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Possibilities and conflicts in professional encounters with young children experiencing parental illness and death

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A sociocultural developmental psychology perspective on child involvement

Ingrid Johnsen Hogstad

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Preface

I have always had a hunger for theory. Not for the theories *per se*, but for the way changes in theoretical perspective and in applying different theoretical terms and concepts have the power to change the way I see things in the world—important things, like the way I raise my kids, my relationships with important persons in my life: my husband, my mother and father and brothers, my contribution to climate change, and, yes, an indefinite chain of things in the world that changes when I look at them differently. Changing perspectives have the power to change the world, and I think I have always wanted to change the world a little bit.

In psychology, as in other social sciences, the investigator and her *biographical* knowledge, as well as the political, conceptual and ethical resources she adheres to, will inevitably influence the object under study (Alldred & Burman, 2005; Bøttcher, Kousholt, & Winther-Lindqvist, 2018; Glynos & Howarth, 2007). I have had experiences in my life that have contributed to my understanding and interpretation of what it means to be a child in a family affected by severe illness and death.

I was two and a half years old when my baby sister died at only two days of age—the presence of death and awareness of it entered my childhood life. Later, as a young adult, I experienced the feeling of having been deceived by my own family when a family secret was revealed, but I have also experienced the healing process, where we as a family together made new meaning of the past.

Still, I mark the beginning of the work on this thesis later, and somewhere else: with my experience as a young assistant in kindergarten, of following "Sandra" in her everyday life in what became her mother's last one and a half year of life. I want to draw a picture of how I remember her, with the aim of making readers aware of how young children's grief is situated in their everyday life.

I remember Sandra as an energetic and smiling girl. She was a bit taller than the other boys and girls her age. Her pants could be a bit short on the legs, revealing a bare lower leg above her pastel-coloured cotton socks. She had blond hair and friendly eyes and a beautiful smile that made me tender-hearted.

She did not always smile. Sometimes she was angry, strong, running after whomever it was (and it often was one particular boy) who had teased or provoked her. One time, she came with me to the kitchen to help me out with making lunch, and with the help of a hand puppet she suddenly told me that an ambulance had brought her mother to the hospital that night.

It was the kindergarten teacher of the group that told me her mum was severely ill with cancer. The cancer had been on and off during Sandra's years in kindergarten. Statistical studies in Norway have estimated that one in five of minor children affected by parental cancer will experience parental death following cancer (Syse, Aas, & Loge, 2012). Sandra was going to be one of these "one-in-fives". When she was five years old, around Easter the year she was going to attend school in the autumn, her mum told me—I was alone with the child group that morning, so we had to talk privately in the bathroom because I could not leave the unit—"I will not survive this. The doctors say that there is nothing more to do." I cannot remember what I said in reply, but remember crying in the staff break room afterwards. The faint odour of institutional toilet accompanies my memory.

Sandra's reactions increased in their frequency and strength. When her dad said goodbye and left from kindergarten in the morning, it was as if all the world's sadness dwelled in her heart, and she cried inconsolably. We comforted her, gave her a lap to sit on. What could we do?

Her mother died when summer came.

The experiences with Sandra gave me the interest and resources to further pursue young children's perspectives on parental illness and death, and a couple of years later, I started working within the specialist health services' bereavement support groups. In bereavement support groups with young children, I encountered children who had experienced parental loss due to cancer, suicide, murder, accidents and heart attacks. Knowing *in advance* that death was anticipated seemed to provide children bereaved by cancer with opportunities that the other children bereaved by sudden deaths did not have. However, there seemed to be wide-ranging individual differences in experiences between the children bereaved by cancer. I wanted to understand more about how we as professionals could contribute to open up children's possibilities to conduct their lives without mum or dad and if these processes of "opening possibilities" could start in the period preceding the death.

With this thesis I want to contribute to the theoretical models for understanding young children's experience of parental illness and death. Hopefully, other people find that applying the theoretical models presented in this thesis has the power to open up new possibilities for their way of seeing things.

Takk (acknowledgements)

Mange har bidratt i arbeidet med denne avhandlingen. Ikke alle vil nevnes her, men alle jeg skal nevne, snakker eller forstår norsk.

Først takk til min hovedveileder Anne Jansen for konstruktive og kritiske spørsmål, kloke innspill og gode samtaler. Din veiledning har gitt et løft hver gang. Takk til medveileder Tor-Johan Ekeland for at du har stilt opp når jeg har trengt det, og særlig med uvurderlig hjelp i innspurten. Din erfaring og faglige tyngde har vært god å ha. Takk til Else Lykkeslet som var min hovedveileder da prosjektet ble utformet og igangsatt og som har bidratt i designet av studien. Takk til Eva Gjengedal som også var med i det tidlige veiledningsteamet. Takk til Kjartan Leer-Salvesen for godt medforfatter-samarbeid. Jeg vil også takke min tidligere veileder ved Sorgstøttesenteret, Eline Grelland Røkholt for inspirasjon til- og tro på at det er viktig å rette blikket mot de minste barnas sorg.

Takk til alle som har bidratt slik at jeg har fått samlet inn datamateriale. Takk til institusjonene som har hjulpet meg, takk til dere som har hjulpet meg med å komme i kontakt med de dere kjenner. Takk til alle leger, sykepleiere og barnehagelærere som har stilt opp med sine erfaringer og historier. Takk til dere familier som har latt barnehagelærerne fortelle om barnet i barnehagen i tida da familien var preget av sykdom og død.

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Sammendrag

Gjennom intervjuer med helsepersonell innen palliasjon og barnehagelærere har jeg i dette phd-prosjektet studert profesjonell praksis knyttet til involvering av barn som opplever at mor eller far blir alvorlig syk og dør. Bakgrunn for studien er påstand om at barn som pårørende i Skandinavia i dag ikke ivaretas godt nok.

I Skandinaviske verdferdsstater lever barn tidlig sine hverdagsliv på tvers av institusjoner som skole/barnehage, SFO, fritidsaktiviteter og familie. Likevel finnes svært lite kunnskap som går ut over familiens- eller foreldrenes betydning for hvordan barna blir i stand til å utvikle seg og leve sine liv ved foreldresykdom eller etter at en mor eller far er død. De yngste barna (0-6 år) synes dessuten å ha blitt helt oversett. Den aktuelle studien bidrar her ved å sette søkelys på barnehagebarna og hvordan profesjonelle med utgangspunkt i barnets hverdagslivsarena kan legge til rette for- og endre utviklingsbetingelser når en mor eller far er alvorlig syk eller døende.

Til grunn for arbeidet ligger en teoretisk antakelse om at profesjonelle praksiser, akkurat som sosiale praksiser, reproduserer handlinger og kunnskap som er sosialt konstruert over tid og betinget av økonomiske, kulturelle, språklige etc. forhold. Et mål med phd-prosjektet har vært å tydeliggjøre og utfordre den kunnskap som ligger til grunn for profesjonelle praksiser knyttet til involvering av barn. Denne kunnskapen er ofte tatt for gitt, men har likevel betydning for hva profesjonsutøveren tenker er riktig og hva han eller hun oppfatter som virkelig i møter med barn, og vil dermed ha betydning for hvordan barnet forstås, snakkes til og generelt håndteres. Den vil også ha betydning for hvilke råd som gis til foreldre og andre samarbeidspartnere rundt barnet.

Phd-prosjektet er designet som en kvalitativ intervjustudie med to faser av datainnsamling. I fase 1 intervjuet jeg elleve doktorer og sykepleiere som arbeidet innenfor palliasjon om deres erfaringer i møte med små barn som pårørende, deres forståelser av barnas behov og deres syn på egen rolle i forhold til disse barna. I fase 2 brukte jeg en intervjuteknikk inspirert av livsformsintervjuet (Haavind, 2019) til å få tak i atten barnehagelæreres subjektive erfaringer med å ha et barn i barnehagen med en alvorlig syk mor eller far, herunder deres samtalepraksiser, vurderinger, konflikter og utfordringer de opplevde underveis i forløpet. I begge intervjufasene var jeg særlig opptatt av begrunnelser for praksis.

Tre artikler svarer til sammen på hvordan profesjonelle møter barn som opplever alvorlig foreldresykdom og død. Artikkel 1 har analysert hvordan leger og sykepleiere innenfor palliasjon bruker fire forskjellige, diskursivt konstruerte argumentasjonsrekker i legitimering av forskjellige involveringspraksiser, imens artikkel 2 analyserte hvordan de samme legene og sykepleierne forholdt seg til det moralske problemet som oppstår når en pasient ikke vil involvere barnet ved å fortelle han eller hun om sykdom og prognose.

Artikkel 3 analyserte hvordan barnehagelærere og helsepersonell bidro i meningsskapende dialoger om døden sammen med de yngste barna.

Det rådende nyliberale verdisettet er en viktig dimensjon ved den aktuelle konteksten, med individualisme og autonomi som sentrale verdier. I nyliberale styringsformer har profesjonsutøverne en funksjon i at de veileder individene til å ta gode, frie og informerte valg. I avhandlingens diskusjonsdel peker jeg på hvordan det nyliberale verdisettet synes å medføre individsentrerte tilnærminger til ivaretakelse av barn hvor den terapeutiske samtalen og individuelt rettede intervensjoner får forrang fremfor ivaretakelse gjennom tilretteleggelse av betingelser i barnets hverdagsliv som har betydning for barnets utviklingsmuligheter. I avhandlingen presenteres begrepet *Nærhetshierarkiet* som en tatt-for-gitt bakgrunn for diskursiv forhandling om hvem som har rett og plikt til å ta ansvar for et barns beste. Avhandlingens kunnskap vil få implikasjoner for profesjonsutøveres praksis knyttet til samarbeid med andre instanser i barnets hverdagsliv, samt for hvordan man ser på betydningen av systemtiltak i forhold til individuelle tiltak.

Overordnet peker resultatene på følgende problem: helsepersonell er den som har det formelle ansvaret for ivaretakelse av de yngste barna, men de har begrensede muligheter til både å vurdere deres behov for ivaretakelse- og å ivareta behovene. Likevel er det nødvendig at dette ansvaret ligger hos helsepersonell fordi det er pasientens (mor/far) behandler som vil vite at han eller hun er alvorlig syk og døende. I tilfeller hvor pasienten benekter sin tilstand eller av andre grunner ikke vil fortelle sin familie eller sitt barn om sykdommen, er barnets ivaretakelse avhengig av at det opprettes kontakt med profesjonelle eller andre sentrale omsorgspersoner i barnets hverdagsliv. Forhandlinger mellom pasient og helsepersonell om opprettelse av en slik kontakt kan imidlertid være konfliktfylt, og resultatene fra denne avhandlingen peker på at det å være bevisst på hvordan man som profesjonell posisjonerer seg diskursivt kan hjelpe til å få innsikt i hvorfor konflikter oppstår i dialog.

Abstract

This thesis is about professional encounters with young children experiencing parental illness and death. Through interviews with palliative health-care professionals and kindergarten teachers, I have studied professional child involvement practices as socioculturally embedded.

The background of conducting this study is the stated insufficiency of professionals' support to young children as next of kin in Scandinavian countries. Severely ill patients who are parents to minor children report difficulties tied to talking to their children about severe illness and death, experiencing challenges in their parenting role and a lack of support from professionals in these matters. Studies from health professionals' perspective point to how the structural conditions of time pressure and the dominating medical logic make supporting children as relatives emotionally and practically challenging. The children seem to want more information about illness and disease, and many of them experience social- and psychosomatical problems related to the stressful situation of having a severely ill and dying parent. Studies on the long-term consequences of parental loss in childhood indicate that family functioning and the remaining parent's psychological health are important factors for the risk of developing pathology in adulthood.

The present study contributes by directing attention to the youngest children (0–6) and to professionals' contribution to regulating children's possibilities to develop their ways of conducting life with a severely ill and dying or deceased parent. In Scandinavian welfare states, children attend kindergarten early in life, and during their childhood they continue to live their everyday lives across institutions, such as school/kindergarten, day-care facilities, leisure time activities and family. The study departs from a theoretical assumption that professional practices reproduce actions and knowledge that are socioculturally constructed within historical, social and cultural conditions. One of the study's ambitions is to make evident and challenge the knowledge that underpins professional practices of child involvement. This knowledge is often taken for granted, but it still functions as an interpretative framework that the professional relies on as a background in his or her encounters with young children experiencing parental illness and death, and it forms the professional's experience of what is right and wrong, real and true, and has direct implications on how he or she talks to, understands and generally handles children.

The project is designed as a two-phase interview study. In phase 1, I interviewed eleven doctors and nurses within palliative care about their experiences with the minor children of their patients, their understandings about children's needs and their own role regarding the young children. In phase 2, I applied an interview technique inspired by the life-mode interview (Haavind, 2019) to learn about eighteen kindergarten teachers' subjective experiences of having a child in the kindergarten who had a severely ill and dying mother or father. I explored their practices of conversation, considerations, conflicts and the challenges they experienced through the illness process. In both phases of the interviews, I was particularly interested in justifications for practice.

Three articles together answer the following overarching question: How do professionals encounter young children experiencing parental illness and death? Paper 1 analysed how doctors and nurses within palliative care draw on four interpretative repertoires to discursively legitimise different child involvement practices. Paper 2 analysed how the doctors and nurses handled the moral problem that occurs when a patient does not want to involve his or her child in matters concerning illness and death. Paper 3 analysed how health professionals and kindergarten teachers contributed as interpretation partners and constructed meaning about parental death together with the youngest children.

The dominating neoliberal culture is an important dimension of the present context, with individualism and autonomy as important values. In neoliberal governance, the professionals have a function in the supervision of patients and parents to help them make well-informed, rational and free choices. In this thesis, I discuss how the neoliberal culture implicates individualised approaches to supporting children, where the therapeutic dialogue and individual interventions repress interventions directed to the child's developmental conditions in the everyday life context. I present the theoretical construct *The hierarchy of closeness* as a socioculturally located meaning structure, toward which professionals and parents negotiate the rights and duties of child involvement.

Overall, the results point to a problem inherent in the practice of positioning health professionals with the formal, main responsibility of taking care of the needs of children as next of kin. Health professionals have limited opportunities to consider children's needs and to contribute to meeting these needs, but it is still essential that the responsibility is placed on the health professionals, as they have primary access to the information about the parent's illness and disease. In cases where the patient denies his or her illness and prognosis, or for other reasons rejects telling his or her child or family about it, the child's possibilities to participate and be involved depend on the establishment of collaboration between health professionals and kindergarten teachers or other significant carers in the child's everyday life. The negotiations between patient and health professional about establishing this collaboration may be conflictual, and the results of the present thesis point to the importance of professionals' awareness of how they discursively position themselves in these encounters.

The knowledge produced in this thesis has implications for professional practices of interprofessional collaboration within children's everyday life contexts and for how interventions directed toward the system rather than the individual may have the power to change developmental conditions in the life of a child anticipating the death of a mother or father.

List of papers

Paper 1:

Hogstad, I. & Jansen, A. (2020) Smart, vulnerable, playful or just disturbing? A discourse analysis of child involvement in palliative care. *Childhood, 27*(4), 468-482. doi:10.1177/0907568220918910.

