Disrupted biographies and balancing identities

A qualitative study of cancer patients' communication with healthcare professionals about dependent children

Dencker, Annemarie; Murray, Scott A.; Mason, Bruce; Rix, Bo Andreassen; Bøge, Per; Tjørrnhøj-Thomsen, Tine

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

Running Head: Parents’ disrupted biographies and balancing identities

Authors:
MA, Ph.D. student Annemarie Dencker\textsuperscript{a,c}
DCH, DRCOG, MD, DFFP, FRCGP, FRCP, St Columba’s Hospice Chair Scott A Murray\textsuperscript{b}
MA, PhD, Research Fellow Bruce Mason\textsuperscript{b}
Head of Development and Documentation MD, MSc, PhD, Bo Andreassen Rix\textsuperscript{a}, bar@cancer.dk, phone +4535257478
Head of The Bereavement Project, Teacher Per Bøge\textsuperscript{a}, phb@cancer.dk, phone +4535257532
Professor MA, PhD Tine Tjørnhøj-Thomsen\textsuperscript{c}, titt@si-folkesundhed.dk, phone +4565507811

Affiliations:
\textsuperscript{a} The Danish Cancer Society, Patient Support & Community Activities, Copenhagen, Denmark
\textsuperscript{b} Primary Palliative Care Research Group, The Usher Institute of Population Health Sciences and Informatics, The University of Edinburgh, Medical School, Edinburgh, UK
\textsuperscript{c} National Institute of Public Health, Research Programme on Health Promotion and Prevention, University of Southern Denmark, Copenhagen, Denmark

Corresponding author:
Annemarie Dencker, Patient Support & Community Activities, Danish Cancer Society Research Center, Strandboulevarden 49, 2100 Copenhagen, Denmark, ade@cancer.dk, +45-35257546

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Abstract (200 words)

Objective
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.

Methods
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.

Results
We identified 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.

Conclusion
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,
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 & Ulfsæt, 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.

Combining interviews with participant observations facilitated for example the exploration of patients’ fatigue, because witnessing patients’ fatigue and poor condition at close quarters, led to a better understanding of their conditions. Moreover, observing patients’ encounters with healthcare professionals, we 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 healthcare professionals.

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 who were responsible for the patients’ care and treatment gave patients information sheets stressing that their decision would not influence relations with healthcare professionals nor their treatment or conditions during hospitalization. The main consideration behind having healthcare professionals 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, first author agreed with healthcare professionals that they would stress that participation was completely voluntary.

17 patients who had dependent children, and who were hospitalized during our field visit, were approached. Everyone accepted to participate except two patients due to fatigue.

Data collection
Participant observations and the interviews, which took place in the hospital, sought to gain a nuanced understanding of patients’ background, experiences and needs (Kvale, 1997; Spradley, 1979). Both interviews and participant observations were semi-structured, guided by our research questions and inspired by the theoretical frameworks of ‘biographical disruption’ and ‘social identity’. With this starting point, we explored specific and preselected areas with openness toward issues and subjects that the interviewees found important. Our aim was to explore and understand how people experience and view, believe and think, aspire the world about them, in this case regarding patients’ experiences communicating about their dependent children with the healthcare professionals (Creswell 2009; Grimen & Ingstad 2007; Kvale 1997; Spradley 1979).
Table 2 shows a topic guide for the qualitative interviews which also inspired the outset for the participant observations.

Participant observations further contributed to understanding the framework of communication for healthcare professionals’ encounters with patients about their children by pointing to 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).

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 we moved back and forth between the generation of interview and participant observation data, and the theoretical literature (Mason 2007). In practice, we moved back and forth between a set of observations based on the research questions and a theoretical curiosity, asking ourselves during the analytical process: “What is this a case of?” (Tavory and Timmermans 2014; Atkinson 2015).

In this process, we found that Bury’s concept of biographical disruption and Jenkins’ concept of social identity could be used as a basis for understanding the patients’ experiences and needs and assessing how their identities were affected by serious illness. Thus, 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). In this case, patients for example had to balance their social identities being seriously ill and having parental responsibility. Relating the biographical disruption of being seriously ill with Jenkins idea of ‘identity’ as a social, relational, contextual and dynamic process constantly in the process of construction and reconstruction we identified that patients overall had two dynamic identities.
‘patient’ and ‘parent’ which surface at various times and situations throughout their illness trajectories (Jenkins 2014). Thus, we counted two overall themes ‘patient’ and ‘parent’ each containing respectively five and four themes.

Following Creswell, we further discussed negative or discrepant information that ran counter to the themes in order to add credibility (Creswell 2009). For example, 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 our initial idea that patients generally would want healthcare professionals to be more proactive.

In that regard, participatory observations made an important contribution because understanding the depth of fatigue can be difficult without encountering patients suffering from it.

