



Smart, vulnerable, playful or just disturbing? A discourse analysis of child involvement in palliative care

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Abstract

In Scandinavian countries, health professionals are legally obliged to involve patients' minor children. A growing field of research focuses on the support to, and needs and experiences of, these children. We add to previous research by analysing discourse in qualitative interviews with nurses and doctors in Norwegian public palliative health care. The analysis identifies four interpretative repertoires picturing the child in different ways and defining possibilities for what health professionals can say and do regarding child involvement.

Keywords

Child involvement, discourse analysis, health professionals, interpretative repertoires, palliative care, parental death

Introduction

A mother or father's severe illness and anticipated death embeds the child's everyday life (Haugland et al., 2015). Parents of minor children, in families where mum or dad is severely ill of a life-threatening disease, report being insecure about how and when to tell children about the diagnosis and how much information they need (Bugge et al., 2009). Parents want support from health professionals in these matters (Aamotsmo and Bugge,

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2014), and according to a new legal regulation in the Health Personnel Act in 2010 (HPA, §10a), health professionals in Norway are obliged to contribute to taking care of and involving children. What is considered the right way – and the right degree of child involvement when a mother or father is severely ill and dying – is, however, under continuous negotiation, and depends on socioculturally shared and *discursively* constructed knowledge about what ‘a child’ is, how children develop and what childhood consists of (Burman, 2008). ‘Discursively constructed’ means that it is embedded in language as frameworks of meaning (Burman, 2008; Parker, 2014). In this article, we turn our attention to the language used by palliative health-care professionals in Norwegian public healthcare. By analysing discourse in 11 qualitative interviews, we explore how patterns in health professionals’ ways of talking construct multiple ‘pictures’ of the child (Burman and Parker, 1993; Taylor, 2001), and further, how health professionals discursively legitimize different child involvement practices when a mother or father is severely ill and dying (Harré and Langenhove, 1999; Wetherell and Potter, 1988).

Background

Palliative care is provided for patients with incurable illnesses. Palliative care today primarily connects to the hospice philosophy founded by Cicely Saunders during the 1950s and 1960s in London (Strømskag, 2012). The philosophy is patient-centred and states that the aim of palliative care is to facilitate a good death by preventing and relieving the patient from suffering their ‘total pain’, defined as a complex of physical, emotional, social and spiritual elements (Madsen et al., 2013; Strømskag, 2012). Even though Saunders included care for the patient’s family, and hence, the patient’s minor children, as an emotional and social element in the patient’s total pain (Madsen et al., 2013), children as next of kin receive little attention in the historical literature.

The attention towards children as next of kin is growing, visible in legal regulations and a field of research focusing on their needs and experiences (Haugland et al., 2012, 2015; Larsen and Nortvedt, 2011; Ruud et al., 2015). Recently established laws and recommendations for health professionals in Scandinavian countries oblige health professionals to involve patients’ minor children by contributing to taking care of their needs, for example, their need for individually adapted information about prognosis and diagnosis (Danish Health Authority, 2012; HPA, §10a; Swedish Law of Health and Medicine (SFS), 2009). Together, the research focus and legal regulations speak of a more overarching, cultural, ideological shift towards acknowledging children as legitimate participants with certain rights of their own (Thuen, 2008).

The majority of studies implicitly argue for involvement rather than segregation and protection, more specifically through openness and communication about illness and diagnosis in the family (Buchwald et al., 2012; Bugge et al., 2009; Kennedy and Lloyd-Williams, 2009a, 2009b) and more and better tailored support from health professionals, both directly to the child (Golsäter et al., 2019) and to the parent, regarding their parental role and communication with their child (Steiner et al., 2017). These studies implicitly contribute to constructing a norm for health professionals’ support to children: they convey building relations with and talking to children about illness and death as an ideal.