Paper 2:

Hogstad, I. J. & Leer-Salvesen, K. (2020) Going against patients' will? A qualitative study of how palliative health-care professionals handle competing considerations when children are excluded from parental illness and death. *European Journal of Oncology Nursing*, 101839. doi:10.1016/j.ejon.2020.101839

Paper 3:

Hogstad, I. J. & Jansen, A. (Under review in *Early Years*) Parental death in young children's everyday lives: Health professionals' and kindergarten teachers' contributions in meaning-making. (Minor review, 17.10.20, resubmitted 21.10.20)

Abbreviations

ASHS Norwegian Act of Specialist Health Services

BC Breast Cancer

BL Kindergarten teachers (Barnehagelærere)

CPS Child Protection Services

HP Health Professionals

HPA Norwegian Health Personnel Act

KA Kindergarten Act

NESH The National Committee for Research Ethics in the Social Sciences and the Humanities

NSD The Norwegian Data Protection Services

PTSD Post Traumatic Stress Disease

SES Socio Economic Status

UN United Nations

UNCRC The United Nations Convention on the Rights of the Child

1 Introduction

This thesis is about professional encounters with young children experiencing parental illness and death. It is about the child’s possibilities to participate when experiencing parental illness and death and how these possibilities are regulated by professional practices of child involvement within the contexts of palliative health-care and kindergarten.

The Norwegian Health Personnel Act was changed in 2010 to require health professionals to contribute to meeting the need for information and follow-up that children might have when a parent is severely ill and dying (HPA §10a). Statistics from the Norwegian Cancer Registry in 2012 show that approximately 3% of minors in Norway have or have had parents once diagnosed with cancer, corresponding to a population prevalence of 1.4% (Syse et al., 2012). A white paper about palliative care from the Norwegian Ministry of Health and Care Services in 2020 states that neither the Specialist Health Services nor the Municipal Health Services in Norway sufficiently meet their legal obligation to identify and take care of children as next of kin (Ministry of Health and Care Services, 2020, p. 58). During my previous clinical experience and the work on this thesis, I have been concerned with—and aware of—health professionals’ limited opportunities to understand and to successfully communicate with the youngest children experiencing severe illness and death. Here, I will use this concern to motivate the three main aims of this thesis.

Communicating with young children about illness and death could be difficult, as children below seven years old traditionally have been considered too young to understand death (Hogstad & Wold, 2016; Mahon, 2011). My worry has been that the youngest children are being excluded from arenas for making meaning of death because of their perceived immaturity, and others share this worry with me (Bugge, Darbyshire, Røkholt, Haugstvedt, & Helseth, 2014; Mahon, 2011; Rosengren et al., 2014). The first aim of this work was thus to direct attention toward the youngest children (0–6 years of age): a group that is under-researched within research relating to parental illness and death.

Young children’s grief plays out in their everyday life, and not necessarily in a mental health care office or in other arenas where health professionals are present. This was something that I became increasingly aware of during my own experience as a young assistant in kindergarten and later through my work with grieving children within specialist health services. The second aim of this work was to produce knowledge needed for developing professional child involvement practices that are situated in the young child’s everyday life. Most children in Norway 1 to 6 years old attend kindergarten[1], and

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[1] Norwegian statistics for kindergarten attendance in 2019, states that approximately 4 out of 5 children attended kindergarten at 1–2 years old, and by March 2020, 92,2% of children in the age-span 1–5 attended kindergarten (https://www.ssb.no/barnehager). High attendance in kindergarten is a trend within other Scandinavian countries as well (Sommer, Pramling Samuelsson, & Hundeide, 2010).

kindergarten teachers' and health professionals' perspectives appear essential to direct attention toward the youngest children in their everyday lives. I therefore conducted qualitative research interviews with, first, eleven health professionals within palliative care (doctors and nurses) having experience from encounters with young children of their dying patients, and then with eighteen kindergarten teachers who recently had a child in his or her group who experienced severe parental illness and death. I asked them about their experiences and views and what they had done or would do in future cases. This second aim resonates with the research focus and theoretical understandings in the Scandinavian culture-psychological research field that focuses on children's everyday life conduct (see for example, Andenæs & Jansen, 2019; Gulbrandsen, 1998; Haavind, 1987; Højholt & Kousholt, 2018; Juhl, 2019), which this thesis aims to contribute to by researching a topic that, at least as far as I know, has not been studied within this tradition previously.

Specifically, I have not found cultural-psychological developmental perspectives in research on children experiencing parental illness and death. In the section Previous research (p. 8), I will show how the field of clinical-directed research on parental illness and death has been dominated and justified by a focus on individual risk factors for developing pathology. In line with a Foucauldian conception of power (Farsethås, 2009; Foucault, 1970/1999; Gallagher, 2008) and knowledge (Foucault, 1969/2002) and poststructuralist approaches to empirical psychological research (Søndergaard, 2002), I have been concerned with how knowledge, including what is claimed to be scientific knowledge and research "findings", is both *produced* and *productive*: It is situated and produced by discursive and material conditions, as well as productive in forming the social phenomena that we are investigating (Foucault, 1970/1999; Søndergaard, 2018). In a way, the state of the art has *enforced* this thesis' critical approach because it has been necessary to destabilise the dominant normative conceptions in the research fields to produce original knowledge situated in the young child's everyday life (Bøttcher et al., 2018). Hence, the third aim of the study was to contribute to the clinical-directed research field by developing models for understanding professionals' encounters with young children as embedded in social, historical, cultural and material conditions.

I will elaborate on what is meant by "professional encounters" in the section *Research questions* (p. 5), but first I will outline terms used to tag, first, different groups of and positions of children, and second, professionals and legal regulations within the current context in Norway.

Young children experiencing parental illness and death – who are they?

The terms *young children* as well as *the youngest children* will, however imprecisely, be used in this thesis to refer to a group of children that has often been considered too young to understand death. The cognitive developmental psychological literature on children’s understanding of death has stated that children may not reach a full, adult or mature understanding of death before approximately 7 to 10 years of age (Hogstad & Wold, 2016; Mahon, 2011). I apply an institutional categorisation, namely, kindergarten attendance as a pragmatic way of reaching children considered too young to understand death. *Children of kindergarten age*, then, refers to children 1–6 years old, as children in Norway start in school the year that they turn 6 years old.

In kindergarten, children experiencing parental illness and death first and foremost are *children*, and at the centre of the activities. Within the health systems context, the patient is at the centre, and in this setting, these children are *relatives to the patient*, and hence they are often referred to in research literature and policy documents as *children as relatives* or *children as next of kin* (Golsäter, Enskär, & Knutsson, 2019; Golsäter, Henricson, Enskär, & Knutsson, 2016; Haugland, Bugge, Trondsen, & Gjesdahl, 2015; Haugland, Ytterhus, & Dyregrov, 2012; Helsedirektoratet, 2010). In Norway, the term “barn som pårørende” is used to tag minor children who are the patient’s relative. Even though severely ill patients have been parents of minor children throughout history, the term “barn som pårørende” is a more recent term. Children as next of kin have received increasing attention in recent decades, particularly in Scandinavian countries, and this is reflected in research (Haugland et al., 2015; Haugland et al., 2012; Ruud et al., 2015) and policy (Danish Health Authority, 2012; Norwegian Health Personnel Act, 2010; Swedish Law of Health and Medicine, 1982). However, I found no English translation that fully covers the term “barn som pårørende”. “Young carers”, “minor caregivers”, “minor children of service users”, “minor children of mentally ill/palliative/cancer patients”, “children as caregivers”, “children as next of kin” and “children as relatives” are all examples of names for this group used in international research publications. HPA §10a applies to children as next of kin who are below 18 years of age, which is the age of majority in Norway, and in the law and in this thesis they are referred to as *minor children.* In some places the same age group is referred to as *dependent children* (Fearnley & Boland, 2017; Hanna, McCaughan, & Semple, 2019).

Professionals and legal regulations in Norway

Bayles (2003) defines *professionals* as fulfilling three necessary criteria: (1) having conducted a specialised education that (2) has an intellectual component and (3) that provides competence to provide welfare services that are important to society. This thesis applies the terms *professionals*, *health professionals*, *palliative health-care professionals*, *health personnel* and *kindergarten teachers*. *Health professionals* refers to professionals in Norway who are authorised to provide health services (see HPA §48). In this thesis, they are doctors and nurses, and only *palliative health-care professionals*, which means that they work in palliative care (see Hogstad & Jansen, 2020, p.469, for more about palliative care). *Health personnel* is defined by HPA §3 as a wider category than health professionals, including students and other personnel conducting health care in addition to authorised health professionals. The professionals referred to in this thesis as *kindergarten teachers* have a bachelor's degree in early childhood education and are considered competent to be a pedagogical leader of a group of children in kindergarten (KA §17a).

As already mentioned, since 2010, health professionals have been positioned by Norwegian law as responsible for contributing to meeting the needs of the minor child deriving from a parent's illness. Kindergarten teachers do not have the same explicit obligation. Two legal obligations came into force in Norway in 2010: in the Norwegian Act of Specialist Health Services (ASHS) and in the Norwegian Health Personnel Act (HPA). ASHS §3-7a gave responsibility to the Specialist Health Care institutions of appointing child-responsible personnel (in Norwegian "Barneansvarlig") for each department, with the tasks of facilitating and coordinating health personnel follow-up, as stated in the legal regulation in HPA §10a. HPA §10a obliges the health personnel responsible for a mother's or father's medical care to "contribute to take care of the child's need for information and follow-up that follows from having a parent (…) that is a patient with (…) severe somatic disease".

Aiming to concretise and contribute to realising the obligations in HPA §10a, "BarnsBeste"[2] has developed four detailed procedures for health personnel's work with children as next of kin[3]. The procedures outline three main interventions for health professionals: 1) addressing the patient's minor child and his or her needs as a topic in the professional–patient conversation, 2) professional–child conversations and 3) collaboration with carers and other professionals in the child's close family, network and everyday life institutions (school/kindergarten).

Early childcare and learning arrangements in Norway are regulated by the Kindergarten Act (KA) (2006). The KA is further explicated in The Framework Plan for the Content and Tasks of Kindergartens (2017). There are no explicit references to children's situation and needs when having a severely ill and dying mother or father in any of these documents. Importantly, the KA mandates kindergartens to "safeguard the children's need for care and play, and promote learning and formation (*danning* in Norwegian) as a basis for an all-round development" (https://lovdata.no/dokument/NLE/lov/2005-06-17-64#KAPITTEL_1). Further, the Framework Plan (2017) mandates that kindergartens provide children with support to cope with misfortunes, deal with challenges and become familiar with their own and others' feelings. Kindergarten staff are in a position where they have close, everyday contact with the children. In national guidelines for the

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[2] Norwegian competence network for working for the best interests of the child as next of kin https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste/

[3] https://www.helsedirektoratet.no/veiledere/parorendeveileder/informasjon-og-stotte-til-barn-som-parorende (latest update in June 2019)

education of kindergarten teachers, one of the learning outcomes is that he or she shall attain knowledge about children's reactions to difficult life situations, the responsibility of adults in these situations and how to support the child and collaborate with other institutions (Universitets- og Høyskolerådet, 2018).

Research questions

In this thesis, I have chosen to focus on professional encounters with young children experiencing severe parental illness and death and on the professional practices of child involvement. I make some comments on the terms "practice" and "professional encounters" below. The research questions for this thesis are as follows:

RQ: How do professionals encounter young children experiencing parental severe illness and death?

> RQ1: How do patterns in health professionals' ways of talking construct multiple "pictures" of the child?
>
> RQ2: How do health professionals discursively legitimise different child involvement practices when a parent is severely ill and dying?
>
> RQ3: What are the main considerations for health professionals in situations when parents withhold information about illness and anticipated death from their children?
>
> RQ4: How do health professionals negotiate conflicting considerations in situations when parents withhold information about illness and anticipated death from their children?
>
> RQ5: In which ways do professionals within the two contexts of palliative care and kindergarten interact with children to make meaning of parental death and which resources do they rely on in their ways of making meaning?
>
> RQ6: How does the professionals' meaning making work to condition children's possibilities to participate within and across everyday life contexts when a parent is severely ill and dying?

The thesis consists of three scientific papers that are concerned with three different aspects of professional encounters with children experiencing parental illness and death: first, how health professionals discursively legitimise child involvement practices (Hogstad & Jansen, 2020); second, health professionals' conflicting considerations in encounters with patients who want to withhold information about illness and death from their child (Hogstad & Leer-Salvesen, 2020); and third, health professionals' and kindergarten teachers' direct dialogical interactions with young children making meaning about parental death (Hogstad & Jansen, Under review). See an overview of the relation between papers and research questions in table 1 below. (Read more about the two phases-design and the empirical material on p. 31.)

Table 1: Research questions and empirical material related to each study

	Research questions	Empirical material
Study/paper 1	*RQ1 & 2*	Phase 1
Study/paper 2	*RQ3 & 4*	Phase 1
Study/paper 3	*RQ5 & 6*	Phase 1 & 2

The Danish psychologist Erik Axel (2011) suggests understanding practice "as the continuous reproduction of actions that are mutually dependent and constitutive" (p. 57). From the professionals' side, these processes involve exercising discretion based on specialised knowledge and particularities of the situation and adapted to the context (Clark, 2012; Ekeland, 2009; Loyens & Maesschalck, 2010). What the professional community regards as established knowledge will hence be productive in forming professional practices, as much as professional practices will be productive in reproducing it (Miller & Rose, 2008; Rose, 1998). Professional "child involvement practices" (ref. RQ2) are professionals' reproduction of actions that regulate the child's possibilities to participate (see more on pages 67-68). Contradictions and conflicts are inherent in (professional) practice (Axel, 2011; Højholt & Kousholt, 2020) and will appear in concrete *professional encounters*.

Professional practices involve concrete professional encounters where the professional and other involved actors take part in and contribute[4] to the reproduction of actions aimed at providing welfare services (Bayles, 2003). *Encounter* is both a verb and noun, and both apply in the present sense. The intention behind applying the term "encounter" in the present thesis is to direct attention toward *dialogical* encounters, which involve a dimension of joint meaning-making inherent in the dialogue (Wertsch, 2000). Previous research on professional encounters applies the term synonymously with "meetings" (Clark, 2012; Ramvi & Gripsrud, 2017; Ådland, Høyland Lavik, Gripsrud, & Ramvi, 2019) but includes a wider meaning than meetings between people; it also involves encounters with phenomena, issues and problems. For all of these mentioned encounters, it is possible to understand them as if the individual is in dialogue with one or more counterparts, either as a dialogue with a person, dialogues with discourses (Wetherell, 1998) or a moral problem (Clark, 2012).

This doctoral thesis will be structured as follows. As the thesis concerns professional practices, in chapter *2 Previous research* I centre the literature review around established knowledge that supports professional practices within clinical nursing (psycho)oncological and palliative care as well as bereavement support. In chapter *3*

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[4] However not mutually understood as 'asymmetrically'. The point is that professional practices are not possible without someone to direct the action towards. For example, professional helping presupposes someone in need of help.

Theoretical framework, I delineate the theoretical foundation of the thesis: sociocultural developmental psychology. Here, I rely on historical and sociological perspectives in addition to cultural psychological ones, which together contextualise professional practices of child involvement as historical and culturally embedded as well as produced by multiple and changing discourses at the interactional level. In chapter *4 Design, methods and ethics*, I present an outline of the methodology of the project, including ethical considerations in the process. Chapter 5 summarises the results of the three sub-studies. Chapter *6 Discussion* consists of four sections. The first contextualises the results within a neoliberal culture, suggesting that psychologisation and professionalisation contribute to produce expectations for professionals and parents. I present the theoretical construct *hierarchy of closeness* as a meaning structure against which rights and duties regarding child involvement are negotiated. The second directs attention to the youngest children by discussing reasons why the youngest children have been ignored in previous research and suggesting new theoretical and methodological approaches that go beyond the poststructuralist discursive focus. The third section highlights the implications of the results for professional practices of child involvement, and the fourth discusses limitations and directions for further research. Finally, in chapter *7*, I conclude with a warning against psychologisation of childhood grief and individualised “early interventions”, which may contribute to producing the problems it sets out to solve.

