perceptions and actions regarding health are continuously created in interactions between people in social contexts rather than being a one-sided delivery of information from professionals to laymen” (ibid). This thesis shares this view that communication with seriously ill patients by doctors and nurses about their dependent children is relational and contextual. It is not a static activity, where HPs deliver information to patients about how to handle their children regardless of other factors, such as the patients themselves, the patient’s family relationships, the interactions with HPs, and the medical context.

In addition to “sharing meanings or information”, several other dimensions in health communication are revealed by Schiavo. These include, “‘influencing individuals or communities’, ‘informing’, ‘motivating individuals and key groups’, ‘exchanging information’, ‘changing behaviours’, ‘engaging’, ‘empowering’ and ‘achieving behavioural and social results, including to support and sustain change’” (Schiavo 2014, p. 7).

This suggests that a major objective in health communication is “to engage, empower and influence individuals and communities to enhance health” (Schiavo 2014, p. 5). That, in turn, means “changing individual behaviour or strengthening the health of vulnerable groups such as the elderly, children, people living with disability or groups affected by stigma and social discrimination, by socioeconomic or educational disadvantage” (Schiavo 2014, p. 6). An important idea in accomplishing these objectives has been that “communication strategies, guided by research and deep cultural understandings, can help close the gap between knowledge and the practice of healthy behaviours” (Kim 2014, p. 2). However, it is now widely acknowledged that “health communication alone cannot close this gap, because other factors can prevent healthy behaviours, such as lack of local capacity, training, infrastructure, or access to health products” (Schiavo 2014, p. 80). Even though such shortages are a major issue mostly in so-called developing countries, “the lack of capability or training affects health care in ‘developed’ countries, too” (ibid). In other words, there are limits to the degree of change that communication interventions on their own can
facilitate, taking into account that human actions and changes are seldom a direct result of reasoning and theoretical knowledge (Gabrielsen 1997).

While behavioural change is a major target in health communication, my research focus is on understanding the views of doctors, nurses and patients in communicating about dependent children, including how the medical context comes to influence this specific kind of communication. In the following, I present the main concepts underpinning the particular area of health communication concerned with interpersonal communication, or in other words communication between healthcare professional and patient, where establishing contact and mutual understanding is preparatory to generating behavioural change. After a brief description of patient-centredness and methods for patient involvement, I demonstrate a knowledge gap when it comes to including patients’ children as part of a patient-centred approach.

‘Patient-centredness’ and methods for patient involvement

A core focus in health communication research into interpersonal communication is the integration of two viewpoints, namely a medical perspective (the doctor’s) and a so-called patient-centred perspective, which covers emotional and relational factors, both between HPs and patient and between patient, HPs and relatives (Bensing 2000; Epstein 2005 et al.; Venetis 2009 et al.).

The part of the health communication area that I have addressed concerns communication and interaction between HPs and patient and within this field there are two important concepts: ‘patient-centredness’ and ‘shared decision-making’, which have become key concepts in health communication. Patient-centredness is most commonly defined as,

“a healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care” (Robinson, JH 2008, p. 601; Institute of Medicine 2001, p.7).

A comprehensive review of patient-centredness has summarized the concept to accommodate five interrelated aspects: 1) the biopsychosocial dimension, involving the patient’s biological, psychological and social conditions, 2) the ‘patient-as-person’ aspect concerned with understanding the individual’s experience of the illness, 3) the sharing of power and responsibility between doctors and patients, including the doctor’s ability to facilitate shared decision-making, 4) the therapeutic alliance, focusing on the quality of the doctor-patient relationship, including patient compliance, and 5) the ‘doctor-as-person’ aspect, referring to the doctor’s ability to use human qualities in the encounter (Mead & Bower 2002).

Research shows that health communication that integrates the medical and the patient-centred perspective reduces anxiety, stress and uncertainty for patients and their relatives, including their children (Ha Fong 2010; Steward 1995; Zachariae et al. 2003). Moreover, this kind of successful communication increases patients’ satisfaction and their understanding of medical information and
improves their experience of being able to cope with the illness (ibid). Nevertheless, even though it has been shown that successful communication involving the patient’s viewpoint makes a positive difference, it is far from common practice (Uitterhoeve et al. 2010; Riiskjær 2014).

There is an extensive literature about methods to include the patient-centred perspective in encounters between healthcare professionals and patients. For example, Steward points to the following specific actions in which HPs involve a patient-centred perspective in encounters: a) investigating the patients’ objective and self-reported health, b) understanding the whole person (as an individual and as part of a family), c) finding common ground, including goals of treatment and/or management, d) enhancing the doctor-patient relationship building on compassion, empathy and confidence (Steward 1995).

Steward gives the following definition of patient-centredness:

“When taking a history, physicians should ask a wide range of questions, not only about the physical aspects of the patient's problem, but also about his or her feelings and concerns, understanding of the problem, expectations of therapy and perceptions of how the problem affects function. Patients need to feel that they are active participants in care and that their problem has been discussed fully. Patients should share in decision making when a plan for management is formulated. They should be encouraged to ask questions and given clear verbal information supplemented, when possible, by emotional support and written information packages. Agreement between patient and physician about the nature of the problem and the course of action appears to bode well for a successful outcome” (Steward 1995, p. 1429.).

According to Stewards definition in 1995, practising patient-centredness involves HPs addressing not only the patients’ symptoms but also their feelings and concerns, their understanding of the problem and their expectations. This definition of patient-centredness approaches focus on the patients as individuals. However, elaborating on the concept of patient-centredness in 2014, Steward includes the clinician’s view of the patient as an individual and as part of a family when outlining concrete actions for patient-centredness (Steward et al. 2014). Hence, clinicians are recommended to understand the patient as a whole person.

Another method to promote the patient-centred perspective is the Calgary Cambridge Guides, which also include the elements described above and thematise the integration of the medical perspective with effective communicative skills such as open questions, consciousness of non-verbal behaviour and summaries. Focus is on the patients’ ideas, worries and understanding (Kurtz et al. 2003).

A third method is the eight-traced method, which has been developed in cooperation between the Picker Institute and the Harvard School of Medicine. This method builds on a systematic collection of patients’ own perceptions of what the preconditions are for a patient-centred hospital. Relatives
are highlighted as an important support for the patient (Gerteis et al. 1993, Cronin 2004, Knudsen & Olsen 2012).

Epstein concludes that research, training and clinical practice regarding shared decision-making should do more to stress the relationship between patients, family members and HPs instead of addressing these groups and individuals separately (Epstein 2013). Supporting this conclusion, this thesis challenges the idea that patient-centredness concerns only the patient, since the patient is part of a family, all of whom, including the children, are affected by the patient’s serious illness.

It is, then, characteristic for the methods described here that they involve the patient-centred perspective in preparing a relevant treatment plan for the patient, obtaining compliance and treatment results as well as securing greater patient satisfaction. Children are not addressed as an independent issue, even when it is relevant to include them.

To further understand patient-centred communication in practice, I will now outline the communication skills highlighted and evaluated in earlier research to promote a patient-centred perspective in health communication. In doing so, I will raise the issue that former approaches to evaluating communication skills have seldom included contextual mechanisms influencing communication, nor the significance to communication of patients having dependent children.

**Communication interventions**

It is an important part of health communication research to design, plan and evaluate communication interventions for HPs. The aim is to promote the patient’s satisfaction, involvement and understanding of medical information (Makoul & Clayman 2006; Mead & Bower 2000; Moore et al. 2013; Moreau et al. 2012; Politi et al. 2012; Taylor 2009).

Within the last 15-20 years, research has developed, implemented and evaluated a number of training programmes targeting HPs using RCT designs (Fallowfield & Jenkins 1999; Fallowfield et al. 2002; Jenkins & Fallowfield 2002; Razavi et al. 1993; Razavi et al. 2002). A core success criterion for these training programmes has been to improve the skills of HPs in integrating the patient perspective in the encounter, including the patients’ feelings and the patients’ understanding of medical information. Thus, evaluating training programmes in former research, researchers have counted the occurrence of specific communication skills (e.g. open or closed questions, signs of empathy and probing the patients’ understanding of medical information) before and after the participation of HPs in communication training (ibid). These studies have shown that communication training has a particularly effect on HPs’ generation of information about patients’ symptoms, which gives more precise diagnosis and improved treatment and empathy in supportive encounters (ibid).

A Cochrane review from 2001 investigating the effect on providers of interventions to promote a patient-centred approach in clinical consultations, including local communities, general practice and hospitals, showed that: a) training in patient-centred communication significantly increased doctors’ ability to uncover patients’ psychological stress, b) the doctors’ empathic communication improves
immediately after training, and c) there was an increased involvement of patients in decision-making and clarification of the patients’ concerns among those doctors who participated in patient-centred communication training – even 10 months after training (Lewin et al. 2001). The number of patients who would recommend the doctor to a friend also increased (Howe 1996; Thom et al. 1999; Langewitz et al. 1998). A later similar Cochrane review supported the conclusions of this review but added that training for less than 10 hours is as successful as longer training (Dwamena et al. 2012).

A number of Danish RCT studies conducted in a paediatric and in an orthopaedic context have investigated communication training. These studies have been shown to have an impact on both the HPs’ self-efficacy (self-perceived ability to conduct patient-centred encounters) and on user experiences, even maintained over time (a three-year period) (Ammentorp & Kofoed 2010a; Ammentorp et al. 2010b; Ammentorp & Kofoed 2011; Nørgaard et al. 2012).

There are several common characteristics in the above-mentioned studies. Firstly, the use of quantitative methods means that communication skills are addressed regardless of their context (e.g. the medical context, and the patients’ relationships). Secondly, children are not included as an independent issue in communication. Thirdly, the patient is mainly seen as an isolated entity, allowing communication to be analysed as a one-to-one relationship between the HPs and the patient. The latter, does not take into account the fact that relatives often participate in encounters.

The aim of this thesis is, therefore, to investigate the mechanisms at stake when HPs communicate with seriously ill patients about their dependent children from the standpoint that patients are not isolated entities but part of relationships, also with their children. Using qualitative methods, I will supplement and contextualise previous research that addresses health communication using RCT designs (e.g. counting the presence of different skills before and after training interventions). While the RCT approach is suitable for measuring the effects of a given intervention by ensuring the compatibility of groups in everything barring that intervention (Blackwood et al. 2010; Creswell 2009), it does not generate knowledge about how individual meanings or relational and contextual mechanisms may influence health communication. Through the use of a qualitative design, my intention is to understand communication skills in a broader context that includes both individual meaning and the complexity of the communication situation, though without addressing a particular intervention (Creswell 2009).

Consequently, my purpose is to investigate those mechanisms whereby HPs communicate with seriously ill patients about their dependent children in a way that includes the dependent children. My aim is, however, not to understand the mechanisms within this particular field of communication in a broader sense nor to investigate the effects of a specific training programme either quantitatively or qualitatively. To be precise, I address the interpersonal dimension of health communication and view the patient as part of a relational whole and not as an isolated entity.

In that way, I subscribe to a burgeoning view of health communication as holistic and context-specific, acknowledging that communicative behaviours are too complex to be predetermined and
assessed with behavioural checklists (Giroldi et al 2017). Recent research suggests a shift from ‘communication skills’ towards ‘skilled communication’ (Salmon & Young 2011), indicating that the context of daily practice, such as factors related to the doctor, the patient and the consultation, may require different skills or ways of handling these skills (Essers et al. 2011; Essers et al. 2013).

**Research questions**

My research questions overall relate to investigating mechanisms influencing the communication between healthcare professionals and seriously ill patients about patients’ dependent children:

- How do HPs address communication with seriously ill patients about patients’ dependent children?

- How does the medical context influence HPs’ perceptions of children and of communicative challenges in encounters with seriously ill patients that have dependent children?

- What are patients’ experiences and needs regarding communicating about their dependent children?

I investigated patients’ experiences of being seriously ill with dependent children because they contribute to framing the communication between patient, relatives and HPs. Since children have not previously been included as a category in patient-centredness, it is necessary to understand patients’ needs regarding communicating about their dependent children.

I hope to contribute to the field of health communication by using encounters regarding seriously ill patients with dependent children to put the concept of patient-centredness into perspective. Furthermore, the inclusion of three different hospital wards in the research design has made it possible to investigate how the medical context influences the understanding of children as a category and the communication challenges that HPs experience. In this way, the PhD thesis paves the way for a new approach to patient-centred care, by including how the medical context influences patient-centred care in practice and taking the patients’ own perspectives into consideration. Finally, this being an industrial PhD, its purpose is also to elaborate on the possible clinical consequences of the results.
3. Methodology

In this chapter, I will first present the PhD’s origin, which includes a presentation of a training programme targeting HPs who encounter seriously ill patients with parental responsibility. Since PhD data was generated together with the evaluation of this training programme, the presentation will be followed by a methodological discussion regarding my dual and simultaneous role as an evaluator and a researcher. I reflect on the differences and similarities between conducting evaluation and research. Thereafter, I present my research design, philosophical position and research methods, including participant observations and interviews. Furthermore, I present my data analysis strategy and my positioning during participant observations and interviews, including my dual role as an evaluator and a researcher in the data generation process. In this section, I also discuss how my different positions provided access to different kinds of knowledge, and how different kinds of knowledge provided access to different kinds of position (Hastrup 2004b).

Hereafter, I present issues that call for ethical consideration.

I follow up on methodological reflections in the later section “Strengths and limitations”, having presented and discussed my result across studies.

The origin of the PhD projects – a process evaluation of an intervention project

The PhD is based on empirical data generated together with a process evaluation of a training programme intervention. I will now describe the intervention and the evaluation strategy to elucidate how the aims of evaluation and research related to each other in the data generation process.

Target group and design

The target group for the intervention were HPs who communicate with seriously ill patients about their dependent children in conjunction with acute or long-term disease. The intervention consisted of a training programme, including a manual focusing on dependent children which targeted HPs on two cancer wards and one intensive care unit.

Since data is generated in both an intensive care unit and on two cancer wards, it was possible to investigate if and how conditions specific to the ward and related to the medical specialty influence how patient-centredness is practised. This has provided unique data about perceptions of children as a category and about specific communication challenges attached thereto.

Aim of intervention

The training intervention followed the recommendations of the Danish Health Authority and aimed: a) to support HPs in ascertaining whether the seriously ill patient has dependent children and identifying their needs in that regard, b) to support patients in supporting their children during the course of illness and c) to find out whether the patients’ children were in need of professional support, including a referral for the children or the whole family to relevant support facilities or referring them to the municipality (Danish Health Authority 2012). To meet this goal there were
two main activities targeting HPs from the participating wards: a) developing a manual, and b) developing and implementing a training programme based on this manual.

I documented and evaluated the implementation of the intervention during the process with specific focus on the training programme’s relevance and usefulness to the issues that HPs face when children are relatives. Moreover, I explored HPs’ working conditions in order to give realistic recommendations at the end of the evaluation.

**Organization**

The intervention was tested and evaluated based on the participation of 45 HPs from three different hospital wards (12 nurses and 3 doctors from each ward):

- A neurointensive ward where patient with critical acute illness are hospitalized and where death regularly occurs
- A haematological ward where patients are hospitalized for long-term treatment
- A gynaecological oncological ward with a palliative section, where patients are investigated and operated for cancer and receive palliative care

The wards represented both acute and long-term illness. Moreover, patients on these wards are often younger and have dependent children. This was especially the case for the neurointensive and the haematology wards. The gynaecological oncological ward had a predominance of older patients, although there were also younger patients within the target group of the project. These patients were hospitalized in the palliative section of the gynaecological oncology ward and suffered typically from cervical cancer, which affects approximately 375 women annually in Denmark, of which 50% are under 45 years (Danish Cancer Society 2017). Conducting participant observations on both an acute ward and two different cancer wards sharpened awareness of how contextual factors influence CSIP. Thus, since the wards had different disease and treatment scenarios, CSIP challenged the HP in different ways.

There were four organisations involved in the intervention project: Danish Cancer Society, Rigshospitalet (represented by the Interdisciplinary Knowledge Center for Patient Support, the Department of Psychology, Play Therapy and Social Counselling, the Juliane Marie Center, the Department of Traumatic Stress, and Church Unit), Copenhagen Centre for Cancer and Health, and the National Institute of Public Health at the University of Southern Denmark.

Overall, the Danish Cancer Society had primary responsibility for the evaluation and the documentation of the intervention project, while Rigshospitalet was principally responsible for the manual and the training programme. Everyone involved and their contribution are shown in Appendix 1.

Initially, the implementation part of the intervention project was meant to form part of the PhD project but was afterwards left out in favour of more general communicative discussions based on further analysis of the data material related to the research questions. These discussions were, for
example, about reproductive mechanisms when explaining HPs’ barriers to addressing dependent children or about new ways of addressing the concept of patient-centredness, including the need of some patients to be more medically than psychosocially oriented.

During the evaluation period, regular meetings were held with those responsible for the manual and the training programme to secure the relevance and the utility of the manual and the training program. For the same reason, each group commented on each other’s documents, namely the evaluation report and the manual.

In the following, I will describe the overall evaluation activities, because the PhD is based on data from the evaluation. My aim is to ensure transparency in the relation between the evaluation activities and the research activities.

**Activities**

As mentioned the intervention consisted of two parts:

1. The intervention (manual, training programme and pedagogical-psychological supervision)
2. Evaluation (process and results)

**The intervention**

The intervention consisted of three parts.

1. **Development of a manual:**
   The manual was developed to support and underline the dilemmas brought up in the training sessions (Kehlet 2015). It was based on “The national recommendations for HPs’ encounters with relatives to seriously ill patients” (Danish Health Authority 2012), on many years of clinical experiences in the intervention group (psychologists, chaplain and pedagogical-psychological consultant), on input from the evaluator (myself) and from other steering committee members, from national and international studies of the field, and from experiences from Norway (Kehlet 2015).

   The manual describes how HPs can identify dependent children who need support and how to deal with situations such as the death of a parent, single patients with a limited network and children visiting the hospital etc. The manual is a practical guide with recognizable cases and the option to look up specific situations or dilemmas.

2. **Training sessions:**
   Along with the development of the manual, a number of training sessions were conducted for HPs. These addressed the challenges initially identified. The training sessions consisted of 3 x 0.5 days training + 2 x 0.5 days follow-up corresponding to a total of 2.5 days training. The training sessions were conducted over six months. The training involved providing knowledge about children’s reactions to serious parental illness, communication exercises, supervision, exchange of experiences, and knowledge about opportunities for referral to the municipality or the Danish Cancer Society.
3. Pedagogical-psychological supervision
HPs could call for a pedagogical-psychological consultant during the intervention period to request supervision both for themselves and for extraordinarily vulnerable families with difficult socioeconomic problems on top of the serious illness. In these cases, the consultant could facilitate additional professional help or contact with the municipality or with the children’s school or day-care.

Evaluation
The evaluation comprised three steps, and the intervention developed underway including the results from each step:

1. **Current practice:** a) investigation of the HPs’ current practice, knowledge, attitudes, needs and interactions with the seriously ill patients with dependent children, b) patients’ experiences communicating with the HPs about their children.

2. **Development of training programme and manual:** a) input to the intervention group based on the preliminary study that is described above under ‘Current practice’ b) evaluation of the training sessions on the levels reaction (satisfaction) and learning (Kirkpatrick & Kirkpatrick 2006) regarding health professionals’ knowledge, attitudes and self-efficacy regarding being able to implement national recommendations for children as relatives.

3. **Implementation:** Evaluation of training and manual focusing a) on how the training and the manual was used in practice, b) on changes in knowledge, attitudes and self-efficacy with regard to ability to implement national recommendations for children as relatives, and c) investigation of factors that influenced the implementation when HPs acted in encounters with diverse families.
This table illustrates the time intervals combining the preparation, implementation and end of the intervention project, including participant observations and interviews:

Table 1: Activities and time table for the intervention

<table>
<thead>
<tr>
<th></th>
<th>September 2013</th>
<th>April 2014</th>
<th>September to October 2014</th>
<th>September 2015</th>
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</thead>
<tbody>
<tr>
<td>Development of manual + training programme/Participant observations + interviews</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Training sessions</td>
<td>3 x ½ day</td>
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<tr>
<td>Pedagogical psychological consultant affiliated</td>
<td></td>
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<td></td>
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<tr>
<td>Training sessions</td>
<td>2 x ½ day</td>
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<tr>
<td>Pedagogical psychological consultant ceases</td>
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<tr>
<td>Pedagogical psychological consultant ceases</td>
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<tr>
<td>Training sessions</td>
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</tr>
<tr>
<td>Participant observations + Interviews/Adjustment of manual and training programme</td>
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<td></td>
</tr>
<tr>
<td>Publication of evaluation report, manual + training programme</td>
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</table>

(Translated from Dencker 2015, p. 48)

The theoretical and the practical framing of the evaluation

The evaluation was formative and its purpose was to provide feedback to the intervention group during the development of the training programme and the manual so the process was regulated in the intended direction (Rieper 2004). The feedback was provided by attending regular meetings with the intervention group, where I, as the evaluator, presented and discussed the results concerning the training and the manual with the intervention group. Moreover, I investigated any dynamics in the clinical practice that weakened or supported the implementation of the intervention (Patton 1987). A core focus in the evaluation was to investigate the healthcare professional’s practice and working conditions in order to ensure the intervention’s relevance and usability. The evaluation involved, therefore, a utilization approach called: ’Utilization-Focused Evaluation’, which is described by Patton as:

“The systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future programming” (Patton 1997, p. 23).

The results from the evaluation are described in a separate evaluation rapport and contain among other things didactical considerations and participants’ ratings of the training’s relevance, usability, and effect on self-efficacy and satisfaction (Dencker 2015).
The specific formative evaluation had two aims. One aim was directed towards the intervention group responsible for the implementation of the training and the manual. The other aim was directed towards research. The qualitative data generated during the formative evaluation served two purposes:

1) Evaluation: To give input to the intervention group in the form of knowledge about dilemmas in HPs practice and about communication challenges regarding dependent children. This knowledge was used to develop the training programme and the manual.

2) Research: To create new knowledge about health communication based on the PhD projects’ research questions by analysing patterns and dynamics in the variations to be found in healthcare professionals’ CSIP about their dependent children in the patients’ perspectives.

Conducting interviews and participant observations before, during and after the training created the opportunity to get to know the medical contexts and the informants in depth. This in-depth understanding was important both for relation-building and for promoting understanding of the relationship between medical contexts and challenges in the communication. Furthermore, building relationships with the informants was important to acquiring insight into the clinicians’ working conditions, professional self-understanding, challenges and actual clinical practice.

Summing up, evaluation and research followed two different methodological tracks. Each track pursued its own logic: the formative evaluation related to the training and pursued the logic of evaluation. The research logic was to explore and to contribute to the field of ‘health communication’. The differences between these forms of logic are described and discussed several places in the literature (Fain 2005; Levin-Rozalis 2003; Patton 2008; Scriven 2004; Stufflebeam 2001). For example, Patton suggests that “evaluation has a specific purpose, focusing on giving action-oriented feedback in a specific context, the aim being to improve, to provide a basis for decisions and to investigate how well something works. The research intention on the other hand is to investigate how something functions, to generalize, to show something and to draw conclusions” (Patton 2008, p. 40).

I will further elaborate on my positioning as evaluator and researcher respectively in the positioning section, where I also discuss other positionings when encountering HPs and patients during participant observations and interviews.

Having clarified the relationship between evaluation and research, I will now further elaborate on my research design, including my philosophical position and how it reflects my way of addressing CSIP.
4. Research design

To explore and understand the complexity involved in communicating with dependent children as relatives, I chose a qualitative research strategy of inquiry. Qualitative research means for exploring and understanding the meaning groups or individuals ascribe to a social or a human phenomenon or problem (Creswell 2009; Denzin & Lincoln 2011; Gliner & Morgan 2000; Kumar 2005a). Qualitative research focuses on how social phenomena and processes are constituted or operate in different contexts, and it is particularly useful in providing detailed, contextual and multi-layered interpretations (Mason 2007). The principal aim is to find out how people experience and interpret their own existence (Grimen & Ingstad 2007). In this case, the experience and interpretation relate to doctors, nurses and patients in their encounters involving dependent children and related to the contexts in which the communication takes place.

A qualitative researcher needs to be aware of pre-existing ideas by constantly making them transparent during the analytical process (Stige et al. 2009). As I explore in the positioning section, I had the basic idea that I could contribute to improving CSIP, which earlier research had been proved to be insufficient, by understanding the complex mechanisms that it brought into play. When reflecting on this basic idea during the analytical process, I found that my pre-existing idea of what ‘to improve’ CSIP meant changed because I achieved a broader understanding of the communicative mechanisms and challenges involved in CSIP. Thus, I went from focusing on increased standardization as a main way to improve CSIP to focusing on achieving a greater balance between standardization and an individualized and context-related approach, including the HPs’ ability to assess the individual patient’s needs here and now, even when they were different than expected. I further explore how my perspectives changed during the research process in the sections: ‘Positioning’ and ‘Discussion’.

The social-constructivist position

This thesis is situated within a social-constructivist position, which assumes a relativistic ontology that there are multiple realities and a subjective epistemology where knower and respondent co-create understandings (Denzin & Lincoln 2011). As Hastrup points out, this has some epistemological implications such as that the generation of knowledge is a social relation rather than a substance, and that the researcher is part of the research field and not separated from it (Hastrup 2004b).

Hence, the social-constructivist position is often described as standing in contrast to rationalist and positivist positions that assert that there is one truth about reality and that this reality exists independently of our experience and of our awareness of it (ibid). In that sense, social constructivism challenges the idea of social phenomena as final and eternal since according to social-constructivism everything changes and is constantly changed as well as everything is under construction and being constructed (Jacobsen MH 2001; Rasborg in: Fuglsang & Olsen 2004; Berger & Luckmann 1966). Berger & Luckmann illustrate this duality when writing: “Society is a human product. Society is an objective reality. Man is a social product” (Berger & Luckmann
1966, p. 79). Their point was “that humans construct society in a continuous process, which then works back on us” (ibid). This continuous process is a major focus for social-constructivist researchers. Hence, social constructivist researchers explore not only individual meanings as varied and multiple to understand the participants’ views on the situation being studied, they also explore the co-construction of meanings among individuals in specific contexts in which people live and work as well as how these meanings work back on the social phenomena studied (Berger & Luckmann 1966; Creswell 2009).

Thus, the aim of the researcher inspired by a social constructivist position is to understand the mechanisms that are crucial for how social phenomena work. Individuals are constantly in the process of co-constructing and developing varied and multiple meanings situated in social and local contexts (Simon & Chard 2014). Therefore, the social constructivist researcher will need to be aware that he or she is always presenting a specific version of social reality which makes it crucial to recognize his or her own background and accounts (Bryman 2008; Creswell 2009). Consequently, I chose to write a separate section in this thesis regarding my positionings in the field of CSIP and how these influenced my versions of CSIP as a social phenomenon, see the section: ‘Positioning’.

I will now show how the social constructivist position has inspired my research in various ways.

Firstly, through my research questions, I explored CSIP from the perspectives of HPs and patients to investigate the multiple meanings connected to their experiences of CSIP and their interactions in different situations. That is the relationship between individual meanings, co-construction of meanings, and situations.

Secondly, I investigated how the three medical contexts influenced the interactions between the HP and the patients, including how HPs perceived children as a category and how these perceptions influenced communicative challenges. That involves the relationship between contexts, interactions, perceptions and challenges. Thus, I was interested in finding out whether and how perceptions of children influenced the communication about them, including the challenges that occurred. That is how meanings (perceptions of children) work back on the phenomena studied (CSIP).

Thirdly, I investigated mechanisms in play regarding CSIP, based on the idea that it was dynamic and that there was no given ‘right way’ to communicate with patients about their children because situations, patients and children’s needs are different. That is to say, I explored CSIP without holding an objective and static truth.

However, being aware of my own ideas from the beginning of the research process, I found that I had the idea early in the research process that CSIP was so emotionally charged that the level of standardization had to be increased. However, this idea directly contradicts the social constructivist position that I have claimed to be inspired by because standardization implies regular routines and procedures, which do not as a starting point include much context sensibility or relational flexibility (Bryman 2008). Nevertheless, reflecting on my own background and accounts made me aware of
my ideas about communication during the research process and how they changed, as I further explain in the positioning section.