Health professionals' perspectives: Previous research

Studies exploring health professionals' perspectives show some interesting findings with regard to perceived barriers to gaining the ideal support from health professionals. Several Scandinavian studies point towards emotional and structural barriers that make it challenging for health professionals to involve and support the minor children of their patients (Dencker et al., 2017a, 2017b; Golsäter et al., 2016; Karidar et al., 2016; Ruud et al., 2015). Emotional barriers consist of health professionals' experienced distress in encounters with children and death, which might lead to withdrawal or professional distance (Dencker et al., 2017b; Golsäter et al., 2016). Structural barriers concern circumstances related to the medical context, such as time pressure, priority given to the patient, medical treatment and medical issues above psychosocial support (Dencker et al., 2017b; Karidar et al., 2016), shortcomings in the medical record systems that prevent health professionals from keeping track of patients' children (Dencker et al., 2017b; Ruud et al., 2015) and lack of professional skills. Regarding the latter, this concerns having too little experience generally, with adolescents particularly (Karidar et al., 2016; Tafjord, 2020), or a weak professional role (Golsäter et al., 2016). Several studies highlight that lacking skills and experience in combination with little support from the health system structures, contribute to increase the emotional impact of encountering children and death (Dencker et al., 2017b; Golsäter et al., 2016). Two reviews from the United Kingdom support the findings from the Scandinavian studies: health-care professionals report that providing support to parents and children during parental life-limiting illness and following the death is emotionally difficult and time-consuming (Fearnley and Boland, 2017; Franklin et al., 2018).

These findings about emotional and structural barriers could very well explain why health professionals' support to children as next of kin is not good enough. However, as we will elaborate in the theory section, rather than understanding the findings as neutrally reflecting a unitary and static 'health professionals' perspective' (Allred and Burman, 2005), we propose understanding health professionals' accounts about barriers as socioculturally legitimate reasons and arguments for involving children or not (Wetherell, 1998). Hence, this article applies a discourse analytic approach to analyse health professionals' accounts, with the aim of discerning (repeated) lines of arguments about child involvement (Wetherell, 1998) that give us knowledge about multiple ways of legitimizing child involvement practices (Burman, 2008).

Theoretical point of departure: Discursive constructions of 'the child'

A commonality between the manifold discourse analytical approaches is their 'attention to the significance and structuring effects of language' (Burman and Parker, 1993: 3). In this article, we combine the following three discourse analytical concepts: discourse, interpretative repertoire and positioning (Burman, 2008; Parker, 2014; Wetherell, 1998; Wetherell and Potter, 1988). This combination enables us to analyse how health professionals' ways of talking functions to legitimize different child involvement practices.

Discourses are culturally shared and socially constructed frameworks of meaning embedded in language that define categories, as for example 'children' and 'adults', and

they limit and open up possibilities for saying and doing (Burman, 2008; Parker, 2014). Erica Burman (2008) explains in her book, *Deconstructing Developmental Psychology*, how cultural and historical conditions produce discourses about childhood, what a 'child' is and how children develop. Burman and others have pointed out how childhood was 'invented' as a distinct period of human life, during the Age of Enlightenment by, among others, the French philosopher Jean-Jacques Rousseau (Burman, 2008; Thuen, 2008). Psychology, and especially developmental psychology, has contributed in producing discursive understandings of the child that have far-reaching consequences, for instance for the way we understand others and ourselves, for social policy and professional practice (Burman, 2008).

In her article about the use of developmental psychology models in public debates about early childhood care in Norway, Agnes Andenæs (2012) presents two models: 'the vulnerable child' and 'the child as researcher'. 'The vulnerable child model' pictures the child as a passive, immature and incomplete individual, who develops through the primary caregiver's (primarily the mother) servicing, protecting and providing for the child's basic, universal needs (Andenæs, 2012; Thuen, 2008). If the child's needs are not satisfied, there is a risk of lopsided development (Andenæs, 2012; Burman, 2008). 'The child as researcher model' views the child as a competent individual who develops through active, systematic investigation of the environment, forming an increasingly complex system of thought (Andenæs, 2012). 'The vulnerable child model' seems to dominate with regard to toddlers, whereas the latter model applies to older kindergarten-children (Andenæs, 2012). Both these models picture child development as following natural laws, and the child as relatively isolated from everyday life (Andenæs, 2012; Hogan, 2005), and rely on an overarching discourse of childhood as distinct from adulthood.