2 Previous research

This thesis contributes to the clinical-directed research field of parental illness and death by applying a sociocultural developmental psychology perspective to challenge existing knowledge within the clinical-directed research field and offer alternative understandings. Sociocultural developmental psychology and the state of the art in the research field of children's cognitive understanding of death were familiar to me from my previous work during my bachelors and master theses (Johnsen, 2011, 2012). However, I was not familiar with the clinical-directed research field and literature concerning children in the specific situation of being a child in a family where the mother or father is severely ill and dying. Literature searches paved my way into this field. In the following, I will first present my approach and rationale for the literature searches I have conducted, followed by the state of the art within two branches of clinical-directed research.

Literature searches

I have conducted several rounds of systematic[5], manual and improvisatory literature searches (first searches spring 2015). The aim was to find peer-reviewed empirical studies that offer knowledge relevant for professionals' work with minor children who experience parental illness and death. A literature search conducted in May 2020 in the Eric, PsychInfo and Medline databases (search strings: attitude to death or grief or bereavement or mourning AND parental loss or death of parent or critical illness AND kindergarten or preschool or early childhood education or daycare or nursery)[6] resulted in no relevant matches for peer-reviewed empirical studies focusing on support to children below school age. Overall, most research does not relate directly to professional practices or it concerns *health* professionals. A few studies concern teachers and school children (Duncan, 2020; A. Dyregrov, Dyregrov, & Idsoe, 2013). To the best of my knowledge, there are no peer-reviewed studies on kindergarten teachers' encounters with young children experiencing parental illness and death. At first, I planned to focus solely on the period before death, and hence on professional support in the time span from diagnosis to death. The second branch of research, on parental loss and bereavement, was included because studies on the impact of parental loss frequently appeared in the previous research sections as justifications for research on the impact of parental illness and as legitimisations for supporting children pre-death (see more in the section *Three lines of argument*, p.13).

These literature searches resulted in the delineation of two branches of a clinical-directed research field. The first is a nursing-, (psycho)oncology- and palliative care-dominated field focusing on parental severe and life-threatening illness, mostly cancer, and not necessarily limited to palliative or terminal states or death as an outcome. The second is a

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[5] Approved of by specialist librarian Japke Stopke

[6] Approved of by specialist librarian Trond Are Johnsen

clinical psychological-dominated research field focusing on parental loss and bereavement in childhood, involving all categories of death causes: naturally caused deaths (sudden or anticipated) and external deaths (accidents, suicide, murder) (Rosengren et al., 2014).

Research from Scandinavian countries is central in both strands of research, in addition to that from some other European countries (Germany, the Netherlands), the UK, the US and Australia. In figure 1, two branches are illustrated within the clinical-directed research field. In the figure, I have placed the present project in a circle covering aspects of clinical-directed research and aspects of the other research field that I also claim to contribute to: research on childhood and child development.

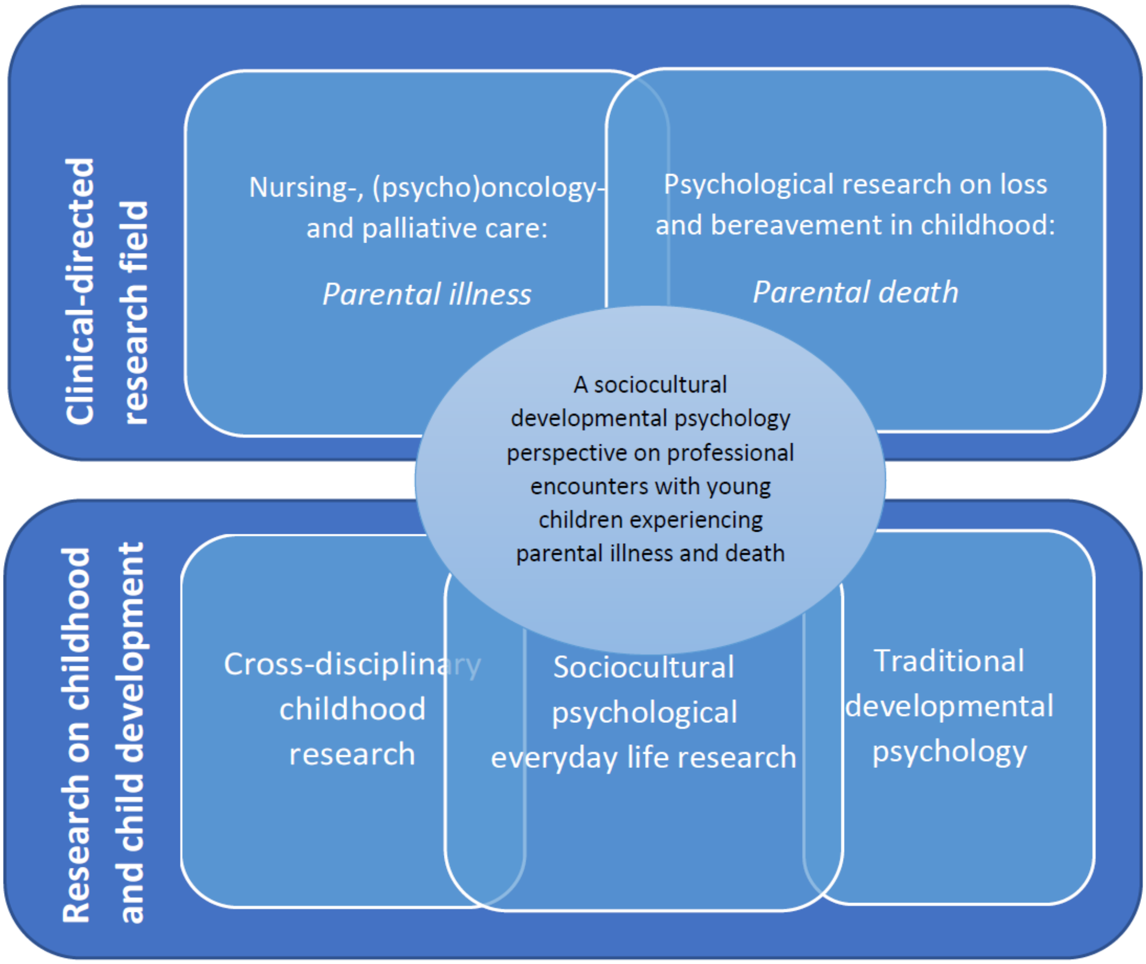

Figure: Two research fields

Regarding this latter field of research, I could have included literature on discursive constructions of children (e.g. Moss, Dillon, & Statham, 2000; Valentine, 1996; Warming, Galløe, Carlsen, & Rasmussen, 2018), research findings from everyday life research on child development as embedded in sociocultural contexts (Gulbrandsen, 1998; Kousholt, 2006; Sundnes, 2018) or traditional developmental psychological accounts of children's understanding of death (Slaughter, 2005). However, I limited myself to research that concerns the particular situation of having a severely ill and dying mother or father.

Accordingly, I have chosen to consider these research contributions as part of the background of and inspiration for defining the research area.

The state of the art in two clinical-directed research branches

As a result of the research process, I have deliberately chosen to apply the term “Child involvement” in the thesis, articles and interview guide (see e.g. *Appendix 6*). The studies included in the literature review do not necessarily apply “child involvement” as a term but rather related formulations and terms, such as *support* (Duncan, 2020; Fearnley & Boland, 2017; Franklin, Arber, Reed, & Ream, 2018; Hanna et al., 2019), *care* (Golsäter et al., 2019; Golsäter et al., 2016; Karidar & Glasdam, 2018) and *inclusion of children* (Dencker, Kristiansen, Rix, Bøge, & Tjørnhøj-Thomsen, 2018), *prepare children for parental death* (Franklin et al., 2018; Hanna et al., 2019) and *empathic connection to parents and their children* (Franklin et al., 2018). A common feature of all the studies is that they contribute to the discursive negotiation of children’s participation in—versus segregation from practices and situations in—the process from the time a parent receives a diagnosis of severe illness until death.

I choose to centre this section on previous research primarily around research reviews in which studies are synthesised, but I make exceptions when recent articles from Scandinavia add substantial knowledge that is not included in the reviews. Since the research reviews, with few exceptions, review articles with qualitative designs, I have added some quantitative articles regarding psychological stress in children.

Parental severe illness

Based on a rough sketch of the research literature on severe parental illness, the present state of professional support to children as next of kin in Scandinavia seems to be that whether or not sufficient support is provided is accidental. This is the picture of the rest of Europe, the UK, the US and Australia as well. However, this rough sketch consists of knowledge from partial perspectives. To be able to generalise this knowledge, we need to consider which perspective it comes from and is situated within (Schraube, 2015). The research literature regarding severe parental illness could be categorised according to three perspectives that have been voiced in the literature: the patients’, children’s and the health professionals’. This thesis’ focus on health professionals’ perspective and their experiences of supporting children and adolescents of severely ill patients, is a relatively recent perspective voiced in the literature. The first wave of research related to patients’ own perspective of being a patient and at the same time parent, and the second wave explored the children’s perspective.

Parenting experiences. A review by Hanna et al. (2019) synthesised 27 qualitative studies from the perspective of parents and children. The review aimed to learn more about how to prepare children for the death of a parent and focused on challenges and support needs of both the parent and the child when a parent is at the end of life with severe cancer, finding that all the included studies point to the importance of open communication and family cohesion. Three reviews of parents' experiences (however with samples strongly dominated by mothers), report that parents put the needs of their children and other family members before their own needs, and that a main challenge for them is that they feel insufficient in their parenting ability (Aamotsmo & Bugge, 2014; Semple & McCance, 2010; Tavares, Brandão, & Matos, 2018). Kühne et al. (2012) reviewed 24 studies of five family-focused interventions and found that all of the interventions aimed to enhance parenting competence, active coping and communication.

A small review by Fearnley and Boland (2017) explored how parents with a life-limiting illness, who have dependent children, perceive health professionals' social, practical and emotional support and communication with them about their illness, diagnosis and treatments. The authors concluded that there seems to be a discrepancy between parents' perceived need for support and the support they actually receive from health professionals. A more recent Swedish qualitative interview study echoes this: the patients perceived that the nurses made efforts to support the child, but those efforts did not meet their individual needs sufficiently to be able to fulfil their assignment as parents (Golsäter et al., 2019).

Children's experiences. Quantitative studies focusing on the time during or immediately after the anticipated death of a parent because of severe illness show increased levels of psychological stress and behavioural disorders in children and adolescents (Thastum et al., 2009; Weber, Alvariza, Kreicbergs, & Sveen, 2019), such as self-injury (Grenklo et al., 2013), maladaptive grief (Kaplow, Howell, & Layne, 2014) and traumatic stress (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005). These studies indicate that the situation of severe illness in the family is highly stressful for children and adolescents. Further, a multinational study by Schmitt et al. (2008) of family functioning in families where a mother or father had cancer found that the children perceived more impairment in family functioning when the mother was the patient than when the father was the patient. The same study found that mothers reported higher levels of depression than fathers (Schmitt et al., 2008).

Qualitative studies reported in the review by Hanna et al. (2019) point to the needs of children and adolescents to have an understanding of the effects of cancer, the treatment and what death would look like to be able to manage their fears and anxieties. A Norwegian review of children's and adolescent's information needs when their mother or father develops cancer points to the parents themselves as most important source of this type of information (Larsen & Nortvedt, 2011). However, children may have limited possibilities to get the information they want from their parents because, for various reasons, it may be difficult to talk within the family (Bugge, Helseth, & Darbyshire, 2008; Helseth & Ulfsæt, 2003).

A closer look at the literature the reviews are based on reveals that a focus on children below the age of six seems to be almost non-existent in the literature, which was also noted by Larsen and Nortvedt (2011). Overall, articles apply the term “children” uncritically. Sometimes “children” refers to the ages before adolescence, while other times it includes adolescents as well.

Health professionals’ experiences. Franklin et al. (2018) synthesised 15 qualitative studies on health professionals’ (primarily nurses) perspectives on supporting children and adolescents of severely ill patients. Their main finding was that nurses feel overwhelmed by the emotional labour required to connect emotionally with patients and children to prepare and support children when one of their parents is dying (Franklin et al., 2018). The authors proposed that for some professionals this might lead to professional distancing and technical care rather than family-focused care and emotional connection (Franklin et al., 2018). An interview study from Denmark (Dencker, Rix, Bøge, & Tjørnhøj-Thomsen, 2017) found this emotional distancing in a sample of doctors and nurses working with seriously ill patients. The researchers tie the professionals’ tendency of emotionally distancing to the structural conditions within the hospital wards: time pressure as well as limitations in the medical record system that make this distancing not only possible but also a necessary means for the health professionals to be able to administer medical care to the patient. Two Swedish studies (Karidar & Glasdam, 2018; Karidar, Åkesson, & Glasdam, 2016) further develops this by pointing to how the patient-centredness and the medical code ruling within the health care system, in combination with time pressure, cause the health professionals to prioritise the patient and medical tasks above psychosocial issues.

A Danish study by Dencker et al. (2018) suggests that the way health professionals view children as relatives is dependent on the ward-specific medical context, including particulars related to the diagnosis and treatment modalities within which they encountered the young child. This applies both to encounters with the young child directly and as an issue in communication with the patient (Dencker et al., 2018). The health professionals primarily viewed and approached the patient’s child through categories that did not facilitate child involvement, such as “sources of infection”, “invisibly present” and “spectators”. It was only in the face of death that they became more likely to view children as “family members”. Dencker et al. (2017) conclude that the *professional code*, that is, what professionals feel is expected of them and what they perceive as good professional conduct, must be seen as a structural barrier to health professionals’ addressing the patient’s dependent children as a subject in communication. Overall, recent Scandinavian studies have found wide ranging variance in health professionals’ ways of relating to the children of their patients in direct encounters and to the topic of minor children in conversations with the patients (Dencker et al., 2018; Golsäter et al., 2016; Karidar et al., 2016).

Across these three perspectives, it seems that parents' need for and expectations of professional support exceed what the health professionals have possibility or resources to provide. The research articles, however, tell little about what should be expected from health professionals regarding their work and responsibility to support children as next of kin. How do health professionals interpret their own role, tasks and responsibilities? And what do parents expect? Formulations and terms such as support, care, include, involve and openly communicate are seldom operationalised, defined, discussed or problematised anywhere in the articles, leaving specific expectations regarding professionals' practices disguised.

Three lines of argument

The majority of research articles and reviews within the two research branches above primarily use previous research to frame their research reports and, with some exceptions (e.g. Karidar & Glasdam, 2018), do not explicitly present the theoretical models to show that they apply to analysing and understanding the phenomena beyond the previous research section. With the aim of making evident the implicit, existing knowledge, I have conducted a thorough reading and systematisation of 36 previous research sections of articles about minor children of palliative patients to look for the *justifications* presented for why children need to be involved (by parents and/or professionals) during the illness process, why they need to be supported and why they need to be talked to by professionals (Wetherell & Potter, 1988). These justifications legitimise conducting the research presented in the previous research sections as claims to knowledge that appear as "truth claims" (Søndergaard, 2002). This exercise resulted in the delineation of a pattern of three lines of argument about child involvement. It is important to note that these three lines are drawn from previous research sections and hence are the authors' references to previous research to provide a justification and background for their own research, not their own study results.