I end up concluding that health communication practice should consider that CSIP is context-dependent and that HPs and patients are constantly in the process of co-constructing and developing varied and multiple meanings situated in social and local contexts (Simon & Chard 2014). Hence, I do not refer to an objective truth in the sense that CSIP should be the same at any given time and in any given context regardless of individuals, relationships and situations. In that sense, ‘my truth’ is more constructivist and somehow relativistic – with the exception of one last idea that did not change during the research process.

Former research has shown that children of seriously ill parents want to be informed about the illness as early as possible and that they prefer honest information about the parent’s condition and treatment (Kennedy & Lloyd-Williams 2009a; Bylund-Grenklo et al. 2015; Tillquist et al. 2016). This knowledge has not been challenged in this thesis because children’s views and needs have not been addressed in my studies. Understanding the mechanisms at stake in CSIP to ensure that children are included in this way has, therefore, been an important driving force in the thesis. Meanwhile, as demonstrated in paper I-III, there is a range of individual, relational and contextual aspects influencing the involvement of the patient’s children and in that sense the social constructivism position has particularly inspired the design and the analysis of this study. From a social constructivist position, I do not end up giving unambiguous solutions. Instead, I outline dilemmas to be further discussed. One important dilemma related to the knowledge of children’s needs for involvement described above is that parents’ needs do not always go in that same direction as their children’s, which points to the need for future clinical attention, see paper III.

**Research methods**

The study draws on data from a qualitative study based on ethnographic methods combining interviews and participant observations on three hospital wards conducted between September 2013 and June 2015. The aim was to investigate mechanisms influencing the communication between healthcare professionals and seriously ill patients about patients’ dependent children:

As mentioned, the three wards were haematology, neuro-intensive care, and oncological gynaecology and the wards were recruited through Knowledge Center for Patient Support, Rigshospitalet, under the Capital Region of Denmark. The HPs who participated in the training were either selected by the ward management, who found that the doctor or the nurse had the interest and the ability to play a future key role in the ward concerning children as relatives, or by HPs themselves, who had signed up because they were especially interested in working with the topic. Thus, all participants were basically motivated and engaged in reflecting on CSIP and wanted to contribute to both evaluation and research.

**Interviews**

I conducted 64 semi-structured, in-depth individual interviews (N=19 doctors, N=30 nurses and N=15 patients) with 39 interviewees (N=9 doctors, N=15 nurses and N=15 patients). The nine doctors were divided into the following groups: three from neuro-intensive care, two from
haematology and four from gynaecological oncology. Four of the doctors interviewed possessed administrative positions apart from having clinical responsibility (one from neurointensive care, one from haematology, and two from gynaecological oncology). The 30 interviews with nurses were distributed across 15 nurses, five nurses from each ward. Four out of the 15 nurses were experienced and had administrative responsibility though without daily patient contact at the time of the interview (one from neurointensive care, one from haematology, and two from gynaecological oncology). One out of the 11 remaining nurses worked as a nurse and as a clinical supervisor for nurse students. In addition, one out of the remaining ten nurses had primarily patient responsibility and secondary responsibility in an assistant departmental manager function. All nurses were women while one third of the doctors were men. The average age for doctors and nurses was 46, and their average number of years of experience was 19. Interviews lasted from 60 to 90 minutes.

Not all the HPs interviewed participated in the training, and not all interviewees were both followed during their working day and interviewed. Thus, five out of nine doctors, whom I both followed in the clinic and interviewed, participated in the training, though two of them could only participate for one day and 1.5 days out of 2.5 days training because they were needed with the patients. Of the 15 nurses whom I interviewed, 11 participated in the training. I both followed and interviewed six of these 11 nurses. The doctors and nurses who did not participate in the training programme and whom I ‘only’ interviewed but did not follow in the clinic had primarily administrative responsibility apart from some clinical duties, though these were not full time.

Finally, I interviewed 15 patients: 10 women and five men (six women and five men from haematology and four women from gynaecological oncology). The average age of patients was 40.1 years; the youngest patient was 29 years and the eldest 48 years. The patients had a total of 32 children with the average age of 10.5 years, the youngest being 0.8 years and the oldest 23 years. The interviews explored patients’ needs and experiences in communicating about their children with doctors and nurses. Interviews lasted from twenty minutes to one hour.
The following table shows how interviewees were divided into wards.

**Table 4: Number of interviewees divided into wards**

<table>
<thead>
<tr>
<th>Ward</th>
<th>Doctors</th>
<th>Nurses</th>
<th>Patients</th>
<th>HPs</th>
<th>Patients</th>
<th>I alt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurointensive care</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Haematology</td>
<td>2</td>
<td>5</td>
<td>11</td>
<td>7</td>
<td>11</td>
<td>18</td>
</tr>
<tr>
<td>Gynaecological oncology</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>9</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>9</strong></td>
<td><strong>15</strong></td>
<td><strong>15</strong></td>
<td><strong>24</strong></td>
<td><strong>15</strong></td>
<td><strong>39</strong></td>
</tr>
</tbody>
</table>

Due to the formative evaluation design, I revisited the wards three times, which meant that I interviewed several HPs more than once. Interviewing informants more than once had a relationship-building and a validating effect, because it facilitated trust and provided the opportunity to follow up on topics and views from previous interviews. I further explore these issues later in the section: ‘Strengths and limitations’.
The following table shows the distribution of those interviewed once, twice or three times.

Table 5: Interview distribution

<table>
<thead>
<tr>
<th>Interviewed once:</th>
<th>Doctors</th>
<th>Nurses</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurointensive care</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Haematology</td>
<td>2</td>
<td>11</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Gynaecological oncology</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2</td>
<td>5</td>
<td>15</td>
<td>22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interviewed twice:</th>
<th>Doctors</th>
<th>Nurses</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurointensive care</td>
<td>2</td>
<td>4</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Haematology</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Gynaecological oncology</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>4</td>
<td>5</td>
<td>0</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interviewed three times:</th>
<th>Doctors</th>
<th>Nurses</th>
<th>Patients</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurointensive care</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Haematology</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Gynaecological oncology</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>8</td>
</tr>
</tbody>
</table>

Overall amount of interviewees: 39

Interviews total: 22+2x9+3x8= 64

The interviews were semi-structured, guided by my research questions. Thus, specific and pre-selected areas were explored with openness toward issues and subjects that the interviewees found important (Creswell 2009; Grimen & Ingstad 2007; Kvale 1997; Spradley 1979). The interview method was derived from the ethnographic interview, which seeks to explore and understand how people experience and view, believe and think, aspire the world about them (ibid). According to this view, the interviewer must grasp the meaning of a person’s behaviour by attempting to see things from that person’s point of view (Bryman 2008).

Exploring and understanding people’s experiences, I used Spradley’s grand-tour and mini-tour questions. Hence, I asked informants about their broad experiences (grand-tour): “When do you typically ask patients about their children?” and about their specific activities and experiences (mini-tour): “Will you describe the last time you spoke with a patient about his or her children?”. To get an in-depth understanding, I typically followed up by asking: “What happened?” “Was there something that made a special impression on you?” and “Why do you think this impressed you in particular?” Using grand-tour questions helped informants to be tracked into the subject of children (grand-tour) while using mini-tour questions encouraged informants to describe their
RESEARCH DESIGN

concrete experiences in more detail (Spradley 1979). Open questions and listening were as important as specific questions (Murray et al. 2004).

Participant observations

Apart from interviewing HPs and patients, I conducted 27 days of participant observations on the three wards, neurointensive care, haematology and gynaecological oncology. Conducting participant observations in hospital settings is an activity on the increase. One important reason is that, even though hospital settings may seem identical clones of a global biomedical model, they may vary considerably, leading to different diagnostic and therapeutic traditions (Van der Geest & Finkler 2004). In addition, conducting participant observations is encouraged in healthcare because hospital settings are unique contexts and will therefore have many different meanings and perspectives to explore (Goodson & Vassar 2011).

The basic idea of participant observations is that, “by “being there” and taking part in and following people’s lives, the researcher has the opportunity to experience and understand what the world looks like from the people’s own perspective” (Tjørnhøj-Thomsen & Whyte 2008, p. 102-103). Participant observation is “a useful tool to experience peoples’ everyday lives directly, to uncover the taken-for-grantedness of social life, and to record whether and how the statements that people make about their lives correspond to what they do in specific situations” (ibid). Thus, participant observations involve sharing time and space with the people whose practice you want to explore, and it implies an importance of context for how people live and act and for what they share (Hastrup 1988). Hence, during participant observations knowledge is generated through a concrete personal engagement in other people’s lives, which is far removed from the telephone interview (Hastrup 2004a). Hastrup suggests that anthropologists must get in to the world they study and thereby expose themselves to the world to understand it (ibid).

Participant observation is often called a contradictory concept since observation implies distance from the research object, while participation implies involvement (Gammeltoft 2003). An example of this contradiction was when I followed and interviewed doctors and nurses. When following a doctor, I wore a doctor’s coat, while when I followed a nurse I wore a nurse’s coat. This attire, apart from living up to standards of hygiene, strengthened my position as a participant while the identification sign I wore on my coat saying, “Scientist Annemarie Dencker, Children as relatives” highlighted my position as a researcher and indicated a distance. Even though I wore a coat, I did not ‘become’ either a doctor or a nurse. As Wind suggests it is difficult to ever truly participate in a hospital context, since ‘doing the nurse, the doctor or the visitor’ are not genuine options (Wind 2008; Long et al. 2008; Van der Geest & Finkler 2004).

Apart from interviewing HPs and patients formally and informally during participant observations, I also participated in medical conferences, nursing conferences, interdisciplinary conferences, days in outpatient clinic (excluding neurointensive care) and clinical rounds. These observations gave me insight into the ward’s daily rhythm, including the time pressure that the healthcare professionals were subject to, and into topics prioritized when patients were discussed. I found across wards that doctors and nurses had different focal points. Not surprisingly, doctors were more treatment and
medically oriented than nurses, while nurses were more preoccupied with the patients’ psychosocial condition, including their children. Even though nurses were more preoccupied with the patients’ psychosocial condition, the common focus was still on the medical aspects in most encounters, unless the patient was declared terminal (Dencker et al. 2017b). Observing doctors and nurses sharing knowledge about patients before and after the rounds, I found that it was mostly about the patients’ physical condition and that the patients’ children were seldom mentioned.

In following the daily life at the wards, I experienced a great acceptance and willingness to let me into these different scenarios despite many difficult and sometimes compromising situations, including discussion about treatment and encounters with patients and relatives, who were not always satisfied. The openness I experienced became part of my empirical data in reflecting on what made the openness possible, and what the openness might have been an expression of (Bengtsson 2015). I suggest several reasons for the openness I experienced.

Firstly, it is crucial for the researcher “to have access to the place and the people” (Tjørnhøj-Thomsen & Whyte 2008, p. 98). The researcher must be accepted temporarily to gather accurate information (Goodson & Vassar 2011). Consequently, the hospital management began by backing up the intervention project represented by Knowledge Center for Patient Support, Rigshospitalet, under the Capital Region of Denmark. The wards were informed about all aspects of the project, including the research part, both at ward meetings and by email before conducting participant observations. However, access is not secured only by formal permission from the central gatekeepers, in this case the chief Health Professional (Tjørnhøj-Thomsen & Whyte 2008). Therefore, I continuously repeated the purpose of my presence as I interacted with informants at the wards, bearing my ethical guidelines in mind, see the section: ‘Ethical considerations’.

Secondly, I introduced myself and the purpose of the participant observations, starting out with interviewing the chief nurse and doctor at each ward. Apart from gaining insight into the wards organization, disease categories, daily tasks, and routines and practices in relation to children as relatives, these interviews contributed to creating relationships and trust between me and the ward management. For instance, I stressed that I would comply with professional secrecy, and that no one from the ward would be recognizable when reporting results. In addition, I mentioned that I was not focusing on individuals alone but on their interactions and their working conditions.

A third reason for the openness I experienced might have been that HPs considered CSIP a sympathetic and important topic, and this might have encouraged them to contribute with their experiences.

Fourthly, and maybe connected to the third reason, my presence and interviewing at the wards provided an opportunity for HPs to speak out about their working conditions. Thus, during participant observations, HPs often gave pressure of time as the reason for not addressing children as relatives as a topic, even though they found it important. Based on my observations and interviews it became clear that working conditions was one among a range of other explanations and mechanisms for not addressing CSIP systematically (se paper I-III).
In the following, I will further discuss my positioning during participant observations because, as mentioned in the social constructivist position section, it is important that the generation of knowledge within this worldview is seen as a social relation rather than a substance and that the researcher is acknowledged as part of the research field and not separated from it (Hastrup 2004b). Hence, reflecting on my positionings during participant observations increases transparency regarding how I reached my results.

**Positioning**

Positioning involves thoughtful attention towards one’s own position and attitudes in relation to the area being studied (Sjørslev 2015). Hence, “acknowledging that the researcher cannot be neutral or objective or detached from the knowledge or the evidence they are generating, the qualitative researcher must actively reflect and seek to understand his or her own role in the research process” (Mason 2007, p. 7). Consequently, I will now further reflect on the importance of reflecting on positioning and discuss the relationship between positioning and knowledge generation. Thereafter, I will reflect on my own positioning in the field of CSIP and how it may have influenced my interactions with my informants. In the later section ‘Strengths and limitations’ I discuss how my positioning may have influenced my results.

Reflections on positioning during participant observations and interviewing is important because different positions provide access to different kinds of knowledge, just as different kinds of knowledge provide access to different kinds of positions (Hastrup 2004b). As Donna Haraway suggests, knowledge is always positioned, partial and situated (Haraway 1988; Tjørnhøj Thomsen 2004). In other words, when seeking knowledge, my research questions had an outset connected to particular positions, and these positions were explored in different contexts, in other words in different hospital wards and situations. The responses I received when exploring my research questions became a starting point for further exploration of particular knowledge areas within the contexts I visited which again strengthened my positions or moved them in new directions.

My positioning during participant observations was connected to the philosophical position of my study which, as I have said, was informed by a social constructivist worldview. As explained, this position asserts that social phenomena and their meanings are continually being accomplished and produced by social actors and are in a constant state of revision (Bryman 2008). Nevertheless, several of my positions were defined beforehand when I introduced myself to HPs and patients, e.g. that I was an evaluator and a researcher, but it was only when interacting with HPs and patients that these definitions became vivid. Hasse suggests that “the researcher’s position is perceived locally, which will ultimately create the specified conditions for research” (Hasse 2015, p. 98). Hence, HPs, patients and I, interacted based on our mutual understandings of each other as e.g. an evaluator, a researcher, a doctor, a nurse or a patient.

Interacting with HPs and the patients, my positions were dynamic, while at the same time I came from ‘somewhere in particular’ (Haraway 1991). Thus, Haraway suggests that “the road to a wider vision is recognition that to be a researcher is to be ‘somewhere in particular’” (Haraway 1991, p. 196). Following Haraway, “instead of having a vision from ‘nowhere’, the researcher must
acknowledge a vision from ‘somewhere’” (Haraway 1991, p. 195). Haraway suggests that “‘somewhere’ is a third vision of positioning transcending the perspectives of a relativistic ‘everywhere’ and a totalitarian ‘nowhere’” (Haraway 1988, p. 584). She argues that “the alternative to relativism is not totalization and single vision but a situated and partial kind of knowledge that is about communities and not about isolated individuals” (Haraway 1988, p. 584 and 590).

It was a continuous investigation process for me to be aware of my ‘somewhere’ position when interacting with HPs and patients in different situations. In the following, I will outline my positions based on Haraway’s idea of coming from ‘somewhere in particular’. In accordance, I will start out with the way I presented myself to HPs and patients, and thereafter reflect on the interactions between me and my informants during participant observations. The aim is to analyse how my altered positioning may have influenced the data generation and ultimately the results of this thesis. The latter will, as mentioned, be explored in the section ‘Strengths and limitations’.

Self-presentation and interactions in the field

When I presented myself to HPs and patients, they got the following information:

- I was an evaluator of a training and a PhD student employed on the Bereavement Project at the Department of Patient Support and Community Activities, Danish Cancer Society, inscribed at the University of Southern Denmark, and cooperating with Knowledge Centre for Patient Support, Rigshospitalet

- My professional background was Master of Arts in Education and Anthropology, specializing in health communication

My self-presentation was the same overall when I introduced myself to HPs and patients. However, I did not address the training in details when communicating with the patients, nor did I give them detailed descriptions of funding or specific collaborators.

In practice, I chose the term ‘researcher’ on my name tag. My idea was that the researcher term was more neutral and general than the term ‘evaluator’, and that ‘evaluator’ would need further explanation to avoid my informants feeling assessed and evaluated, which was not the primary purpose of my presence, either as an evaluator or as a researcher. As an evaluator, I wanted to gain knowledge from HPs and patients to inform the training and not primarily to rate performances or outcomes. In other words, in evaluating the training I did observe and interview HPs about changes in their behaviour before, during and after participating in the training, but this did not include patients, and HP were openly informed and involved in this part of the investigation. Hence, the term researcher was more accurate for all informant categories, especially because patients were not evaluated.

Participants were also patients whom I visited in their hospital room or in the out-clinic clinic. When interacting with the patients, I still wore either a doctor’s or a nurse’s coat. Nevertheless, when meeting the patients, I explained that I was wearing a coat not because I was a doctor or a
nurse but because I was following a doctor or nurse that day. I emphasised that I was not a healthcare professional but a researcher exploring mechanisms influencing communication about dependent children and an evaluator of an intervention targeting HP and designed to strengthen their efforts in supporting patients hospitalised while having dependent children.

When I presented myself as an evaluator to HPs, I mentioned my collaboration with, among others, two respected and well-known chief psychologists and a chaplain from Rigshospitalet. Moreover, I told them that I was employed by the Danish Cancer Society and as a researcher received supervision from a professor at the National Institute of Public Health, at the University of Southern Denmark. Finally, I told the HP that the Innovation Fond Denmark contributed financially to my PhD project.

These collaboration relationships seemed to underline the importance of CSIP and motivated HP to participate with their experiences. Several HPs said that they found it a privilege to participate in the training and that they looked forward to receiving training from such experienced people while also having the opportunity to get a break from the busy clinic to get new ideas. I interpreted these reactions as a sign of engagement and willingness to generate new ideas and variety in their busy everyday schedules.

Positioned as an evaluator, I stressed that their contribution was anonymous and that it was important for the training that they freely expressed both their needs for training and how the training could improve in the process. I also mentioned the importance of anonymity, stressing that I would not bring anything further that could be tracked back to them. The latter was also relevant for the position as a researcher as described in the section: ‘Ethical considerations’.

When I told HPs that my study formed part of a PhD project several of them said: “Oh how exciting!” and “That is good!”; “Children are a very important topic and unfortunately mostly overlooked”. I interpreted these expressions as indicating that HPs were genuinely interested in the topic of children, while at the same time recognizing that children were overlooked. As mentioned, I found a discrepancy between HPs’ professions that children were an important topic and their daily practice where for various reasons children were seldom mentioned or involved, see paper I-III. As explained earlier, I found that the issue of children became a window that permitted discussion of hard working conditions in general.

During the participant observations and the interviews, I discovered various pitfalls related to my positioning. These pitfalls became evident when HPs provided interpretations of my positioning that were not in accordance with my own understanding of my purpose, my presence or my abilities. As Hasse suggests, the researcher’s position, as mentioned earlier, is perceived locally, which will ultimately create the specified conditions for research. In other words, “the definer also becomes defined as well as the classifier becomes the classified” (Hasse 2015, p. 98). Hence, as I will illustrate in the following, I sometimes received invitations to adopt positions that were not in accordance with the purpose of my presence. In those cases, I had “to negotiate the conditions governing my presence” (Tjørnhøj-Thomsen 2008, p. 99), which suggests that, when positioning
myself, my choice was not entirely free because positioning is relational, and others are co-definers (ibid).

During participant observations, my positioning sometimes triggered reactions that, apart from showing the need to be even more clear and explicit about the aims of my presence, also became data because I found they expressed HPs’ needs.

For instance, my positioning as employed by the Danish Cancer Society and with a Master of Arts in Education and Anthropology specializing in health communication seemed to generate ideas that I was a child expert or a communication expert. HPs sometimes asked: “What do you think we should recommend?” (nurse, fieldwork) or “How about I set up a meeting between you and the family” (nurse, fieldwork). In other cases, HPs asked me “How do you think it went?” (doctor, fieldwork). These questions typically arose after particularly emotional encounters. For example, there was a case, where several family members had requested a meeting, because they were not sure that their seriously ill relative had received the best possible treatment, which left them quite frustrated. In another case, there was a family suffering from such severe social, psychological and financial difficulties that it was almost unbearable for HPs to reveal that there was no more treatment to offer their seriously ill relative, who was therefore going to die.

When HPs asked me for feedback I became aware of several things.

Firstly, I became aware of the need to be even more explicit about my purpose, background and reason for my presence; that I was in the position of an investigator and not of a consultant with the aim of supervising, which HPs sometimes invited me to adopt when they were challenged in supporting the families in the best possible way.

Secondly, I became aware that HPs probably felt exposed having me as an evaluator, which led them to want to know my opinion about their work. In these cases, I emphasised, as outlined in paper II, that it was HPs who were to evaluate the educational programme related to their needs and working conditions and not the other way around. In addition, I told them that I wanted to discuss my observations with them to understand the mechanisms involved regarding CSIP. In practice, this meant that I was transparent and explicit about the ideas that came up during interviews and observations, which contributed to the validation both of the feedback to the intervention group and of the discussions outlined in paper I-III.

Thirdly, I found that HPs in some cases confused my role(s) with that of the pedagogical psychological consultant that formed part of the intervention project. My job at the Danish Cancer Society might have strengthened this view of me – as an expert on children or a counsellor. The Danish Cancer Society is known for their counselling centres all over Denmark, which could have promoted this view of me as an expert associated with this organisation. Therefore, I became even more aware of distinguishing myself from the role of the pedagogical psychological consultant e.g. by saying that I was not “the one” they could call to get supervision or to support the families.
Another example of how I became “defined and classified” (Hasse 2015, p. 98) was when HPs included me in their daily routines, as if I was a medic or a student nurse. The HPs included me as a student when they explained their clinical and sometimes quite technical dispositions, which I had observed their colleagues perform with the students that followed them. Knowing that they knew and I knew that I was not a student in that sense, I chose to join these ‘classifications’ when, for example, they gave thorough explanations about the patient, pointing up to the screen and telling me about the patient’s condition, medication and what to do next and why. Joining the ‘student-classification’, I asked in-depth questions about clinical matters. As described in paper II, this knowledge turned out to be an important way of understanding the medical context that CSIP was part of.

**Positioning when encountering patients**

When I communicated with patients, I positioned myself explaining where I was employed and the aim of my presence, which was to get to know about patients’ experiences and needs when communicating about their children with HPs in order to help others in a similar situation in the future. In addition, I followed the ethical considerations as outlined in the section ‘Ethical considerations’.

Encountering patients, I found that several patients knew and had received support from the Danish Cancer Society. These experiences, combined with my aim of improving the support for families when at the hospital, seemed to generate an initial positive attitude towards my presence. Patients generally spoke openly about their difficult situation, their parental role during the course of illness, and their experiences communicating with HPs. Nonetheless, one patient especially did not seem to have much to share, which puzzled me because she had been described by HPs as quite open and inspirational in her way of handling her difficult situation, among other things by keeping her family and HPs close by sharing her thoughts and feelings about life and death with them. I interpreted this patient’s unexpected lack of openness as a sign that she was saturated with contact and sharing beforehand. Moreover, she was expecting an answer to as whether she could continue her treatment or not, which must have been stressful for her, and would have left her with fewer resources for inviting new and unknown people, like me, into her universe. Hence, as I suggest in paper III, patients are not always prepared to talk about their children because of their current situation – not even with well-meaning researchers.

Patients were also occupied with their socioeconomic situation and logistics surrounding being seriously ill. It seemed to be important to them to convey these points, as they were an important part of the picture, though not within the HPs’ competences to change. In fact, patients said they felt more allied with HP in these cases than with the authorities, whom they often thought did not have a realistic view of their situation. When meeting patients in such situations, I felt generally that I became, and let myself be positioned, as a kind of spokeswoman. Someone outside the system with whom they could share their battles and worries and who would pass on their experiences in order to improve the support for families in similar situations in the future.
Encountering patients, I was especially aware of what I will call ‘the therapeutic pitfall’. The qualitative interview can cause misunderstandings and result in complicated and shifting boundaries drawing on attributes such as warmth, interest, trustworthiness and concern (Kendall & Halliday 2014). Therefore, the interviewer must be clear about the boundaries of their research by being explicit and reflexive about their professional background in order not to harm the interviewee (Richards & Schwartz 2002; Hewitt 2007).

Fog suggests that an unintended result of good contact in the research interview might mean that the interviewee acquires new insights but it is not, and should not be, the goal in the research interview (Fog 1994). However, the research interview and the therapeutic interview are not the same, and this is marked by the fact that the person has sought the therapist with a wish for increased personal insight and change, which often implies loss of illusions and distorted self-perceptions. This means, that the person has agreed to enter a process of change and increased insight in contrast to the research interview where the person has not sought the conversation or asked for increased insight or change. The researcher has not been invited to intervene, to question the person’s stories or to challenge how the interviewee is living his or her life (ibid).

In practice, this meant that I was aware of clarifying my position from the beginning more as a listener to the patient’s experiences with the aim of improving the general situation for families in similar situations than as a helper of their individual situation. Clarifying my position, I focused on my research questions and was aware of the patient's boundaries and limits of what they wanted to discuss with me when it came to asking them about their illness and their communication with their children. As explained in the ‘Ethics’ section, I considered patient’s consent in participating an on-going process rather than a one-off event, which implied that participants should be given several opportunities to withdraw, even during interviews (Kendall et al. 2007).

Furthermore, if the patient asked me for support that went beyond the research purpose, I referred to relevant support provided by other professionals. I elaborate on these issues in the ‘ethics’ section, where I include HPs, with whom I also had the awareness described above, especially when they trusted me about personal issues relating to their work.

**Alternating between being an evaluator and a researcher**

As mentioned, I had a double position while conducting my Ph.D. study, because I was both an evaluator and a researcher during the data generation process. I chose to handle the double position in the following way.

Firstly, I made explicit the various aims, as described above, while contacting both HPs and patients both verbally and in writing – for example, in the information letter to the patients (see appendix II).

Secondly, I designed my interview guide and my preparation for the field work observations so they covered both the evaluation aim (*how well*) and the research aim (*how something functions*) (See interview guides A-E).
Thirdly, I focused on what the two positions had in common, namely that neither of the two positions was free of intention. As a researcher, I also had an intention, though it was different from that of being an evaluator. Thus, the aim of my research investigation was not only to understand the research object, CSIP itself, but also to improve this particular area, which has proven to be inadequate, among other things because there is no systematic initiative. Hence, my idea was that by creating new knowledge on social processes influencing the contents and the framing of CSIP, new possibilities of actions would arise that could improve CSIP.

Nevertheless, during the research process, my idea of what ‘to improve’ meant changed. Initially my idea was that ‘to improve’ was to increase standardization for HPs to bring up and follow up on CSIP systematically, for example by following a manual. At that time, I was sceptical towards the idea that HP’s personal intuition should guide their effort, because it would be too random. To depend on HP’s personal interests and on whether a particular ward had focus on the subject is too vulnerable as a primary approach to the field, which explains why my focus became predominantly on standardization (Dencker et al. 2017a). Meanwhile, taking paper III into consideration has made me reconsider the dynamics between the two extremes of a standardized approach on the one hand and an intuitive approach on the other. Balancing these approaches is important to avoid patients being forced into positions that they are unable to cope with (Dencker 2017c).

However, as a researcher I did not know in advance what ‘improve’ would mean, while as an evaluator measuring improvement was related to a more fixed set of objective success criteria represented in the national recommendations describing goals and expectations concerning the HP’s way of addressing the issue of patients’ dependent children in a one-to-one relationship. As a researcher, my starting point for improvement was more open, in the sense that I addressed earlier literature and national recommendations from a critical perspective, working from the idea that ‘to improve’ could mean something else than previously described.