To be able to grasp multiple, smaller and fragmented 'pictures' of the child among health professionals in the palliative care context, we found the concept *interpretative repertoire* useful. Margaret Wetherell (1998) defines interpretative repertoires as 'culturally familiar and habitual line(s) of argument comprised from recognisable themes, common places and tropes (doxa)' (p. 400). Interpretative repertoires are ways of talking about objects and events in the world that are relatively coherent (Edley, 2001). As an analytical tool, the interpretative repertoire concept helps us to produce knowledge about several possible ways of arguing for or against child involvement. In combination with the concept *position*, referring to shifting possibilities for saying and doing as a function of applying the interpretative repertoires (Harré and Langenhove, 1999; Parker, 2014), we become able to explore palliative health-care professionals' ways of managing their professional positions in encounters and interactions with patients, parents, children and other professionals.

The study

Participants

Aiming to obtain insight into how frameworks of meaning produce different child involvement practices towards minor children as next of kin to a severely ill and dying parent, we chose palliative health-care professionals as participants. A discourse

theoretical assumption is that these professionals share socially constructed knowledge that will be reflected in their language use, and hence, the recruitment strategy involved obtaining participants 'typical' of this group of professionals (Burman, 2008; Taylor, 2001).

The Data Protection Official for Research in Norway was notified of and approved the research project. The first author visited two geographically dispersed public hospitals in Norway and provided palliative teams and wards with information about the project. Six participants made contact with the first author by giving written consent to participate. All except one of them were female nurses. To obtain a sample covering the variation within the population in terms of profession (nurse/doctor), gender and institutional affiliation, we specifically contacted four more potential participants (Taylor, 2001). We used mediators to make contact with a male nurse and a female doctor and two professionals in municipal health services. The mediators provided them with information about the project, whereupon all of the four agreed to participate by personally contacting the first author to make appointments and provide written consent. In addition, one of two pilot interviews were included to ensure that the gender distribution within palliative care was represented.

In total, 11 professionals participated. At the time of interview, they had 2 years to 17 years of experience within palliative care. They were eight women and three men, three doctors and eight nurses, two from municipal – and nine from specialist health services.¹ Culturally, the sample was relatively homogeneous, all having majority origin from Norway or other Protestant Western European countries.

Interviews

As we were interested in the way health professionals talk about and discursively legitimize practices of child involvement, we needed longer sequences of dialogue. Open-ended, semi-structured interviews appeared to be a suitable method for data collection. The first author conducted all of the interviews. We revised and further developed the interview strategy and the interview guide after two pilot interviews. The revision process continued during the data collection period, as insights from interviews helped us focus our questions.

All interviews were divided into two main parts, where the first relied on health professionals' stories from practice, whereas the second asked more specifically for their meanings and views. The interview guide consisted of four main questions with several subordinated questions. First, the participants were asked to tell about themselves and their professional background. Second, they were asked to tell their stories about the children they had encountered during their years of practice within palliative care. The interviewer asked follow-up questions to encourage the participants to elaborate on their experiences in specific situations. The third main question focused specifically on children of kindergarten age (1 years old–6 years old). The participants were asked questions about their views and understandings about young children's needs, children's understanding of death and illness, and how the follow-up of the children should be conducted when the parent is a palliative patient. For example, one question was, *How would you tell a child of kindergarten age that his or her parent was going to die?*

The fourth main question asked for health professionals' considerations about their own role and competence.

Interviews lasted from 62 minutes to 128 minutes and all were audio recorded. The first author transcribed all the interviews verbatim, resulting in 315 pages of text.

Analysis strategy

To be able to identify the interpretative repertoires used, the first author started by reading the transcripts looking for 'different ways of talking' (Parker, 2014: 3) about children. This reading involved what Parker (2014) calls occupying a *critical distance* to language, reading it as one of many possible texts and not as a reflection of an underlying reality. Hence, the task was to get an overview of possible ways of talking, and involved looking for images, metaphors or figures of speech (Edley, 2001), together with a focus upon how the way of talking about the child functioned to convey certain pictures of the child or certain connotations. We looked for ways of constructing the child through the way children were referred to, for example as 'the little girl' ('lillejenta' in Norwegian – a kind of pet name conveying care and childishness) and for recurring phrases and *truth claims* (Søndergaard, 2002) about the child, for example 'children go in and out of grief'. Truth claims are useful in detecting commonsensical understandings. In this initial phase, the software NVivo was applied to code text sections with nodes close to the language used.

Second, in individual- and group-based analysis sessions, we started with the text sections identified using NVivo and elaborated on them with help from theoretically informed analytical questions. These questions were the following: How do these ways of talking picture the child, and what is the effect of this way of talking about the child? What understandings of the child are implicitly conveyed through the participants' stories? What understandings of the child are not conveyed?