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 verbal consent to the healthcare professional after reading the letter and stated that they thought addressing the issue of children was important. We conducted interviews with patients during 2014-2015 according to the Danish law regarding personal data, law No 429 of May 31st 2000 (Persondataloven). According to this law, written consent was not required. After giving their participation consent to the healthcare professionals, patients met with the researcher (first author). Before beginning the interview, the researcher explained that the interview was confidential, that all data would be anonymized, and reiterated that the interview was voluntary and that the patient could end the interview at any time without providing a reason.

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 (Kobbennagel 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. Consent relating to the interaction with the children was not sought because children were not addressed directly in our study.

RESULTS

Participant 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*

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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:

“Somehow 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 be 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 than 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 feel 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 ice cream 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 acknowledged as a parent in addition to 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 neither 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>
</tr>
</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 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 children’s 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 to not feel 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.

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Table 1: Patient characteristics

<table>
<thead>
<tr>
<th>Name (anonymized)</th>
<th>Age</th>
<th>Civil status</th>
<th>Children</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Haematology</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PtH1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walter</td>
<td>36</td>
<td>Married</td>
<td>2 aged 2 and 5</td>
<td>Hospitalized, having a</td>
</tr>
<tr>
<td>PtH8</td>
<td>Carol</td>
<td>40</td>
<td>Married</td>
<td>2 aged 9 and 14</td>
</tr>
<tr>
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</tr>
<tr>
<td>PtH9</td>
<td>Eric</td>
<td>38</td>
<td>Married</td>
<td>3 aged 11, 9 and 4</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>
</tr>
<tr>
<td>PtH11</td>
<td>Jason</td>
<td>48</td>
<td>Married</td>
<td>2 aged 20 and 23</td>
</tr>
<tr>
<td>Gynecology</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<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>
</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>
</tr>
<tr>
<td>PtG14</td>
<td>Jane</td>
<td>43</td>
<td>Married</td>
<td>2 aged 9 and 5</td>
</tr>
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<td>---------</td>
<td>----------------</td>
</tr>
<tr>
<td>PtG15</td>
<td>Lisa</td>
<td>42</td>
<td>Married</td>
<td>1 aged 6</td>
</tr>
</tbody>
</table>
Table 2: Topic guide for qualitative interviews

<table>
<thead>
<tr>
<th>Aim – lines of inquiry</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Situation (illness, civil status, and children: name and age, family network)</td>
</tr>
<tr>
<td></td>
<td>You and your closest relatives: what are you most preoccupied with regarding your children?</td>
</tr>
<tr>
<td></td>
<td>When did you last talk about the illness in the family?</td>
</tr>
<tr>
<td></td>
<td>How did you experience that conversation?</td>
</tr>
<tr>
<td></td>
<td>How do you talk with your children, spouse or other significant person about the illness?</td>
</tr>
<tr>
<td></td>
<td>Do you talk with anyone else about your children?</td>
</tr>
<tr>
<td><strong>Research question 1</strong></td>
<td>Experiences</td>
</tr>
<tr>
<td><strong>Conversations with and about children</strong></td>
<td>Did you talk to the healthcare professionals about your children?</td>
</tr>
<tr>
<td></td>
<td>If yes:</td>
</tr>
<tr>
<td></td>
<td>Will you give an example of such a conversation?</td>
</tr>
<tr>
<td></td>
<td>Who took up the issue?</td>
</tr>
<tr>
<td></td>
<td>What subjects have you talked about?</td>
</tr>
<tr>
<td></td>
<td>What thoughts did you have regarding the conversation?</td>
</tr>
<tr>
<td></td>
<td>What do you think that the conversation contributed?</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Research question 2</th>
<th>Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there specific questions regarding your children that you are especially concerned with?</td>
<td></td>
</tr>
<tr>
<td>How do you deal with these questions?</td>
<td></td>
</tr>
<tr>
<td>What do you think that healthcare professionals could do to support you as regards these questions?</td>
<td></td>
</tr>
<tr>
<td>Do you have other needs regarding talking with healthcare professionals about your children that you would like to mention?</td>
<td></td>
</tr>
</tbody>
</table>
| What role do you think that the healthcare professionals
<table>
<thead>
<tr>
<th>Ending the interview</th>
<th>could play concerning these needs?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What is the next thing that you are going to do today?</td>
</tr>
<tr>
<td></td>
<td>When do you see your children again?</td>
</tr>
<tr>
<td></td>
<td>What was it like for you to be interviewed?</td>
</tr>
<tr>
<td></td>
<td>Do you have something that you would like to ask me?</td>
</tr>
<tr>
<td></td>
<td>Thank you very much for your time and for sharing your thoughts.</td>
</tr>
</tbody>
</table>

| Follow-up | Referral if needed. Contact information and office hours were handed out for follow-up. |