My assumptions about HPs also formed part of how I positioned myself. Thus, my basic assumption on meeting HPs during participant observations was that they were competent professionals doing their best as regards CSIP while treating and taking care of the patients. I held onto the idea that, if the issue of children was not the central subject in encounters, everyone had their reasons to act as they did, and that it was my task to find those reasons and to understand the issue of children as part of a larger whole. Being respectfully interested and acknowledging HPs’ practice while interviewing them, one of the HPs asked: “When will you come again? It is so cosy when you are around” (nurse, fieldwork). Another healthcare professional said on my third visit: “It is good that you come back several times. You are good at following up” (doctor, fieldwork).

I interpreted these comments to mean that HPs perceived me a friendly visitor, as a ‘stranger’, to use Simmel’s definition: “not an owner of soil, not belonging or committed to the group and still present” and somehow in a free position for HPs to share their experiences, including their challenges regarding CSIP (Simmel 1950, p. 403). According to Simmel, the stranger often receives the most surprising confidences, which sometimes “have the character of a confessional and would be carefully withheld from a more closely related person” (Simmel 1950, p. 404). Hence, I
interpreted the HPs’ expressions of ‘nice having you around’ as a welcome opportunity for them to talk about challenges while being acknowledged and recognized for their efforts in their hectic everyday work, despite difficulties. Focusing on CSIP put the HPs’ daily work into perspective, including their efforts and their limitations resulting from their occasionally hard working conditions. These conditions showed that CSIP was part of a larger whole, influenced by a range of other topics and tasks.

*Communication about dependent children as part of a larger whole*

When following HPs, they sometimes prepared me by saying: “The next encounter will probably not be relevant for you because there is nothing about children” (nurse, fieldwork) or “If you want, you can take a break while I am in the operating room because there is nothing about children there” (doctor, fieldwork). These comments made me aware that, even though communication about children was my main focus, I needed to clarify from the beginning of each field visit that I was interested in understanding ‘the whole situation’ encompassing CSIP. Actually, ‘the whole situation’ formed an important focus for my investigation as I tried to understand the relationship between HPs’ communication about patients’ dependent children and their other tasks. For example, visiting the operating theatre on the gynaecological ward, I found that for HPs operating was just one of a number of tasks making up a composite whole. These included attending the outpatient clinic, taking part in different kinds of conference, giving microscopy responses and so on, depending on the ward and on whether HPs were doctors or nurses.

As an example of understanding the whole not directly related to the subject of children, I found that doctors sometimes had no time to eat lunch, which was why one doctor had to eat sweets during an operation.

In the operation room. The doctor: “Oh, I am so hungry. I didn’t manage to eat lunch.” The nurse: “That doesn’t sound nice. Do you want a sweet?” The doctor: “Yes please!” The nurse picks up a jar with sweets and offers it to the doctor who puts a sweet in the mouth and continues to operate.

Along with other similar examples, this incident illustrates the tight timetable that was a basic working condition, sometimes preventing HPs, especially doctors, from addressing potentially time-consuming issues like that of children. Moreover, I understood that all the changes during the day from rounds to operating within a short time interval made it difficult to create room for investigating patients’ thoughts about their children.

Nevertheless, since nurses spent more time with the patients, they spoke more with them about their children. In the process of participant observations, which felt like “running around”, especially when following the doctors, I found that patients became more or less objectified, depending on their treatment, e.g. the operation room, pathology conferences or rounds. Thus, in several cases, it was not possible to see the patient as a whole person, for instance at the pathology conferences, where the patient was a picture on a large screen represented by cells in various colours, or during robot operations in the operating room, where the patient was sometimes packed in paper and therefore not recognizable. In these situations, patients became objectified due to the tasks doctors
had to perform, which underlined the hospital setting and the main purpose of the patients’ hospitalization, namely to treat and cure the patient. Due to this main purpose, children were not a main topic. Thus, a picture of cells does not have children.

Summary
I conducted 64 semi-structured, in-depth interviews (N=19 doctors, N=30 nurses and N=15 patients) with 39 interviewees (N=9 doctors, N=15 nurses and N= 15 patients). Moreover, I conducted 27 days of participant observations. Both interviews and participant observations were conducted within haematology, neuro-intensive care and oncological gynaecology.

Combining interviews and observations, I found that HPs considered CSIP important. However, the importance expressed was not reflected in actions, since CSIP was seldom addressed. Even though nurses did address CSIP more often than doctors, when doctors and nurses interacted, their focus was mainly on the patients’ physical condition. When conducting participant observations and reflecting on my positioning, I found that CSIP became a window for both HPs and patients to reveal the need for more appropriate conditions for dealing with CSIP. HPs felt a time pressure, and their asking me for feedback and advice during participant observations also seemed to reflect a need for further training concerning how to relate to CSIP. Patients for their part were occupied with their difficult situation being simultaneously a parent and a patient and trying to cope with their socioeconomic situation and the logistics of being seriously ill. When HPs and patients disclosed their experiences and needs, I found that I became a potential spokeswoman for both HPs and patients during participant observations with the potential to throw light on the fact that something as important as the patients’ children was not addressed more often.

In further analyzing my data, based on my three research questions and drawing on relevant theories, I found that various dimensions play a part in explaining the discrepancy between the perceived importance and actual practice of CSIP, see paper I-III.

Data analysis
Interviews were digitally recorded and transcribed verbatim. Interview recordings and transcribed interviews were thereafter sifted several times, together with fieldnotes and carefully reviewed to reach an overall and in-depth assessment of the main themes and the diversity of practice (Mason 2007; Miles & Huberman 1994).

I conducted data analysis from two angles, in connection with the evaluation purpose and in relation to my research questions. In the following, I will specifically focus on how I analysed data based on my research question.

Overall, my analysis was guided by my research questions following the general criteria for qualitative analysis with open coding and a thematic approach to the material (Hastrup et al. 2011; Denzin & Lincoln 2011; Mason 2007; Miles & Huberman 1994). From reviewing the interview recordings, the transcribed interviews and fieldnotes, I built up a general and a more profound impression of the empirical diversity, and I analysed the recurring patterns of meaning in each
interview as well as across interviews and fieldnotes. I took both the similarities and differences between the informants into account and my observations perspectivized the interviews in relation to the informants’ actions in the field (ibid).

In relation to observations and interviews, I discovered, for instance, that, even though HPs expressed in interviews that CSIP was an important topic, they did not address it accordingly in practice. This observation became important when analysing my empirical material because I wondered what was at issue, since HPs did not address more often what they found important. In further analysing my empirical material on the meaning of the medical context and the patients’ perspectives, I was also aware of this observation, which pointed to a diverse range of explanations both regarding why CSIP was seldom conducted and what mechanisms were involved when the topic was finally assessed. Thus, I found that, apart from HPs’ barriers, the medical context and the patients’ perspectives influenced how and when CSIP was addressed (see paper I-III).

Data analysis began already in the field. Hence, data generation and data analysis were developed in a dialectical process, also called an ‘iterative process’, where I moved back and forth between the generation of data and the theoretical literature (Mason 2007). In practice, I moved back and forth between a set of observations based on my research questions and a theoretical curiosity, asking myself during the analytical process: “What is this a case of?” (Tavory and Timmermans 2014; Atkinson 2015). For example, I found that HPs had various explanations for not addressing CSIP. Using Maturana’s theory of domains helped me to identify and categorize these various barriers into two overall barriers, namely emotional barriers and structural barriers (Dencker et al. 2017a; Maturana & Varela 1987; Lang & Cronen 1990). Thus, I found that HPs’ barriers were a case of Maturana’s personal domain and domain of production, and that these domains could help to understand how HPs’ barriers interacted when relating to CSIP. Across studies this meant that, when I identified themes during the open coding of my empirical material using my research questions as a starting point, I formed ideas in the coding process of which theories I could draw on to explain and put my findings into a broader perspective (Tavory and Timmermans 2014).

This explanatory process is indebted to Charles S. Peirce’s concept of abduction, where research is recursively moving back and forth between a set of observations and theoretical generalizations (ibid). Thus, my approach was neither purely deductive nor inductive in its form. A deductive theory approach is when theory comes first and is tested, moving from the general to the particular while an inductive approach implies that theory comes last and is generated through data generation and analysis, moving from the particular to the general (Bryman 2008; Mason 2007). The theoretical frameworks of Maturana, Bateson, Bury and Jenkins informed my analytical work. In that sense, the analytical process was neither theory empty nor completely theory driven. Rather, it was “a process where data generation and theory interacted through the analytical process, making ‘additions’ to the observed data to render them more broadly applicable” (Miles & Huberman 1994, p. 262).
I will now explain this process for each of my papers\(^1\).

**Paper I:**
The outset for Paper I was the research question concerning how HPs address CSIP about patients’ dependent children. When conducting the initial open coding based on this research question, I found that there were several barriers involved in explaining why HPs seldom addressed CSIP. Using Maturana’s theory of domains as a lens, I could identify and categorize these various barriers into two overall barriers, namely emotional barriers and structural barriers. Maturana operates with three domains, “each representing a different communicative logic that exists side by side with others in conversations, with one domain typically dominating at any given time” (Dencker et al. 2017a, p. 2).

The three domains are the personal domain, the domain of production and the domain of reflection. “In the personal domain, values, morals, ethics and private attitudes, feelings and opinions are dominant. In the domain of production, it is rules, procedures, routines and guidelines dominate, while in the domain of reflection reaching a conclusion is not as important as listening to other perspectives on a subject and developing a potentially more nuanced understanding” (Dencker et al. 2017a, p. 2; Maturana 1987; Lang & Cronen 1990). Thus, I found that healthcare professionals did not have any procedures or known routines to guide their practice towards CSIP (the domain of production) which meant they had to invent actions themselves, which became based on their own values, private attitudes, feelings and opinions (the personal domain) (Dencker et al. 2017a).

Drawing on Maturana, I was not only inspired to categorise barriers but also to discuss the relationship between barriers which pointed to the discovery of emotional barriers as a primary explanatory model in previous literature. Using Maturana’s theoretical framework that proposes three co-existing domains, I was led to the awareness of the tendency to oversee the importance of structural barriers founded in the domain of production, as well as the tendency to reproduce avoidance of CSIP when not recognizing structural barriers, that is barriers outside HPs’ emotional lives.

Finally, I used Maturana’s theory of domains to reflect on my own involvement in the analytical process, investigating how I positioned myself both emotionally and structurally in relation to the empirical material. This approach, gave me a ‘third’ aspect, which helped me to avoid focusing unidimensionally on emotions as the dominant explanatory model and to take the structural conditions (or the domain of production) into consideration as well.

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1 I have chosen to use ‘I’ instead of ‘we’ when referring to the authors of my three papers in order to be consistent throughout the thesis, well-knowing that ‘I’ also included the co-authors. However, it is evident from the papers who the co-authors are.
Paper II:

Paper II explored the research question concerned with the influence of the medical context on HPs’ perceptions of children and on the communicative challenges in encounters with seriously ill patients that have dependent children. When addressing this research question, I was indebted to Bateson’s conceptualization of communication as multifunctional, to the notion that every conversational utterance conveys both a digital and an analogic aspect (Dencker 2017b). As explained in paper II, “the digital aspect refers to the ‘literal’ content, while the analogic 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” (Dencker et al. 2017b, p. 3).

As explained in paper II, I used Bateson’s notion of context, “acknowledging that context is not something given and stable (Dilley 1999)” (Dencker 2017b, p. 3). Bateson’s concepts of ‘context markers’ and ‘frames’ helped me to understand that defining context 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’, while a frame provides a context within which new messages can be interpreted (Rawlins 1987; Van Gorp 2007)” (Dencker et al. 2017b, p. 3-4). As I further explain in paper II, “identification of context markers and frames varies from tacit agreement to the identification of ‘differences that make a difference’ (Rawlins 1987)” (Dencker et al. 2017b, p. 4).

I began the coding for my second research question “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)” (Dencker et al. 2017b, p. 4). I found that “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 of children and related challenges to communication” (Dencker et al. 2017b, p. 4).

In my 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” (Dencker 2017b, p. 4).

In my second paper Bateson’s theoretical framework also served to analyse and frame the discussion across all three papers as illustrated in the BACIC model, described in the ‘Discussion’ section. This model shows that apart from medical contexts as context markers for communicating about dependent children, patient identities, and HPs’ barriers, context markers also influence communication with seriously ill patients about their dependent children.
**Paper III:**

My third research question concerned patients’ experiences and needs regarding communicating about their dependent children. I found that some patients, contrary to my expectations, did not want to - or could not - always have their children on visits. Combining interviews with participant observations facilitated the exploration of this perspective, because I witnessed patients’ fatigue and poor condition at close quarters, which led me to a better understanding of their conditions. Moreover, observing patients’ encounters with HPs, I found that encounters were primarily about the patients’ actual condition and their ability to receive further treatment. However, the thematic coding also showed that patients sometimes missed talking about their children with HPs.

In practice, I coded the empirical data based on my research questions regarding experiences and needs for communicating about dependent children. In this process, I found that the concept of biographical disruption could be used “as a basis for understanding the patients’ experiences and needs and assessing how their identities were affected by serious illness (Bury 1982, 1991, 1997, 2001)” (Dencker 2017c, p. 4). As explained in paper III “Bury suggests that illness causes a biographical disruption that challenges patients’ everyday life structures, social relationships and identities (Bury 1982, 1991, 1997, 2001; Cayless et al. 2010)” (Dencker 2017c, p. 4). Although the concept was initially developed from interviews with chronically ill patients with rheumatoid arthritis, I found it relevant for my analysis – particularly the way the dynamics between identities and social relationships are influenced by illness” (Dencker 2017c).

As outlined in paper III, the framework of biographical disruption has been further developed to include the interrelationship between illness and key sources of identity. “For example, studies of women diagnosed with breast cancer or as HIV positive suggest that the intense threat caused by their potentially fatal illness forces the women to reconstruct, re-formulate and renegotiate their identities as mothers (Fisher & O’Connor 2012; Wilson 2007), ‘identity’ being seen as a social, relational, contextual and dynamic process constantly in the process of construction and reconstruction (Jenkins 2014)” (Dencker 2017c, p. 4).

In paper III, my analysis was particularly focused on the following: “a) on patients’ relational experiences with their children and with healthcare professionals, b) on contexts influencing the patients’ identities such as the specific type of illness and the hospital setting, including ward specific characteristics, and c) on the task of equilibrating roles as parent and patient” (Dencker 2017c, p. 4-5).

When retrospectively looking back on my analytical processes, I realize that the theoretical frameworks of Maturana and Bateson functioned as lenses for understanding my empirical material earlier in the process compared to the use of Bury and Jenkins who were drawn in later in the analytical process. Hence, what surprised me most in analysing data was patients’ ‘dynamic identities’, including the fact that patients did not always want - or were able - to involve their children.
5. Ethical considerations

I conducted my PhD in a field where people had parental responsibility while being seriously ill and at risk of dying from their illness or treatment. While some of the interviewed patients were hospitalized, felt exhausted, suffered from severe symptoms and diverse severe treatment side effects, others attended the outpatient clinic with the awareness that they could get a relapse of their serious illness. A few patients were under investigation for serious illness and thereby shared feelings of existential uncertainty with the patients in treatment, which was distressing, not least because they also had dependent children living at home. Healthcare professionals for their part were daily reminded of their own mortality, working in the field of serious illness, which, as they explained during participant observations and interviews, made them extra vulnerable in times of personal crisis.

In this section, I will focus on my ethical conduct towards the patients and the HPs. I will mainly refer to patients when explaining my ethical considerations. However, I include HPs to abide by the overall rule to minimize any possible harm or disturbances that my study might cause for any of my participants (Kumar 2005b). As Oliver 2003 suggests, “the kinds of ethical issues raised by the research process involving human beings are basically no different from the ethical issues raised by any interactive situation with human beings” (Oliver 2003, p. 22). However, I recognized that the participants, especially the patients, in my study were particularly physically and emotionally vulnerable and that gatekeeping should be especially rigorous (Lawton 2001).

The basic values in my way of addressing participants was to treat everyone with respect by acknowledging their personal integrity and personal limits concerning what they were willing to share. Moreover, I carefully made a point of avoiding any form of harm or discomfort to any of the participants, and to give them the opportunity to decide for themselves whether they wanted to participate or not by providing full information about my project and purpose from the beginning and during the research process when necessary (Oliver 2003). Hence, consent might be seen as an ongoing process rather than a one-off event, which implies that participant should be given several opportunities to withdraw, up until and even during interviews (Richards HM & Schwartz 2002; Kendall et al. 2007).

In practice, I followed the ethical guidelines formulated by Richards HM & Schwartz 2002 to protect the participants in my study: 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 and 4) ensure participants’ anonymity (Richards HM & Schwartz 2002).

1) Avoid creating anxiety and mental strain

Patients in my study were vulnerable from the outset. I therefore considered beforehand whether asking them about their communication experiences regarding their children was appropriate, since I did not want to upset them. Nevertheless, I decided to address patients for two reasons. One reason
was that patients should have the opportunity to make decisions for themselves based on relevant information about the study and its purpose. Making the decision for them would imply the risk of disempowering competent people, who would maybe want to contribute (Lawton 2001). Another argument was based on studies showing that most potentially highly distressed people, for example those close to dying or bereaved after a close relative’s suicide, are motivated to participate in research and want to be offered the chance to participate (Kendall et al. 2007; Dyregrov et al. 2010).

However, I was aware that even though most patients might want to participate, some patients could be in such bad condition that even asking them to participate in an investigation concerning their communicative experiences about their children could be distressing for them. To meet this consideration, I included the HPs in the assessment of whether this could be the case for some patients. Thus, there was one patient who was not asked to participate in my study because she was in acute crisis relating to the situation with her children, which meant that the HPs had called for professional help. The HPs judged that it would further upset the patient to be asked to participate, an assessment that I followed. Hence, it is a balance to present patients with information and at the same time ensure that they do not get upset by them (Kendall et al. 2007). In my study, I chose to involve the doctor or the nurse who knew the patients best in assessing whether it would harm the patient to ask for participation. I made this choice to reduce the risk of harming anyone, even though it involved the risk that patients would not have the opportunity to decide for themselves.

To minimize anxiety and mental strain during interviews and participant observations, I strived not to problematize communication issues, primarily asking about what had been helpful for the patients in communicating with the health professionals about their children and what the patients could wish for more of. Moreover, I asked patients at the end of each interview how it had been for them to participate. I wanted to make sure that patients were feeling okay, and that there were no loose ends or questions that they would like to ask. I also gave my contact information, so that patients could contact me if any questions or comments should occur. If the patient needed further support during the interview, I helped with options of referral (Richards HM & Schwartz 2002). I did not receive any inquiries for follow-up, and I only had to refer patients for further support a few times.

At the end of interviews, most patients said that even though they felt exhausted or affected by their situation, they were pleased to participate because they wished to help others in a similar situation.

To reduce anxiety in situations where patients encountered HPs about their sensitive situation, I chose not to write notes during rounds with hospitalized patients. Consequently, it was not always possible to collect long and complicated quotes from patients (Lawton 2001). Instead, I wrote my notes just after encounters and elaborated on them at the end of each day (ibid). Moreover, to respect patients during encounters, I tried to position myself physically in a neutral place, that is in a ‘third place’ not as part of the HPs’ group and not as a patient relative.

In one case where a woman was having a gynaecological examination, I chose to leave the room because I thought my presence could not be justified, given the number of healthcare professionals
present and since my purpose in participating which was to understand the whole of the ward. In the minutes before leaving the room, I felt a bit physically uncomfortable, perhaps, apart from the amount of people in the room, I could identify myself with the woman lying there, who had to go through an unpleasant intervention.

The patient in this case had given informed consent for my presence, but afterwards two students also entered the room which meant that the premises for her consent for my presence changed. Leaving the room, I spoke up, saying that I was leaving the room because I thought we were too many and I wanted to make it transparent that I was not leaving because of something the patient had said or had done. I found this incident an example of the way in which following formal ethical guidelines, in this case the patient having given informed consent, sometimes needs to be overruled by an individual’s practical judgement (Richards HM & Schwartz 2002). In other words, “ethical considerations and decisions are situational, or in other words conditional on the situation and on how the anthropologist relates knowledge of the context using intuition, moral personal convictions and humanity” (Tjørnhøj-Thomsen & Hansen 2009, p. 231: my translation). Hence, I was afraid that my presence would infringe the patient’s personal limits. This is the theme that I will elaborate on in the following. Nevertheless, before doing so, it is important to state that the HPs I met were generally very aware of the patients’ limits and well-being, including the number of observers appropriate during encounters. Therefore, the above example is not representative for my experiences during participant observations.

2) Ensure that participants participated voluntarily without infringement to their personal limits

As described in the sections ‘participant observations’ and ‘positioning’, I carefully explained my purpose before initiating participant observations and interviews, and during encounters, when interactions demanded it. Patients were informed about my stay on the ward before I participated in rounds, and in the out-patient clinic patients were asked in advance for acceptance of my presence. As I have explained, there were cases where questions arose concerning my role that I had to answer. For example, I had to clarify that I was not an expert on children or a supervisor. In that way, I sought not to promise something that I could not deliver, e.g. a therapeutic intervention or supervision.

HPs gave patients a letter informing them about the investigation and emphasizing that participation was completely voluntary, which was also written in the letter itself. In the letter, I presented my purposes: that I wanted to ask them about their experiences in communicating about their children with healthcare professionals with the aim of: a) strengthening the HPs’ communication with families who experience a parent being seriously ill, and b) creating the best possible help to families in similar situations. I wrote that patients could withdraw any time during participation, and that non-participation would not affect patients’ treatment or stay at the hospital in any way. Finally, I wrote that participants would be guaranteed anonymity and that in any subsequent use of interviews, individual identities would be not be recognizable (see appendix II).

All patients gave oral consent to HPs after reading the letter, and several stated that addressing the issue of children was important. The main consideration behind having HPs give the patients the
information letter was that it would be easier for the patients to say no to participating if they did not want to. In promoting the freedom to say no, I agreed with HPs that they would stress that participation was completely voluntary.

To avoid infringement of the participants’ personal limits, I had the basic rule that the well-being of any participant should always be prioritized above the interests of the PhD projects. In practice this meant that I was aware of signs, and not only verbal signs, indicating that interviewees for some reason did not want to talk further about a subject and that they were not obliged to share it with me (Fog 1994; Hewitt 2007). As Fog suggests, the interviewer must see and acknowledge the interviewee’s full right to set his or her limits, even though it may be against the interviewer’s interests or if she does not understand why the interviewee closes communication with him or herself (Fog 1994).

I had two examples of this mechanism. In the first example, some HPs told me that a colleague of theirs had suffered a personal loss which he/she was very good at handling and integrating in his/her professional work. When I interviewed this particular health professional, I asked, as I asked all others, if he/she had personal experiences that he/she used in his/her professional life. It turned out, that even though this person openly spoke about challenges regarding CSIP, including how it affected him/her personally, he/she did not talk about his/her personal loss. I noticed this avoidance of the subject and consciously let it not cross the person’s personal limit. The situation confronted me with my own implicit expectation that because HPs were open about some issues, it would also imply confidences from the person’s personal life and how it related to their professional work. Nevertheless, as a researcher one cannot expect that openness in one area implies openness in other areas, which is important to acknowledge to respect interviewees’ limits in this regard.

Another example was a patient who I could see was exhausted but who told me at the same time that she really wanted to contribute. In this case, I slowed down the interview and asked the patient a couple of times how she was doing in order not to go on for a longer time than the patient could bear, though still leaving the decision with the patient who obviously wanted to participate.

As mentioned in the beginning of this section, consent might be seen as an on-going process rather than a one-off event, which implies that participants should be given several opportunities to withdraw, up until and even during interviews (Richards HM & Schwartz 2002; Kendall et al. 2007). Consequently, I was constantly aware of the patients’ right to withdraw, noticing not only verbal but also non-verbal behavior, probing if it was okay to go on with the interview, or if the patient preferred to rest, which I said that I would completely understand.

Finally, as mentioned in the positioning section, I clarified my position from the beginning as a listener to the participant’s experiences with the aim of improving the general situation for families in similar situations in the future, and not as a therapist who could support them in their present situation. Hence, there is a fundamental difference between a therapeutic interview and a research interview (Fog 1994).
ETHICAL CONSIDERATIONS

3) Prevent breaches of the participants’ sense of autonomy
Preventing breaches of the participants’ sense of autonomy includes respecting participants’ perceptions and avoiding stigmatization in the analysis (Richards HM & Schwartz 2002). Analysing the empirical data and disseminating results, I carefully sought to be loyal to the participants’ contributions and concepts as well as to the themes that arose across interviews. I also included an investigation of the structural conditions surrounding participants to increase an understanding of the background to their views and actions. Hence, in meeting all participants my basic assumption was that they were competent human beings doing their best to manage whatever situation they were in.

4) Ensure participants’ anonymity
To ensure participants’ anonymity I used codes after quotes that could not be traced back to the interviewees. Quotes from interviews were referred to using profession and number, “doctor 4:1”, for example, indicating that the interview was with doctor number 4 and that it was the first interview. Quotes from participant observations were referred to as, for example, “nurse from fieldwork”. Patients referred to with H, as in PtH1, come from haematology, while patients referred to with a G, as in PtG1, come from gynaecological oncology (see paper I-III). Hence, I left out specific details such as the participants’ names, surnames and place of residence, and quotes were only used when they represented general themes. Finally, when having interviews transcribed, I informed the transcribers about their duty to maintain professional secrecy, to which they consented, and data was stored confidentially.

According to Danish ethical committees, my study did not need to seek permission because it was not an intervention involving biological material. Since it is unique that Danish ethical committee waive the need for permission for cases not involving a biological sample, and since nearly all other countries have some form of approval process, I asked the Danish ethical committee for a letter in English documenting this lack of approval (see appendix III). However, the project followed the Helsinki declaration, including demand for informed consent and voluntary participation (World Medical Association, 2013) and was approved by the Danish Data Protection Agency. Registration number: J.nr. 2016-41-4895, see appendix IV.
6. Results

I overall found a discrepancy between, on the one hand, doctors’, nurses’ and patients’ perception of CSIP as an important topic and on the other encounters in the clinical every day where CSIP was seldom addressed. In this connection, I observed that HPs admitted me into their daily work life with great openess. I interpreted this openess as an opportunity for the HPs to share their working conditions with me, which showed that it was not immediately possible for them to address CSIP systematically. Thus, even though HPs found CSIP important, they could not address it systematically due to factors such as time limits, lack of training and lack of space and structure for registration of children in the medical record system.

Patients seldom addressed CSIP themselves. Encounters mainly focused on the patient’s current health and treatment situation and on making a future treatment plan. However, most patients expressed a need for HPs to address the topic of their children more often by asking them how they manage being seriously ill while having parental responsibility. Nevertheless, not all patients always had this need. Sometimes patients could feel too physically and/or psychologically exhausted to talk about their children.

In this chapter, I will briefly present the results of each paper before reflecting on them collectively and discussing their shared contribution to the field of health communication, especially focusing on the concept of patient-centeredness.

Paper I: ‘A qualitative study of doctors’ and nurses’ barriers to communicating with seriously ill patients about their dependent children’

Paper I is based on 49 semi-structured, in-depth interviews with doctors and nurses working with haematology, gynaecological cancer and neuro-intensive care and 27 days (9 days in each ward) of participant observations. It explores how HPs address communicating with seriously ill patients about patients’ dependent children. Informed by Maturana’s theoretical framework of domains (Dencker et al. 2017a; Maturana 1987; Lang & Cronen 1990), it shows that HPs have two overall barriers to addressing CSIP, namely structural and emotional barriers (Dencker et al. 2017a). Structural barriers were, for example, lack of space in the medical recording system, inadequate professional code, time pressure and lack of training, while emotional barriers derived from the painful nature of the situation and the perceived need of keeping professional distance (ibid). As explained in paper I, “structural barriers reflect Maturana’s domain of production and relate overall to the HP’s working conditions and tasks. These include their professional code, understood both as what HP feel is expected of them and as what they themselves perceive as good professional conduct. Emotional barriers refer to the personal domain and relate overall to the HP’s affective responses such as avoidance of CSIP and withdrawal from CSIP during encounters” (Dencker 2017a, p. 2).

Paper I also shows that emotional barriers tend to get more influential when structural barriers are not addressed and indicates “a) the need to use templates and manual procedures to gather and
process information about children in medical records, b) the need for managerial backing for CSIP and for time spent on it, and c) the need for future HP training programmes to include how to implement procedures and how to address all barriers” (Dencker 2017a, p. 1).