Furthermore, we looked for patterns of talking that clustered together in relatively coherent ways (Edley, 2001) based on how they pictured the child and whether they comprised a coherent line of argument about child involvement (Wetherell, 1998). From this analysis step, we identified a pattern of four interpretative repertoires across participant accounts, and elaborated on how the interpretative repertoires functioned to place the health professional, other professionals or parents in *positions* with possibilities for saying and doing.

Four interpretative repertoires

The names of the four interpretative repertoires reflect how they discursively construct pictures of 'the child': 'Children as individual thinkers and interpreters', 'Children as belonging to their parents', 'Children as playful and full of life' and 'Children as disturbing elements'. The repertoires are discernible analytically and we present them here as if they operate separately from each other. However, especially the more experienced health professionals drew on several of the interpretative repertoires interchangeably during the interviews. Still, years of experience did not seem to influence the mere availability of the repertoires: all four were traceable in most participant accounts.

Children as individual thinkers and interpreters

The health professionals talked about how children 'sense' or observe their parents' concerns, anxious behaviours and symptoms of illness, and how the children might reflect on these observations on their own and create their private beliefs and questions. Phrases and truth claims such as the child being 'smart', 'understands everything', 'have already understood beforehand', being 'concrete' in their thinking, 'loyal', 'responsible', 'clever' and 'resourceful' clustered together in the participants' accounts. Anaesthesia nurse Elisabeth, working in a palliative ward, talked about children having already understood that the parent was severely ill and going to die:

Some children say that they saw it, but still never asked because they did not dare or that it just did not occur as a topic in conversation. However, children are smart. It must be painful to go around being afraid, not daring to ask. Maybe they do not get the answers they need. (Elisabeth)

This way of talking about children pictures them as competent, thinking individuals in a way similar to the model of 'the child as researcher' outlined previously, but with an inherent vulnerability that might hinge on the fact that these children are in a critical life-situation. The health professionals argued that even though children are smart and understand much on their own, they do not know everything and might be wrong in their interpretations. The health professionals referred to child-specific ways of thinking that are concrete or imaginative and may create misconceptions, and to children's loyalty to their parents: when parents show that they do not want to talk about illness and death, the children are loyal to them and do not talk about it either.

The health professionals seemed to handle the children's thoughts, questions and feelings as private, already existing entities to be revealed or discovered. Several stories involved children's maladaptive behaviour and anxiety, some indirectly referring to parents' reported problems with the children in school, and so on, and others directly, where the health professional experienced the child's behaviour as maladaptive. The health professionals related the maladaptive behaviour to 'hidden' misconceptions or unanswered questions about the illness, defining a need for someone to discover and correct the misconceptions. In some of the stories, the health professionals described how the child's maladaptive behaviour ceased, or how the child showed relief or contentment as a consequence of the health professionals talking to them about their parent's illness and death. One example is a story from a cancer nurse, Gunda, working in an ambulant palliative team, who told about her meeting with two siblings with a severely ill and dying father. The siblings knew their dad was ill, but were not explicitly informed that he was going to die. The parents did not want Gunda to mention the word death. However, Gunda said in the interview that she could *see* by 'the way they looked at me with their big, open eyes that they knew, and wanted to ask [if dad was going to die]'. Alone with the children for a moment, she asked the siblings if they wondered if their dad was going to die, and the children confirmed that they did. Gunda said in the interview that she observed the relief, especially in the oldest sibling, after this conversation.

By presenting this story, Gunda implicitly put across a positioning of the parents as overprotective. They tried to protect their children by avoiding talking about death, but Gunda revealed that the children already had thought about it. We found this positioning

of parents as overprotective implicitly and explicitly across interviews, linked to claims about how parents often underestimate their child's competence in sensing, observing and reasoning. As Elisabeth said when talking about parents withholding information about illness and death from their child, 'it is a misunderstanding not to let the children know the realities'.

The positioning of parents as overprotective in combination with the construction of the child as in need of objective knowledge about illness and disease, makes available a position for health professionals as experts: capable of seeing the child's real competence in sensing and observing, while at the same time providing corrective, objective information to the child. This position specifies for the health professionals the possibility, perhaps even a *duty*, to be involved with the child by talking to, seeing and trying to interpret the child. At the same time, the position legitimizes doing what the health professionals consider necessary, regardless of what the parents say.