The first line of argument is associated with coping theory and holds that, as severe illness in the family is highly stressful, the child needs support to be able to cope with the situation. Open communication and information about illness and death help the child, and families need professional support to develop open communication in the family system (e.g. Buchwald, Delmar, & Schantz-Laursen, 2012; Fearnley & Boland, 2017; Hailey et al., 2018; Kennedy & Lloyd-Williams, 2009; Kennedy & Lloyd-Williams, 2009; Kühne et al., 2012; Tavares et al., 2018). A second line of argument is tied to the parent's perspective. Parents, ill and healthy, experience stress related to their parenting tasks, role and function in combination with encountering death or the death of a partner. They do not have the knowledge, resources or energy to cope with the stress, make informed end-of-life-decisions *and* at the same time function in their parenting role. Support to the parent will indirectly benefit the child and will also contribute to better end-of-life-decisions and quality of life for the patient (Asbury, Lalayiannis, & Walshe, 2014;

Dencker et al., 2018; Dencker et al., 2017; Golsäter et al., 2019; Krauel et al., 2012; Steiner, Shlonsky, & Joubert, 2017). The third line is associated with the risk–resilience discourse (Gladstone, Boydell, & McKeever, 2006), focusing on the child’s psychological health in the future (rather than his or her coping here and now). The idea is that illness and parental loss in childhood represents a risk factor in development that might lead to depression, post-traumatic stress disease (PTSD) or other mental illnesses or delinquency in late adolescence and adulthood. Children need professional support to alleviate these effects (e.g. Ellis, Dowrick, & Lloyd-Williams, 2013; Franklin et al., 2018; Saldinger, Cain, & Porterfield, 2003; Zaider, Salley, Terry, & Davidovits, 2015).

Looking further into these three lines of arguments, I became aware of how they all use arguments from an overarching psychological health discourse. Psychological health-related arguments rather than, for example, rights-based arguments, operate as legitimate justifications for conducting research or professional practice. As most studies highlight the need for open communication and family cohesion, it is even more surprising that arguments from care ethics and family relations etc. seldom appear as justifications in the previous research sections, even though there are some examples of it (e.g. Hanna et al., 2019; Tavares et al., 2018). In this process of looking for how the previous research section justifies research and practices of involving and supporting children as next of kin, I further traced the cited studies. I did this first through manual searches and with a snowball effect, followed by database searches with search strings developed from keywords found in the snowball searches. These searches provided me with 12 of the articles reviewed in the next section.

Parental loss and bereavement

The research field I have called “Parental loss and bereavement” does not discriminate causes of death but rather focuses on grief and bereavement following the death of the parent. Researchers back to the late 1960s have debated the links between childhood bereavement and the individual’s functioning throughout his or her life span (Harrington & Harrison, 1999). Various undesirable psychological outcomes have been examined, such as risk of suicide attempts (Jakobsen & Christiansen, 2011), mental disorders or hospitalisation because of mental and affective disorders (Appel et al., 2013; Berg, Rostila, & Hjern, 2016; Stikkelbroek, Prinzie, de Graaf, ten Have, & Cuijpers, 2012), delinquent behaviour (Draper & Hancock, 2011), substance abuse, behavioural disengagement, emotional eating (B. L. Høeg et al., 2017) and the inability to form and remain in intimate relationships in adulthood (B. L. Høeg et al., 2018). The designs in these studies have been primarily quantitative, relying on self-reports through survey data, data from national registers or population-based longitudinal studies.

With some exceptions (Stikkelbroek et al., 2012), most studies on childhood parental loss show some increase in risk for adverse psychological or behavioural consequences. The effect sizes generally are low, which may indicate that most individuals are resilient (B. L.

Høeg et al., 2018; Lytje & Dyregrov, 2019). Still, some individuals develop serious adversities (Lytje & Dyregrov, 2019), and within the research field, it is highlighted that the identification of particular risk factors is important, as it enables delineating vulnerable subgroups in special need of support and intervention.

Parallel to the age span represented within parental research on severe illness, most studies within the parental loss branch focus on adolescents or children above 6–7 years of age and give sparse definitions of what is meant by “early parental death” or “childhood parental loss”. With only one exception (Kranzler, Shaffer, Wasserman, & Davies, 1990), none of the studies identified during the literature searches on parental illness and death direct their attention toward children below 6 years of age, even though many of them include families and parents having children below 6 years of age in their samples when applying register data, surveys and parental reports. Some of the studies have looked into the age at time of loss as a particular risk factor. According to a review by Lytje and Dyregrov (2019), the increase in suicide risk for children who lost a parent to suicide have been found to be greater if bereaved at a “very young age”, and the same is true with the use of antidepressants: the younger at the time of loss, the greater the consumption. A Swedish register-based study by Berg et al. (2016) reports that loss during preschool age (0–5) increased risks of developing depression in adulthood compared to loss during adolescence.

It appears that naturally caused deaths do not pose the same risk of developing different forms of social and psychological deviance in adulthood as externally caused deaths (Berg et al., 2016). In particular, suicide seems to pose a large risk (Appel et al., 2013; B. L. Høeg et al., 2018). When focusing on the child’s functioning in childhood, closer to the time of loss, the picture looks a little different. Kaplow et al. (2014) finds a heightened risk of maladaptive grief among children 7–12 years olds six months after having experienced parental death, and the risk was higher for those who had experienced anticipated death because of severe illness compared to sudden death by external causes. Saldinger et al. (2003) and Kaplow et al. (2014) highlights how anticipated deaths expose children to potentially disturbing elements (medical procedures, the dying person’s progressing deterioration) that they are not able to cope with.

Not surprisingly, the quality of the relationship with the surviving caregiver and their parenting capacity is a consistently identified mediating variable for children’s adaption to a parent’s death (Christ & Christ, 2006). In particular, depression in the remaining caregiver seem to be a risk factor (Kranzler et al., 1990). Interestingly, some studies indicate that the gender of the deceased may be important, as maternal deaths seem to increase risks more than paternal deaths (Appel et al., 2013; Draper & Hancock, 2011; Lytje & Dyregrov, 2019). Appel et al. (2013) suggest that stronger emotional ties to mothers may make a mother’s death more harmful. However, as noted by Draper and Hancock (2011) the associations producing (small) statistical gender differences are complex. For example, a study by Jakobsen and Christiansen (2011) shows that, in cases of maternal death, high income of the father moderated the heightened risk due to maternal death.

Gender differences and other variables measured as potential risk factors are connected and converge (Draper & Hancock, 2011), giving reason to believe that the linear, statistical models dominating the above-mentioned studies fall short of explaining, or even capturing, the complexity of resilience processes. A recent narrative review by Lytje and Dyregrov (2019) illuminates the complexity of measuring the impact of parental loss in childhood, as it is a phenomenon with multifaceted effects across physical, psychological, social and health-domains. Their review demonstrates the challenge of isolating the psychological consequences of grief from the socio-economic factors present in the family before the death (Lytje & Dyregrov, 2019).

Inter-professional collaboration and school research

Collaboration with other institutions and other professionals in the children's everyday life, as formulated in the third intervention in the BarnsBeste procedure[7], is mainly absent as a theme in the literature. Exceptions are a couple of studies from the parent's perspective, in which parents report that support from school was helpful regarding advice from the teacher about how to talk to the child (Tavares et al., 2018) and direct help given by the school nurse to the child (Golsäter et al., 2019). A Swedish study on interprofessional collaboration about minor children as relatives in palliative teams shows that the children are being referred to school or child mental health care *after* the parent's death, but there are no references to contact between the professionals and school during the illness span (Karidar & Glasdam, 2018). In her study of practitioners support to children when a parent is at end of life or has died, Fearnley (2010) notes the same absence of discussion of how practitioners work together across agencies.

Research within the school context does not contain references to collaboration with health professionals or palliative teams. Mainly, this research has been focused on the academic performance of bereaved individuals (Lytje, 2016), recommendations for how teachers and management should approach death in schools (I. M. Høeg, 2013) or how teachers should support bereaved students (Duncan, 2020). Studies exploring children's, adolescents' or teachers' experiences indicate that it is important how schools (management and teachers) as well as peers encounter and involve children who are experiencing parental illness and death (Grelland, 2001, cited in Bugge & Røkholt, 2009; Duncan, 2020; K. Dyregrov, 2009; Lytje, 2016). Danish and Norwegian school children and adolescents have reported that, upon school return after a loss, they may feel different, and their peers and teachers are uncertain about how to behave (Grelland, 2001, cited in Bugge & Røkholt, 2009; Lytje, 2018). Many report feeling isolated or alone for a long

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[7] https://www.helsedirektoratet.no/veiledere/parorendeveileder/informasjon-og-stotte-til-barn-som-parorende):

time after the loss, and that the academic, peer and teacher support fell away before the pupils were done needing it (Grelland, 2001, cited in Bugge & Røkholt, 2009; Lytje, 2018).

Limitations of previous research

Samples

The samples in the qualitative studies on parental illness represent a particular, limited population in three important aspects. First, the samples consist of white, middle-class, two-parent families, highly educated or with high SES in Australia, UK, Scandinavia and other Western European countries and the USA, primarily woman (mothers or female nurses). The only exception is the review by Tavares et al. (2018), which included some studies from Japan, South Korea and Saudi Arabia. Second, because the recruitment strategies mostly involve convenience samples, there are some voices that might not be represented, while others become over-represented. For example, in their mixed-method systematic review of parenting experiences of women with breast cancer, Tavares et al. (2018) observe that participants “tended to be more open and comfortable for talking about their BC experiences” and that they belonged to “families who were adapting more satisfactorily” (p. 8). Third, most research on children experiencing parental illness and death have been conducted with adolescents or school-age children as participants, so the knowledge base is founded on research with children above 6 years of age. The lack of research concerning the youngest children is particularly problematic when knowledge from research with school children and adolescents is applied uncritically to practices regarding all children, including kindergarten children. Professional advice and practice guides regarding children below 6 years of age are often developed solely based on clinicians’ experiences (see for example, Boyd Webb, 2011). More research focused on these youngest children is needed to better understand the particular conditions prevailing in their everyday lives.

Descriptive, concealing complexity

The body of clinical research regarding parents who are severely ill and at the end of life is dominated by qualitative descriptive studies that in different ways “reduce data to themes” (Jackson & Mazzei, 2012). When the literature reviews apply thematic analyses or thematic syntheses as well, this further reduces insights into complexity and conflicting voices (Jackson & Mazzei, 2012) and makes variation and diversity appear unequivocal. This concealing of the range of variation in the data makes it difficult to explore the psychological processes involved (Andenæs, 2000). However, some of the more recent Scandinavian studies do capture more variance in their results (e.g. Dencker et al., 2018; Golsäter et al., 2016).

Individual model of the child. The studies on parental death may also contribute in simplifying a complex picture. The parental loss tradition is the subject of well-known criticism coming from the sociology of childhood, namely, that it focuses on children as *becomings* rather than on children as *beings* (see for example, Gladstone et al., 2006). In addition, it applies an individualised model to understand the child and child development, where the child is isolated from the child’s context, as a passive object (Hogan, 2005), which fails to explain the complexity of the developmental processes children engage in in their daily life conduct. Professional advice and practice guides regarding children below 6 years of age either have no explicit outline of theoretical assumptions or, as argued by Rosengren et al. (2014), they draw “primarily on Piaget’s (1929) account of children’s understanding of death” (p. 11), which is an individualised model, outdated and criticised for underestimating young children’s capabilities. The research field’s categorisation of individuals as “vulnerable” and “at risk” (Burman, 2008; Gladstone et al., 2006) may contribute to essentialising psychological phenomena (Andenæs, 2000) without actually contributing to the understanding of resilience processes.

Taking a poststructuralist perspective, it is problematic that the research literature on parental illness and death does little to contextualise results within the current sociocultural context in which they are produced. Scientific knowledge and research “findings” do not neutrally reflect objective knowledge. Rather, they are discursively and socioculturally *produced* as well as *productive* in forming the phenomena under investigation; for example, professional practices, professionals’ interpretation and self-understanding, or patients’ expectations to professional support (Foucault, 1970/1999; Søndergaard, 2018).

3 Theoretical framework

The project of researching professional encounters with young children experiencing parental illness and death relates to a theoretical interest in how children develop through their changing participation in social, cultural activities in their communities, which also change (Højholt & Kousholt, 2018; Rogoff, 2003a).

The theoretical framework of this thesis consists of sociocultural developmental psychology and poststructuralist-inspired discourse analysis. Sociocultural (or cultural-historical) developmental psychology has its origins in the work of the Russian psychologist Lev Vygotsky (1896-1934), and Urie Bronfenbrenner (1979) has also been an important contributor (Rogoff, 2003a). In this thesis, I rely primarily on the work related to the Scandinavian research field that has developed as a theoretical branch within developmental psychology tied to cultural psychologists, such as Barbara Rogoff, Jean Lave, James Wertsch and Jan Valsiner (Andenæs & Jansen, 2019; Hedegaard, Aronsson, Højholt, & Ulvik, 2018; Hundeide, 2003). The tradition is nicely combined with the critical poststructuralist movement within psychology inspired by, among others, the French philosopher and poststructuralist Michel Foucault (Burman, 2008; Smith, Harré, & Langenhove, 1995). Based on these traditions, I consider children as agents in their own development and child development as embedded in and produced by interpersonal, social, cultural, historical and political contexts (Burman, 2008).

I will begin the theory section by presenting two basic assumptions of sociocultural psychology: human beings are fundamentally meaning-making, and the principle of contextualisation. These basic assumptions apply to researchers, caregivers and professionals as interpretative and actively meaning-making, and of course also to the child. I will further give a short introduction to changing death cultures and death practices as well as to how conceptions of childhood, what “a child” is and how children develop, have changed throughout history. The main purpose of bringing these cultural and historical accounts to light is to contextualise contemporary negotiation of child involvement when a mother or father is severely ill and dying by understanding it as anchored in transindividual cultural and historical conflicts and contradictions (Højholt & Kousholt, 2020). As an alternative to an individualised model of the child, I will present a theoretical model of the child as fundamentally meaning-making, a social agent and a participant. Here, I apply *The dual socialisation butterfly model* of Sommer, Pramling Samuelsson, and Hundeide (2013) to illustrate how children develop their ways of conducting their lives across everyday life contexts that are populated by professionals. Finally, I will present positioning theory and the poststructuralist concept *positioning* (Harré & Langenhove, 1999; Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009) as a theoretical tool to understand how overarching meaning structures influence and shape encounters at the interaction level.

Meaning: socioculturally shared and discursively negotiated

The "meaning-making" principle of sociocultural psychology is based on the universal theory about human understanding as fundamentally interpretative, which can be traced back to hermeneutic philosophy and, among others, Martin Heidegger, Hans-Georg Gadamer and Paul Ricoeur (Alnes, 2020). People always rely on pre-conceptions and background knowledge that functions as a *horizon* in the interpretation of that which is to be understood (Gadamer, 2003/1959). The study of *meaning* is an essential part of both sociocultural developmental psychology (Hundeide, 2003; Vygotskij, 1978; Wertsch, 1992) and discourse analysis (Parker, 2014). The emphasis here is on how human beings are fundamentally interpretative and communicative as well on the fact that their subjective experience of their everyday life is constituted/comes to be through joint meaning-making in dialogues and encounters with others (Bråten, 1992; Hundeide, 2003) and within the frames of socioculturally shared background knowledge. The idea is that, when individuals use language and take part in sociocultural activities, they inevitably draw on transindividually located meaning systems or structures of meaning called *discourses* (Burman, 2008), which are inherent in language and in social and cultural practices (Hundeide, 1993, 2003; Parker, 2014).