**Paper II: ‘Contextualization of patient-centred care: A comparative qualitative study of healthcare professionals’ approaches to communicating with seriously ill patients about their dependent children’**

Paper II is based on the same 49 semi-structured, in-depth interviews with doctors and nurses working with haematology, gynaecological cancer and neuro-intensive care and the 27 days of participant observations (nine days in each ward) as paper I. It deals with ways in which the medical context influences HPs’ perceptions of children and the communicative challenges in encounters with seriously ill patients that have dependent children. Using Bateson’s theoretical framework of ‘context’ and ‘context markers’ (Bateson 1972; Rawlins, 1987; Van Gorp, 2007; Dencker et al. 2017b), the paper shows 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” (Dencker et al., 2017b, p. 5).

Across wards, paper II illustrates a close link between the patients’ diagnosis and treatment and perceptions of both children and patients. For example, “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” (Dencker 2017b, p. 10). Children were more often talked in gynaecological oncology than on the other wards but they were seldom present, and patients were seen more as part of a family here than on the other two wards (Dencker 2017b).

Paper II suggests 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. Thus, some HPs in gynaecology found that they focused more on the patient as part of a family in gynaecology than in other wards they had known, because it was “women lying in the beds”. In addition, “in neuro-intensive care, children mostly became spectators while an adult relative was included as a communicative substitute for the patient” (Dencker 2017b, p. 10). Paper II also shows “that the more patients were perceived as units due to, for example, the demands of their treatment or their present state of unconsciousness, the more children seemed to be absent from encounters” (Dencker 2017b, p. 10). Finally, looking across wards, paper II shows that the prospect of death seemed to dissolve all categories regarding how children were perceived, because healthcare professionals became genuinely concerned to include children both psychologically and physically.

The results of paper II point to “the need for further exploration of the influence of medical contexts on the inclusion of children in patient communication” (Dencker 2017b, p. 1). In addition, paper II suggests that “patient-centred care in general could 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” (Dencker 2017b, p. 12).
Paper III: ‘Disrupted biographies and balancing identities: a qualitative study of cancer patients’ communication with healthcare professionals about dependent children’

Paper III is based on interviews with 15 patients, six female and five male haematological patients, and four gynaecological oncological patients. It also includes data from the 27 days of participant observations (nine days on each ward). Paper III explores patients’ experiences and needs regarding communicating about their dependent children. Informed by the theoretical frameworks of Bury (illness as a biographical disruption) (Bury, 1982, 1991, 1997, 2001) and Jenkins (‘identity’ as a social, relational, contextual and dynamic process constantly in the process of construction and reconstruction) (Jenkins 2014), it shows that “there are two overall identities at stake for seriously ill patients with parental responsibility: ‘patient identity’ and ‘parent identity’” (Dencker 2017c, p. 1). In their identity as ‘patients’, “patients were ambivalent about relating to their children, but as ‘parents’ they wanted HPs to talk about their children” (Dencker 2017c, p. 1).

Paper III suggests that in order to be patient-centred, clinicians should “acknowledge that patients have these conflicting perspectives and identities, which surface at various times and situations throughout their illness trajectories” (Dencker 2917c, p. 1). Hence, it is important “to avoid patients being forced into positions that they cannot cope with having been encouraged to act in ways for which that they do not have the mental or physical resources” (Dencker 2017c, p. 16).
7. Discussion
In this chapter I will further reflect on the results presented as a whole, discussing the three papers’ contributions to the field of health communication focusing especially on the contribution to the concept of patient-centeredness. To structure the discussion, I present a new communication model called the BACIC model. BACIC stands for: BArriers, Contexts and Identities in Communication. The model summarizes the results of this thesis’ three papers. The model is intended to be a tool for HPs to reflect on CSIP and more broadly on topics that HPs find challenging to address.

The BACIC model sets the stage for a discussion of the relationship between standardization and individualization in clinical encounters, and points to the challenge of putting a topic such as CSIP systematically on the agenda while acknowledging that contextual factors, such as the individual patient, make it impossible to communicate systematically in predefined ways. The discussion looks back at reflections from the positioning section regarding what ‘to improve’ can mean in CSIP, and includes a description of the three papers’ progression in that regard.

Finally, I discuss the strengths and limitations of my papers, practical implications, and future research possibilities.

As mentioned in the introduction, former methods to promote patient-centred practice have focused mainly on preparing a relevant treatment plan for the patient, obtaining compliance and treatment results and promoting greater patient satisfaction. These foci have mainly been addressed using RCT designs. (Fallowfield & Jenkins 1999; Fallowfield et al. 2002; Jenkins & Fallowfield 2002; Razavi et al. 1993; Razavi et al. 2002), which have evaluated training programmes by counting the occurrence of specific communication skills (e.g. open or closed questions, signs of empathy and probing the patients understanding of medical information) before and after HPs’ participation in communication training (ibid).

These studies have contributed to showing that communication training is particularly effective for HPs’ generation of information regarding patients’ symptoms and gives a more precise diagnosis and treatment and greater empathy in supportive encounters. However, due to the interests of this research, where use of quantitative methods has been beneficial, communication skills have been addressed regardless of their context (e.g. the medical context, and the patients’ relationships), and it has therefore not been possible to get insight into more detailed mechanisms influencing particular communication situations.

More recent research supplements these earlier RCT studies, taking a more holistic stance and suggesting that communication is context-specific and that communicative behaviours are too complex to be predetermined and assessed with behavioural checklists (Giroldi et al 2017). As described earlier, there has been a shift from ‘communication skills’ towards ‘skilled communication’, meaning that communication skills must be seen in their context to be evaluated (Salmon & Young 2011). Thus, ‘skilled communication’ includes the context of daily practice, such
as aspects related to the doctor, the patient and the consultation, which may require different skills or ways of handling these skills (Essers et al. 2011, Essers et al. 2013).

My research relates to ‘skilled communication’, because it has investigated the mechanisms at stake regarding CSIP focusing on a) the patient as part of a relational whole and b) communication as contextually situated e.g. taking the medical context, HPs’ structural conditions and patients’ identities into consideration. Using qualitative methods, I have explored the individual meanings and relational and contextual mechanisms that influence CSIP affecting HPs and patients’ (Creswell 2009).

**BACIC: A model for communicating about dependent children during parental illness**

Using my three papers as a basis, I developed a model for communicating about dependent children during parental illness. The model is called ‘the BACIC model’ and BACIC stands for: **BArriers, Contexts and Identities in Communication.** The idea of the BACIC model is that it can be used in future communication training programmes as a tool for HPs to reflect on what is at stake when topics in clinical encounters are experienced as being difficult to address. Altimier & Lasater (2014) suggest that “reflective practice is a learning process taught to professionals from a variety of disciplines with the aim of enhancing abilities to communicate and make informed decisions” (Altimier & Lasater 2014, p. 34). The BACIC model is a tool for ‘reflection-in-action’ as well as a tool for ‘reflection-on-action’, as described by Donald Schön (1983). ‘Reflection-in-action’ takes place when an incident is occurring, for example when a nurse explores and examinies responses to a situation while being involved in it and adopt their actions accordingly (Schön 1983; Altimier & Lasater 2014). ‘Reflection-on-action’ on the other hand takes place after an incident has occurred and implies that the nurse become self-aware and identifies feelings in relation to certain nursing events after they have happened (ibid).

In addition, as suggested by Poland et al. reflexivity contributes to “maintaining a self-critical attitude and questioning taken-for-granted assumptions regarding the (political) nature of work and its (intended and unintended) effects, as well as the social distribution of these effects” (Poland et al. 2005, p. 61). In other words, using the BACIC model as a tool for reflection allows HPs to reflect on their own assumptions, their working conditions and on the effects of their contribution.

Although the model addresses communication about dependent children during parental illness, it might be used in a broader perspective because barriers, contexts and patient identities can be at stake in other communication areas that are perceived to be challenging for HPs to address, such as conversations about death and dying, sexuality and religious beliefs (Abazari 2016; Murray et al. 2004; Vermeer et al. 2016; Fowler 2009).

It is important to note that it is not possible for HPs to change structural deficiencies by reflecting on communicative challenges. It is widely acknowledged that health communication alone cannot close the gap between knowledge and practice of healthy behaviours because other factors can prevent healthy behaviours such as lack of local capacity, training, infrastructure, or access to health products (Kim 2014; Schiavo 2014). In the same way, reflection alone cannot solve problems
caused by lack of resources just by putting CSIP on the agenda. However, reflecting on specific cases or on topics that are generally considered difficult based on the BACIC model may help HPs to identify aspects in their particular setting that influence communication, such as: diagnosis and treatment modalities, structural conditions, HPs’ own emotional involvement, and patients’ identities. Hence, using the BACIC model as a tool for reflection can enhance HPs’ own reflections and their reflection with colleagues.

The BACIC model

The model covers the findings from the thesis’ three papers. It starts with paper I at the bottom, paper II in the middle and paper III at the top. The model is dynamic in the sense that all layers of the model influence each other, and in that sense there is no given order. However, given that HP are mainly responsible for framing encounters with patients, reflecting on HPs’ barriers might be prioritized in looking into whatever topic HP find it difficult to address. Consequently, I have chosen to shape the model as a triangle to promote a reading from bottom to top, and in this way to address HPs’ barriers first. Meanwhile, identifying what is important for patients to discuss requires investigating patients’ perspectives, which points to the necessity of HPs simultaneously looking at patients’ needs and their own barriers. Thus, it might be a barrier in itself for HPs to ask patients about their needs, when they experience a lack of resources to meet those needs. HPs discussed whether patients should have the opportunity to discuss all the psychosocial topics they find important and whether there are limits to be set due to lack of resources – and if so, where they should be set. Ultimately, this means questioning whether CSIP should be HPs’ task and, if so, to what extent and with what content.
The above means that, for the BACIC model to make sense as a tool for reflection, it should start by investigating how the clinical topic in question is prioritized by the management and what conditions need addressing and acting upon. Using CSIP as a case, this would ultimately mean investigating whether and how CSIP is a topic that management, and this includes management at the national level, prioritize economically and practically.

**The thesis contribution to the concept of ‘patient-centeredness’**

Earlier in this thesis, patient-centred communication has been described as a kind of communication that integrates patients’ perspectives in the medical encounter, covering the emotional and the relational aspects between HP and patient and between patient, HP and relatives (Bensing 2000; Epstein 2005; Venetis 2009). By understanding the patient holistically (Steward 1995), the aim is to promote the patients’ satisfaction, involvement and understanding of medical information (Makoul & Clayman 2006; Mead & Bower 2000; Moore et al. 2013; Moreau et al. 2012; Politi et al. 2012; Taylor 2009).

Using the BACIC model, this thesis contributes to the concept of patient-centeredness by introducing three new dimensions to the concept: HPs’ barriers and how they interact, the medical contexts and how they influence communication, and patients’ identities as a dynamic influence on their needs in communication. In this way, this thesis contributes to the concept of patient-centeredness by focusing on the following aspects: a) the significance of structural conditions for the HPs being able to communicate in a patient-centred way, b) the medical contexts as ‘shapers’ for the HPs’ challenges and perceptions, and c) an interpretation of patient-centeredness that admits the possibility of not discussing patients’ emotions and difficulties, including issues regarding their children. Finally, this thesis contributes to the concept of patient-centeredness by including children as a category in relation to the patient which to my knowledge is unique when it is the parents and not the children who are patients.

**Barriers**

With CSIP as an example, the first layer in the BACIC model contributes to the concept of ‘patient-centeredness’ pointing to the importance of acknowledging HPs’ barriers towards addressing CSIP. Hence, HPs must have adequate conditions for adopting a patient-centred approach, which here includes the patients’ children as a topic in encounters. That is, adopting a patient-centred approach is not only about HPs having the skills but also about them having the conditions to put them in effect.

I found that there were no standards stipulating how HPs addressed CSIP in the form of explicit and clearly described work assignments regarding what was expected from them when patients have dependent children. Therefore, HPs’ efforts became dependent mainly on their own individual assessment of who, how and when CSIP should be addressed. HPs experienced structural barriers in the form of lack of space in the medical recording system, of inadequate professional codes, of time pressure and of lack of training, and these barriers often made them avoid CSIP (Dencker et al. 2017a). As pointed out in paper I, HP tended to be overwhelmed by emotions when addressing CSIP because of the painful nature of the situation and the perceived need of keeping professional...
distance. In that connection, I argue that emotional barriers tend to grow when structural barriers are not addressed (Ibid).

Acknowledging that HPs’ structural and emotional barriers are related, I suggest more standardisation and less individualization when relating to HPs’ barriers in order to ensure that CSIP is systematically addressed. By more standardisation, I mean that, if HPs are to address CSIP systematically, they must know what is expected of them, have adequate conditions and relevant competences. This involves the knowledge and ability to act in accordance with the patients’ needs regarding their children, knowing at the same time when to refer to other professional help (Danish Health Authority 2012). In that way, more standardisation would prevent CSIP being addressed only randomly, depending predominantly on factors such as HPs’ individual feelings of competence and limited time available. This would ensure that all patients were offered qualified support as to how to support their children. The idea is that if, when addressing CSIP, HPs depend predominantly on the individual HP, the situation is too vulnerable for the HPs themselves, and for patients and their families, because HPs must invent actions for themselves without knowing what is expected from them. This again affects the quality of their effort and overload them emotionally. Therefore, less individualization.

Consequently, and to enhance standardisation of CSIP at the level of the HPs, I propose the introduction of templates and manual procedures to gather and process information about children in medical records, managerial backing, of allotted time, and of training programmes to include how to implement procedures and how to address all barriers.

Contexts

The second layer of the BACIC model contributes to the concept of ‘patient-centeredness’ by highlighting the significance of the medical context linking the patients’ diagnosis and treatment to communicative challenges and to HPs’ perception of children and patients. I found that the medical context influenced what become the main topics and challenges in CSIP (Dencker et al. 2017b). Adopting a patient-centred approach, therefore, demands seeing the patient in a wider context than as ‘a patient’ understood as a person who is ill or seriously ill. The patient with children is also a ‘particular patient’, who experiences specific challenges related to the diagnosis and treatment in question. Patients may be ‘particular’ in other ways as well, because, for example, they are in different phases of their illness trajectory, have different socioeconomic backgrounds or physical and psychological conditions during their cause of illness. However, I found some general characteristics on each ward that influenced CSIP. For example, 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. Consequently, a main challenge to communicating with patients about their children in haematology was how patients could combine the isolation period with having parental responsibility (Dencker et al. 2017b).

Since ward differences influenced CSIP and challenges to it, I suggest more context consciousness and less standardisation. By more context consciousness, I mean increasing awareness of how context influences communication. Less standardisation as a future intervention is important.
because global guidelines targeting all hospital wards may overlook medical context-specific challenges. Therefore, guidelines should be adjusted conditions on each ward. For instance, regarding CSIP it would be possible to address and train skills that are connected to challenges related to specific wards. For example, as also shown in paper II, it was especially difficult in neuro-intensive care to include children in encounters because the healthy adult was in acute crisis and had to be substitute for the patient who was unconscious (Dencker et al. 2017b). This recurrent challenge, how to include children in encounters when the healthy parent is in crisis, could be trained more in detail. Moreover, I suggest that local action plans on the ward, based on systematization of the effort as described under ‘HPs’ barriers’ at the bottom of the model, might take the wards specific characteristic into consideration when describing ways to assess challenges in communication.

I also found similarities across wards that had to do with patients’ conditions as seriously ill or dying. As mentioned, the prospect of death seemed to dissolve all categories regarding how children were perceived, because HPs became genuinely concerned to include children both psychologically and physically. However, the ways HPs included children in encounters when addressing the prospect of death may still depend on the medical context and the cause of illness. To increase awareness of how the medical context influences communication, I suggest further exploration of the influence of medical contexts on the inclusion of children in patient communication (Dencker et al. 2017b). In the same way, areas of communication other than CSIP might be explored in regard to ways in which the medical context influences them.

**Patient identities**
The third layer in the BACIC model contributes to the concept of ‘patient-centeredness’ by questioning whether it is always patient-centred to address patients’ feelings and challenges, e.g. with their children. As described by Bensing 2000; Epstein et al. 2005 and Venetis et al. 2009, the encounter should, to be patient-centered, integrate the patients’ perspectives in the medical encounter covering the emotional and the relational between HP and patient and between patient, HP and relatives. Meanwhile, I found that patients were not always prepared to integrate their emotional perspectives, in this case emotional challenges concerning their children.

As shown in paper III, there were two overall identities at stake for seriously ill patients with parental responsibility: ‘patient identity’ and ‘parent identity’. That is, as ‘patients’, patients were ambivalent about relating to their children, but as ‘parents’ they wanted healthcare professionals to talk about their children (see paper III). Consequently, I suggest more individualization and less standardization meaning that any effort regarding the patients’ children should be on the patients’ premises and not only as a result of standardized actions. Hence, actions solemnly based on standardization may have the disadvantage that patients become forced into positions that they cannot cope with having been encouraged to act in ways for which they do not have the mental or physical resources. Consequently, I suggest in paper III that, to be genuinely patient-centred, clinicians should acknowledge that patients have these conflicting perspectives and identities, which surface at various times and situations throughout their illness trajectories (paper III).
**Standardization vs. individualization**

The BACIC model contains the contradiction that the HPs’ level points to more standardization and less individualization while the patient level point to less standardization and more individualization. This contradiction actualizes the premise for HPs’ daily clinical decision-making, where following standards and evidence must be related to individual patients with different preconditions. In 2011, Zilberberg described this premise as a tension between treatment of individuals and treatment of groups of individuals. Treating individuals in a standardized way can be beneficial, at best, if the individual is representative - which individuals seldom are - and “at worst potentially harmful if compliance with standards in the form of guidelines are followed without any consideration for clinical judgement or preferences” (Zilberberg 2011, p. 1496).

The tension between treatment of individuals and treatment of groups of individuals is also found under the headings of ‘evidence-based medicine’ and ‘cultural competence in medicine’ (Hasnain-Wynia 2006; Engebretson et al. 2008; Goldman & Shih 2011). For example, Hasnain-Wynia defines evidence-based medicine as “the conscientious, explicit, and judicious use of current best evidence, primarily from clinical trials, in making decisions about the care of individual patients to improve quality through the standardization of medical care” (Hasnain-Wynia 2006, p. 1). The same author defines, by contrast, cultural competence in medicine as “the delivery of health services that acknowledge and understand cultural diversity in the clinical setting and respect individuals' beliefs, values and behaviors” (ibid). The latter implies that HPs take contextual aspects into account when addressing the patient.

Related to the BACIC model, the dilemma is the following: on the one hand CSIP is not systematically addressed, and, when addressed, it is arbitrary who, when and how it is addressed, which points to the necessity for standardization. That is “delivering care in a standardized fashion, healthcare providers attempt to ensure e.g. efficiency, consistency, and quality” (Engebretson et al. 2008, p. 175). Standardization is thereby meant to avoid harmful or discriminatory practice using quality measures, educational materials, tools and guidelines, for example (Hasnain-Wynia 2006). Moreover, standardization can promote transparency in ways that are consistent with accountability as well as allowing “consistent coordination of people and things in ways that would be difficult to achieve on an ad hoc basis” (Timmermans & Epstein 2010, p. 83).

On the other hand, patients are not always prepared to relate to their children, which indicates the need for clinical caution in taking the individual patient’s needs and preferences into consideration. As suggested by Engebretson et al., (2008) if standardization is implemented rigidly, supposedly to ensure equal treatment, there is a risk of blindly assuming that all patients are alike (Engebretson et al. 2008). Thus, a critique of standardization is that “it discourages individualized patient care and promotes a ‘cookbook’ approach to medicine based on population-based means that may not represent each individual patient” (Hasnain-Wynia 2006, p. 3). That is, patients can have unpredictable preferences. For instance, some patients prefer a more physician-centred direction of treatment, defaulting to the current favoured professional standard of shared decision-making, which without individualized dialogue can provoke feelings of abandonment (Barnard 2016).
Following Timmermans & Epstein 2010, I suggest that addressing CSIP does not become a question of an either-or approach to standardization, but rather a question of finding a balance between flexibility and rigidity in the implementation of standards regarding CSIP (Timmermans & Epstein 2010). From this perspective, standardization is understood as an active process that aspires to stability and order, in this case by putting CSIP on the agenda. Introducing guidelines – not the same as the more voluntary recommendations – would oblige HPs to register whether the patient has children, if there are any special needs, and to offer or refer to support if needed. However, to oblige HPs to systematically register and follow up on CSIP requires that they have the opportunities and resources to perform these tasks, including a clear description of what is expected from them. That is, neither reflection on communicative challenges nor guidelines for CSIP can eradicate structural deficiencies. Therefore, I propose the introduction of templates and manual procedures to gather and process information about children in medical records, alongside backing from management, allocated time, and training programmes to include how to implement procedures and how to address all barriers (Dencker et al. 2017a).

Nevertheless, I will argue that standardization as a one-sided solution to HPs’ barriers is insufficient for CSIP, because, given differences between patients and their situations, the demands of HPs prove more complex, context-dependent and inconsistent. Therefore, practice cannot completely rely on principles to determine what to say (Salmon & Young 2011). As Essers suggests, “context factors should rather be considered as ‘signals’ than as ‘noise’” (Essers et al. 2013, p. 7) and be integrated in the HPs’ way of addressing encounters, which requires considerable ingenuity and imagination (Essers et al. 2013). The point is that contextual aspects make it impossible to communicate in predefined ways. Therefore, it is necessary to emphasize the value of intuition and deviation from the rules, rather than application of previously defined skills (ibid). Hence, the opposite of standardization has been described as diversity, individualism or uniqueness (Timmermans & Epstein 2010). This implies that HPs must have individualized dialogue with patients, as suggested by Barnard 2016, to identify if, and when, patients are prepared to address the topic of their children. In addition, HPs must involve the patients themselves when addressing the question suggested by, for example, Goldman & Shih, concerning how HPs can decide “in what situations value-based or opinion-based alternatives would better serve the individual case than the evidence-based recommendation” (Goldman & Shih 2011, p. 27).

As described in the positioning section in chapter 4, my idea of what ‘to improve’ CSIP means changed during the research process. As illustrated in the BACIC model, I recommended increased standardization when addressing the first research question about ways in which HP addressed communicating with seriously ill patients about patients’ dependent children (paper I). Addressing my second research question, I recommended increased context consciousness in relation to the influence of medical context on HPs’ perceptions of children and on the communicative challenges in CSIP (paper II). Finally, when addressing my third research question, I suggested less standardization and more individualization taking patients’ experiences and needs into account (paper III). Relating the papers to each other has given an overview of the papers as a whole and has indicated that the tension between standardization and individualization is at play simultaneously.
DISCUSSION

and is not a linear process. Consequently, HPs must hold a double awareness when addressing CSIP systematically, considering that patients are not always prepared to talk about their children.

Strengths and limitations
The results of this thesis build on a large quantity of data material: 64 semi-structured, in-depth individual interviews (N=19 doctors, N=30 nurses and N=15 patients) with 39 interviewees (N=9 doctors, N=15 nurses and N=15 patients) and 27 days of participant observations within neuro-intensive care, haematology and gynaecological oncology (nine days on each ward). The data was generated over almost two years from September 2013 to June 2015, a timespan that provided a unique opportunity to get an in-depth understanding of the three research questions concerning mechanisms influencing the communication between healthcare professionals and seriously ill patients about patients’ dependent children.

Interviewing healthcare professionals several times and conducting repeated participant observations on the wards strengthened this in-depth understanding. Following HPs during their clinical practice strengthened my understanding of the context within which they worked, their tasks and challenges. In addition, participant observations also created a common frame of reference for the interviewer and the healthcare professionals, which meant that I could ask about some of the situations that had happened during the participant observations. For example, I could ask questions about situations in which professionals spoke with patients about their children or when they chose not to do so (Dencker et al. 2017a).

Important limitations of the study were that the participating HPs were mainly women in their mid-forties with more than fifteen years of experience, given that gender, age and years of experience might influence the experiences of barriers. For example, being of lower age and with fewer years of experience might increase the experience of barriers and underline the importance of clarity in the domain of production because participant had less experience in inventing actions themselves. Investigating the matter, these variables could also show opposite results, such as a connection between fewer years of experience and curiosity and courage. Likewise, a further investigation of the relationship between gender issues and HPs’ barriers to addressing CSIP could throw light on whether, how and when gender influences HPs’ experiences of barriers and ways of addressing them. However, this was not in the focus in my investigation.

Moreover, most of the participating HPs were engaged in the training programme and were either recruited because they were considered particularly suited for engaging in the subject or had signed up for themselves. Therefore, they were probably more motivated to reflect on CSIP than their colleagues. A broader selection might have given a more nuanced picture of HPs’ level of reflection regarding CSIP and their willingness to integrate CSIP as a working task among their duties. In addition, the distribution of doctor and nurses was unbalanced, since there were nine doctors participating compared to fifteen nurses. Hence, a corresponding sample of doctors could support a comparison between experiences in general and between barriers as experienced by the two groups (Dencker et al. 2017a). For example, doctors may have to balance between medical and
psychosocial perspectives in encounters to a larger extent than nurses, while nurses may be more emotionally challenged because they probably engage more in CSIP.

Regarding the investigation of patients’ perspectives, a major limitation was the imbalanced distribution of patients on haematology and gynaecological oncology wards, their gender distribution and their being in different phases of their illness. I interviewed eleven patients from haematology and only four from gynaecological oncology. Moreover, I interviewed twice as many women as men, namely 10 women and 5 men (6 women and 5 men from haematology and 4 women from gynaecological oncology). In addition, the interviewed patients were at different phases of their illness: as outpatient, as hospitalized or as awaiting diagnosis. These imbalances might have influenced results, for example regarding patients’ dynamic identities, because patients in haematology go through an isolation period where they are often in an extremely poor condition that might strengthen their need to keep a distance from their children. Moreover, gender might influence patients’ identities in the sense that female and male patients might be vulnerable regarding their children in different ways. Therefore, paper III proposes further exploration of ‘patient’ and ‘parent’ identities in different illness groups and cultures. However, as suggested in paper III, by highlighting the uncertainty of patients at risk of dying and their experiences of being seriously ill, we found that all the interviewed patients balanced between the two patient identities I have described, that is: across diagnosis, gender and phases of their illness.

There are some examples of inconsistency when comparing the descriptions of strengths and limitations in paper I and in the thesis. In paper I, I pointed out that it was a limitation of the study that it was exclusively based on what participants themselves had said about their actions. In addition, I pointed out that this can be a problem, because participants’ self-understanding does not always reflect their actions in practice (Tjørnhøj-Thomsen & Whyte 2008). Nevertheless, I have now described a discrepancy between HPs’ expressed intentions and their actual practice in chapter 4 under the section ‘participant observations’. I here underline the importance of HPs’ structural conditions when addressing CSIP, which supports the results presented in paper I. However, due to word counts in paper I, it was not possible to integrate participant observations.

Reliability, validity and generalization
In the following, I will further discuss the quality of my study, and relate to possible criteria in that connection.

Criteria for assessing and ensuring the quality of findings as a qualitative researcher are often discussed in relation to the criteria used for evaluating quantitative research: reliability, validity and generalizability (Creswell 2009; Mason 2007; Long & Johnson 2000). I choose to discuss and relate to these criteria but in a revised form, because I conducted my study within the medical field where these concepts are often used and acknowledged.

In quantitative terms, reliability is commonly defined as “the degree of consistency of dependability with which an instrument measures the attribute it is designed to measure” (Long & Johnson 2000, p. 30). Thus, in this sense ‘reliability’ builds on the assumption that methods of data generation can
be conceptualised as tools, and can be standardised, neutral and non-biased (ibid). Validity, again in quantitative terms, is defined as “the degree to which an instrument measures what it is intended to measure” (Long & Johnson 2000, p. 31). The latter indicating that an instrument, no matter what the context, can measure something that is already defined ‘out there’ and which has nothing to do with the instrument itself. Finally, generalizability is a standard aim in quantitative research and is achieved by statistical sampling procedures ensuring the representativeness and the possibility of applying results to new settings, people or samples (Silverman 2010; Creswell 2009).