Children as belonging to their parents

The health professionals talked about children's lack of competence and ability, and used phrases like 'they just need to feel safe', 'he was so little', 'do not understand', 'cannot grasp', 'cannot comprehend', 'too little to . . .', 'hard to reach' and 'do not want to be abandoned'. This recurring way of talking about the child is similar to the vulnerable child model introduced earlier, as it pictures children as cognitively incompetent, with a special emphasis on the little child's inability to understand death and time, having a strong dependence on their parents, primarily their mother. The health professionals talked about the patient and the child in a way that made the child as subject become almost invisible. At the same time, this pictured the child as *belonging* to or being an inherent part of a dyadic parent-child unit. The strong belongingness to the parents produces parental death as a definite separation of the parent-child unit, and, at the same time, highlights how brutal the anticipated parental death will likely be.

This repertoire was prominent when the health professionals talked about children of kindergarten age, especially evoked by questions about young children's needs. This reference to younger children seems to make certain positions available for health professionals: they position themselves in two different parent-related positions: as parents themselves or as health professionals, and hence, 'not parents'. Earlier, we referred to Elisabeth, who stated, 'it is a misunderstanding not to let the children know the realities'. Here she talked from a position as health professional. However, in another text section, when discussing timing and degree of child involvement, she positioned herself as parent, and said hypothetically that if *she* had been ill, she would not have wanted to cause her children to worry – and hence, would have waited to tell them to 'spare' them.

The repertoire positions parents as experts and health professionals as 'not parents' – having little to offer when it comes to contributing to meet the child's needs. Cancer nurse Cecilie, working in a palliative team in a small hospital, made an observation about the dependency of children on their parent, with a positioning of health professionals as 'unknown people':

Small children depend heavily on their parent. It can be frightening for them when visiting mum or dad in hospital, that there are many unknown people wearing white coats. (Cecilie)

Some expressed despair and shortcomings regarding the youngest children, and seemed to experience being inadequate, with limited possibilities to act. However, a few of the health professionals drew on this repertoire to position kindergarten teachers and other professionals in the child's everyday life as key persons having the opportunity to meet the child's need for security, safety and comfort. Two of the nurses, both working ambulant, told about collaborating with the kindergarten by supervising the staff. They advised the kindergarten to make sure that one person among the staff had a special responsibility to follow up the child in question and that the child should be offered extra care and closeness.

Children as playful and full of life

One recurring way of talking among the health professionals consisted of statements about the child 'going in and out of grief', being 'themselves', 'living in the present', living in their 'own world', and descriptions of the child as 'innocent', 'curious', 'spontaneous', 'playful', 'open-minded', 'natural', 'happy', 'light-hearted', 'impudent', 'honest' and 'direct'. This way of talking seemed to echo the words and phrases from Rousseau's philosophy about the nature of the child, picturing children as natural, uncultivated beings living spontaneously, driven by curiosity and play (Burman, 2008; Thuen, 2008):

I think children are more protected by being the way they are: in and out of grief. While adults, we bring it with us all the time. Even though doing something else, we feel the lump in the stomach. It is with us. (Jenny, municipal nurse)

Jenny's dichotomous phrase describing children as 'in and out' is characteristic of this repertoire. The phrase implicitly conveys that when children are 'out' of grief and doing something else, they do not bring their sadness and worries with them. Later in the interview, Jenny said that parents should take children seriously when they are 'in it'. The medical doctor Andreas, working in a palliative team, said, 'children want to be allowed to not think about bad matters', and he and others talked about how children do not like hospitals. Several of the health professionals highlighted hospitals as an unsuitable environment for children and talked about the importance of facilitating children's play so that children could be 'themselves' in their own arena – for example, by providing home visits and playrooms in hospitals.

Although all repertoires hinge on a demarcation of childhood as a distinct period of life, this repertoire goes even further in constructing children as qualitatively different from adults, with *child-specific qualities*. This qualitative difference becomes especially evident by the use of the phrase 'child world', implying that children are separate from adults in certain ways. Interestingly, the health professionals talked about child-specific qualities as resources, hence, producing a positive picture of the child. As Jenny said, children protect themselves by going in and out.