How people actively relate to and continuously make meaning of matters in their lives, other people and things in the world is thus dependent on context. The principle of *contextualisation* (Andenæs & Jansen, 2019) is that human behaviour, thoughts and feelings are understood as embedded in cultural and historical contexts as well as in the person's life history.

The two principles are tied together by the social constructionist assumption: that the meaning structures are continuously—through social interactions of all sorts—negotiated and constructed in a dynamic relationship to social, historical, material and economic conditions within the sociocultural context (Harré & Van Langenhove, 1999). As formulated by Michel Foucault (1970/1999), we have no possibility of "stepping out" of the order of the discourse: by applying language we are always indebted to the social, historical and cultural meanings that language carries. These socially constructed meaning structures contribute to forming the reality we experience in our daily lives (Schutz, 1975/2005), and for all practical reasons they are "real" (what Guba and Lincoln (1994) called "historical realism" (p. 110)). At a micro-, interactional level, realities are apprehendable in the form of multiple, intangible *dialogical or discursive* constructions[8]

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[8] These assumptions underlie, for instance, the poststructuralist concept *positioning* outlined in the theory chapter, and the discourse analysis in paper 1 (Hogstad & Jansen, 2020), where we discerned multiple discursive constructions that legitimized different child involvement practices.

(Guba & Lincoln, 1994). Guba and Lincoln (1994) use the term *mental* constructions, but I apply *dialogic* instead to adhere to the view that meaning is jointly constructed through the use of discursive resources and is not essentially located within minds as “inner” mental constructions. This is an assumption shared by cultural psychological, poststructuralist and posthumanist approaches: psychological phenomena, such as *hope* (Winther-Lindqvist, 2017), *views* (Gulbrandsen, Seim, & Ulvik, 2012) and *subjectivity* (Højgaard & Søndergaard, 2011), are not to be “found” within the individual’s mind or head as finished products or isolated phenomena. Rather, hoping, forming views and having subjective experiences are constructive processes of situated and meaningful practices in which hopes, views and experiences are being constituted in dialogical encounters (Harré & Van Langenhove, 1999). Transferring these insights to meaning-making about death (Hogstad & Jansen, Under review) relocates death concepts from where the cognitive psychologists located them: from belonging to the child as an individual (although developing) cognitive concept located inside the child’s mind to being located *in encounters* between people and relying on transindividual meaning. All human communication and meaning-making relies on transindividual discursive and material conditions constituting and preceding communication, and this is as true for adults as it is for children.

Hence, children are discourse users and actively construct meaning in joint production with peers, caregivers and professionals through the use of language and other discursive resources (Alldred & Burman, 2005). Young children, however, are in an asymmetrical power relationship with adults and may struggle to make their contributions in conversations, social activities etc. *count* (Van Langenhove & Harré, 1999). Partly because adults will have more developed linguistic competence and access to a wider range of discursive resources, young children are indebted to adults’ awareness of and willingness to interpret and understand their actions, utterances, behaviours, movements and emotional expressions. When adults direct their attention “towards an understanding of children’s perceptions, experiences, utterances and actions in the world” to take the child’s perspective (Sommer et al., 2013, p. 463), they will never be able to reach the child’s own subjective experience, but will always present an approximation (Sommer et al., 2013). Within the contexts of palliative care or kindergarten, when professionals encounter young children experiencing parental illness and death, their understanding of these children’s utterances, behaviours etc. will be underpinned by their preconceptions (Hundeide, 1992, 2003). These preconceptions involve the *naïve theory* of that particular child (what competences he or she has, who she is, knows, wants etc.) (Hundeide, 2003), the socioculturally shared discourses about what children in general need and should or should not do and are capable of at certain ages and stages etc. (Burman, 2008) and also his or her cultural and theoretical understandings of death, grief and loss.

Changing death cultures and death practices

The present thesis' social constructionist stance is based on the premise that even death, which may appear as the "most natural, biological, unchanging or inevitable phenomenon (…) is firmly embedded within, shaped by and constructed in concrete historical, social and cultural contexts" (Jacobsen, 2013, p. 13). Conceptions of death, death rituals and the management of death and dying are formed within the dominating discourse and the economic, social, historical and cultural conditions to shape people's experiences of dying and grief (Gripsrud & Thoresen, 2019; Jacobsen, 2013; Walter, 2020) as well as cultural conceptions of what it means "to die well" ("Ars Morendis" or "The Art of Dying") (Amundsen, Oftestad, Rasmussen, & Aavitsland, 2019). Many authors have wrote about Western communities' ways of handling death and dying in historical epochs, and the most cited is likely the French historian of the family and childhood, Philippe Ariés, with his "four phases in the history of handling death from the Middle Ages to the late 20th century" (Graven, Lund, & Jacobsen, 2013, p. 29). Another much-cited writer is sociologist Tony Walter, who points to some of the same trends as Ariés, which are mentioned in Graven et al. (2013):

> "(1) in pre-modern or traditional societies death used to be handled in the community by the extended family, neighbours, the priest and other key care persons, and (2) in the late 19th century, as a result of medical progress, death moved into hospitals to be handled by doctors and nursing staff; death, then, became an increasingly private matter." (Graven et al., 2013, p. 29)

Walter takes Ariés' account one step further and "labels the new awareness of death, dying and bereavement arising in the late 20th century the 'neo-modern revival of death'" – the trend toward a more visible, individualised, self-expressed and person-centred death (Graven et al., 2013, p. 29)[9]. Others have also pointed to today's medicalisation, professionalisation and institutionalisation of death, which could be tied to the neoliberalist shift of the cultural ethos (Gripsrud & Thoresen, 2019; Jacobsen, 2013; Walter, 2020). The development of the field of palliative care must be understood against that backdrop. Graven et al. (2013) notes that "professionalization of the palliative field has added to the development of a specialized focus on death and dying that increasingly views death as something the dying person is supposed to accept and relate to" (Graven et al., 2013, p. 41) and explains how this relates to the discourse about what makes a "good death" and individual autonomy in shaping "their own dying trajectories" (Graven et al., 2013, p. 41).

The patient's individual, autonomous choices are given due weight by health professionals caring for them at the end of life, and paternalism no longer has legitimacy. Free market economy discourse intervenes into the language of the professions (Ekeland, 2019) and

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[9] In a more recent work, Walter highlights the context-dependency of regional and local differences in modern death cultures that needs to be taken into account (Walter, 2020)

makes patients autonomous and atomistic customers who are free to choose their own ways of dying. At the same time, this represses the unavoidable fact that family members and members of communities are related and dependent upon each other. Considerations for individuals' needs and wishes combined with this inevitable connectedness clearly give rise to contradictions and conflicts.

Child development as embedded in and produced by interpersonal, social, cultural, historical and political contexts

Discourses about childhood shape the way we organise society and institutions like family, kindergarten, school and leisure time activities (Burman, 2008; Korsvold, 2016). The whole idea of researching professional encounters with young children relies fundamentally on a socially constructed boundary between "child" and "adult" and on the accompanying construction of "childhood" as a distinct period of human life separate from adulthood. This is a socially constructed distinction that, among others, Jean-Jacques Rousseau (1762/1997) has been credited with introducing (Burman, 2008; Thuen, 2008)—and which I am not able to "step out of". The present thesis could be seen as a contribution to the overarching sociocultural discourse that continuously negotiates children's participation in versus segregation from certain cultural practices and situations (Rogoff, 2003a). Hence, the work of this thesis is in line with the overarching ideological change in contemporary Western societies, toward viewing children as individuals with rights of their own.

How conceptions of childhood, what "a child" is and how children develop have changed throughout history

Looking into historical changes is powerful as a contextualisation: what we take for granted as requirements for "good parenting" and how we define what makes an "appropriate child" have not always been taken for granted. In her book *Deconstructing Developmental Psychology*, Erica Burman (2008) delineates an account of historical changes in the history and sociology of childhood regarding different moralities governing approaches to child care in Western societies. The account demonstrates how major historical events and present living conditions contribute to developing child-rearing practices. In the period around 1750–1850, a religious morality dominated, where child-rearing was legitimised by the way it prepared children for death. The child mortality rates were high as was religious authority overall. In the early 1900s, a medical morality grew out of the decline in birth morality rates, which in turn was due to sanitation reforms and the post-war decline in religious faith. This was followed by a shift from medical to mental hygiene, where behaviourist principles of childcare started dominating—and with them the importance of the regularity of habits to make the child obedient. From 1930 to 1950, a psychoanalytic orientation turned the focus towards children's needs and natural development, including a focus on the importance of early experience. From about 1950 until today we have what Burman (2008) calls individualism and fun morality, where flexibility, rather than prescription, has governed. The obedient child is no longer the goal: the individual, independent child has become the ideal. This latest shift within individualisation has been tied to *neoliberalism*, which focuses on the individual and the self rather than on communities (Burman, 2018; Ekeland, 2019).

In the Nordic countries, the childhood historians Tora Korsvold (2008; 2016) and Ellen Schrumpf (2007) are among those who give historical accounts of how cultural views (the hegemonic view of the child in a culture or society) of the child have changed according to and in line with social, economic and political changes. In the 1950s, most children in Norway were at home with their mother, which was at that time considered in the children's best interest. Kindergarten was an offer to children in particular need for protection, and kindergarten was a Child Protection Service institution until the first law of kindergartens in 1975 (Korsvold, 2016). The increase in kindergarten attendance in Nordic countries and the accompanying change in the view of what kindergarten is and should be for children must be seen in light of the increase in women's workforce participation.

In the Norwegian kindergarten tradition, the conception of childhood as characterised by freedom and free play was central until the neoliberal orientation began to grow in the mid-1980s (Alvestad & Berge, 2009; Korsvold, 2008). Korsvold (2016) and Thuen (2008) point to the view of the child in Nordic countries today as active, influencing his or her daily life and environments and with a focus on child rights and child participation, visible, for example, in the UN convention's rights of the child (UNCRC, 1989) and the underlying neoliberal ideology of individualism (Thuen, 2008).

Neoliberal ideology as a current contextual condition

The growth of neoliberalism has been influential in creating a bias toward individualism, for example, in the interpretation of children's rights to participation (Bae (2010). It has also involved a change in focus toward kindergarten as an educational institution (Korsvold, 2008). This involves instrumentalism, and the view of the child as "free" and "natural" with the right to be "themselves" became moderated (Korsvold, 2008). Today, an "early intervention" discourse dominates in school and early childhood education (Vik, 2014), and critical voices have pointed to how early intervention could be understood as a neoliberal governing rationality (Nilsen, 2016, 2017). This rationality contributes to place problems *in* the child, producing "problem children", who are deviant and "othered" (Franck & Nilsen, 2015; Pettersvold & Østrem, 2019). Early intervention may contribute to producing the problems it sets out to solve.

Neoliberalist individualism (and accompanying psychologisation) is accompanied by a reduction of "the social" to "the interpersonal" (Burman, 2008), together with an increasing weight put on emotions as a structuring and motivating force for both public and private life (Burman, 2018; Ekeland, 2019). Burman (2018) refers to this latter tendency by applying Williams' (1977) concept "structures of feelings", citing Lesnik-Orbstein (1998, p.7) to illustrate how the "the very idea of childhood itself is crucially implicated in the structures of feeling that define the bourgeoise nuclear family". What Burman points to here is the normative family definition as nuclear families consisting of heterosexual couples with their genetic children, which she calls the "textbook model of family" (Burman, 2008, 2018). Within this cultural meaning structure, psychology as a discipline has addressed families as the primary arena for the care and upbringing of children (Burman, 2018, p. 1607), and within neoliberalism's cultural ethos, an individualised "early 2000 version" of attachment theory developed that has had a tremendous impact (Burman, 2008). The upbringing of children has shifted from the goal of making children "be like us" toward "becoming themselves" as free, unconstrained and sound members of society (Ekeland, 2019)—a psychological development made possible by the attentive mother's provision of a secure environment (Burman, 2008). Accordingly, separation from the primary caregiver, insecure or ambivalent attachment and/or emotionally disturbed mothers are a breeding ground for delinquent behaviour, "unhealth" and psychological pathology (Burman, 2008). In the Norwegian public debate about young children's kindergarten attendance, lines of argument from attachment theory are frequently used to argue for more time with mother and less time spent in the kindergarten (Andenæs, 2012).

These historical and sociological accounts illustrate the dominant child view in the Nordic countries currently of an individual with subjective experiences and individual rights, and, at the same time, we lose sight of the child as a social participant who participates in *communities*, not only in interpersonal relations (Burman, 2018). A *psychological* point, however, is that, in actual encounters, multiple discourses or interpretative repertoires (Hogstad & Jansen, 2020) and storylines (Davies & Harré, 1999) will offer different frames and discursive resources that compete and conflict in negotiations of meaning. Professional encounters are one of many "sites" where meaning is discursively negotiated and constructed.

Individualised theories of child development and childhood grief offer models for understanding that essentialise and individualise grief as isolated, individual phenomena. The present study shifts the focus from individual risk factors and psychological adversities toward developmental conditions in the child's everyday life and focuses on children as social participants. In the following, I further elaborate on a sociocultural model of the child that provides an alternative theoretical understanding that may be applied in both research and practice (Højholt & Kousholt, 2018, 2020).

Children are agents who develop through their varying participation in social, cultural activities in their communities

Experiencing parental illness and death in childhood has multifaceted effects across physical, psychological, social and health domains (e.g. Lytje & Dyregrov, 2019), and linear statistical models and individualistic models of the child remain too simple. In this chapter, I elaborate an account of children's development that aims to capture more complexity and represents a competent model of childhood with a better understanding of "how childhood is lived and experienced" than individualised theories of child development (Burman, 2008, p. 82).

Children are social participants and agents in their own development, and child development is embedded in and conditioned by interpersonal, social, cultural, historical and political contexts (Burman, 2008; Højholt & Kousholt, 2018; Rogoff, 2003a). The concept of *participation* is central in this thesis and also relates to the idea of researching professional encounters, as the child participates in and develops through these encounters. I highlight two aspects of participation in the following. The first is that participation always concerns participating *in* something. Second, participation presupposes agency.

Children participate in sociocultural activities of their communities

In her book *The Cultural Nature of Human Development*, Barbara Rogoff (2003a) presents an overarching concept of human development as "changing participation in the sociocultural activities of their communities, which also change" (p. 36). Children are inevitably and already participating by living their life together with others, in the families, institutions, communities and cultures they are born into. The wide-ranging cultural variation in child-rearing practices and ways of organising family life etc. is related to economic, cultural-historical and climatic conditions. The Norwegian psychologist Karsten Hundeide (2003) elaborates on the sociocultural frames of children's development and how professionals and caregivers direct dialogues and educational activities toward context-dependent goals for development and according to existing values and norms (Lave & Wenger, 1999; Rogoff, 2003b). For example, in line with the ideal of independence in Scandinavia, cultural practices of sleeping in one's own bed, apart from one's parents, becomes a meaningful child-rearing practice (Rogoff, 2003a). Given this way of understanding participation, children's *degree of* participation may be legitimately regulated by practices of inclusion and exclusion from sociocultural activities related to parental illness and death, such as funerals, hospital visits and communication about illness.