Applying these described quantitative measures of quality to qualitative research is “considered problematic since quantitative and qualitative research hold different assumptions about reality and have different worldviews” (Merriam 2009, p. 211). Thus, “qualitative research stresses the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational aspects that shape inquiry” (Denzin & Lincoln 2011, p. 8). In contrast, “quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes” (ibid). Consequently, according to Kvale & Brinkmann (2014), some qualitative researchers have rejected assessment of qualitative research on the basis of questions regarding validity, reliability and generalizability because they find “that it inhibits creative and liberating qualitative research while being originally associated with a positivistic worldview” (Kvale & Brinkmann 2014, p. 317). However, other qualitative researchers suggest that due to the different scientific worldviews, concepts should not be eradicated but instead rethought and reconceptualised when used to assess qualitative research; that is, withholding and acknowledging the concepts’ methodological significance for obtaining trustworthiness and rigour in research (Merriam 2009; Kvale & Brinkmann 2014; Mason 2007).

In the following, I will further reflect on the quality of my study using the concepts reliability, validity and generalizability, though adjusted to the fact that I conducted a qualitative study.

**Reliability**

Reliability is about ensuring that data collection is undertaken in a consistent manner free from unnecessary variation, which unknowingly has an effect on the nature of the data (Long & Johnson 2000). In other words, as Merriam says of quantitative studies, “if the study is repeated, will it yield the same results?” (Merriam 2009, p. 220). However, because the researcher is ‘the instrument’ and part of the research field in qualitative research, and because human behaviour is never static, a qualitative study cannot be repeated (Golafshani 2003). In addressing reliability, Mason suggests that “the qualitative researcher demonstrate to others that data generation and analysis have not only been appropriate to the research questions, but also thorough, careful, honest and accurate” (Mason 2007, p. 188). Miles & Huberman 1994 suggest that “the researcher at the minimum make inevitable bias explicit, and consider if conclusions depend on ’subjects and conditions of the inquiry’ rather than on the inquirer” (Miles & Huberman 1994, p. 278).

My study is reliable in the sense that interviews and participant observations were relevant methods for exploring my research questions, which aimed at getting an in-depth understanding of mechanisms at play regarding CSIP. In accordance, the questions I developed to investigate my
research questions were explorative. Thus, I combined grand-tour and mini-tour questions respectively, based on my research questions, to investigate informants’ broad experiences and the specific activities and experiences that promoted a nuanced understanding of CSIP.

In my study, reliability – seen as pertaining to the stability of data collection measurement as suggested by Long & Johnson (2000) when it comes to quantitative research – has not been unambiguous since data have not been collected as if they were already ‘there’. Instead I have generated data as a result of relational processes between myself and my informants, where contextual aspects, such as ward characteristics, the condition of the individual patient, and the HPs’ openness influenced data generation. Therefore, I have outlined my positionings to create transparency, well-knowing that it can never be completely adequate nor exhaustive.

Validity
Creswell (2009) suggests that qualitative validity implies that the researcher checks for the accuracy of his or her findings to enhance trustworthiness, authenticity and credibility (Creswell 2009). Thus, Creswell recommends multiple strategies to enhance the researcher’s validity in qualitative research, that is, “the researcher’s ability to assess the accuracy of findings as well as convince readers of that accuracy” (Creswell 2009, p. 191).

In the following, I will describe and discuss the grounds on which I claim validity in this thesis. Here I draw on Creswell’s strategies, also described by Merriam (2009) and Miles & Huberman (1994) and others. The strategies are: triangulation, member checking, rich, thick description to convey findings, clarifying bias, negative or discrepant information that runs counter to the themes, prolonged time in the field, peer debriefing and use of an external auditor. Using these strategies, I will also critically address their limitations, taking into account that I conducted a qualitative study.

Thereafter, I will discuss my study’s validity concerning generalisation. Generalisation in qualitative research is often referred to as ‘analytical generalization’ (Halkier 2011) in contrast to ‘empirical generalization’, where analysis of one empirical statistical representative population is generalised to another wider population (Mason 2007).

According to Creswell, the validity of a study is strengthened if several sources of data or perspectives from participants show converging themes (Creswell 2009). That is, to triangulate different data sources of information investigating the same research questions building a converging justification for themes (ibid). In my study, I combined interviews with participant observations. Using this combination, I found, for instance, that both interviews and participant observations pointed to the interplay between emotional and structural barriers. Visiting different wards with the aim of investigating the same research questions, using the same methods showed both similarities and differences across wards, similarities in, for example, barriers and involvement of children in the face of death, and differences in, for example, how children were perceived in different ways. Hence, the combination of qualitative methods combined with visiting different wards several times underpinned my findings containing both similarities (barriers) and differences (communicative challenges) when comparing the wards.
At the same time, combining interviews and participant observations contributed important data when findings were contradicting. For instance, HPs expressed in interviews that CSIP was important, while participant observations showed that they did not address the topic accordingly. Golafshani argued that, “when using triangulation in quantitative research any exception may lead to a disconfirmation of the hypothesis where exceptions in qualitative research are dealt with to modify the theories and are fruitful” (Golafshani 2003, p. 603). In relation to my results, this means that differences and similarities across results drawing on different methods, in this case interviews and participant observations, has been equally important to understand the mechanisms at stake regarding CSIP.

Regarding investigator triangulation, which is mentioned by Merriam 2009 and means that there are multiple investigators collecting and analysing data, I was the only researcher collecting and analysing data – at least initially. This can be seen as a weakness if we draw the conclusion that the analysis was therefore subjective. However, if we accept that this subjectivity was paired with transparency as regards positioning and the application of theory and that others were involved in ongoing analyses, then the data processing here might be termed inter alia subjective. Qualitative research does acknowledge as a premise that knowledge is socially constructed and based on an interaction between the researcher and the researched, where the researcher is part of the research field and not separated from it, which is why clarifying one’s positionings is important in order to create transparency (Golafshani 2003; Hastrup, 2004b). Moreover, I discussed the analysis of my data related to my research questions with colleagues at the National Institute of Public Health, Danish Cancer Society and at the University of Edinburgh, including at two hospices, as well as on international conferences e.g. in Dublin and Malaga. Engaging in these discussions gave me the opportunity to probe my findings and analytical practice, including the interplay between my observations and theories.

Member checking means taking the final report or specific descriptions or themes back to the participants and determining whether these participants “feel that they are accurate” (Creswell 2009, p. 191). In my studies I did not conduct member checking after the final report. However, I conducted follow-up interviews with various informants during the study, which provided an opportunity for them to comment on my preliminary results (Creswell 2009) That is, revisiting the wards and interviewing several HPs more than once gave me the opportunity to probe my findings during the research process. For example, I shared my observations of different ways of perceiving children at each ward with the HPs and the patients, who found them recognizable. Even though I did not interview patients more than once, I did probe findings from interview to interview, though with different patients, concerning, for example, the interaction between being a parent and being a patient who was not always prepared to talk about their children. However, as Long & Johnson among others point out, member checking as a validation strategy can be deficient. That is “participants’ memory might fail, they may be unconscious of some of the non-verbal clues that they transmit which forms part of the data, or they may simply (consciously or unconsciously) deny less attractive aspects of their behaviour” (Long & Johnson 2000, p. 34).
DISCUSSION

*Rich, thick description* implies “to convey findings transporting readers to the setting and give the discussion an element of shared experiences” (Creswell 2009, p. 191). Throughout the research process, I sought to give rich and thick description, drawing both on interviews and on observations when outlining my results. However, due to word counts in paper I-III, especially in paper I, there were limits to these descriptions. It has therefore strengthened the validity of my findings across papers that I have had the opportunity to describe the research and the analytical process in greater detail in this part of the thesis concerning, for example, findings during participant observations, positioning and ethical considerations. For instance, I have given a more nuanced description of HPs’ working conditions and patients’ vulnerability, both of which were aspects influencing data analysis and results.

*Clarifying bias* in qualitative research is associated with self-reflection (Creswell 2009). Using myself as an ‘instrument’ both as an interviewer and as a participant observer, I was deeply involved in the generation of data. Thus, “reflexivity in qualitative research refers to reflecting critically on the self as a researcher, ‘the human as instrument’” (Merriam 2009, p. 219). Therefore, I have thoroughly described my positionings e.g. as an evaluator and a researcher respectively, the pitfalls I became aware of during the research process, such as ‘the therapeutic pitfall’, and the pitfall of being perceived as a consultant more than as an investigator, and my ethical considerations. A limitation of my study in that regard might have been my double positioning as both an evaluator and a researcher since these roles have not been possible to separate completely, (see the section on “Positioning”). Thus, I cannot exclude the possibility of HPs having seen me as an evaluator of their actions, which might have resulted in wishes for keeping some distance or trying to be extraordinarily engaged in CSIP. However, I did not actually experience such strategies, since my impression was that HPs were generally open about their strengths and weaknesses concerning CSIP, both regarding their emotions and their structural limitations. As described earlier, I sought to separate my positions and to be transparent regarding my investigative aims, both when developing my interview guides and when presenting myself to HPs and the patients.

In addition, I reflected on the extensive acceptance and willingness I experienced during participant observations, where I was let into different scenarios despite many difficult and sometimes compromising situations. Apart from having described thoroughly how I gained access and created openness on the wards, I reflected on how this openness became part of my empirical data. Hence, I interpreted HPs’ openness as an opportunity for them to speak up about their working conditions.

According to Creswell, discussing *negative or discrepant information* that runs counter to the themes adds to the credibility of an account. That is, real life is composed of different perspectives that do not always merge, which is why discussing contradictory information adds to a study’s credibility (Creswell 2009). Thus, I have thoroughly explained how themes were generated in each of my three papers. In paper I, I not only identified HPs’ emotional and structural barriers influencing CSIP, I also found that they were co-existent and influenced each other. In that sense, my findings were not discrepant, but, in analysing the interactions between them, I found nuances indicating HPs’ practice regarding CSIP was more complex than initially assumed.
Regarding paper II, I showed significant differences between how wards perceived children and how these perceptions were influenced by patients’ diagnosis and treatment modalities, which again lead to different communicative challenges. The *discrepant information* in that connection is paradoxically that similarities between wards as regards ways in which children were perceived differently, dissolved on each ward in the face of death. However, this finding did not break down the differences I have mentioned. Instead, it showed what was at stake when differences dissolved, namely that the patients’ impending death changed the HPs’ perspective.

In the third paper, two overall identities were presented: ‘patient identity’ and ‘parent identity’. Exploring patients’ views on parental responsibility implied understanding that patients could be in such poor condition that they were not always able to include their children. This finding was in itself a piece of *discrepant information*, since the starting point was to investigate patients’ perspectives who were managing being a parent while seriously ill. In that sense, it was *negative information* that patients sometimes did not accept this premise, because it broke with my initial idea that patients generally would want HPs to be more proactive.

Finally, when considering the three papers in a meta-perspective, I found that there was a discrepancy between them regarding recommendations related to future clinical implications, in other words the tension between individualization and standardization when addressing CSIP. I have explicitly discussed this *discrepant information* earlier in this section, suggesting that HPs must hold a double awareness when addressing CSIP systematically, considering that patients are not always prepared to talk about their children.

*Prolonged time in the field* contributes to developing an in-depth understanding of the phenomenon under study and especially of the setting. I visited and revisited the three participating wards over almost two years which, apart from promoting an in-depth understanding of mechanisms influencing CSIP, created mutual trust between me and the informants. Mutual trust promoted an open atmosphere in which informants could express themselves openly and freely.

*Peer debriefing* involves “a person reviewing and asking questions about the qualitative study, so that the account will resonate with others than the researcher” (Creswell 2009, p. 192). In this regard, I discussed my qualitative study with my supervisors during the whole research process and with colleagues at National Institute of Public Health, University of Southern Denmark and at Danish Cancer Society. In addition, the co-authors of all papers, including international co-authors from University of Edinburgh, Scotland, made important contributions in discussing my material. Finally, two papers are published in international peer reviewed journals, while the third paper is under review, likewise in an international peer reviewed journal. In that way, my study has lived up to the so-called ‘*external auditors’* validation strategy (ibid).

**Generalization**

It is argued that “the value of qualitative research lies in the particular description and themes developed *in context* of a specific site” (Creswell 2009, p. 193). Thus, focus is on “particularity rather than generalizability because the researcher wishes to understand the particular in depth, not
to find out what is generally true of the many” (Merriam 2009, p. 224). Acknowledging that qualitative research is contextual and relational, or in other words different from statistical sampling procedures that ensure representativeness and the possibility of applying results to new settings, people or samples, I chose to address generalization in qualitative research as ‘analytical generalization’ (Halkier 2011). Halkier (2011) refers to three different ways of analytical generalization that I will draw upon in exemplifying and discussing the potential for generalization in my research. The three ways are: ideal typologizing, category zooming and positioning (Halkier 2011).

Halkier (2011) defines building an ideal typology as one of the most common ways to create analytical generalization (Halkier 2011). According to Halkier “ideal typologies are used to represent a comprehensive covering kind of pattern of the empirical data material, central to the main research question” (Halkier 2011, p. 792). An important part of ideal typologizing is to condense coded data patterns into a smaller number of descriptions “which one-sidedly underline particular characteristics at the expense of others” (Halkier 2011, p. 790).

Examples of ideal typologies from my studies are ‘children as sources of infection’, ‘children as spectators’, and ‘children as invisible present’. These are all specific and context-bound typicalities covering patterns of how children were perceived on different wards, derived from interviews and participant observations. Thus ‘children as sources of infection’ covered a pattern on the haematological ward, ‘children as spectators’ covered a pattern on the neuro-intensive wared, while ‘children as invisible present’ represented the main view on children at the gynaecological oncological ward. The point is that these ideal typologies were found in particular medical contexts, which means that they cannot be transferred to hospital wards in general regardless of medical speciality. Thus, I suggest that they can be transferred to other similar wards, for example other haematological wards regarding ‘children as sources of infection’. However, a limitation of these exemplified typologies is that other ways of typologizing children at each ward have not been outlined, such as ‘children as a vulnerable group of relatives’ or ‘children as visitors’. However, I was guided by the part of my research question investigating how the medical context influenced HPs’ perceptions of children, which was therefore the main focus of my coding process.

According to Halkier, category zooming is a way of going into depth with the details and complexities at one single point of the study. Category zooming aims at “building some analytical generalizations that can represent contradictions, exceptions, and processes that glide between established types” (Halkier 2011, p. 792). In that way, category zooming builds on the perspective that single categories are context dependent and nonessential in their character (Halkier 2011). Drawing upon this approach, a zooming in on the typicalities of children described above, investigating the dynamics both individually and across wards of how children were perceived, I found that these typicalities dissolved in the face of death. Thus, in the face of death children became family members on a par with the rest of the family, which underlined the unstable and dynamic character of typicalities. Interestingly, when demonstrating the unstable character of the categories as a common feature across wards, this became a result in itself.
Halkier’s last example of ways of making analytical generalizing in qualitative research is about positioning. Following Halkier (2011), positioning as a form of generalizing achieves to underline the situational and the dynamic about how a phenomenon, in this case CSIP, is performed in everyday life (Halkier 2011). The point is that positioning as a form of generalisation takes into account that “the contents of expressions and actions are constituted by the forms of social dynamics such as e.g. group interactions, negotiations and conversational processes” (Halkier 2011, p. 793). Conducting interviews and participant observations on three different wards and encountering both nurses, doctors and patients gave me the opportunity to explore how CSIP was either conducted or avoided in various situations and interactions.

Dependent on the settings in which doctors and patients interacted, I found that they took different stances regarding CSIP. For example, on the haematological ward, children were talked about and treated as ‘sources of infection’ whereas interactions on the other wards, changed the perceptions of children kaleidoscopically. When exploring CSIP from the HPs’ perspective, I found specific barriers to addressing CSIP while exploring patients’ perspectives, and I found that needs were different. However, in spite of the different perspectives I also found similarities across wards, groups of HPs and patients. The main similarity was that CSIP was considered important but for various reasons difficult to address.

Finally, concerning generalisation as a whole, I introduced the BACIC model as a generalized tool for reflection, suggesting that it might be used in a broader perspective than CSIP, a view promoted by discussing my results in a meta-perspective. Thus, I introduced a tension between standardization and individualization in the field of addressing CSIP. In addition, I indicated that barriers, contexts and patient identities might be general aspects at stake in other communication areas that are found challenging for the HPs. The idea that my results can be generalized to other communication topics and settings within the field of health communication might be investigated in the future using the model as a tool for reflection.

**Clinical implications**
Throughout the discussing section I have suggested several clinical implications of my results.

Firstly, since children were seldom addressed across wards no matter the diagnosis and treatment, I suggest that standardization is introduced to secure focus on children as a vulnerable group of relatives on all wards. An example of standardisation could include to commit the HPs to ask if the patient has children, their names, ages and who takes care of them. These actions are outlined by the Danish Health Authority in 2012 as recommendations but HPs are not obliged to follow them. Consequently, I suggest that recommendations are converted into guidelines, including that legislation is developed regarding CSIP similar to that in Norway, Sweden and Finland.

Recognizing that guidelines cannot be implemented without sufficient structural conditions, I would recommend a) the introduction of templates and manual procedures to gather and process information about children in medical records, b) management backing, c) allocation of time, and d)
training programmes to include how to implement procedures and how to address all barriers (Dencker et al. 2017a).

Secondly, I would recommend future pre- and post-graduate training programmes targeting both doctors and nurses to take the following into consideration: a) the significance of structural conditions for the HPs’ ability to communicate in a patient-centred way, b) the medical contexts as ‘shapers’ for the challenges and perceptions of who patients and their children become, and c) an emphasis that communicating in a patient-centred way sometimes implies letting the patient be concerned with his or her medical treatment and survival more than with discussing the emotional and difficult aspects of their lives.

Hence, acknowledging that there is no ‘cookbook’ for CSIP, since medical contexts and patients’ preferences are different, HPs must have access to training and supervision providing them with feedback when reflecting on practice. For example, formative feedback is intended to foster individual reflection and remediation (Epstein & Hundert 2002). That is, since each communication situation is unique, its demands cannot be reduced to a combination of rules. The right thing to do or say cannot be completely clear (Salmon & Young 2001). In addition, according to Salmon & Young, it should be acknowledged that a large part of communication is intuitive and imaginative. However, this does not mean that communication should be undisciplined and without training. Instead HPs should be supported in reflections on their own creativity as well as on their effectiveness in encounters with patients (Salmon & Young 2001).

This implies that HPs must have individualized dialogue with patients to identify if and when patients are prepared to address the topic of their children, that is finding a balance between flexibility and rigidity in the implementation of guidelines. However, in doing so HPs must know what is expected of them and what they can contribute, both in the encounter but also in referrals to bereavement groups in primary schools, counselling for families or individual counselling and so on.

**Direction for future research**

As mentioned, I have identified three additional dimensions to patient-centeredness: a) the significance of structural conditions for HPs’ ability to communicate in a patient-centred way, b) the medical contexts as ‘shapers’ for the challenges and perceptions of who patients and their children become, and c) an interpretation of patient-centeredness that admits the possibility of not discussing patients’ emotions and difficulties, including issues regarding their children. These dimensions are summarized in the presented BACIC model targeting HPs in future training programmes that future research might further explore.

More broadly, future research might further investigate these dimensions and consider other possible aspects influencing CSIP, such as the timing related to the patients’ illness trajectory, patients’ and HPs age and gender, children’s perspectives and needs, including their age and gender. Thus, female and male patients might experience being seriously ill and having parental
responsibility differently, while boys and girls with a seriously ill hospitalized parent might have gender-related experiences.

For example, breast, lung and prostate cancer patients in one study accepted emotional distress early in the cancer trajectory as temporary and expressed no need for professional help while welcoming emotional support at a later stage when engaged in treatment (Baker et al., 2013). In contrast, another study among glioma patients and their relatives showed that receiving reassurance and support was acute during the early phase of the illness when distress and uncertainty were at peak (Cavers et al., 2013).

Moreover, barriers and patients’ identities could be investigated in greater depth to explore whether they differ according to wards and diagnosis, for example by further comparing how acute or long-term illness affects CSIP. For example, it has been shown that the risk of conflict is high on intensive care units and can arise, for example, out of family tensions, divergent views on visiting times and treatment decisions. This risk of conflict might be one of several important ward-specific aspects influencing CSIP (McAndrew et. al. 2014, Riley et.al 2014, Fassier &Azoulay 2010, Azoulay et al. 2002).

This study builds upon previous research to underline children’s need for open communication. Future research may find diversity among children of seriously ill cancer patients as a group, and may well point to differences in children’s needs that have yet not been recognized. Moreover, the healthy partner or other individuals significant for the patient or their children in our study might be included in future studies, because a patient’s relationship to such a person might influence both their experiences and their needs for communication about the children and the way they balance patient and parent identities (paper III).

As shown in paper III, patients sometimes feel too exhausted to relate to their children. Future research might, therefore, also further investigate how network members surrounding families in crisis can be supported in supporting the family. Research has indeed shown that network members often feel insecure about how to help these families (Hauken MA et al. 2015).
CONCLUSION

8. Conclusion
This thesis contains three studies answering the following three research questions:

1) How do HP address communicating with seriously ill patients about patients’ dependent children?

2) How does the medical context influence HPs’ perceptions of children and communicative challenges in encounters with seriously ill patients that have dependent children?

3) What are patients’ experiences and needs regarding communicating about their dependent children?

Answering these questions, I found that for HPs to be genuinely patient-centred in CSIP, there are overall three aspects to consider:

- Adequate structural conditions, including legislation and resources for implementation
- Local adjustment of procedures and training to suit medical context
- An individual approach to patients with awareness of their dynamic identities

Firstly, since emotional barriers tend to grow when structural barriers are not addressed, there is a need for templates and manual procedures to gather and process information about children on medical records, a need for management backing for CSIP, for time allocated to it and for future HP training programmes to include how to implement procedures and how to address all barriers (Dencker et al. 2017a).

Secondly, in this thesis communication skills have been shown to be context-dependent as regards HPs’ perceptions of children and related communicative differences. Consequently, I suggest that CSIP should be addressed more locally, taking ward characteristics into account and how these influence communication, including patients’ and children’s needs (Dencker et al. 2017b).

Thirdly, addressing CSIP has shown that patients are not isolated entities but form part of relationships including with their children. Being seriously ill with the risk of dying involves patients having competing perspectives and identities, which surface at various times and situations throughout their illness trajectories. The identified ‘parent’ identity implies that it cannot be taken for granted that patients always want to talk about their children, since they sometimes feel too exhausted and preoccupied with their treatment. Consequently, I suggest a situational and individualized approach where patient-centred communication skills are considered context-dependent (Dencker 2017c).
Addressing the results of this thesis from a meta-perspective, presenting the so-called BACIC model, indicated a tension between the needs for standardization and for individualization when addressing CSIP, which challenged the idea of manuals and systematization as a unilateral solution.

The thesis builds on a large qualitative study. Future studies might try to include a similar number of doctors and nurses and the same number of patients representing different wards, also wards that have not been included in this study. In addition, future research might secure a wider spread in gender and age for participants. As regards doctors and nurses, a wider spread of years of experience might be appropriate here, too.

The thesis suggests further research into other possible mechanisms influencing CSIP. Finally, future research might be concerned with children’s views on having seriously ill and hospitalized parent.
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Appendix I: Participants in the intervention project

**Danish Cancer Society**
I conducted the evaluation and the documentation, and functioned as the overall coordinator of the intervention project as well. Head of Development and Documentation MD, MSc, PhD, Bo Andreassen Rix (BAR) and Head of The Bereavement Project and Teacher Per Bøge (PB) were responsible for the evaluation and the documentation of the intervention as well. PB was economically responsible for the whole intervention project. BAR and PB were also my industrial PhD supervisors.

**Rigshospitalet**
Kristine Halling Kehlet, MSc in Public Health, project manager at Knowledge Center for Patient Support, Rigshospitalet, under the Capital Region of Denmark, wrote the manual and described the training programme alias the intervention together with: Carolina Magdalene Maier, MSc in Sociology, head of The Interdisciplinary Knowledge Center for Patient Support (pr june 2015 member of Parliament for the Alternative); Svend Aage Madsen, superior psychologist PhD, and clinical manager for Department of Psychology, Play Therapy and Social Counselling, Juliane Marie Center, Rigshospitalet; Anders Korsgaard Christensen, superior psychologist, Department of Traumatic Stress, Rigshospitalet; Christian Busch, chaplain, the Church Unit, Rigshospitalet and Gitte Frydendal Stark, Pedagogical psychological consultant, Department of Psychology, Play Therapy and Social Counselling, Juliane Marie Center, Rigshospitalet.

**Copenhagen Centre for Cancer and Health**
Copenhagen Centre for Cancer and Health represented by Jette Vibe-Petersen, Medical Specialist in Internal Medicine, Head of Centre, The City of Copenhagen and Marie Lawætz, Psychologist, Head of Counseling, The Danish Cancer Society contributed with their experiences regarding referral and recruitment to counselling of patients and their families, including children.

**National Institute of Public Health, University of Southern Denmark**
Tine Tjørnhøj-Thomsen, professor, anthropologist, MSc, PhD from National Institute of Public Health, University of Southern Denmark contributed to the discussions regarding the intervention project. At the same time Tine Tjørnhøj-Thomsen was my main PhD supervisor.
Appendix II: Information letter to patients

9. december 2014

Informationsbrev til patienter og pårørende om projekt: “Børn som pårørende”


Kræftens Bekæmpelse, Rigshospitalet og Københavns Kommune har indgået samarbejde om at styrke sundhedspersonalets indsats for børn som pårørende - og der skal laves et undervisningsprogram. Mit besøg skal sikre, at undervisningsprogrammet bliver:

- Relevant og brugbart for sundhedspersonalet
- I overensstemmelse med patienters og pårørendes ønsker, behov og forventninger til sundhedspersonalet

Projektets overordnede formål er: 1) at styrke sundhedspersonalets kommunikation med familier, hvor en forælder er syg og har hjemmeboende børn og 2) at sikre den bedst mulige hjælp til familier i den situation. Projektet vil også resultere i en ph.d.-afhandling om, hvordan sundhedspersonale kan tage højde for den indlagte forældres samlede livssituation i kommunikationen. Det værende sig medicinsk, psykologisk og socialt og i et omfang, som den indlagte finder ønskværdigt.

Firmanavn og adresse

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Informationsbrev til patienter og pårørende om projekt: “Børn som pårørende”


Kræftens Bekæmpelse, Rigshospitalet og Københavns Kommune har indgået samarbejde om at styrke sundhedspersonalets indsats for børn som pårørende - og der skal laves et undervisningsprogram. Mit besøg skal sikre, at undervisningsprogrammet bliver:

- Relevant og brugbart for sundhedspersonalet
- I overensstemmelse med patienters og pårørendes ønsker, behov og forventninger til sundhedspersonalet

Projektets overordnede formål er: 1) at styrke sundhedspersonalets kommunikation med familier, hvor en forælder er syg og har hjemmeboende børn og 2) at sikre den bedst mulige hjælp til familier i den situation. Projektet vil også resultere i en ph.d.-afhandling om, hvordan sundhedspersonale kan tage højde for den indlagte forældres samlede livssituation i kommunikationen. Det værende sig medicinsk, psykologisk og socialt og i et omfang, som den indlagte finder ønskværdigt.

Firmanavn og adresse

9. december 2014

Firmanavn og adresse
Hvis du kunne tænke dig at dele dine tanker og erfaringer om emnet i et kvarter til en halv times tid, så står jeg til rådighed her på afdelingen i dag tirsdag. Det skal understreges, at det er frivilligt at deltage, din deltagelse er anonym og din eller din pårørendes videre behandling vil på ingen måde blive påvirket af din beslutning.

Med venlig hilsen
Annemarie Dencker
Projektleder, ph.d. studerende
Kræftens Bekæmpelse
Health Communication when Seriously Ill Patients have Dependent Children

By mail of 2016-10-28 you have requested whether above research project must be notified to the Danish Committee System on Health Research Ethics.

As defined by the “Danish Act on Research Ethics Review of Health Research Projects” Section 2 the project does not constitute a health research project, but is considered a quality development projects concerning communication. The project/study can thus be initiated without approval from The Committees on Health Research Ethics for the Capital Region of Denmark.