The health professionals talked about the child-specific qualities as serving not only the child, but also the sick parent, because of the joy, aliveness and innocence the child represents. For instance, a dying mother enjoying the inhalation of her baby's scent, and a sick father 'resting his eyes' on his children watching television. Facilitating children's play and their presence in the hospital are then implicitly legitimized by how this contributes to the promotion of positive experiences and emotions for the patient. Hence, the child should be present for the sake of the patient. Health professionals are positioned with the duty of facilitating child-friendly environments, such as playrooms and more homely environments in hospitals. The repertoire could also position children with the right not to be disturbed in their natural coping, and hence, exempt health professionals from the responsibility of involving with the child.

Children as disturbing elements

At times, the health professionals talked about children in a way that pictured the child as an element that did not fit in. This repertoire pictures children as *active*, as the repertoire *Children as playful and full of life*, but as disturbing in their activity. The health professionals talked about the child with words and phrases such as 'annoying', 'being restless', 'everywhere', 'active', 'uncontrollable', 'hanging on the lamp' and 'rampaging'. Cancer nurse Cecilie told about an immigrant family with two children where the father had fallen ill. The health professionals did not know the family's language, and experienced problems in communicating. The children barely visited the father in hospital at all, as Cecilie explained,

because they were everywhere and very busy. The father almost did not handle them being here, because . . . well, one and two years old, they are rather active. (Cecilie)

She linked the active and disturbing features of the children to their young age, something that is indicative of this repertoire.

The health professionals overall seemed to consider it normal and inevitable that small children are active. When they used this repertoire in talking about (slightly) older children, however, they seemed to see them as *hyperactive*. As Elisabeth vaguely said, 'it was something about him'. The diagnosis ADHD was also mentioned several times during interviews. A tendency when applying this repertoire seems to be that health professionals position themselves as outsiders to the problem of disturbance, in that the disturbing effect of the child derives from an inherent quality of either age-specific behaviour or psychopathology, instead of talking about emotional and behavioural distress as resulting from the context and circumstances. In cases of older, hyperactive children, some of the health professionals said it is not 'their job', and they cannot 'go into cases like that', and that they would refer the child to mental health services.

The medical doctor Kristine, working in a palliative team, talked about how the nurses in their ward were adept at handling the children by taking them to the kitchen and showing them the biscuit drawer so that the doctor could do his or her job. Such references to giving children biscuits, lemonade and ice cream as a way of handling

them are common in the material. In addition, the tendency seemed to be that both professions regarded handling the disturbing children as the nurses' duty, not the doctor's.

Discussion

Discourse analysis contributes with knowledge about palliative health-care professionals as both *discourse users* and *submitted to discourse* (Parker, 2014; Søndergaard, 2002). Whereas the overarching, cultural ideology about the child is shifting towards acknowledging children as legitimate participants with certain rights of their own (Thuen, 2008), health professionals are submitted to other overarching discourses embedded in language and cultural practices as well, creating ideological dilemmas that need to be managed (Edley, 2001). In the following, we discuss how medical discourses and discourse of the good death as well as discourses of individualist psychology come into play when health professionals locally manage their professional positions.

Medical discourse and discourse of the 'good death'

In line with previous studies that found that the conditions of the medical context limit health professionals' possibilities to involve children (Dencker et al., 2017a; Karidar et al., 2016), our analysis indicates that the palliative context might contribute to health professionals viewing the child from 'outside'. This objectified view limits the health professionals' possibility to empathically tune into children and see them as experiencing subjects when in the palliative context (Sommer et al., 2013). Understanding *children as individual thinkers and interpreters* is an exception, making it possible to explain (hyper) activity as a reaction to the special conditions and not an inherent essence. However, this repertoire was seldom evoked when talking about the youngest children, who seem to be most vulnerable to objectification.

The patient-centred palliative care ideology legitimizes involving children (Dencker et al., 2017a) by inviting them to stay in the hospital *insofar* as it contributes to the well-being of the patient, and not if it disturbs the patient. In the same vein, the ruling medical logic defines the doctor's job as most important, and the young, active child should not disturb the doctor in delivering medical treatment. Another interesting interplay here is with a doctor-nurse-discourse: it becomes the nurses' duty to handle the children, taking them out if they disturb the doctor's work, and giving them sweets so that they become controllable and calm.