In Norway and in most other European and North-American countries, the "nuclear family" is the normal structure and form of families. When living with their closest family like this, children are necessarily participants when the family is hit by cancer or other forms of incurable diseases (e.g. ALS, MS, chronic obstructive pulmonary disease, dementia). In Scandinavian contexts with a high level of kindergarten attendance (Sommer et al., 2010), children not only participate in the family but also live their lives across everyday life arenas. The dual socialisation butterfly model (Figure 2, p. 27)[10] of Sommer et al. (2013) illustrates the socialisation processes typical of Scandinavian countries.

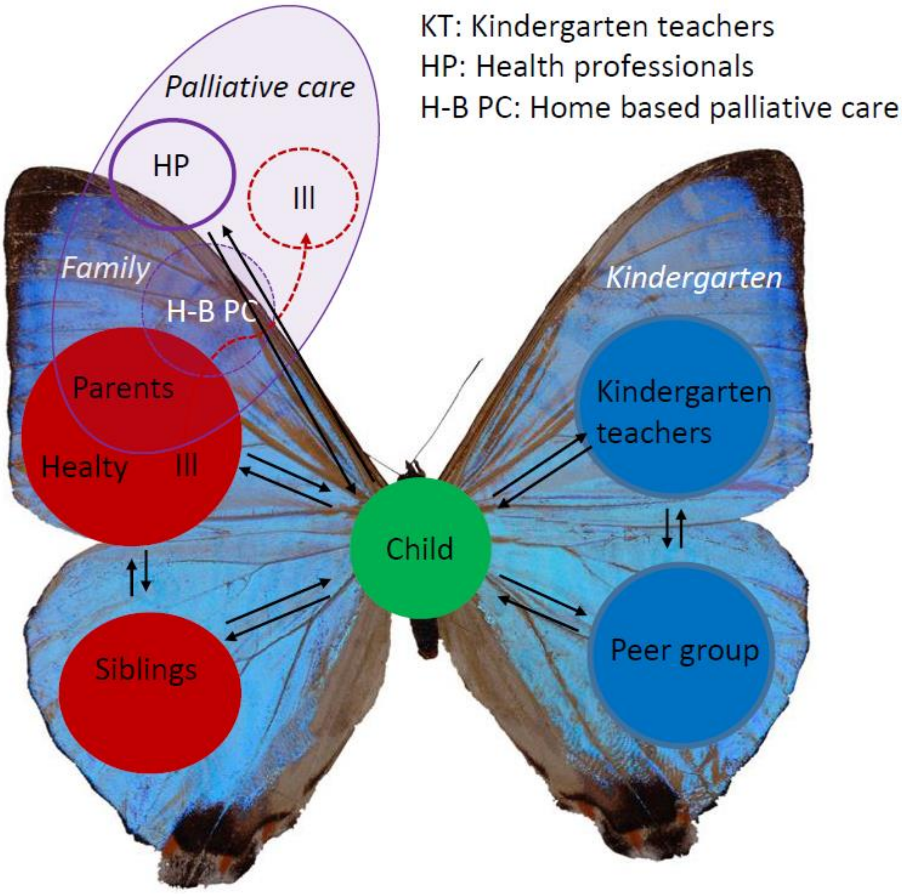

Figure 2: Dual socialisation butterfly

The model centres around the child, as the “body” of a butterfly, being an actively experiencing and meaning-constructing agent between the wings, which consist of family and kindergarten (Sommer et al., 2013). The arrows illustrate interactions between socialising agents in the child’s life: social activities and interactions with professionals, peers, parents and siblings. The model nicely illustrates how interwoven professionals, and particularly kindergarten teachers, are in Scandinavian children’s everyday lives. A theoretical point is that the butterfly is to be considered a system, meaning that all relationships, regardless of whether the child is directly involved in them or not, are potentially crucial for developmental processes (Sommer et al., 2013). In a situation of parental severe illness, the family as an everyday arena will in different ways change as a

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[10] Adapted from Sommer et al. (2013)

response to or consequence of changes tied to the illness of the mother or father, which will impact all members of the family in different ways. The child's participation in the family will change as well, both as a result of the change in the family and as part of the process of developing. For some, home-based palliative care becomes a temporary part of daily life in the family, with health professionals coming home to visit the ill parent. Palliative care departments in nursing homes or in hospitals could also constitute temporary everyday life arenas for children living with severe parental illness in the family.

Højholt and Kousholt (2018) highlight how responsibility for children's development and socialisation is structurally distributed between adults (parents and professionals) in everyday arenas and how the different developmental conditions within these different arenas need to be understood in relation to each other (Højholt & Kousholt, 2018). *The dual socialisation butterfly model* illustrates these arenas in relation to each other, but not regarding collaboration between adults. It also does not capture the importance of collaboration between the kindergarten management and the parent's group, collaboration between parents of the children in the peer group or the context of the institutional order of the kindergarten as part of the system.

Children are agents in their own development

The Danish psychologists Charlotte Højholt and Dorte Kousholt (2018, 2020) align with the cultural-historical approaches presented above but apply the concept of participation with a more existential meaning. This meaning is tied to the view of children *as agents* with personal things they care for and that matter to them in their life (Højholt & Kousholt, 2020). For Højholt and Kousholt (2018), participation as a theoretical point of departure and developmental potential is connected to living one's life and developing the conduct of life:

> Children develop ways of conducting their life, not just through adjusting to given conditions but also through arranging conditions together with others, contributing to social practice and taking part in negotiations about different matters in their life. (Højholt & Kousholt, 2018, p. 1582)

Hence, a child experiencing parental illness and death will, together with peers, professionals and caregivers, continuously negotiate what the present conditions come to mean in his or her life. By including children as agents, the "objectively same" developmental conditions may mean very different things for children situated in different positions. As noted by Pernille Juhl (2019), "[S]hared conditions have assorted personal meanings and become premises and reasons for acting in different ways" (p. 56).

Rather than focusing on degrees of participation, viewing children as agents enables studying different forms of and *ways of* participating as well as different possibilities to develop ways of conducting their life when a mother or father is severely ill and dying. For example, one child's active questioning and play about illness and death and another child's total refraining from all conversations about everything related to illness and death can both be considered as ways of participating. The same is true of “behavioural disorders” (as pointed to in the previous research section, p.11), such as withdrawal from social situations or aggressive or deviant behaviour.

The child’s endeavours and collaboration are still dependent on the developmental conditions in his or her everyday life arenas (school, kindergarten, family), and these arenas also represent different demands and possibilities for participation (Højholt & Kousholt, 2018). The kindergarten teacher has to make arrangements to coordinate the whole group of children’s individual needs, ideas, plans and priorities (Højholt & Kousholt, 2018), including those of the anticipating or bereaved child. Other children’s parents may want to limit their own child’s participation in conversations about illness and death or in rituals (visiting graveyards etc.), and this will impact the professional’s practices. The coordination must also be done within the demands of the institutional order of the kindergarten and within the given resources. For example, a limited amount of adults per child leads to a need for children to follow rules, routines and be competent and physically independent and self-controlled (Franck & Nilsen, 2015). Franck and Nilsen (2015) point to how this opens up for subject positions of deviance. When children take up or are positioned in subject positions, it opens and closes their possible ways of being as well as the possibilities of being heard and being allowed to contribute (Van Langenhove & Harré, 1999), which has further implications for the possibilities they have to develop their ways of conducting their life.

Positioning in professional encounters

I have found positioning theory (Harré & Langenhove, 1999) helpful in tying together poststructuralist insights about the power of overarching discourses (Burman, 2008) and how these plays out at the interactional level (Wetherell, 1998), allowing me to understand more about the dynamics in *professional encounters*[11] between parents/patients, health professionals, kindergarten teachers and children as well as in the research encounter.

Positioning theory offers a conceptual and methodological framework that allows reading the professionals’ accounts not merely as neutral representations of a “perspective” “view” or an objective source to their experiences but rather as *speech acts*. *Positioning* is a discursive practice, and hence it is an act; that is, something an agent *does* (Van Langenhove & Harré, 1999). In performing speech acts, agents draw upon discourses and established storylines to discursively *position* themselves and others in *subject positions*. “(Subject) position” is a metaphorical concept (not an action) (Van Langenhove & Harré, 1999) for locating persons within the storylineswhich could also be called *cultural*

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[11] Professional encounters are here understood primarily as acts of interaction: episodes, situations in limited time spans (occasions).

narratives) or within the "discourse" or "interpretative repertoire", that speakers can take up or position others within. "Positions" are features of the local moral landscape. Harré et al. (2009) define positions in relation to the concepts "rights and duties":

> "Rights" and "duties" are shorthand terms for clusters of moral (normative) presuppositions which people believe or are told or slip into and to which they are momentarily bound in what they say and do. Positions are clusters of beliefs about how rights and duties are distributed in the course of an episode of personal interaction and the taken-for-granted practices in which most of these beliefs are concretely realized (Harré et al., 2009, p. 9).

The *clusters of beliefs*, as cited here, are not contained or found in the mind of the speaker but belong to the discursively produced frameworks of meaning or meaning structures (discourses) embedded in language, and hence they are *transindividual*. Departing from an account of language and meaning where speech acts get their meaning *in* the occasions where they are used[12], several possible meanings of the same speech acts are possible. With this comes the multiplicity of positions and the multiplicity of different "rights" and "wrongs".

What positioning theory offers is interesting in several ways. First, it is interesting to read how the health professionals and kindergarten teachers preform or how they do *performative positioning* (Van Langenhove & Harré, 1999), that is, how they talk about their interactions with children, parents or patients in the interviews with me as a researcher. How is the story created, what storylines and discourses do they draw upon and how do they position themselves and others within these? Second, it is possible to theorise, in interactions between the nurses and patients and between the kindergarten teacher and the parent, the ways that *first order* and *second order positionings* plays out in these encounters (Van Langenhove & Harré, 1999). How do they position themselves, as a mother, as a nurse, as an expert, as a therapist? And, how do they through that positioning simultaneously position others? Other people may take up the position made available to them by a discourse, or they may reject it and in that way position themselves and the other speaker within other discourses or normative frames. Some storylines and, accordingly, speech acts may function to position others in "troubled subject positions" (Wetherell, 1998), which may be rejected by the other. With knowledge of these ways of positioning, we may gain insight into potential conflicts in these interactions as well as a better understanding of why, for example, some parents seem to reject the support offered to them by professionals about how and why to talk to their child about illness and prognosis (Hogstad & Leer-Salvesen, 2020).

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[12] By Harré and Langenhove (1999), called "the immanentist account of orderly human productions" (p. 33).

4 Design, methods and ethics

The present PhD project is a study of professional practice. In the theory section above, I pointed to how professional practices of child involvement consist of both knowledge and practices. I elaborated on how general, cultural knowledge about "the child", child development and death function as discursive resources legitimising child involvement practices when a mother or father is severely ill and dying. Another point was how this knowledge together with specific knowledge about the actual situation and the child in question functions as the professional's interpretative frame in the encounter with the young child. My ambition is to *challenge and destabilise existing knowledge* about young children experiencing parental illness and death and *to offer alternative understandings* that open up other child involvement practices (Bøttcher et al., 2018; Søndergaard, 2002). The *professional encounter* is the site where existing knowledge is concretised in practice and where alternative understandings may have the power to change practice. I have studied the professional practices of child involvement by engaging with empirical material from interviews with health professionals about their professional encounters with young children experiencing parental illness and death.

In this section, I will first outline the design of the two-phased interview study with two groups of professionals, where I take inspiration from the concept "retroduction" described by Glynos and Howarth (2007) to explain the reasoning process involved in the whole research process. Second, I will explain how I went about generating empirical material for the two phases (one by one). Third, I will discuss how I have examined professional child involvement practices through analyses of discourses, practice stories and descriptions. I will end the section with a discussion of three ethical challenges encountered during the process.

Qualitative, exploratory design

In studying professional encounters with young children experiencing severe parental illness and death, social phenomena are under investigation: people encountering other people, what they say, what they do, how they relate to others and how they relate to all sorts of issues that surround these encounters. Certainly, I am focused on *meaning*, and the overall study design thus had to be *qualitative*. The design was exploratory and consisted of two main phases of generation of empirical material (interviews) and three sub-studies with theoretically informed analyses, resulting in three papers. The process is illustrated in figure 3 (p. 32).

To study professional practices of child involvement, I needed to reach professionals with experience from actual encounters with young children experiencing parental illness and death. The first phase of interviews was conducted with health professionals within palliative care, and the second phase was conducted with kindergarten teachers. I have discerned the phases of generating empirical material from the individual studies (1, 2 and

3). “Study” in figure 3 refers to the systematic process in which I engaged with data from one or both of the interview phases with the specific aim of answering a research question (presented in table 1, p. 6).

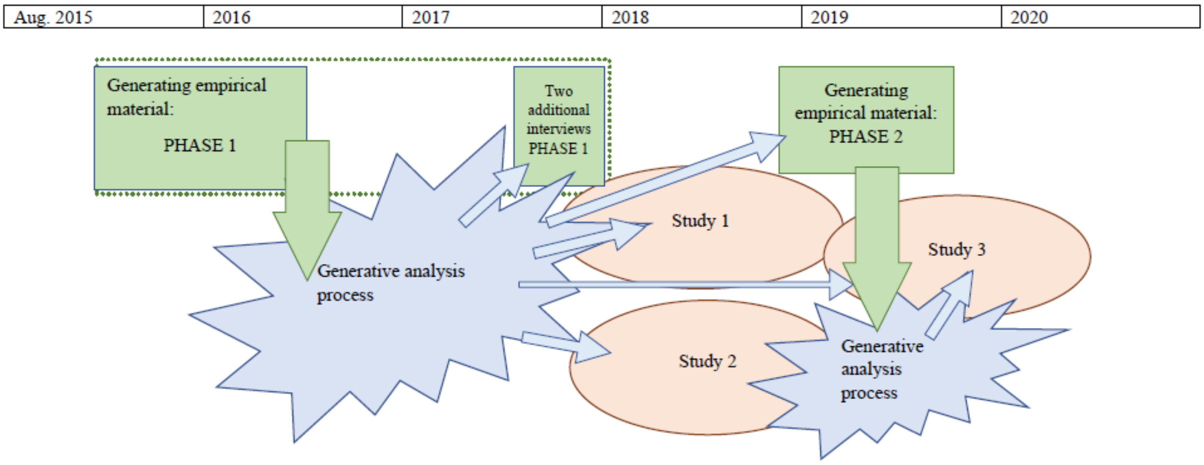

Figure 3: Project design

Before and beyond each “delimited” study-specific analysis process, lie what I have named *generative analysis processes*, illustrated as vaguely outlined with projections in several directions. These are processes that have contributed to *generate* the three studies included in this thesis and, generally, the direction of the research project, including new research and analysis questions as well as informing the process of developing and revising the interview guides etc. for later parts of the study. Hence, the three studies are part of a continuous, dynamical and shifting reasoning process. In hindsight, I found the concept “retroduction” suitable for explaining this generative analysis process as well as the epistemological assumptions underpinning it.

The generative analysis process: retroduction

In the theory section *Meaning: socioculturally shared and discursively negotiated* (p. 20), I outlined some (related) basic assumptions that also apply to the research endeavour: human understanding is fundamentally interpretative (Gadamer, 2003/1959), scientific knowledge and research “findings” are *produced* and *productive* (Foucault, 1970/1999; Søndergaard, 2018) and what we take to be “real”, true and morally right is continuously negotiated and constructed through social interaction of all sorts (socially constructed) (Harré & Langenhove, 1999; Schutz, 1975/2005).