In Denmark it is the responsibility of the committee system to evaluate health research projects being defined as: clinical trials involving live born human individuals, human gametes intended for fertilization, fertilized human eggs, embryonic cells and embryos, tissue, cells and genetic material from humans, embryos etc. or deceased persons, as well as clinical trials of medicines in humans, and clinical trials of medical devices.

Health research primarily comprises research within medical subjects, clinical and sociomedical-epidemiological research. In addition to research of somatic diseases, it also covers psychiatric and clinical-psychological diseases and conditions as well as odontological and pharmaceutical research.
Register research projects and questionnaire-based surveys are to be notified only if human biological material is included in the project. In case of interview based surveys similar regulations apply.

Health research projects that solely involve anonymous human biological material collected in accordance with legislation at the site of collection need only be notified to the Committee System of Ethical Research if the project involves fertilized human eggs and genetic material cf. Section 25 and 27 (2) in the “Act on Artificial Insemination used for fertilization in connection with medical treatment, diagnostics and research etc.”

It is a requirement, that the biological material is fully anonymous. This means the material must not be individually identifiable; no code must be available for the data.

Trials involving cell lines etc. which originate from a trial regarding the collection of cells or tissue, and which have obtained the required permission, need only be notified if the trial concerns the use of fertilised eggs, stem cells and stem cell lines from these, cf. Sections 25 and 27 (2) of the act on artificial insemination in connection with medical treatment, diagnostics and research etc.

As a matter of form, our rejection to evaluate your project does neither constitute an ethical nor a negative evaluation of the content of the project.

For additional inquiries, please contact the Secretariat for the Committees of the Capital Region at +45 38666395 or by e-mail: vek@regionh.dk.

**Complaints procedure**

Any decision concerning approval and rejection from the regional committee may be brought before the National Committee on Health Research Ethics no later than 30 days from receipt of the decision from the regional committee, cf. section 26(1) of the Committee Act.

The complaint must be submitted electronically with the use of digital signature and encryption in case of confidential protocol content (confidentialities). The complaint must be justified and copy of the decision from the regional committee must be enclosed as well as the case files used for the decision.

Please forward to: dnvk@dnvk.dk

Yours Sincerely,

Louise Kobbernagel
Juridisk konsulent
1. Datatilsynet meddeler tilladelse til projektet

Ovennævnte projekt er den 27. oktober 2016 anmeldt til Datatilsynet efter persondatalovens § 48, stk. 1. Der er samtidig søgt om Datatilsynets tilladelse. Det fremgår af anmeldelsen, at behandlingen udelukkende finder sted i videnskabeligt eller statistisk øjemed.

Datatilsynet meddeler hermed TILLADELSE til behandling af personoplysninger i forbindelse med projektets gennemførelse, jf. persondatalovens § 50, stk. 1, nr. 1.

Tilladelsen gives på følgende vilkår, som Kræftens Bekæmpelse, Annemarie Dencker er ansvarlig for overholdelsen af:

Generelle vilkår

1. Oplysningerne må kun anvendes til brug for projektets gennemførelse.


3. Alle, der deltager i behandlingen af personoplysninger, skal være bekendt med de fastsatte vilkår.

4. Databehandleres behandling af oplysninger skal også leve op til de fastsatte vilkår.

5. Lokaler, der benyttes til opbevaring og anden behandling af oplysninger, skal være indrettet således, at uvedkommende ikke kan få adgang.

1 Lov nr. 429 af 31. maj 2000 om behandling af personoplysninger med senere ændringer. En sammenskrevet udgave af persondataloven kan ses på Datatilsynets hjemmeside www.datatilsynet.dk under punktet ”Lovgivning”.

Vedrørende anmeldelse af: ”Sundhedskommunikation når børn er pårørende til alvorligt syge”

1. Datatilsynet meddeler tilladelse til projektet

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7. Oplysninger må ikke opbevares på en måde, der giver mulighed for at identificere de personer, der behandles oplysninger om, længere end det, der er nødvendigt af hensyn til projektets gennemførelse.

8. Offentliggørelse af resultater fra projektet skal ske på en sådan måde, at det ikke er muligt at identificere enkeltpersoner.

9. Anden lovgivning med krav til behandling af oplysninger i forbindelse med projektet forudsættes overholdt.

**Elektroniske oplysninger**


11. Adgangen til oplysninger må kun finde sted ved benyttelse af et fortroligt password. Password skal udskiftes mindst én gang om året, og når det i øvrigt er nødvendigt af hensyn til sikker behandling af oplysningerne.


**Manuelle (”papir”) oplysninger**

14. Manuelt materiale, herunder udskrifter, fejl- og kontrollister mv. med oplysninger, der direkte eller indirekte kan henføres til bestemte personer,
skal opbevares forsvarligt aflåst og på en sådan måde, at uvedkommende ikke kan gøre sig bekendt med indholdet.

**Biobank og biologisk materiale**

16. Prøver med biologisk materiale og biologisk materiale i biobanker skal opbevares forsvarligt aflåst, således at uvedkommende ikke har adgang til materialet, og på en sådan måde, at det sikres, at materialet ikke fortabes, forringes eller hændeligt eller ulovligt tilintetgøres.

17. Biologisk materiale, der er mærket med personnummer eller navn, skal opbevares under iagttagelse af særlige sikkerhedshensyn.


**Oplysningspligt over for den registrerede**

19. Ved indsamling af oplysninger hos den registererede/deltageren (ved interview, spørgeskema, klinisk eller paraklinisk undersøgelse, behandling, observation m.v.) skal der uddeles/fremmendes nærmere information om projektet til den registererede/deltageren i overensstemmelse med persondatalovens § 28, stk. 1.

Den registererede/deltageren skal heri oplyses om den dataansvarliges og denne repræsentants identitet – herunder navn, adresse og andre kontaktoplysninger – formålet med projektet, at det er frivilligt at deltage, om identiteten på eventuelle modtagere af oplysningerne og formålet med at videregive oplysninger, samt eventuelle andre oplysninger, som er nødvendige for, at den registererede/deltageren kan varetage sine interesser.

Den registererede/deltageren skal desuden oplyses om, at projektet er anmeldt til Datatilsynet efter persondataloven, samt at Datatilsynet har fastsat nærmere vilkår for projektet til beskyttelse af den registreredes privatliv.

**Behandling ved databehandler**


21. Hvis databehandleren er etableret i en anden EU-medlemsstat, skal det desuden fremgå af aftalen, at de yderligere bestemmelser om
sikkerhedsforanstaltninger for databehandlere, som eventuelt er fastsat i den pågældende medlemsstat, også er gældende for databehandleren.

Ændringer i projektet

22. Væsentlige ændringer i projektet, f.eks. (nye) påtænkte overførsler af oplysninger til tredjelande, skal i overensstemmelse med persondatalovens § 51 anmeldes til Datatilsynet forud for iværksættelsen (som ændring af den eksisterende anmeldelse). Ændringer af mindre væsentlig betydning, f.eks. anvendelse af (ny) databehandler, kan anmeldes til Datatilsynet efterfølgende, dog senest 4 uger efter iværksættelsen.

Ved projektets afslutning

23. Oplysninger (herunder biologisk materiale) skal slettes, anonymiseres eller tilintetgøres senest ved projektets afslutning, medmindre en fortsat opbevaring kræves efter anden gældende lovgivning. Det må efterfølgende ikke være muligt at identificere enkeltpersoner i projektet.\(^2\) Alternativt kan oplysningerne overføres til arkiv efter arkivlovens regler.

24. Sletning af oplysninger fra elektroniske medier skal ske på en sådan måde, at oplysningerne ikke kan genetableres.\(^3\)

2. Yderligere opmærksomhedspunkter

Videregivelse af oplysninger mv.


Datatilsynet skal for god ordens skyld gøre opmærksom på, at der i sundhedslovens §§ 46-47 findes særlige regler om videregivelse af oplysninger fra patientjournaler til brug for forskning og statistik, herunder regler om Sundhedsstyrelsens godkendelse.

Advarsel – ved brug af Excel, PowerPoint mv.

Den dataansvarlige skal til enhver tid sikre sig, at dokumenter og andre præsentationer, som publiceres eller på anden måde gøres tilgængelige for andre på internettet, usb-nøgle eller på andet elektronisk medie, ikke indeholder personoplysninger.

\(^2\) Læs om anonymisering på Datatilsynets hjemmeside: www.datatilsynet.dk/erhverv/forskere-og-medicinalfirmaer/anonymisering/

\(^3\) Læs om sletning/destruktion af datamedier på Datatilsynets hjemmeside: www.datatilsynet.dk/offentlig/sikkerhed/sletning-af-datamedier/
Der skal vises særlig agtpågivenhed i forbindelse med brug af grafiske præsentationer i Excel og PowerPoint, da de uforvarende kan indeholde indlejrede persondata i tabeller mv. Det er den dataansvarliges ansvar, at sikre sig, at indlejrede personoplysninger er fjernet, inden præsentationer mv. gøres tilgængelige for andre.

**Overførsel af oplysninger til tredjelande**

Overførsel af personoplysninger til et tredjeland kræver et særskilt grundlag i persondatalovens § 27. Bestemmelsen gælder både ved videregivelse af personoplysninger til en anden dataansvarlig, ved overladelse af personoplysninger til en databehandler samt f.eks. ved overførsler inden for en koncern.

Persondatalovens § 27 skal ses i sammenhæng med persondatalovens 50, stk. 2, der sammen med lovens § 27, stk. 4 og 5, regulerer hvornår Datatilsynets tilladelse skal indhentes til overførsel af personoplysninger til et tredjeland.

For en nærmere gennemgang af reglerne for overførsel af personoplysninger til tredjelande henvises til vejledningen på Datatilsynets hjemmeside.

**Ny lovgivning på vej**


Med venlig hilsen

Suzanne Stenkvist

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4 Ved et tredjeland forstås en stat, der ikke indgår i EU, og som ikke er et såkaldt EØS-land
5 www.datatilsynet.dk → Erhverv → Tredjelande
6 Europa-Parlamentets og Rådets forordning (EU) 2016/679 af 27. april 2016 om beskyttelse af fysiske personer i forbindelse med behandling af personoplysninger og om fri udveksling af sådanne oplysninger og om ophævelse af direktiv 95/46/EF (generel forordning om databeskyttelse)
Interview guide A: Management

/Ledelse – klinikchef, Lægelig leder og afdelingssygeplejerske

Fakta om afdelingen
Antal ansatte: sygeplejersker, læger og andre.
Det særlige ved de sygdomme, afdelingen huser (indlæggelsesforløb, alvorlighed, børn som pårørende)
Patienter på sengeafsnit – patienter i ambulatoriet, der går til hyppige kontroller (deres tanker, prognose og overlevelsesrate).
Hvad er det særlige ved afdelingen i det hele taget?
Hvad er afdelingens stærke sider (personale, patienter, pårørende)?
Hvad er ledelsens holdninger til pårørende, særligt børn som pårørende?
Er det noget, afdelingen arbejder for at udvikle (personale, patienter, pårørende)?
Praksis vedr. børn som pårørende:
Hvem gør hvad?
Hvad forventes af hvem?
Hvordan ved personalet, hvad de skal gøre hvornår?
Kendte dilemmaer?
Eksempler?
Hvem gjorde hvad?
Hvilke overvejelser havde man?

Nuærende praksis:
Hvordan forløber kommunikationen mellem sundhedspersonale og alvorligt syge patienter og pårørende, hvor der er hjemmeboende børn?
Hvordan oplever sundhedspersonalet denne kommunikation i relation til deres kompetencer? Hvad ved de? Hvilke holdninger og behov har de?
Hvordan tror du, at de voksne pårørende og børnene oplever disse samtaler?
Interview guide B: Healthcare professionals I

Først: Hvem er du (navn, alder, faglig baggrund, antal års erfaring, afdeling, din særlige rolle)

Praksis
Hvornår taler du typisk med patienter om deres børn? (Fast procedure?)
Hvordan (og af hvem) bliver emnet bragt op?
Hvad går samtalerne ud på?
Hvad er din oplevelse af disse samtaler?
Er der tidspunkter, hvor du har overvejet at tale om børn som pårørende, men hvor du har valgt ikke at gøre det alligevel?
Hvad var baggrunden for dit valg?
Kan du huske din sidste samtale om børn som pårørende?
Hvad gik den ud på?
Hvad skete der?
Hvordan følste du dig tilpas i denne samtale?
Hvad så du som samtalens udfordringer?
Var der noget, der gik særligt godt i samtalen?
Vil du fortælle om en samtale om børn som pårørende, der har gjort særligt indtryk på dig?
Hvad tænker du, der gjorde at netop denne samtale gjorde indtryk på dig?

Viden
Når du taler om børn som pårørende – hvilken viden vil du sige, at du trækker på?
Hvordan vil du karakterisere denne viden? (personlig, faglig)
Er der noget, du gerne vil vide mere om? (eksempler: indhold – børn reaktioner, eksempler: form – samtaleredskaber, andet?)

Holdninger
Hvor meget mener du, at børn som pårørende kan/skal fylde som samtaleemne i forhold til andre emner, som patienten er optaget af? Hvilke andre emner ”fylder”?
Hvilke andre personlige emner taler du ellers med patienterne om?
Hvad mener du, at I som sundhedspersonale har mulighed for at tage ansvar for, når det gælder børn som pårørende? Hvilke opgaver ser du som realistiske? Hvad er realistisk?

Behov
Hvad kunne du tænke dig at:
Få mere viden om i undervisningssammenhæng?
Hvad kunne du tænke dig at træne?
Hvad mener du bør være målet med en undervisning om børn som pårørende?
Hvad kunne du selv tænke dig at få ud af undervisningen?
Interview guide C: Healthcare professionals II

Først: Hvem er du (navn, alder, faglig baggrund, antal års erfaring, afdeling, din særlige rolle) og hvad hold er du deltager på (1 eller 2)?

Opfølgning på undervisning.

 Hvad er dine umiddelbare tanker om den undervisning, du deltog i (april 2014)?

Børn og unges livsverden og forståelse
Den akutte krise og egenomsorg
Eksistentielle/åndelige og religiøse perspektiver
Børn som pårørende – tilknytning og krise
Introduktion til samtalemodellen.

Var der noget, du fandt særligt brugbart?
Var der noget, du savnede?
Hvordan oplever du, at undervisning og manual spiller sammen?

Har du siden kurset foretaget handleringer i relation til børn som pårørende som er nye - og som du finder er inspireret af kurset? Hvilke?

Har du gjort dig nye tanker/reflekteret på nye måder i situationer, hvor børn er pårørende - og som du finder er inspireret af kurset? Hvilke?

Hvilke undervisningsaspekter fandt du mest brugbare?

Hvilken betydning finder du, at de organisatoriske rammer har for dit udbytte af undervisningen?

Hvilken betydning finder du, at dine egne familiære kommunikationserfaringer har for dit udbytte af undervisningen/din praksis?

Samtaleredskaber-refleksion
I evalueringerne var der flere, der godt kunne have tænkt sig nogle flere samtaleredskaber/konkrete samtaleværktøjer.

Var du en af dem?

Hvad betyder konkrete samtaleredskaber for dig?
Hvad kan de hjælpe dig til?
Hvad gør dem vigtige, f.eks. tradition, magtesløshed?
Hvad tror du gør, at konkrete samtaleredskaber kan være vigtige for dine kolleger?

Hvad synes du er vigtigst i undervisningen (i forhold til manual):
Redskaber og/eller refleksion: Har du idéer til hvordan disse kan kombineres?
Sammenfletning af teori og deltagertilnærmelse
Diskussion af teori i forhold til implementering
Praksisrelevante cases
Konkrete kommunikationseksempler/handleanvisninger
Ligelig vægtning mellem det akutte og det langvarige

Spørge informanter om de husker situationer, hvor de har været i tvivl, og hvad var afgørende for de beslutninger, de traf. Hvilke overvejelser gjorde de sig om, hvad der var det rette at gøre?

**Kombination af perspektiver i forhold til undervisningen**
Hvordan oplever du, at undervisningen hjælper dig til at:
kombinere det medicinske perspektiv og det patientcentrerede perspektiv, når patienter er alvorligt syge og har hjemmeboende børn (generelle tanker herom)?
Opdage andre perspektiver, end de to nævnte (det medicinske og det patientcentrerede - eksempelvis pårørendecentrering) som er afgørende for kommunikationen

**Kombination af perspektiver i forhold til undervisningen - generelt**
Hvilke mekanismer er afgørende for, hvordan disse to-tre perspektiver kombineres i praksis?
Hvilke konsekvenser har det for kommunikationen (kvalitet), at samtale og kommunikation ikke kun omfatter læge - eller anden sundhedsperson - og patient (og eventuel anden voksen) i et én-til-én-forhold, men også omfatter hjemmeboende børn som pårørende?
Hvad gør sig særligt gældende, når der er flere til stede i samtaler udover sundhedspersonale og patient?
Interview guide D: Healthcare professionals III

Først: Hvem er du (navn, alder, faglig baggrund, antal års erfaring, afdeling, din særlige rolle) og hvad hold er du deltager på (1 eller 2)?

Opfølgning på undervisning
Hvad er dine umiddelbare tanker om den undervisning, du deltog i?

Dine erfaringer siden sidst
Casearbejde med udgangspunkt i manuallen
Afrunding og videreformidling: Powerpoint til videre præsentation
Arbejdet med introspektion. Er du blevet mere opmærksom på din egen involvering

Oplever du, at undervisningen har givet dig et bedre kendskab til manuallen, og at den er blevet mere brugbar?
Oplever du, at du (og dine kolleger) er blevet mere opmærksom på dine/jeres opgaver og din/jeres rolle, når børn er pårørende?

Hvilke dilemmaer anser du for vigtigst i dit arbejde?
Hvordan agerer du i de konkrete dilemmaer? Eksempler.
Hvordan agerer du i direkte kontakt med børnene? Eksempler.

Den pædagogiske konsulent:

Viden
Introspektion ”Supervision”
Inddragelse

Brug af viden fra akut krise og egenomsorg
Brug af viden om børn og unges livsverden og forståelse
Brug af viden om den akutte krise og egenomsorg
Brug af viden om eksistentielle/åndelige og religiøse perspektiver
Brug af viden om børn som pårørende – tilknytning og krise

Manualens idéer til samtaler om børn som pårørende (samtalemodellen).
Dele eller helhed. Implementérbar?
Er der noget, der er blevet anderledes på afdelingen efter undervisningen? Hvad har du lagt mærke til? Hvilke dilemmaer ang, børn som pårørende er du mest optaget af i dit arbejde?
Var der noget, du fandt særligt brugbart?
Var der noget, du savnede?
Hvordan oplever du, at undervisning og manual spiller sammen?

Har du siden kurset foretaget nye handlinger i relation til børn som pårørende - og som du finder er inspireret af kurset? Hvilke?

Har du gjort dig nye tanker/reflektet på nye måder i situationer, hvor børn er pårørende - og som du finder er inspireret af kurset? Hvilke?

Hvilke undervisningsaspekter fandt du mest brugbare?

Hvilken betydning finder du, at de organisatoriske rammer har for dit udbytte af undervisningen?

Hvilken betydning finder du, at dine egne familiemæssige kommunikationserfaringer har for dit udbytte af undervisningen/din praksis.

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I evalueringerne var der flere, der godt kunne have tænkt sig nogle flere samtaleredskaber/konkrete samtaleværktøjer.

Var du en af dem?

Hvad betyder konkrete samtaleredskaber for dig?
Hvad kan de hjælpe dig til?
Hvad gør dem vigtige, f.eks. tradition, magtesløshed?
Hvad tror du gør, at konkrete samtaleredskaber kan være vigtige for dine kolleger?

Hvad synes du er vigtigst i undervisningen (i forhold til manual):
Redskaber og/eller refleksion: Har du idéer til hvordan disse kan kombineres?

_Sammenfletning af teori og deltagerinddragelse_
Diskussion af teori i forhold til implementering
Praksisrelevante cases
Konkrete kommunikationseksempler/handleanvisninger
Ligelig vægtning mellem det akutte og det langvarige

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Kombination af perspektiver i forhold til undervisningen

Hvordan oplever du, at undervisningen hjælper dig til at:
Kombinere det medicinske perspektiv og det patientcentrerede perspektiv, når patienter er alvorligt syge og har hjemmeboende børn (generelle tanker herom)?
Opdage andre perspektiver, end de to nævnte (det medicinske og det patientcentrerede) som er afgørende for kommunikationen, f.eks. pårørendecentrering?

Kombination af perspektiver i forhold til undervisningen - generelt

Hvilke mekanismer er afgørende for, hvordan disse to-tre perspektiver kombineres i praksis?
Hvilke konsekvenser har det for kommunikationen (kvalitet), at samtale og kommunikation ikke kun omfatter læge - eller anden sundhedsperson - og patient (og eventuel anden voksen) i et én-til-én-forhold, men også omfatter hjemmeboende børn som pårørende?
Hvad gør sig særligt gældende, når der er flere til stede i samtaler, udover sundhedspersonale og patient?
Interview guide E: Patients

Situation (sygdom, civilstatus, børn: navn og alder, øvrigt netværk)

Hvis ja:
Vil du fortælle om samtalen?
Hvordan kom den i stand?

Hvilke emner berørte I?
Hvilke tanker gjorde du dig om samtalen?
Hvad synes du samtalen bidrog med?
Var der eventuelt noget, som du syntes manglede i samtalen?
Var der noget, du overvejede at tage op med sundhedspersonen, som du valgte at lade ligge?
Hvad tænkte du, da du traf dette valg?
Var der noget, som du gerne ville have talt med sundhedspersonen om, som ikke blev taget op?

Hvis nej:
Når du ikke har talt med sundhedspersonalet om dine børn, er der så nogen særlig grund til det?
Egne grunde?
Sundhedspersonalets? (at de fx ikke har spurgt ind til det)

Er der specifikke spørgsmål vedr. dine børn, som du er særligt optaget af?
Hvordan tager du vare på disse spørgsmål?

Hvad tænker du sundhedspersonalet kan gøre for at støtte dig i de spørgsmål, som du har om dine børn?

Er der andre behov i forhold til dine børn, som du gerne vil nævne?
Hvilken rolle kunne hospitalaet have i den forbindelse?

Hvad er det næste, der skal ske for dig i dag?
Hvornår ser du dine børn igen?

Har du noget som du gerne vil spørge mig om?
Hvordan har det været for dig at blive interviewet?
Tak for din tid og for, at du delte dine tanker.
Henvisning, hvis behov. Udlevering af kontaktoplysninger og træffetid.
Papers I-III
A qualitative study of doctors' and nurses' barriers to communicating with seriously ill patients about their dependent children

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Abstract
Objective: Research indicates that health personnel caring for seriously ill patients with dependent children aged 0 to 18 years often avoid discussing with them the challenges of being a family with a parent in treatment. Children of seriously ill patients risk serious trauma and emotional difficulty later in life and depend on adult support to minimize these consequences. Patients suffer anxiety about supporting their children during their illness. Because of their potentially pivotal role in supporting patients in enabling parent-child communication, we examined HP's structural and emotional barriers to communicating with patients about their children.

Methods: The study was based on 49 semi-structured, in-depth interviews with doctors and nurses working with haematology, gynaecological cancer, and neurointensive care. Both interviews and analysis addressed emotional and structural barriers, drawing on the theoretical framework of Maturana's domains.

Results: The study found structural barriers (eg, lack of space in the medical recording system, professional code, time pressure, and lack of training) and emotional barriers (eg, the painful nature of the situation and the perceived need of keeping professional distance). We found that emotional barriers tended to grow when structural barriers were not addressed.

Conclusions: Our study indicates (1) the need to use templates and manual procedures to gather and process information about children in medical records; (2) the need for managerial backing for addressing children of seriously ill patients and time spent on it; and (3) the need for future HP training programmes to include how to implement procedures and how to address all barriers.

KEYWORDS
cancer, family, oncology, psychosocial support, training

1 BACKGROUND

Of the 1.2 million children under 18 years in Denmark, approximately 40 000 experience a parent being hospitalized with a serious illness, including cancer. The Danish Health Authority's National Recommendations for Health Professionals Encounters with Relatives of Seriously Ill Patients prescribe that health personnel (HP) should support patients in enabling parent-child communication. However, this is rarely implemented.

The few qualitative studies that have addressed HP's barriers regarding dependent children identify, for example, a shortfall of professional confidence, a lack of knowledge of means to support parents in supporting their children, and a fear of being emotionally overwhelmed. Even though these studies acknowledge that structural barriers such as time pressure and access to specialist service providers play a role for HP avoidance of children of seriously ill patients (CSIP), they tend to emphasize the emotional burden of the supportive care role as a key challenge.

Research shows that such children are exposed to an increased level of psychosocial stress and develop greater behavioural and emotional difficulties than peers with healthy parents. In addition, children who experience parents with cancer are at a significantly higher risk of depression and of using antidepressants in their adult life than children without such experience. These risks are minimized if...
children can feel confident that the adults around them can cope with the trauma and the changes that it creates in their own lives.\textsuperscript{11-13} Meanwhile, studies indicate a degree of parental insecurity as to how to inform children and how to cope with their reactions and a tendency to underestimate children’s need for information.\textsuperscript{14-16} Furthermore, evidence suggests that children need information about the illness as early as possible and that they prefer honest information about the parent’s condition and treatment.\textsuperscript{17-19}

The rationale for focusing on HP lies in the pivotal role they could play in helping patients to enable parent-child communication, if their barriers to addressing the subject could be overcome. Our study aimed to examine HPs structural and emotional barriers to providing the necessary support.

Regarding the theoretical background for our research, we are indebted to the theoretical framework devised by the Chilean biologist Humberto Maturana.\textsuperscript{20,21} He operates with 3 domains, each representing a different communicative logic that exists side by side with others in conversations, with 1 domain typically dominating at any given time.\textsuperscript{20,21} The 3 domains are the personal domain, the domain of production, and the domain of reflection. In the personal domain, values, morals, ethics, and private attitudes, feelings, and opinions are dominant, while rules, procedures, routines, and guidelines dominate in the domain of production. Whereas, in the domain of reflection, reaching a conclusion is not as important as listening to other perspectives on a subject and developing potentially more nuanced understandings (Ibid).

2 | METHODS

A qualitative study was conducted in three hospital wards—haematology, neurointensive care, and oncological gynaecology—exploring doctors’ and nurses’ experiences of and attitudes to challenges and barriers to supporting patients in enabling parent-child communication.

2.1 | Participants

Doctors and nurses were recruited through the Capital Region of Denmark’s Knowledge Centre for Patient Support. All the nurses were women while one third of the doctors were men. The average age for doctors and nurses was 46, and their average number of years of experience was 19.

2.2 | Procedure

The 49 semi-structured interviews were conducted with 9 doctors and 15 nurses. Some of the informants were interviewed several times to acquire a deeper and more detailed understanding of their experiences. Using Maturana as a theoretical basis, the interviews sought an understanding of HP’s experiences and attitudes towards emotional and structural barriers, while remaining open towards the issues and topics that the interviewees found important.\textsuperscript{20,22,23} In addition to the interviews, the interviewer conducted 27 days (9 days in each ward) of participant observations. These focused on HP’s working conditions, including conditions for addressing CSIP. Participant observations created a unique understanding of the HP’s working environment and helped to build relationships with them. This was crucial for the quality of the interviews. However, data from participant observations are not included in this article since results are based solely on analysis of interviews.

2.3 | Data analysis

Interviews were digitally recorded and transcribed verbatim. Interview recordings and transcribed interviews were sifted several times and carefully reviewed to reach an overall and in-depth assessment of the main themes and the diversity of practice. The analysis was informed by Maturana’s theoretical framework, within which we coded the content of HP’s structural and emotional barriers corresponding to the domain of production and the personal domain, respectively.\textsuperscript{20,24} For example, “registration” and “distress caused by the situation” emerged as relevant codes, indicating a structural barrier (a deficient record system) and an emotional barrier (being emotionally overwhelmed). Recurring patterns of meaning were analyzed in each interview and across interviews.

3 | RESULTS

Using Maturana’s theoretical framework, we identified HP’s structural and emotional barriers in addressing CSIP. Structural barriers reflect the domain of production and relate to the HP’s working conditions and tasks. This includes their professional code, understood both as what HP feel is expected of them and as what they themselves perceive as good professional conduct. Emotional barriers refer to the personal domain and relate to the HP’s affective responses.