Furthermore, ideas and discourse about the 'good death' central in palliative care philosophy create 'normative expectations and institutional frames or guidelines of what a successful or good dying trajectory necessarily must look like in order to be deemed "good"' (Hviid Jacobsen and Dalgaard, 2013: 311). In turn, this influences the ways in which children are meant to participate during a dying trajectory. Implicit ideas about the good death as authentic, peaceful, well prepared and marked by as many positive experiences and emotions as possible accord with the presence of a calm, beautiful and quiet child, but seems to conflict with the presence of a restless, uncontrollable and rampaging child.

Discourse of individualist psychology and age

As commented in the 'Introduction' section, it seems the contemporary ideal for how to involve children regarding parental illness and death is through open, verbal communication – talking to the child and being able to tailor support to the individual child. This ideal is in line with an individualized understanding of the child (Andenæs, 2012), especially visible through the repertoires *children as individual thinkers and interpreters* and *children as disturbing elements*.

Children as individual thinkers and interpreters seem to rely on a tendency to locate psychological phenomena inside the individual (Burman and Parker, 1993). The health professionals seem to take up a position as therapist, trying to discover the child's hidden thoughts and feelings to be able to help them, like Gunda, who discovered that the siblings were worried that dad was going to die. An alternative is to understand psychological phenomena as embedded in particular situations, relations and contexts (Andenæs, 2012), which have consequences for the understanding of the health professional's role. Looking at it through this theoretical lens opens up the possibility that Gunda was a co-creator of the children's anticipation of parental death, not a neutral discoverer.

Individualization has another function in the repertoire *Children as disturbing elements*. Here, the phenomenon of the disturbing child is individualized as a biological pathology belonging to the individual (Ekeland, 2009). However, with an important exception: if the disturbing behaviour is considered age-appropriate, it seems to be understood as an inherent feature of the young child, and not pathological. This illustrates how age-categories and age grading contribute in defining 'normal development' and 'the normal child' (Burman, 2008), and further legitimizes practices of taking children away from the situation where they disturb. Handling mental health problems is the task of other professionals, hence, is outside of the palliative health-care professionals' tasks. As a parallel is the positioning of kindergarten teachers as resources in providing closeness and care to small children. A tendency to push responsibility to other professionals or other colleagues is found in previous research as well (Golsäter et al., 2016; Karidar et al., 2016), and seems to have the potential to ease the emotional impact of health professionals' own shortcomings, regardless of whether they take actual steps towards interprofessional collaboration or not. It hence represents a risk that no one assumes the duty and responsibility to follow-up on the child.

Concluding remarks

Previous research from Scandinavian contexts has pointed to a gap between on the one hand, the legal and professional intention to involve children as next of kin, and on the other hand, that health professionals' actual support to children as next of kin is not good enough. This study contributes by pointing to multiple, sometimes contradictory, lines of argument about child involvement available for palliative health-care professionals that function to legitimize current practices.

The study is conducted within the Norwegian public health care. It is likely that the findings reflect the context of Scandinavian countries, being characterized by high living standards, public health care for all, high gender equality in employment rates and that the majority of children attend kindergarten during the first years of their life. Hence, readers should be cautious in generalizing the results to contexts outside of Scandinavia. Another

point is that the frameworks of meaning are embedded in language, and with Norwegian as the study language, it is probable that meaning is lost in translation to English.

Another limitation is that the interview data provide no direct sources of information about the actual children the health professionals have encountered, hence the analysis cannot capture how different children may 'activate' different discursive constructions. Still, the study provides insight into how different conversational contexts activate certain interpretative repertoires, for example how questions about children's needs seem to evoke the repertoire *Children as belonging to their parents*.

Providing insight into how health professionals' practices may be discursively legitimized may contribute thinking tools that enable health professionals to become aware of the position they themselves or the patient occupy when negotiating child involvement. For example, the above-mentioned expert-position legitimizes doing what the professional considers necessary regardless of what the parent says, and is a position with an inherent risk of conflict with the patient's position as parent. Awareness of these positions as socially constructed and not neutrally reflecting an underlying reality (such as parents 'actually' overprotecting) may make them available as resources for reflecting upon own practice.

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Note

1. With respect to retaining the participants' anonymity, we do not provide here a full summary of how the sample's characteristics combine.

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