A central point deriving from the above assumptions is that I as a researcher cannot “step out of” existing knowledge and established, dominating understanding. Hence, it is not possible to assume that the investigator and the investigated object are independent from each other (Duhem, 1976; Quine, 1953/1998). As I wrote in the introduction, previous research and the present PhD study all contribute to the discursive negotiation of children’s participation in versus segregation from practices and situations in the process from the time a parent receives a diagnosis of severe illness and until death. What I at the outset defined as the problem to be investigated, in this case how professionals' preconceptions of children and of children's understanding of death form their interactions with young children experiencing parental illness and death, and how I go about exploring and explaining the phenomena cannot be delineated from each other as separate processes.

Glynos and Howarth (2007) illustrate the interconnection of discovery and justification in social science research with the "retroductive circle" (see figure 4 below)[13]. This circle illustrates the reasoning process involved in qualitative research within the social sciences as interpretative and, in addition, involving a series of dialogical processes with others, within which the research problem is defined and problematised as well as explained, argued for and "tried out".

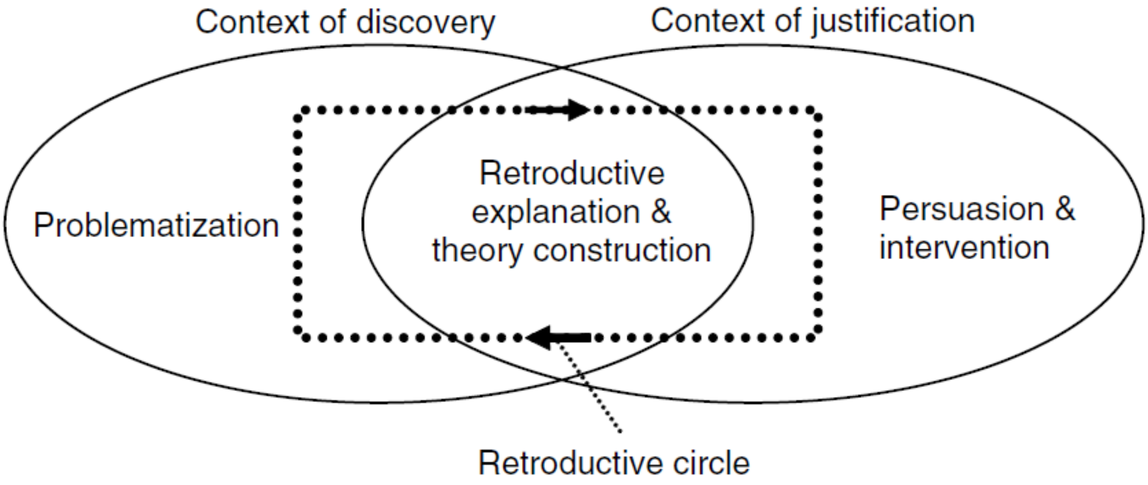

Figure 4: Schematisation of the retroductive circle

Central to the retroductive reasoning process was the active process of constituting the problem at hand. A core element in this process was the continuing struggle to settle on concepts, problem descriptions and terms to delineate and focus what I was exploring, studying and eventually explaining (Glynos & Howarth, 2007). I started out with a naive engagement for facilitating professionals' "successful communication", which through continuously refining and revising research questions was changed and focused toward professional encounters and child involvement. Revision of research questions is an acknowledged methodological technique in working qualitatively within psychology, and, in line with a retroduction logic, psychologist Carla Willig (2001) suggests considering the research questions as part of the results of the research endeavour.

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[13] The schematisation is taken from Glynos and Howarth (2007, p.33). The overlapping circles "context of discovery" and "context of justification" refer to the difference between positivist inquiry, where these contexts are delineated from each other as separate processes.

To avoid merely reproducing existing knowledge, the research process must involve critique—“a permanent questioning of the apparently obvious”—but also a reflexive practice of self-critique, where own prejudices are scrutinised (Klaus Holzkamp (1983), cited by Schraube, 2015, p. 537). I have found discussions and dialogues with others to be central in the reasoning process, as these encounters have helped me make evident the established truths (Schraube, 2015) and being encountered with my own preconceptions through others’ different and sometimes contrasting views (Enosh, Ben-Ari, & Buchbinder, 2008). These “others” include peers, students, supervisors and other colleagues, peer-reviewers and journalists, practitioners in the fields of kindergarten and palliative health care as well as my family, friends and other people in my local community. In the following, I will present an example of how practitioners in the field of palliative care have acted as dialogue partners.

At a palliative care conference, I presented and discussed a preliminary version of the analyst-constructed typology of different positions on a continuum between working for patient autonomy and going against patients’ will to secure children’s right to be involved presented in paper 2 (Hogstad & Leer-Salvesen, 2020). A practicing palliative nurse in the audience commented that she had been using all these strategies in encounters with patients, even though she had never thought of it in these terms before. This made me aware that all these positions seemed to be legitimate to take up with practitioners in the field. This surprised me at first, as my legal and theoretical understanding (with an almost total lack of experience from the palliative field) was that the extreme position “It’s the child’s right”, by the principle of confidentiality, would be considered illegitimate. The stories told by practitioners at the conference, as well as at lunch with colleagues who were also practicing as nurses etc., told me that the position and strategy associated with “It’s the child’s right” might be more commonly used than the empirical material was able to capture.

Generating empirical material – phase 1

As a backdrop to designing this PhD study, I had an idea that palliative health-care professionals felt insecure and insufficiently trained to talk to children. The idea derived from my previous experience as a clinician within mental health care for children and collaborating with palliative health-care professionals. I experienced that children as next of kin “fell between chairs” when the palliative team referred the children to mental health care when a mother or father was dying. Mental health care workers seemed to be afraid of death and life-threatening illness, and most of the children referred to the service did not seem to be in need of mental health *treatment*. I wanted to understand more about the structures that allowed for this to happen, and I was particularly interested in how the professionals discursively legitimised referring the children to other professionals and institutions. In addition, from previous experience and research I was aware of how caregivers’ and professionals’ conceptions about children’s limited ability to understand death legitimise excluding children from information-sharing and other forms of shared meaning-making about illness and death in the family (Hogstad & Wold, 2016; Mahon, 2011). I therefore wanted to explore palliative health-care professionals' conceptions about the youngest children's ability to understand illness and death. In the following, I outline how I went about generating empirical material that I could engage with to produce this kind of knowledge.

Recruitment and participants

I needed to gain insight into the established (sociocultural) knowledge and subjective experiences of health professionals who encounter children who are anticipating or have recently lost a parent because of severe illness. It was convenient, but also a methodological aim that the professionals were distributed across different institutions that were geographically dispersed and of different sizes (the hospitals). This ensured variation in experience and also allowed me to "tap into" commonalities across local contexts and hence the discursive resources shared among the group of health professionals (Taylor, 2001b).

Table 2: Participants phase 1

Profession (woman/man)	*Years of experience*	*Institutional affiliation*
3 doctors (1/2)	**3–17 years of palliative care experience**	**1 in a small hospital** **2 in university hospitals**
8 nurses (7/1)	**2–10 years of palliative care experience**	**From 2 different hospitals:** **- 2 palliative wards** **- 1 ambulant team** **- 2 ambulant/hospital teams** **From municipal health services: 2**

The first seven participants in the first phase were recruited through their institutional affiliation. Five of them contacted me after information meetings in their institutions, where they had received oral and written information directly from me, whereas two consented to participate after receiving the same written information from a mediator within the health system. This recruitment process resulted in a sample that consisted primarily of health professionals aligning with the stereotypical "female nurse" and "male doctor" roles. After presenting my preliminary results in one of the research groups I attend, I became aware that readers and reviewers would read the variances and diversity in my results merely as gender differences. To counter this, I recruited a male nurse and a female doctor as well. See an overview of the participants in table 2 (p. 35). Recruitment letters in Norwegian are attached in appendix 3.

Interviews with health professionals

Being interested in discursive construction and discursive legitimisation, I needed discourse as data. A convenient and appropriate method for producing such data was to conduct semi-structured, qualitative interviews. At the outset, the idea was to conduct focus group interviews with palliative teams after conducting individual interviews, to elicit data on how the professionals together discursively and dialogically negotiated rights and duties regarding child involvement of the children of their patients. For practical reasons, I had to discard the plan. As part of the development of the interview guide, I conducted two pilot interviews. One of them was included in the main study. The other was not included because the participant had no previous experience with minor children as next of kin to her patients.

The interview procedure is outlined in paper 1 (Hogstad & Jansen, 2020, pp. 472-473) and paper 2 (Hogstad & Leer-Salvesen, 2020, pp. 2-3). In paper 2, an English translation of the interview guide is found in appendix 1 on pages 7–8. The Norwegian version of the interview guide is attached in appendix 5. I was interested in stories that could provide insight into the professionals' contributions to exclusion and inclusion processes as well as their understandings of children's understanding of illness and death. These were meant to be covered the interview guide's main questions 2 to 4.

All interviews were introduced by making the participants aware that: 1) patients and their families were anonymised, 2) there were no right or wrong answers to my questions and 3) I wanted the interview to proceed as a dialogue between the interviewee and me.

The first point concerns the fact that health professionals have a duty of professional confidentiality through their professional codes of ethics as well as HPA §21. They were bound by this duty of confidentiality in their interviews with me, and it was important to make them aware of the anonymisation because the interview situation creates an atmosphere that invite openness and confidence, and it is sometimes even seductive (Jansen, 2011) (more about anonymisation in the section *Retaining participant and third-person anonymity*, p.45).

The idea behind the two latter points was that the interview situation was constructed as an opportunity to jointly explore the interviewee's opinions, thoughts and experiences from practice. I assumed at the outset that interview situations are inevitably social, communicative situations (Hundeide, 1992, 2002; Taylor, 2001b) and do not represent a "neutral peephole" into the phenomena under investigation. Rather, they involve a joint construction of the data material (Taylor, 2001b). In this joint construction, both myself and the interviewee are *language users*, relying on discursive resources and submitted to discourse (Hundeide, 2002). This means that it is not possible for me and the interviewee to communicate without drawing on shared meaning structures inherent in language (Foucault, 1970/1999). The generated empirical material will thus carry traces of socioculturally shared meaning structures.

In an ideal interview situation, the interviewee contributes as the insider with expert knowledge, experience and specific situations from practice to reflect upon, whereas the interviewer contributes as an outsider with directed questions, probes and a curious, open attitude (Patton, 2015; Taylor, 2001b). In real situations, both parties inevitably bring expectations to the interview, which influence how interview questions are posed and interpreted (Hundeide, 1992, 2002; Taylor, 2001b), and there is a continuous opportunity for aspects of and variations within the phenomena under investigation to "get lost" in the process. This is especially true if the interviewees are reserved about sharing their accounts on certain topics, for example, because of gender issues (Taylor, 2001b). During the interviews with health professionals, I recognised the impact of my "outsider position": I represented someone from outside of the field, having no clinical experience in palliative care.

I could elaborate on several things concerning my outsider position but limit myself to making two points. First, the interviewees gladly shared their expert knowledge with me on topics related to illness, death and palliative care practices, and I experienced that the accounts from "within" the health professionals' perspective nuanced and corrected my preconceptions about child involvement practices. Their stories and the reasons they gave made meaning for me in a way that might have been tacit if I had been in an insider position. Second, the interviewees' awareness of my education as a psychologist with in-depth knowledge within developmental psychology seemed to function to position me as an expert within the interview (explicitly and implicitly stated by the interviewees), and I struggled to make the interviewees share their opinions regarding child development topics.

I did not always experience being an outsider. As a mother and a woman, the female interviewees and I became insiders (Taylor, 2001a) on certain topics related to being a mother and *mothering*. During most of the interviews in phase 1, I was (visibly) pregnant with my third child, which made it difficult to hide my identity as a mother.

Generating empirical material – phase 2

During the work in study 1 and 2, I became increasingly aware of how limited and problematic the direct encounters between palliative health-care professionals and the youngest children were. This awareness became possible because the stories from the health professionals contrasted with my preconceptions established from previous experiences (Enosh & Ben-Ari, 2016). I carried with me the experiences of being a kindergarten assistant and following a young girl through her everyday life in the kindergarten having a severely ill and dying mother. I experienced her as intensely involved in her mother's disease—in her own bodily and relationally anchored way. Compared to these previous experiences, the health professionals' accounts of the youngest children seemed limited and focused on the *lack of* skills, *lack of* understanding and *lack of* competence. This discrepancy made me want to know more about kindergarten teachers' experiences and their ways of encountering children as well as about possibly conflicting considerations and resources within the kindergarten context. Such knowledge would also be useful for understanding more about the possibilities for developing interprofessional collaboration between palliative health-care professionals and kindergarten teachers. In the following, I outline how I went about generating empirical material that I could engage with to produce this kind of knowledge.

Recruitment and participants

It was essential to recruit kindergarten teacher with direct experience from professional encounters with young children having a severely ill and dying mother or father. To obtain this, kindergarten teachers were recruited through contact with families that were in or had been in this situation and included at least one child who attended or had attended kindergarten during the illness process. Information about the research project was distributed to families with the help of a university hospital-based bereavement support centre and a national health institution for cancer patients as well as a municipal public health service.

I encountered some problems in the recruitment process. Initially, the national health institution for cancer patients was going to pass on information letters to a group of families in which the mother or father was severely ill (still alive). After their stay in the institution had ended, the mediators told me that they had not been able to pass on the information letters because of the way they were formulated. The information letter mentioned that the inclusion criteria included that the mother or father was "dying", and this formulation prevented the health care workers in the institution from delivering the letters. They were aware that patients do not want to identify themselves as "dying". We also found this to be true in study 2 (Hogstad & Leer-Salvesen, 2020). The information letter was changed so it did not involve "dying", and in addition I made an informational video in which I presented the project orally.

Eight families with a total of nine children who attended kindergarten during illness processes (5 girls, 4 boys) contacted me by mail. Through written consent, they released the kindergarten teachers from their duty of professional confidentiality for the specific purpose of the interviews and at the same time provided contact information for the kindergartens. All 18 kindergarten teachers and their leaders volunteered to participate and provided their written consent. See an overview of the participants in table 3.

Table 3: Participants phase 2

Profession (woman/man)	***Years of experience***	***Institutional affiliation***
18 kindergarten teachers (16/2)	**4–36 years of experience as kindergarten teacher**	**From 7 different kindergartens:** **- 6 administrative leaders** **- 12 leaders in groups of children:** **- of mixed age (2)** **- 1–3 years old (4)** **- 3–6 years old (6)**

Interviews with kindergarten teachers

Even though, as I mentioned in the introduction to this section, the health professionals accounts were characterised by a focus on the youngest children's "lack of", the empirical material also included rich, detailed descriptions of practices and practice situations conveying a different picture. When planning the interviews with kindergarten teachers, I wanted to conduct the interviews in a way that was suitable to elicit such detailed descriptions from practice. The close everyday life contact between the kindergarten teacher and the child opened for another interview method than that used with the health professionals. The life-mode interview (Haavind, 2019) inspired the development of the interview technique and interview guide.