3.1 | Structural barriers

We identified the following structural barriers as being most significant: (1) lack of space in the medical record system, (2) professional code, (3) time pressure, and (4) lack of training.

3.1.1 | The medical record system

Interviews with HP showed that they did not register patients’ children systematically with their age, names, and needs and that the design of the record system was an obstacle. Thus, HP often lost track of whether the patient had dependent children or not. Nurses had a place in their record called “mental and social” where they sometimes wrote information about children:

\begin{quote}
But it disappears in the new system because they [the notes] just run further down, and when a month has past you can’t see the old notes anymore. [I]. What we need is a small place called “family relations” that we can easily find and that pops up every time we go in (N 2:3).
\end{quote}

The HP explained that doctors and nurses registered comments in different systems, so information about children was seldom coordinated or shared and often sank without trace:

\begin{quote}
And you know what—it is not the only thing that sinks, because the record system we have here is dreadful (D 5:3).
\end{quote}
3.1.2 | Professional code
The HP felt that they would not be rewarded professionally if they offered a patient psychosocial care:

“It's hard to tell a colleague who comes in on a night shift —"Listen, it's best you know that I haven't changed that dressing, and the catheter is full and about to explode, too. Instead, I have been supporting the family and talking to them, and offering support to all the children living at home with them, who really felt awful and had so many questions to ask. They have been here, and we have had a three-hour conversation." That's not a scenario we have ever experienced, and if we did, and now we are back to this culture issue, then it would not be appreciated. You wouldn't be considered to be a good nurse... (N2:3).

Lack of professional appreciation meant that HP avoided addressing CSIP. They found that their primary task was to provide physical care for the patient, medicating patients or giving them relief when no further treatment was available:

“Our main task is to try to cure the patient and deal with the complications that can occur, and there are plenty in a special ward like this, right? (D 5:3).

In contrast to adult relatives, HP did not consider the children's role in the treatment to be of primary importance.

It is not the children providing the primary support, so as a result I have to be honest and admit that they fill a very small part of my awareness... (D2:1).

3.1.3 | Time pressure
The HP considered that shortage of time and cuts were barriers for identifying CSIP.

“It is really, really difficult. There has to be more staff, right? Nurses and doctors have to have time for it. Because it is no use if you are called out on another case in the middle of everything (D6:1).

In cases of comorbidity, most of the HP’s time was taken up due to the increase in medical complexity. Doctors especially spend time giving explanations and ensuring that patients understand their medical situation. As a doctor said before seeing a 48-year-old patient:

“I have to admit that I haven't checked the situation regarding his children, because I have been forced to focus on all his other problems. He suffers from several other diseases, including type 2 diabetes, and obesity and sleep apnea. He is in a high-risk phase of his treatment and his prognosis is very poor.

The HP felt that addressing CSIP went beyond the strict call of duty. Since HP did not experience CSIP as an integral part of their professional communication, time became an even more important issue. In cases of comorbidity, patient's children tended to fade into the background.

3.1.4 | Lack of training
Generally, HP did not feel comfortable addressing communication about patients’ children:

“We have not sufficiently practised talking about such taboo subjects as death and destruction. And just think what kind of questions they [the patients] could come up with and what if I turned out to be inadequate (N2:1).

The HP felt that they were not trained in counselling skills for helping patients to support their children and had to rely on their personal experiences, which left younger HP feeling especially vulnerable:

What I also think can be difficult is that we do not know shit [laughs] about any of this either. We do not have the professional skills to say, if there are children, how do we help them on their way. Because we don't know much about that either. Not many of us have children as our patients or are necessarily used to dealing with children (D2:1).

The HP wanted to discuss how general training about children's responses could be, when they did not know the patients' children. Lack of training and options made HP less proactive because they felt insecure about what to offer patients when communicating about CSIP.

3.2 | Emotional barriers
Emotional barriers are those that arise out of the emotional reactions occasioned by patients with dependent children. They inhibited HP from asking about children. We found 2 main emotional barriers: the distress caused by the situation and the need to maintain professional distance.

3.2.1 | The distress caused by the situation
This distress reflected how painful it was for HP to witness patients dying in front of their children, knowing that they would be unable to be a part of their children's future upbringing.

And then I also think about our reactions. Why do we become so affected when children are patients or when children are the patient's loved ones? Then it is like we keep a tight rein on ourselves, and we also become guarded, umm ... actually I think it is a kind of a taboo (D3:1).

These distressing facts made HP avoid the subject.

... And maybe we are also unsure about these things ourselves. And then I find that people avoid the subject a lot (N2:1).

The distress was intensified when HP identified themselves with the patients' situation. The HP considered death too sensitive to talk
about, because they were confronted with their own mortality, especially when HP were of the same age as the patient. What caused the distress became a taboo:

Death is still taboo, even though we encounter it almost every day, in a way, it is still difficult to talk about. Moreover, it is maybe especially difficult to talk about because these are women in a similar situation as yourself, right. Because then ‘it could also be me’, right? [...][N1:1]

Similarities in age or life situation led the HP to identify themselves with the patients and made them emotionally vulnerable in their encounters. Such identification could show up unexpectedly. This was the case for a doctor who was treating a patient, a young mother, who had 2 children and was dying. The doctor spoke with the patient about being discharged from the hospital in order to end her life at a hospice. Initially, the patient did not want to go to the hospice, but she eventually accepted it. After this agreement, the doctor had a conversation with the patient and her children about the decision.

I had said that I would take that encounter too – the one with the children. I thought that I was well prepared for it until I entered the room and those... um... two boys looked like my own boys. They were the same age as them. And then it just hit me – bang! There was only one thing I could do and that was to leave the room again. I simply could not do it. Tears just poured down my cheeks. I had expected that they would be slightly different. However, when I saw them and the fear in their eyes and all that, then they reminded me of my own boys. I just couldn’t. Instead, a super nurse took over. She said that it was perfectly ok to back out. Then, I came back a bit later. I just had to prepare myself in another way. At first it was as if I wasn’t wearing the right armour (D4:1).

The doctor was unprepared for the patient’s sons to be similar to her own children and for a moment, this made the situation unbearable. We found that HP generally were concerned about the unpredictability of both their own and the patient’s reactions:

I think that sometimes it happens that this is not addressed because you, yourself, as a HP are scared of addressing it... Because what if I get too affected by it or upset about the situation or something like that, right...?] It can be really scary, because what do you even say to a patient like this, if they don’t react in accordance with how the books say they’re supposed to react, right (N1:1).

### 3.2.2 Keeping a professional distance

Some doctors expressed the need to keep a distance from the patient in order to make the right medical decisions. Addressing children could affect this distance and thereby challenge their primary professional task:

If you know a patient and a family really, really well then you can sometimes get to a point where... I would not say you become part of the family, but you get very close and I don’t know if you can cross a boundary – I do not think that I ever did this myself – but you have to be able to make the right decisions. That is, the right decisions medically, because that is what we are here for and sometimes you can worry that becoming too involved with a family can make it more difficult (D2:1).

Keeping a professional distance became a way to cope with difficult emotions.

Because there are also some things that can be very hard to carry as a professional so that one can continue to bear it and to be in here all the time (D2:1).

Since children evoked strong feelings, staying off the subject was perceived as a necessity to keep control of the situation.

### 4 CONCLUSIONS

The present study provides detailed insight into barriers associated with identifying and addressing CSIP, and this is important because such children depend on adult support. Drawing on the Maturana's theoretical framework, we examined HP's structural and emotional barriers to enabling supportive parent-child communication. We found each barrier to contain various subcategories. Structural barriers included lack of space in the medical record system, the professional code, understood both as what HP feel is expected of them and as what they themselves perceive as good professional conduct, time pressure, and a lack of training. Emotional barriers included the distress caused by the situation and the perceived necessity of keeping professional distance.

In line with previous research, we found that structural and emotional barriers are especially prone to cause avoidance in HP. Previous research has argued that HP’s lack of knowledge and their uncertainty regarding their supporting role are in contrast to the traditional active, task-focused roles of nurses and provide an appealing explanation for avoidance. Yet not sufficient explanation. For HP, the burdens of medical caring tend to overwhelm their supporting role. This legitimizes the avoidance of emotional connection with the person who is so intensely distressed, and this creates problems because children are emotionally dependent on adult support.11-13 Our contribution to this earlier research indicates that the medical journal system is poorly designed for the identification of CSIP and that avoidance of CSIP is maintained in a reciprocal interaction between record systems and emotional impact.

We found that emotional barriers served not only to protect HP from being personally overwhelmed but also to keep control of the situation in order to make the right medical decisions. This meant that there was no pressure exerted by HP to change the electronic medical journal system. Information about dependent children was only sporadically mentioned in the records, allegedly because this information has no direct function in the course of treatment. Hence, the medical record system reflects HP's most important tasks, namely,
administering medical care. Changing the electronic medical journal system would give HP yet another task to accomplish—one that HP feel insecure about and ill-prepared to handle and one that they are not rewarded to perform.

With reference to Maturana’s domains, our research shows that the personal domain is fairly active when HPs address CSIP. Since a systematic registration of children was not supported by the medical record system, HPs actions came to be determined by their individual preferences and perceived abilities. We argue that the HP’s personal domain becomes even more active (i.e., HPs become more emotionally involved) when the domain of production is not sufficiently expanded, eg, by developing the electronic medical journal system and improving HP’s training. It is evident that the tasks and expectations for CSIP are not clear to the HP, and this, together with HP’s lack of training, maintains avoidance. Thus, legitimation of CSIP requires it to be clear from the domain of production what HP should identify and address regarding CSIP and how and why they should do so. We assume that HP would be more likely to address CSIP and be better able to reflect on their own involvement, if the domain of production and the personal domain were more equally balanced, also taking the perceived time pressure into account along with HP’s general conditions of possibility.

We argue that as long as structural conditions are not defined and made explicit, CSIP will not be considered legitimate, and emotions continue to generate avoidance. Furthermore, any discussion of how structural conditions can be strengthened and how CSIP can be acknowledged as an integrated part of HP’s formal tasks will only be impeded if strong emotions are retained as the prime explanation for HP’s avoidance of CSIP. The HP made clear that their workplace offered no support to their attempts to address CSIP because of, for example, time constrains and lack of training. Moreover, HP did not feel that working with CSIP formed a natural element either in their specific duties or as part of their workplace culture. Accordingly, HPs had to improvise actions in the field. This creates a vulnerable position since addressing CSIP becomes more dependent on the individual HP than on explicit and shared tasks and expectations.

4.1 Limitations and directions for future research

Our study builds on a large number of qualitative, semi-structured, in-depth interviews. We consider that interviewing HP several times was important in deepening our understanding of general barriers in the field of CSIP. Nevertheless, HP worked in different wards with specific characteristics, and this may have influenced their experiences of barriers.

Our study implies some weaknesses. Firstly, it is exclusively based on what participants themselves say about their actions. This can be problematic because participants’ self-understanding does not always reflect their actions in practice.25 Secondly, an emphasis on individual experience of barriers may not have fully captured how social interactions in HP’s daily work contribute to reinforcing and reproducing their avoidance of CSIP. Thirdly, most participants were women in their mid-40s with more than 15 years of experience. These factors call for further investigation of barriers for male HP and of the links between barriers, lower age, and fewer years of experience. A corresponding sample of doctors could support a comparison between the barriers experience by the 2 groups.

Finally, our focus on barriers to CSIP may have omitted other important aspects influencing this field of communication. Future research may explore issues influencing CSIP, such as ward-specific characteristics, patients’ diagnosis, the viewpoints of patients and relatives (including children), gender, and interdisciplinarity. In the same way, future studies might investigate how the professional code is influenced by contextual factors such as those described above.

4.2 Clinical implications

While more data is needed to make clinical recommendations regarding barriers for addressing CSIP, this particular study would support the introduction of templates for collecting information about children in medical record systems and manualizing procedures for the use of this information. Furthermore, we propose management backing for CSIP, for example, by legitimizing time spent and the inclusion in future HP training programmes of considerations regarding the implementation of procedures and HP’s approach to structural and emotional barriers.

4.3 Ethics

We have followed basic rules for ethical conduct in qualitative research, and the study was approved by the Danish Data Protection Agency. Registration number: J.nr. 2016-41-4895.

CONFLICT OF INTEREST

No conflict of interest.

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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 & Ulfås, 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; Zaider, 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, Henrikson, 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).

## 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; Grimén & 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 (Bryan, 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.
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 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 of dependent children as relatives, and the process of inclusion and exclusion of dependent children during these encounters.
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 “invisibly 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.

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

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 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).

| TABLE 4 | Result overview |
|---|---|---|
| **Medical context** | **Children** | **Patient** |
| Haematology | Risk of infection with bone marrow transplantation, isolation, long-treatment processes | “Children as sources of infection,” ambivalence regarding children’s presence | Patient focus. Patient as a unit, to be isolated from the family |
| Gynaecology | Female patients, microscopy answers and palliation, long-treatment processes | “Children as invisibly present,” children are more talked about medically and socially than present | Family focus. Patient as part of a family |
| Neuro-intensive | Unconsciousness, high-tech treatment and crises, acute treatment | “Children as spectators,” children fade into the background with one parent unconscious and the other in acute crisis | Adult relative focus. Adult relative as substitute for the unconscious patient |
| Communication | 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 |

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.

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
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 (Riksjaer, 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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Disrupted biographies and balancing identities: a qualitative study of cancer patients’ communication with healthcare professionals about dependent children

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Abstract (200 words)
About 14% of cancer patients live with dependent children. Healthcare professionals are well placed to help patients support their children as part of a patient-centred practice. Children tend to appreciate open communication during the course of illness, but patients often find this difficult. However, research is unclear about patients’ preferences and their willingness to talk with healthcare professionals about their dependent children. Therefore, we conducted 15 in-depth interviews with patients from haematological (N=11) and gynaecological oncology (N=4). The interviews and subsequent analysis focused on patients’ communicative preferences, taking the theoretical framework of ‘biographical disruption’ as a starting point and using Jenkins’ concept of identity as a social, relational and dynamic process to identify two overall identities at stake for seriously ill patients with parental responsibility: ‘patient identity’ and ‘parent identity’. As ‘patients’, patients were ambivalent about relating to their children, but as ‘parents’ they wanted healthcare professionals to talk about their children. In order to be patient-centred, clinicians should, we suggest, acknowledge that patients have these conflicting perspectives and identities, which surface at various times and situations throughout their illness trajectories. Research is needed to further explore these findings in different illness groups and cultures.

Key words:
Cancer, Communication, Family, Psychosocial Support, Training, Qualitative Research, Patient-Centered Care
### Introduction

About one-third of cancer patients worldwide receive their diagnosis at an age when they could have children between the ages of 0 and 25 years (Ferlay et al., 2008). In Denmark, approximately 40,000 out of 1.2 million children under 18 experience a parent being hospitalized with a serious illness, including cancer (Statistics Denmark, 2015). Parental cancer results in children being exposed to increased psychosocial stress and to the risk of developing behavioural and emotional difficulties (Gabriak, Bender, & Puskar 2007; Osborn, 2007; Huizinga et al., 2011). Moreover, early parental death increases children’s risk of being hospitalized with affective disorders in adulthood and of using antidepressants later in life (Appel et al., 2013; Appel et al., 2016). These risks are minimised if children feel confident that the adults around them can cope with the trauma and the changes that serious illness and early parental death bring (Black & Young, 1995; Goodyer, 1990; Pynoos et al., 1993).

Seriously ill patients with parental responsibility experience an increased level of psychosocial distress, major depressive disorder and generalized anxiety compared to peers (Muriel et al., 2012; Park et al., 2016). Patients with parental responsibility tend to make more aggressive treatment decisions, including receiving highly toxic treatment, and less often initiate advance care planning, write ‘do-not-resuscitate’ (DNR) orders or leave a living will (Nilsson et al., 2009; Yellen & Cella, 1995; Park et al., 2017).

Studies also show that maximizing time spent with children and preserving a role as a parent are important concerns underlying patients’ preferences (Check et al., 2016; Zaider, Salley, Terry, & Davidovits 2015). Such patients are concerned about how to maintain parental responsibilities and how their illness and death will impact on their children (Park et al., 2017). Patients with parental responsibility struggle to balance their roles as a parent with being a seriously ill patient, agonising, for example, about whether to spend time with their children or to rest to combat their illness (Bell & Ristovski-Slijepcevic, 2011; Morris, Martini, & Preen 2016).

But patients with parental responsibility also feel insecure about informing their children and coping with their children’s reactions. Furthermore, they tend to underestimate their children’s need for information (Buxbaum & Brant, 2001; Helseth & Ulsæt, 2005; Semple & McCane, 2010). Although parents may support their children by communicating openly and honestly, they often find it extremely difficult to communicate, for example, the risk involved in their treatment or their chances of survival (Moore & Raunch, 2006). This is a problem because children need such information as early as possible and prefer honest information about the parent’s condition and treatment (Bylund-Grenklo et al., 2015; Kennedy & Lloyd-Williams, 2009; Tillquist, Bäckrud, & Rosengren 2016).

Research shows that healthcare professionals seldom address patients’ concerns and uncertainties regarding their dependent children. They feel inhibited by a lack of professional confidence, by inadequate knowledge of means to help parents support their children, by fear of being emotionally overwhelmed and by a lack of organisational support (Dunne, Sullivan, & Kernohan 2005; Odling, Norberg, & Danielson 2002; Turner et. al., 2007, 2008; Dencker, Rix, Bøge, & Tjørnhøj-Thomsen 2017).
It has also been suggested that open communication is crucial to supporting children in that it minimizes parental stress and their symptoms of bereavement (Krauel et al., 2012; Morris et al., 2016). A study of patients receiving palliative chemotherapy shows that 80% of these patients did want to discuss family issues with the healthcare professionals though they waited for oncologists to bring up the subject. The remaining 20% of the patients did not want to discuss family-related issues, indicating that it cannot be assumed that patients will want to discuss their children (Detmar, Aaronson, Wever, Muller, & Schornagel 2000).

The above research suggests that seriously ill patients with parental responsibility struggle to balance their identities as a patient and a parent simultaneously. However, we lack knowledge of the mechanisms employed to manage these identities in practice, how these identities interact, and what the patients’ needs are in relation to the healthcare professionals.

The aim of this paper is to explore how patients balance the demands of parenthood with those of being a seriously ill patient, and how this balancing act influences the patients’ communication preferences with healthcare professionals.

METHODS
This qualitative study was part of a larger study of the interaction of healthcare professionals with seriously ill patients about patients’ dependent children, including 49 interviews with doctors and nurses, 15 patient interviews and 27 days of participant observations within haematology, gynaecological oncology and neuro-intensive care (Dencker et al., 2017). This paper focuses on patients’ experiences and is based on the interviews with patients and on participant observations, including observations of encounters between patients and healthcare professionals. Although patients’ adult relatives and children were sporadically present during the participant observations, they played no part in the interviews.

Participants
We interviewed 15 patients from September 2013 to June 2015, six female and five male haematological patients, and four gynaecological oncological patients. The average age of patients was 40.1, the youngest being 29 and the oldest 48. The patients had a total of 32 children, their average age being 10.5. The youngest child was 0.8 and the oldest child 23. Nine patients were hospitalized with life-threatening illness. Four of the haematological patients attended outpatient monitoring after bone marrow transplantation and were subject to restrictions in their daily lives. These patients experienced a range of side-effects and profound uncertainty from the knowledge that they could relapse. Finally, two patients were awaiting results of a hysterectomy to ascertain possible cancer. One of these patients had earlier been treated for breast cancer (see table 1).

We recruited patients during field visits facilitated by the Knowledge Center for Patient Support, Rigshospitalet, under the Capital Region of Denmark. Healthcare professionals gave patients information sheets stressing that their decision would not influence relations with healthcare professionals nor their treatment or conditions during hospitalization. Fifteen patients consented while two refused due to fatigue. We excluded only one patient ourselves because she was receiving psychiatric treatment. One other patient was so affected by morphin that he was not contactable.
Data collection

The interviews, which took place in the hospital, sought to gain a nuanced understanding of patients’ background, experiences and needs (Kvale, 1997; Spradley, 1979). Patients shared their concerns about their illness, explained what support they had, detailed their experiences of communicating with their children about their illness and their principal preoccupations in that regard.

Patients’ experiences of communicating with the healthcare professionals were explored by asking who initiated such conversations, what was talked about, and whether there were issues they would have liked to talk about that did not come up. Finally, we asked how patients thought that healthcare professionals could support them in their needs and concerns regarding their children (see table 2).

Participant observations further contributed to understanding the framework of communication for healthcare professionals’ encounters with patients about their children by pointing up what was or was not spoken about and the situational context for these encounters (Tjørnhøj-Thomsen & Hansen, 2017). Moreover, the participant observations allowed relationships to be built and provided an insight into patients’ situations as hospitalized or into conditions governing their outpatient status which might increase the interview quality.

Data Analysis

Interviews were digitally recorded and transcribed verbatim. The interview material was sifted several times and carefully reviewed to reach an overall in-depth assessment of the main themes and the diversity of practice (Miles & Huberman, 1994).

We coded the empirical data based on our research questions (table 2) and used the concept of biographical disruption as a basis for understanding the interviewees’ experiences and needs and assessing how their identities were affected by serious illness (Bury, 1982, 1991, 1997, 2001). Bury suggests that illness causes a biographical disruption that challenges patients’ everyday life structures, social relationships and identities (Bury, 1982, 1991, 1997, 2001; Cayless, Forbat, Illingworth, Hubbard, & Kearney 2010). Although the concept was initially developed from interviews with chronically ill patients with rheumatoid arthritis, we found it relevant for our analysis – particularly the way the dynamics between identities and social relationships are influenced by illness.

The framework of biographical disruption has been further developed to include the interrelationship between illness and key sources of identity. For example, studies of women diagnosed with breast cancer or as HIV positive suggest that the intense threat caused by their potentially fatal illness forces the women to reconstruct, re-formulate and renegotiate their identities as mothers (Fisher & O’Connor, 2012; Wilson, 2007), ‘identity’ being seen as a social, relational, contextual and dynamic process constantly in the process of construction and reconstruction (Jenkins, 2014).

In our analysis we focused particularly a) on patients’ relational experiences with their children and with healthcare professionals, b) on contexts influencing the patients’ identities such as the specific
type of illness and the hospital setting, including ward specific characteristics, and c) on the task of equilibrating roles as parent and patient.

**Ethical aspects**

This study was conducted with seriously ill patients at risk of dying. Several of the patients interviewed were hospitalized, suffering from exhaustion or severe symptoms and/or diverse treatment side-effects. Before conducting the study, we gave careful consideration to whether asking these patients about communication with their children was appropriate since these questions might disturb them. We decided that they should have the opportunity to judge for themselves whether they wanted to participate after being thoroughly informed about the study and its purpose. Our main ethical concern in recruiting participants for interviews and conducting interviews was to minimize any possible harm or distress that our project might cause the patients (Kumar, 2005).

To comply with our concerns, we followed the ethical criteria developed by Richards & Schwartz (2002), which requires research not to create anxiety and to ensure the anonymity of volunteers and participants. Our letter to patients emphasised the fact that patients could withdraw from the interview at any time and that any information given would be anonymised. No one withdrew from the interviews, but the interviewer was aware of possible participant fatigue, at which point the interview would be concluded.

All patients gave oral consent to the healthcare professional after reading the letter and stated that they thought addressing the issue of children was important. At the end of each interview, the interviewer asked the patient how it had been for them to participate. The participating patients answered positively, saying that even though they may have felt exhausted they were pleased if their contribution could be useful for helping others in the same situation. We also handed out contact information and contact hours for follow-up and referred patients to further help if necessary (see table 2).

According to Danish ethical committees, this study did not need to seek permission because it was not an intervention involving biological material (Kobbernagel 2016). The project followed the Helsinki declaration (World Medical Association, 2013) and was approved by the Danish Data Protection Agency. Registration number: J.nr. 2016-41-4895.

**RESULTS**

Partipant observations showed that children were not a given topic in everyday encounters, and they were seldom present themselves. Patients and healthcare professionals talked about the patients’ physical condition, side-effects and future treatment. The subject of the patients’ children was mostly absent unless the patient was dying. The same also applied when the patient’s partner or other relatives were present. When the subject of children was addressed during field visits, healthcare professionals had no systematic way of knowing whether the patient had dependent children or not. While the healthcare professionals were aware how important children were to their patients, the subject was not at the forefront of their consciousness. Patients, too, were ambivalent in addressing the subject of their children, the interviews showing patients struggling to balance two competing identities that alternately took precedence when communicating with
healthcare professionals: ‘patient identity’ and ‘parent identity’. We argue that, given the dynamic and contextually related nature of ‘identity’, both these identities are constantly and concurrently present, one identity typically dominating at any given time (Jenkins, 2014). We use the terms ‘foreground’ and ‘background’ to indicate this dynamic.

We use the term ‘patient’ across both identities because we conducted the interviews in a hospital setting. In the following, patients referred to with H, as in ‘PtH1’, come from haematology while patients those with a G, as in ‘PtG1’, come from gynaecological oncology.

We begin by describing the patient identity, since becoming a patient is the reason why the parent identity is challenged in the first place and therefore frames the dynamics.

**Patient identity**

Patients’ identities became challenged because of the illness’ severity has deep and disruptive implications for their lives.

We found that the disruptive nature of the patients’ illness and treatment meant that their view of self became centred around being an individual suffering, and that relationships became severed by illness. In these situations patient identity was foregrounded, and patients wanted healthcare professionals to be concerned with their suffering self confronting the proximity of death, existential isolation and the search for meaning (Jacobsen 2007).

**The proximity of death**

Patients confronted with the imminence of death and with the fragility of their own existence often found themselves facing despair. In these situations patients needed to be cared for and were unable to care for others, including close relatives and children. The need for care did not necessarily require conversation but could involve other supportive actions, as in the following example:

“When I was hospitalized and feeling really bad and crying, thinking life was terrible, thinking it was awful to consider whether I should be buried or cremated, the nurse came in and said: ‘You know what – don’t you want some candles or some nice music or something like that in here..?’ And then she came in and did these things, like a mum. Like a caring person taking care of her daughter somehow. And she said: ‘Now take it easy. Close your eyes.’ And then she stood there and stroked my hair” (PtG2).

Another patient appreciated the healthcare professionals simply listening to him:

“Sometimes I would call them semi-psychologists, because often they just sit there and listen, write things down and not speak at all. They just sit there and listen. As if they know how great our need is for getting things off our chests sometimes, and how important it is that we can do it in here” (PtH2).

Several patients thought about their own funeral, acknowledging the potential proximity of death.

**Being isolated**
Haematology patients, who were physically isolated as part of their treatment, described feelings of living alone in a parallel universe as distanced observers to other peoples’ everyday lives. In these situations patients felt a disconnection from the outer world and a lack of freedom to act as they would like to.

“When I had my transplant, I sat in the transplantation room and looked down at the hospital entrance. I sat there sick to death and didn’t know if I would survive. Then you looked out of the window that you couldn’t even open because the air had to be sterile – and you could just see people come and leave work. You could see the world was going on but you couldn’t be part of it. All I knew was that I was going to sit in that room for a month if I survived and I could see the same people coming to work and going home. Once I saw one of my friends, but I hadn’t an earthly chance of opening the window and yelling hi. It really was a parallel world because you sat there completely isolated in a completely other world looking down. It was surreal.” (PtH2).

Here, the patient had to be isolated with no possibility for interaction with family and friends. Being disconnected from the world outside was experienced as a deep existential loneliness that thoughts about the patient’s children could not relieve.

**Searching for meaning**

Several patients often pondered why the illness had happened to them asking “Why me?”. Patients sometimes expressed guilt related to how they had lived their lives.

“The thought also comes to me, ‘Is it because of all that shit that I have been through that I am ill? Must I make a break?’ But how can I make that break when things keep coming at me? Now you heard about some of the things that I have been struggling with in my life [difficult life situation, e.g. seriously ill with two children whose father did not want to see them]. So I walk around wondering if that is the reason why I am ill” (PtG1).

For some patients, a difficult life situation prior to getting ill seemed yet another biographical disruption in a turbulent life. Patients sometimes attributed their illness to difficult life circumstances. Dependent children in these families were extra vulnerable because of the family’s prior psychosocial and economic problems.

**Separating treatment and children**

Patients’ main preoccupation was to survive their illness and treatment and to deal with their fatigue and pain. This sometimes meant that they preferred not to have visits from their children because they felt too exhausted to care for them and tried to protect their children from seeing them in this state. In these situations, patients wanted to separate out the demands of treatment (their patient identity) from the demands of children (their parent identity), though we did find concurrency, where the patient preferred on the one hand to separate treatment and children while on the other maintaining a parent identity by caring about how children would experience seeing them. One patient said:
“I am glad that I didn’t have my children around during the transplantation process. At some point, they told me that I could get them in but I chose not to because I still thought it was risky and when I got out of here I just wouldn’t be sick anymore, you see. Then I would rather wait two or three days more to be sure that there was no risk. Moreover, I didn’t want them to see me like this” (PtH4).

A gynaecological patient expressed the same kind of tension:

“When I was lying in a pain hell for twelve days, I didn’t want them to come in here and see me like that, so it was a long time not seeing each other. I didn’t think they could take it. You see, for them I’m the tough Viking in their lives.” (PtG1).

Here the patient is trying to maintain her parental responsibility and her status as the anchor of her children’s lives by preventing them from seeing her as anything but that.

Ambivalence in talking about children

Patients sometimes wished not to talk about their children because it reminded them of their difficult situation. One patient said: “Sometimes it is nice when they ask me about my children, sometimes it is not, because sometimes it makes me sad” (PtH1).

For some patients it was unbearable to talk about the gravity of their illness and of having children dependent on them in the same breath.

“I don’t want to talk about how I am, or about how or what I feel. Actually, I don’t feel like talking about the illness at all. I would rather think about positive things – my child, the future, my husband and my family. So in that way I think that ordinary talk helps the most. To talk about signs that show me that life hasn’t ended. That we continue somehow” (PtH3).

Here the patient is balancing patient and parent identities. On one hand she does not want to talk about how she feels about being ill, which can be a way of coping with her patient identity. On the other hand, she wants to enlarge on the positive things in her life, including her child, who is a sign of continuity.

When the identity as patient was in the foreground, being ill was enough to handle and existential considerations could push relationships to one side.

“Being this ill is a fulltime job. Because I have to remember to eat and drink, and I have to eat the right thing because I can’t eat that much. So this occupies me. You know, some days you don’t have the energy for other people. I also have to rest because if I don’t, my tolerance gets even shorter, and then I need to be on my own even more” (PtH8).

Part of the patient identity involved the extreme side-effects from symptoms and treatment. Therefore, patients’ children were not always the focus of the patients’ attention, as in the above quote, where the patient uses the term ‘other people’ rather than mention her children explicitly.
Nevertheless, we found that the parent and the patient identity cannot always be separated. Patients could express the need for space where they were not confronted by their children, either physically nor psychologically, while at the same time acknowledging a need to protect their children from seeing them in that state. Hence, in some cases patients preserved their identity as a good parent by distancing themselves from their children.

We suggest that healthcare professionals acknowledge that patients’ needs may vary in the sense that they sometimes need to be taken care of by healthcare professionals solely as patients and sometimes as patients who are also parents.

**Parent identity**
When their identity as parent was uppermost, patients struggled to find out how to practise parenthood while being seriously ill. Patients were primarily concerned about the extent to which they should involve their children and how to ‘be there’ for their children despite fatigue and hospitalization. Moreover, patients wanted healthcare professionals to see and acknowledge them as a parent, in other words as ‘more’ than a patient. Some patients also expressed a need for healthcare professionals to be pro-active in raising children as a topic.

**Involving children**
Participants struggled to find out how much and in what way they should involve their children and expressed a need for advice, especially at the beginning of their treatment. Some felt unprepared when their children asked them about death. One said:

“I think it was hardest with my daughter, who is four years old, because it is really difficult to know what she needs to know and what she does not need to know” (PtH4).

The patient as parent wished to weigh up the information she gave her child to protect her as much as possible. Another recalled being “totally flabberghasted” when her five-year-old asked what she should do when she no longer had a mum.

The patients’ ‘parent’ identity implies a need for healthcare professionals to help them support their children by enabling an understanding of the illness and its consequences. One patient said:

“However it would be nice if the healthcare professionals had time when the children were here to explain the whole trajectory, what is going to happen and so on” (PtH1).

In addition to the uncertainty posed by articulating the consequences of their illness, both for themselves and for their children, there was also the uncertainty associated with the risk of relapse. Relapse could challenge the children’s belief in the doctor:

“My fifteen-year-old don’t believe shit all they say anymore because last year they said that they had removed everything. And this time they said it was a fibroid, but it wasn’t. It was cancer. So he doesn’t believe the doctors anymore. He says that they’re just lying and that I will die anyway. It is hard” (PtG1).
Here, too, patients signalled their need for help from professionals in communicating with children. This patient thought that it would be helpful if the doctor explained the process to her son, “because she is an authority. I am just a mum” (PtG1).

‘Being there’
Patients often talked about the importance of ‘being there’ for their children in spite of their fatigue and hospitalization. Nevertheless, ‘being there’ as a parent was difficult in cases where patients were too ill, too tired, and too sad. Patients suffered from not being able to take care of their children as they used to. As one patient said:

“I want to say that it was really hard to face such a disease with two children that young [three months and four years] and to feel that you couldn’t be there for them. Um, so, I think it has been really hard” (PtH4).

At the same time, patients could feel so tired that they were unable to be with their children in the same way as they were used to.

“I can’t do the same stuff with them as before. I have always been the big and strong man throwing them around. And now I feel that I can’t do that as much as before but I hope that I can do it again at some time” (PtH6).

Thus, patients expressed ‘being there’ as both a psychosocial and a bodily presence, both important dimensions of parental responsibility.

Patients associated being a good parent not only with ‘being there’ but also with doing the right thing in supporting their children during the illness and worrying about how their illness affected their children. One patient expressed it as follows:

“I think that what you are most afraid of is doing the wrong thing and how it will influence them the rest of their lives. We talk a great deal about our four-year old daughter’s reactions, e.g. if the things she does are because of her age or because of the things she has been through” (PtH4).

Patients sometimes noticed changes in their children’s reactions that caused them concern, and they wanted their children and other relatives to get psychological support:

“My oldest daughter [eight years old] has sort of taken the mother role at home. It would be nice if there was some psychological help here so that my mother and other relatives, including my children, could have someone to talk to” (PtH1).

Several patients, especially from haematology, used Skype to communicate with their children because of the risk of infection.

“We communicated a lot via Skype. Because children as small as that bring a lot of things with them [infections] from the kindergarten and stuff like that. So I didn’t want them to
come over here either and you [i.e. the patient] were completely exhausted and things like that” (PtH6).

Nevertheless, using Skype was not always enough to keep contact, especially with young children.

“We used Skype a lot when I was hospitalized for six weeks. We did. But then I also came out to a child who didn’t recognize me because my youngest couldn’t recognize me after I had been in here for six weeks” (PtH4).

Or from another patient:

“Once my child got very confused because she heard my voice but she couldn’t understand who it was because I was bald” (PtH3).

It was painful for the patients to find that their children could not recognize them.

Patients with smaller children found that ‘being there’, fulfilling parental responsibility during hospitalization, was especially difficult and that healthcare professionals supported them by providing practical help. One, a mother to a ten-month-old son, said:

“So I think it has been really, really hard but I think that the nurses were really good. When I had to shower or take my medicine or things like that, they [the nurses] like to help by giving the bottle [to her son] and things like that. And that has been very important to me because it made it possible for me to have him here” (PtH4).

The same nurses had also helped the patient by advising her to bring her son to the hospital so he could see where his mother was. This she had found helpful because she sensed that: “In the beginning he couldn’t understand why I was living in another house and why I wasn’t at home anymore” (PtH4).

Times of separation seemed to be harder on patients and children when the children were under about five years of age, probably because the parent-child relationship relies more on physical presence and proximity than on verbal interactions at this age.

**Being seen as ‘more’ than a patient**

Apart from being an opportunity to being with them, for some patients children’s visits were a way of being seen as ‘more’ than a patient, namely as a person with resources and skills rather that ‘just’ a weak patient. One patient said:

“It is feels good when you stand there …. and someone says, ‘She is nice or can you count to ten?’ - and things like that. And then you get proud somehow and happy, but you also feel stronger because suddenly I am in my role as a mother and not in my role as a patient. And it can actually be really nice to step out of that role, being ill and weak. It means a lot to me” (PtG2).
Having children visiting at the ward made some patients fell less anonymous:

“You can feel really destroyed somehow as a human being in this system. And then I feel that it is not only that you are allowed to have your family in here, it is also the fact that they get to see you as ‘more’ than a patient” (PtG2).

When healthcare professionals talked about their children or devoted attention to them on the ward, patients had an increased sense of contact with them:

“The healthcare professionals have treated my children very well. They have, for example, welcomed them by giving them icecream and biscuits and they have taken them on their lap. They have also praised me for my children” (PtG3).

A few patients, who were hospitalized for a longer period, found that their healthcare professionals built relationships with their children. One patient had been hospitalized for several months and had her children and husband in every day. She found that the health professionals had done ‘a great deal’.

“They speak to them a lot and build relationships with them. They have also spoken about the possibilities for further support. They also praised me for my children which was nice” (PtH5).

If healthcare professionals asked about the patients’ children, they didn’t necessarily have to problematize the issue. Talking about ordinary things improved communication and contributed to the patients’ feelings of being acknowledgement as a parent in addition to a being patient. One patient said:

“I think that mothers and fathers feel happy when they get the opportunity to talk about their children, and it doesn’t necessarily have to be about problematic stuff regarding the illness and the situation. The most important thing is ordinary talk such as: ‘Do you have a picture of your child? Can I see the picture? What is your child’s name? Is she happy? Does she have friends?’” (PtH3).

Patients appreciated healthcare professionals actively foregrounding their parent identity by addressing their children either directly and indirectly. This was also reflected when healthcare professionals did not recognize the children. As one patient said:

“When my daughter was here, they didn’t even realize that she was my daughter and they didn’t talk to her. It made me quite mad” (PtH11).

Being seen as more than a patient was also encouraged when healthcare professionals recognized the patient’s feelings towards their children, as in this example:
“There was a day when I cried all day long because I missed her so much [daughter 2½ years old]. Then the healthcare professionals told me that it was a healthy sign, because I was beginning to feel better, so I could think of others in the family and not only of myself” (PtH3).

This example shows that the healthcare professionals sometimes manage to address patients’ dynamic identities simultaneously, combining the patients longing (the parent identity) and the patient’s physical condition (the patient identity). At the same time it shows that the healthcare professionals’ might realise that the parent identity requires affirmation when foregrounded by the patient.

**Managing as a parent**

When patients foregrounded their parent identity, they wanted healthcare professionals to ask them about their children and about their parental challenges, and to support them in supporting their children.

> “During hospitalization we missed someone asking us: ‘How will you manage? And who takes care of your children?’ We also needed help finding out a lot about logistics and legal stuff” (PtH9).

Some patients were surprised that healthcare professionals hadn’t asked about the struggle involved in being seriously ill and having children.

> “They have not asked us how we will manage everything and we have a lot to handle with five children” (PtH10).

Some patients had not received any advice about how to support their children during their hospitalization, because they had not raised the issue themselves. Likewise, we observed during participant observations that children were not systematically included as a subject. The lack of attentiveness to patients’ children was also brought up in interviews:

> “Actually, we didn’t get any advice. We didn’t really ask for it either, even though we have two small children through all this. But when you stand in a situation like this, I think it is easier that things come to you and not the other way around because you can’t really manage to make contact yourself. If the health professionals had addressed us regarding our children, I think we would have appreciated it and used it, but somehow I think we managed fine ourselves. (PtH4).

Patients appreciated healthcare professionals asking them pro-actively if they needed advice regarding their children because it made them feel recognized as parents. For example, haematological patients were quite occupied with childhood diseases as a risk factor for their health and they would like healthcare professionals to tell them more about it:

> “It is always us who have to ask questions about childhood diseases. And I think that is wrong, because not everyone asks questions about it... I would be nice if the healthcare professionals asked more about it themselves” (PtH2).
Some patients hesitated about bringing their children into the hospital because they thought children were generally unwelcome.

“Somehow it would be nice if someone said ‘you can bring your children in here’. At first we didn’t bring her because we thought the atmosphere wasn’t right for it and there were no other children” (PtG2).

‘The atmosphere’ that the patient refers to in this example might reflect the absence of children we observed during participant observations, where children were not naturally included in encounters either personally nor as a subject. Certainly, our interviews showed that most patients wanted the healthcare professionals to be more pro-active in demonstrating that children were welcome.

Some patients would have liked to be better prepared for their discharge from the hospital so they could have clarified expectations with their children. One patient said:

“After the transplantation you feel so bad and you are so extremely tired and this goes on for a very, very long time. So the story you tell your children that now you are not going to see mum for a very long time while she is hospitalized but afterwards when she comes home then she is all right. But she is not! It lasted much longer than I had expected” (PtH4).

We found that patients needed healthcare professionals to be pro-active regarding children throughout, from the initial treatment, during treatment and after treatment, including before discharge from hospital.

While most patients wanted healthcare professionals to be more proactive in foregrounding their parent identity, we found that patients sometimes wanted to foreground only their patient identity because they felt too exhausted to exercise their parental role as carer. This scheme summarises these two identities and indicates how they are context dependent and interact dynamically:

<table>
<thead>
<tr>
<th>Patient identity</th>
<th>Parent identity</th>
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</thead>
<tbody>
<tr>
<td>View of self: as an individual suffering</td>
<td>View of self: how can they manage as parent</td>
</tr>
<tr>
<td>Relationships: severed by illness</td>
<td>Relationships: attempt to keep parent relationship foregrounded.</td>
</tr>
<tr>
<td>What they want from the staff: focus on self</td>
<td>What they want from the staff: foreground children</td>
</tr>
</tbody>
</table>

**DISCUSSION**

We used the concept of biographical disruption as a starting point for understanding how serious illness may fundamentally affect patients’ lives. The theory stresses both the individual dimension of becoming seriously ill and the effect of illness on the interrelationship between illness and key sources of identity. We found that two overall identity perspectives were alternately foregrounded when patients communicated with the healthcare professionals about their children: ‘Patient identity’ and ‘parent identity’. These identities were constantly present, though each identity
appeared more dominant in some situations and with some patients than others. Patients view of self, how they related to their relationships, and what they wanted from the healthcare professionals depended on which identity they were displaying.

Biographical disruption led to patients’ anxiety about death, to feelings of loneliness, and to questions about the meaning of their illness. These considerations, combined with severe physical symptoms and exhaustion due to the illness and the treatment, sometimes excluded patients’ thoughts about their children. In these situations, patients felt the need to be cared for rather than to take care of others, even their own children. With the patient identity in the foreground, patients tended to concentrate on their illness and treatment and they did not always want to have their children present, because they lacked the physical and emotional reserves to address their children’s emotional and communicative needs. Furthermore, patients wanted to protect their children from seeing them so ill. They therefore had to balance patient and parent identity.

When the parent identity was in the foreground, patients were confronted with the challenge of ‘being there’ as a parent for the children and helping them in this difficult situation. In these situations patients wanted the reassurance of parental identity and needed healthcare professionals to be asking them about their children and helping support their children. Moreover, recognition as a parent made some feel more resourceful than seeing themselves as a patient.

Our study has shown that little is known about how to balance being a patient against being a parent, or about the influence of the sensitive dynamics involved in communication between healthcare professionals and patients about children. We also want to challenge the idea that clinicians should routinely ask patients about their concerns as parents in order to communicate with their children about their illness, as has been suggested by Russel & Raunch, 2012. We question, therefore, whether patients are always prepared to be ‘empowered’ as regards their children, and ask whether there may at times be other issues that take centre stage.

Our results contribute to previous research by stressing that the majority of patients the healthcare professionals engaged with them about their children and provide emotional support about parental identity (Turner et al., 2007; Krauel et al., 2012). Research shows that, although patients say that they value emotional support, they prioritize instrumental support from healthcare professionals in the form of being properly informed and involved in treatment decisions over emotional support in telling the family about the cancer (Brown, Parker, Furber, & Thomas 2011). In addition, patients diagnosed with haematological malignancies are more concerned with medical than psychosocial information (Rood, Eeltink, van Zuuren, Verdonck-de Leeuw, & Huijgens 2014; Friedman, Coan, Smith, Herndon, & Abernethy 2010; Friis, Elverdam, & Schmidt 2003). Finally, a Norwegian study of 20 inpatients with various cancer diagnoses in different stages and with different prognoses found that patients did not always want to talk to nurses about their difficult feelings regarding the future. The study suggests that so-called cognitive avoidance and distancing can be important coping mechanisms helping to find meaning and hope (Kvåle, 2007).

In line with the above findings, we also found that we cannot take it for granted that patients always want to talk about their children or have them visit. This result is important because patients who are struggling to balance the parent and the patient identity are at risk of being further pressured
by cultural notions of good parenthood and parental responsibility. Thus, according to Danish Health Authority, 2012, and Russel & Raunch, 2012, 'good parenthood' is associated with talking with and about their children and inviting them into the hospital as suggested in official guidelines and manuals (Danish Health Authority, 2012; Russel & Raunch, 2012). Patients may thereby be forced into positions that they cannot cope with having been encouraged to act in ways for which that they do not have the mental or physical resources.

As a consequence, healthcare professionals are confronted with the dilemma that, even though most patients wish for the healthcare professionals to be more active in asking about their children, some patients prefer to separate out dealing with their illness from caring for their children. This presents a problem because most research suggests that open communication minimizes dependent childrens’ anxiety levels (Ellis, Wakefield, Antill, Burns, & Patterson 2017; Meriggi et al., 2017). These issues raise two important clinical questions: 1) how should healthcare professionals navigate when children’s needs conflict with patients’ needs? And 2) how can healthcare professionals support the dynamic relation between patient’ and ‘parent’ identities?

Former studies have recommended that asking about the patients’ children should be routine as the patients’ identity as a parent should be acknowledged (e.g. Fisher & O’Connor, 2012; Wilson, 2007). We agree with this recommendation, though our study also suggests caution. We found that patients should not systematically be confronted with their parent identity because struggling with the illness and treatment, the risk of dying, isolation and lack of meaning can be enough to handle. So, whereas our study clearly demonstrates that patients benefit from being seen and recognized as parents, it also points out that the demands of being a patient set limits to the degree to which patients can function as parental carers.

Patients switch, then, between two identities depending on context, symptoms and mental surplus and should be consulted continuously, though sensitively, on their needs as regards their children. Another aspect is that the healthcare professionals should help the patient not feeling guilty for not living up to the ‘expected’ parental norms and responsibilities.

Finally, our study suggests that it is not only the healthcare professionals who define whether and how children should be included in the conversation. Patients also have their individual preferences – some wanting healthcare professionals’ advice as how to inform their children about their illness, others not wanting to discuss problems concerning their children. Therefore, discussing patients’ children is not only about identifying healthcare professionals’ barriers and how to overcome them (Turner et al., 2007; Dencker et al., 2017). We suggest that it is also about identifying patients’ preferences and needs being aware of patients’ different identities and the dynamics between them.

**Strengths and Limitations**

Our study provides a nuanced picture of patients’ experiences and needs in communicating about their dependent children with healthcare professionals. Patients freely revealed their thoughts and feelings about being seriously ill, their insecurities and feelings of insufficiency in being a seriously ill patient with parental responsibility, their wishes to fulfill their parent role, and their honest feelings of being so exhausted that they couldn’t take care of their own children.
Using the theoretical framework of biographical disruption as a starting point, we investigated the interrelationship between illness and key sources of identity, which helped us to identify the dual identities at stake in being seriously ill while having parental responsibility. Identities are dynamic, and we showed episodes of identity concurrency, where patients' simultaneously avoided children’s visits because of exhaustion while simultaneously to protect them from seeing their parent in a poor condition.

However, our study has limitations. Firstly, we analyzed our interviews with the fifteen patients at different phases of their illness: as outpatient, as hospitalized or as awaiting diagnosis. The limited number of participants made it impossible to identify variations in identities foregrounded and in communicative needs dependent on the phase of the illness. Nevertheless, by highlighting the uncertainty of patients at risk of dying and their experiences of being seriously ill, we identified these two overall patients' identities, setting them against the communicative needs that occurred during the whole illness trajectory.

Secondly, we related needs to the specific kind of illness, e.g. needs for guidance in keeping in touch with the children during isolation while having a bone marrow transplant, but we have omitted other important aspects influencing this field of communication such as gender issues, family characteristics, and the actual interactions with the healthcare professionals. Even though there were twice as many women as men participating in our study, we did not find any difference in how they managed their identities as respectively patients and parents. Due to the relatively small number of participants in our study, this aspect may be further investigated through a larger scale study. Moreover, while we found that patients’ needs appeared to be more physical and practical in relation to the smaller children, we haven’t identified if needs differ for older children and we have not investigated the childrens’ perspectives.

Thirdly, this study builds upon previous research to underline children’s need for open communication. Future research may find diversity among children of seriously ill cancer patients as a group, and may well point to differences in children’s needs that have yet to be recognized.

Finally, we did not include the healthy partner or other individuals significant for the patient or their children in our study. This is a limitation because a patient’s relationship to such a person might influence both their experiences and their needs for communication about the children and the way they balance the patient and the parent identity.

Conclusions and implications for practice
In recent years, researchers, non-governmental organisations and ministries have increased their awareness of healthcare professionals who support seriously ill patients in supporting their dependent children. Guidelines and manuals have been developed in order to clarify the healthcare professionals’ tasks and roles in accomplishing this. Previously, dependent children have featured little either in practice or in official documents (Dencker et al., 2017).

In the future, healthcare professionals may draw on the knowledge that patients may shift balance between different identities in order to communicate in the relevant patient-centred way. This involves three priorities: 1) the need to identify patients’ needs in the communication, 2) the need
to investigate healthcare professionals’ own contribution to the choice of identity foregrounded, and 3) the need for caution in not to forcing patients to deal with the parent identity, causing blame for patients struggling with the parent identity. As a consequence, we suggest that guidelines and manuals are implemented cautiously respecting patients’ diverse identities when subject to biographical disruption.

Finally, there is the built-in dilemma that the needs of the patients are not necessarily the needs of the patients’ children. This needs to be further investigated in order to develop clinical ways for the healthcare professionals to ensure they are acting in the interests of both patients and their children.

**Acknowledgements**

We are deeply grateful to all participating patients, and to the healthcare professionals and the Knowledge Centre for Patient Support, The Capital Region of Denmark to help set up the interviews.
<table>
<thead>
<tr>
<th></th>
<th>Name (anonymized)</th>
<th>Age</th>
<th>Civil status</th>
<th>Children</th>
<th>State</th>
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</thead>
<tbody>
<tr>
<td><strong>Haematology</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PtH1</td>
<td>Yvonne</td>
<td>33</td>
<td>Cohabiting</td>
<td>2 aged 5 and 8</td>
<td>Transplanted 2 months ago. Hospitalized with side-effects</td>
</tr>
<tr>
<td>PtH2</td>
<td>Ben</td>
<td>40</td>
<td>Married</td>
<td>1 aged 0.8</td>
<td>Transplanted 4 years ago. Ambulatory monitoring</td>
</tr>
<tr>
<td>PtH3</td>
<td>Elsie</td>
<td>32</td>
<td>Married</td>
<td>1 aged 2.5</td>
<td>Transplanted 1.5 months ago. Ambulatory monitoring</td>
</tr>
<tr>
<td>PtH4</td>
<td>Eve</td>
<td>29</td>
<td>Married</td>
<td>2 aged 0.9 and 4.5</td>
<td>Transplanted 6 months ago. Ambulatory monitoring</td>
</tr>
<tr>
<td>PtH5</td>
<td>Linda</td>
<td>48</td>
<td>Married</td>
<td>3 aged 17, 19 and 21</td>
<td>Hospitalized to be transplanted</td>
</tr>
<tr>
<td>PtH6</td>
<td>Albert</td>
<td>42</td>
<td>Married</td>
<td>2 aged 3.5 and 2.3</td>
<td>Transplanted 8 weeks ago. Hospitalized with side-effects</td>
</tr>
<tr>
<td>PtH7</td>
<td>Walter</td>
<td>36</td>
<td>Married</td>
<td>2 aged 2 and 5</td>
<td>Hospitalized, having a transplantation</td>
</tr>
<tr>
<td>PtH8</td>
<td>Carol</td>
<td>40</td>
<td>Married</td>
<td>2 aged 9 and 14</td>
<td>Transplanted 3 and 1 year ago. Ambulatory monitoring</td>
</tr>
<tr>
<td>PtH9</td>
<td>Eric</td>
<td>38</td>
<td>Married</td>
<td>3 aged 11, 9 and 4</td>
<td>Hospitalized, preparing for transplantation</td>
</tr>
<tr>
<td>PtH10</td>
<td>Gina</td>
<td>37</td>
<td>Cohabiting-stepfamily</td>
<td>5 children, Ginas own: 10 and 12, partners: 12, 10 and 7</td>
<td>Transplanted a year ago. Hospitalized with side-effects</td>
</tr>
<tr>
<td>PtH11</td>
<td>Jason</td>
<td>48</td>
<td>Married</td>
<td>2 aged 20 and 23</td>
<td>Hospitalized, preparing for transplantation</td>
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<tr>
<td><strong>Gynecology</strong></td>
<td></td>
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<td></td>
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<tr>
<td>PtG12</td>
<td>Celia</td>
<td>48</td>
<td>Single, children have no contact with their father</td>
<td>2 aged 11 and 19</td>
<td>Hospitalized after removal of the uterus, waiting for microscopy response</td>
</tr>
<tr>
<td>PtG13</td>
<td>Jill</td>
<td>46</td>
<td>Single, children have no contact with their father</td>
<td>2 aged 19 and 15</td>
<td>Hospitalized with gynaecological cancer, went through treatment for malign melanoma 14 years ago</td>
</tr>
<tr>
<td>PtG14</td>
<td>Jane</td>
<td>43</td>
<td>Married</td>
<td>2 aged 9 and 5</td>
<td>Hospitalized with gynaecological cancer, waiting for hospice</td>
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<tr>
<td>PtG15</td>
<td>Lisa</td>
<td>42</td>
<td>Married</td>
<td>1 aged 6</td>
<td>Hospitalized to have the uterus removed, was treated for breast cancer one year ago</td>
</tr>
<tr>
<td>Aim – lines of inquiry</td>
<td>Questions</td>
<td></td>
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</tbody>
</table>
| **Background**        | Situation (illness, civil status, and children: name and age, family network)  
You and your closest relatives: what are you most preoccupied with regarding your children?  
When did you last talk about the illness in the family?  
How did you experience that conversation?  
How do you talk with your children, spouse or other significant person about the illness?  
Do you talk with anyone else about your children? |
| **Research question 1** | **Experiences** |
| Conversations with and about children | Did you talk to the healthcare professionals about your children?  
*If yes:*  
Will you give an example of such a conversation?  
Who took up the issue?  
What subjects have you talked about?  
What thoughts did you have regarding the conversation?  
What do you think that the conversation contributed?  
Was there perhaps something that you thought was left out of the conversation?  
Was there something that you considered bringing up with the healthcare professionals that you chose not to?  
What did you think about when you made that choice?  
Was there maybe something that you would have liked to talk to the healthcare professionals about that was not brought up?  
*If no:*  
If you did not talk to the healthcare professionals about your children was there then some particular reason for that?  
Your own reasons?  
Healthcare professional’s reasons? E.g. that they did not address the issue. |
| **Research question 2** | **Needs** |
| Are there specific questions regarding your children that you are especially concerned with?  
How do you deal with these questions?  
What do you think that healthcare professionals could do to support you as regards these questions?  
Do you have other needs regarding talking with healthcare professionals about your children that you would like to mention?  
What role do you think that the healthcare professionals could play concerning these needs? |
| **Ending the interview** | What is the next thing that you are going to do today?  
When do you see your children again?  
What was it like for you to be interviewed?  
Do you have something that you would like to ask me?  
Thank you very much for your time and for sharing your thoughts. |
| **Follow-up** | Referral if needed. Contact information and office hours were handed out for follow-up. |
References


Richards, H.M., Schwartz L.J. (2002): Ethics of qualitative research: are there special issues for health services research? Family Practice 19, 135-139.