The life-mode interview technique was originally used to gain insights into first-person perspectives (Winther-Lindqvist, 2018) in studying, for example, the everyday organisation of family life (Andenæs, 1996; Haavind, 1987) or the everyday life conduct of children (Gulbrandsen, 1998) or adolescents (Jansen, 2011). The technique involves the interviewer drawing a timeline from the start of the day and following the participant's movements detailed throughout the day. In exploring professionals' encounters with children in the kindergarten, I am not interested in the professionals' first-person perspectives in themselves but rather in their knowledge, views and experiences related to the child and their professional practices together with the child and his or her parents. Hence, it did not make sense to develop a timeline from the start of the day to follow the participant's movements during a "regular day". Rather, I made a timeline covering the illness process to follow the participants' experiences of their encounters with the child and the parents as well as their considerations and experienced conflicts tied to events and issues as they occurred during the process.

The interview started by asking about the time when the kindergarten became aware that the mother or father was severely ill. It proceeded as a joint search, where we alternated between following the chronological order and "stopping the time" to linger on specific events and challenges. Following the chronological order helped me construct a picture of the events during the illness period and their "typical" patterns across kindergartens. Lingering on specific events was useful to explore and elicit detailed accounts of interaction sequences of the interviewees' reflections about why they did what they did etc. (Kousholt, 2018). The interview technique appeared suitable for eliciting detailed descriptions of practices as well as of justifications for practice because it required me to be much more detailed than in a normal conversation. For example, when a kindergarten teacher described welcoming the child to the kindergarten in the morning, I lingered on the event and asked follow-up questions to make the interviewee draw a picture of the situation: How did you welcome him? What did you say? Where were you? What happened next? The interview guide (in Norwegian) is found in appendix 6.

In the outline of the interviews in phase 1, I commented on my outsider position. The converse was true in phase 2, where my position was characterised as an insider, having worked in kindergarten myself and having two young children who attended kindergarten at the time of the interviews. I was familiar with kindergartens as a site as well as the professional work of kindergarten teachers.

Transcription

The interviews was audio-recorded with an mp3 recorder. I transcribed all the interview records to plain text myself. All the interviews was conducted in Norwegian, and all the transcriptions are hence in Norwegian language. As part of the transcription, all personal data contained in the audio records were de-identified upon transcription. This meant removing or changing names for persons and places as well as specific descriptions about the educational background and year. The transcription files are thus de-identified but not anonymised, as it is still possible for me to link individuals and data (NESH, 2016, pp. 17–18).

As I was interested in discourse as transindividually located meaning and not as naturally occurring interaction (as a conversational analyst would), I performed a simple, verbatim transcription, with little further detail (Taylor, 2001b; Wooffitt, 2001). Details I did add were small, affirmative responses, like “m-mm” and “yes” within the text where it occurred (without shifting the line as if it was an exchange of turn); interruptions in the text (when the interviewee and I interrupted each other); as well as things that happened in the room that affected my attention and that of the interviewee, thus interrupting the conversation. For example, a bottle of soda showered over, a telephone rang or someone could knock on the door of the room where we conducted the interview. In addition, I marked places where the interviewee or I became very emotional, crying or having problems talking because the voice turned “thick”. As I conducted all the interviews myself and performed the transcription just after, I had a clear view of each interviewee, the atmosphere and the feeling of the interview when transcribing them. The transcription process also allowed me to interpret the interviewee’s contributions in new ways, realising that I on some occasions had misunderstood them in the first place.

Analysis processes

In the first encounters with the transcripts from the health professionals' interviews, I was particularly aware of all instances of text related to *exclusion* and *inclusion* of children. At first, I used NViVo, a qualitative data analysis program that allows for coding and systematisation of text, to code these text sections for further analysis. This process generated preliminary results and *analytical "shoot-ups"* (Kousholt, 2018) and became the starting point for several, parallel retroductive reasoning processes. These can be summarised in three questions: How do discursive constructions of the child relate to professional child involvement practices? Who has the power to decide how much and in what ways the child is involved? How do professionals contribute to forming the child's view? A red thread through these processes was the interest in professionals' discursive negotiation of their right and duty to take responsibility for the involvement of a child whose mother or father is severely ill and dying. In the following, I handle these four processes one at a time. I make transparent how theoretical inspirations and concepts have opened up particular readings and areas for attention in the encounter with the empirical material (Bøttcher et al., 2018). The description below involves simplification: I have drawn a tidier and more linear picture of the analysis process than what actually occurred.

How do discursive constructions of the child relate to child involvement?

My preconception about the importance of professionals' preconceptions of children's competence and abilities equipped me with a particular interest in health professionals' statements about children's needs, nature or lack of skills and abilities that appeared as "truth claims" (Søndergaard, 2002, p. 188) about children. With this interest, I read text sections from interview transcripts coded in NViVO concerning inclusion and exclusion. This reading was done with a critical distance from the content level of the stories, with a focus on health professionals' *ways of talking*, regarding text sections as one of many possible *texts* (Parker, 2014). I asked these theoretically informed analysis questions: 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? First, I performed this reading crosswise before looking systematically for patterns across interview transcripts. I regarded these patterns as transindividual meanings located in language. As the patterns in the ways of talking about the child became clearer, the research interest turned more toward the practice implications of these ways of talking about the child. The concept *interpretative repertoire* of Wetherell and Potter (1988) was useful in the further analysis of how the patterns of ways of talking about the child functioned to legitimise certain child involvement practices. Turning to the data again, I asked these analysis questions: How do the professionals talk about child involvement? How do they proceed in their child involvement practices? How do they legitimise their child involvement practices? Paper 1 presents some of the results from this analysis.

Who has the power to decide how much and in what ways the child is involved?

During one of the pilot interviews, a dilemma arose: when patients' withhold information about illness and death from their child, the health professionals are bound by professional confidentiality and cannot contribute to the child's need for information about the parent's illness and prognosis. A PhD course in professional ethics gave me the opportunity to become immersed in this dilemma through literature regarding professional confidentiality (Bok, 1988, 2010a, 2010b; Kipnis, 2006) and professional–patient relations (Faber, 2003). After conducting ten more interviews with health professionals, however, the picture seemed more messy and complex than patients' withholding information or being open in their communication about illness and death. During the initial readings and coding of the health professionals transcripts, it became clear to me that there were many agents involved that contributed in the inclusion and exclusion processes. I struggled trying to come to terms with *who* has the power to decide how much or in what way the child is involved. I left NViVo, and based on this question, I made a grid of the persons or parties involved (patient, healthy parent, child, health professional) and whether they wanted the child to be involved or not and noted all the possible combinations of alternatives in the grid. I made analysis notes on the different combinations, where I elaborated on the possibilities of professionals to involve in each situation (row) with accompanying text extracts from the transcripts. A simplified version of the grid can be seen in table 4. The insights from the work with the grid gave rise to several new analyses.

Table 4: Analysis grid

	Ill parent	**Healthy parent**	**The child**
1	Yes	Yes	Yes
2	Yes	Yes	No
3	**No**	Yes	Yes
4	**No**	Yes	No
5	**No**	No	Yes
6	No	No	No
7	Yes	**No**	Yes
8	Yes	No	No

Grid of the parties involved who may say "Yes" or "No" on whether child be involved (should have information about illness and prognosis and be involved by visiting in hospital etc.)

The grid made me aware of how the persons represented in the grid had unequal opportunities to voice their choices and needs, and these opportunities varied according to the “status” of the other persons in the grid. The grid made it clear to me that there were more combinations that could create different “versions” of this dilemma, particularly regarding the role of the healthy parent (“No” in the “Healthy parent” column, rows 5–8). For example, a child who wanted to be involved and to know more about the parent’s disease etc. had the opportunity to talk to the healthy parent even though the ill parent was “in denial”, but only if the healthy parent was open to involving the child and then going “against” or “behind the back” of the ill parent. I read the interview transcripts again with this new awareness, and on this basis I developed the analyses resulting in paper 2 (Hogstad & Leer-Salvesen, 2020).

How do professionals contribute to forming the child’s view?

Including the column “The child” was also important to grasp the complexity of the dynamics surrounding situations of parental illness and death. In the interviews, several of the health professionals talked about the child’s right to decide for themselves whether they wanted to know more, whether they wanted to visit the hospital and so on. I was familiar with similar statements from previous research (e.g. Søfting, Dyregrov, & Dyregrov, 2013). Giving children the opportunity to choose not to be involved and not to know opened up the possibility of the parent dying without the child knowing in advance that the parent was severely ill and dying (even though both parents and health professionals offered information and were open to involving them). This puzzled me, as, based on traditional developmental psychology, I *doubted* the child’s possibilities and preconditions to actually make these decisions about their own participation since children—at least the youngest ones—will not know what they are opting in or out of if they do not have a developed concept of death (Hogstad & Wold, 2016). Further, based on sociocultural developmental theory about how children form their views in joint meaning-making together with others (Gulbrandsen et al., 2012; Ulvik, 2015), I became aware of how the professionals, in claiming that “children should decide for themselves”, were blind to their own contribution and *power* in the formation of the child’s view and choice.

Michael Gallagher’s (2008) suggestion to theoretically understand children’s participation in decision-making processes (UN Convention of the Child’s Rights) through the Foucauldian concept of power as “actions upon actions” opened my eyes to how adults’ (parents, health professionals’, kindergarten teachers’, priests’) actions regulate children’s possibilities to “decide for themselves” how they want to participate when a parent is severely ill and dying. I also found inspiration in Højholt and Kousholt’s (2018) concept of participation, where professionals contribute to the distribution of conditions for children’s opportunities to develop ways of conducting their life. I read the transcripts again, looking for descriptions of meaning-making work in practice situations, not limited to “successful communication” but also involving actions such as ignoring the child, using euphemisms and expert language (for example medical terms), keeping secrets, lying and distracting the child with ice creams and sweets. These analyses helped me grasp greater range and variability in the health professionals' child involvement practices than I would have if I only focused on child involvement practices based on professional advice on child involvement, for example, open communication about illness and death and physical presence (visits etc.). This helped me to further develop 1) a theoretical definition of child involvement as actions upon actions (see discussion, p. 67) and 2) new rounds of analyses, now including transcripts from the interviews with the kindergarten teachers.

In the analyses of the transcripts from both phases of interviews, I systematically analysed how the professionals contributed as interpretation partners in the joint meaning-making about parental illness and death by analysing professionals' verbal descriptions of direct encounters between the professional and the child (see details in the methods section of paper 3 and a detailed analysis plan in appendix 7). The preliminary analyses made me aware of the physical body as a meaning-making resource, and this analytical "shoot-up" made me look for all types of resources used in the meaning-making processes within both contexts. Hundeide's (2003) concept of dialogues that form and expand meaning towards socioculturally shared meaning allowed me to open up for the reading of meaning-making towards several parallel, and sometimes competing and conflicting, socioculturally located discourses of death (Hogstad & Wold, 2016). An important methodological aspect of this analysis was the inclusion of embodied and affective responses and initiatives from children (body movements, singular words or sounds, silence, listening) as contributions in joint meaning-making, in line with Berit Bae's (2009) theorisation of children's participation as embodied and dialogic. As an illustration, see the second example in table 2 in paper 3, where a two-year-old boy responds by standing up and saying "mum" upon listening to music as part of a gathering in the kindergarten. Here, the kindergarten teacher "Vilde's" knowledge about his mother playing the instrument they had heard played in the music allowed her to interpret the boy's response as an initiative to memorise his deceased mother, and she built on this response by expanding it further with a picture of the instrument and verbalising that his mother played the instrument. The results from this analysis are presented in paper 3 (Hogstad & Jansen, Under review).

Discursive negotiation of moral positions

Through all of these readings and analyses, I became increasingly aware of how health professionals and kindergarten teachers have discursively negotiated their moral position in relation to the child, with references to attachment and emotional bonds, to numbers of hours in the week spent in kindergarten compared to at home with their parents etc. This awareness, theoretically informed by Erica Burman's (2008) deconstruction of attachment theory and positioning theory (Harré & Langenhove, 1999), contributed to the development of the theoretical construct “hierarchy of closeness”, which I will outline in the discussion.

Translation

As all interviews were conducted in Norwegian, the analysis processes were primarily “located” within the Norwegian language. I was not aware of the implications of that in the beginning, but when I was going to translate text sections from Norwegian to English during the manuscript writing, I became aware of how much of the meaning was located in the Norwegian language. For example, in the discourse analysis for paper 1, I interpreted a section where a nurse described a home visit to a dying mother, where the youngest girl of the family was present in the living room and the rest of the family (patient, her husband and her mother and father) had a conversation with the health professionals from the palliative team that was visiting. He talked about this little girl as “lillejenta” and described her presence in the living room as running back and forth. It was something in the way he said “lillejenta”, which directly translates to “little girl”, that I could not find a good English translation for, as if the alternatives in English did not carry the meanings that I felt lay in the phrase because he used it in the specific context. I felt that each translation from Norwegian to English had the same problem to a greater or lesser degree. I thus added text sections in Norwegian in appendix 8 so Norwegian-speaking readers have the opportunity to consider my translations.

Ethics

Ethical considerations were an integral part of the considerations throughout the research endeavour. There are three issues regarding ethical considerations that I want to discuss in the present section: 1) retaining anonymity for participants and third persons, 2) informed consent and 3) the research interview as an intervention.

Retaining participant and third-person anonymity

Confidentiality and privacy are central in codes of conduct for both professionals and for researchers, and they were central issues for me when designing the study and arranging recruitment processes. The first approval from the Norwegian Data Protection Services (see appendix 1) did not involve retaining consent from patients, and hence a presupposition was that patients and third parties were not identifiable to me.

During recruitment, one of the nurses shared her worries that she might reveal confidential information about her patients and their families if participating. Before giving her consent to participate, she needed me to reassure her that participant and third-person anonymity would be retained. The code of ethics defined by The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH, 2016) states that, in protecting privacy (pp. 12–13), the researcher “must be particularly attentive and responsible” in situations like the one at hand: when the participant actively contributes by being interviewed, when the person might be identified (through a relatively small and transparent palliative milieu as in Norway) and when the research affects third parties. In my writing, I have therefore been sparing in describing details about the participant characteristics as well as in the stories they told.

During the review processes for papers 1 and 2, however, I felt pressure from two reviewers to reveal more about the participants' characteristics and stories than I was comfortable with. They made requests for more insight into the empirical material and more detailed participant characteristics to provide more transparency and nuance in the discussions. One reviewer stated that "More evidence from the actual stories included would benefit the reader". I found it ethically problematic to addresses these suggestions directly because I was concerned that the research participants' anonymity would not be retained. I was also concerned that detailed stories could make the families identifiable.

Transparency, however, is a good argument for why it might be legitimate to share more details. Being transparent is foundational for the possibility of conducting peer review, quality assessment and the assessment of the trustworthiness of the study and conclusions made. If the knowledge contribution presupposes transparency of the specificities of the stories at hand, it might be unavoidable that the people (third persons or participants) involved in the situations would recognise themselves or their close relations in the publications. Still, I tried my best to balance the way I presented the empirical material and participant characteristics so that relevant characteristics and information were provided, but with limited possibility to combine the information so that it would become identifiable.

In hindsight, I think that in the future I will be more hesitant if a potential participant worries whether he or she will retain the confidentiality that he or she advocates, and I will grasp the opportunity to reflect upon the ethical dilemmas and potential consequences together with the person. In the present case, I might have been too eager to recruit her as a participant, perhaps relying too much on my own duty to confidentiality that I have as a researcher. One of the sources of these reflections in hindsight comes from the experiences of interviewing in the second phase.

In the second phase of interviews, being able to maintain the children's and their families' anonymity was a much bigger challenge, as kindergarten teachers would not be expected to have experience with more than one, or maybe two, incidences of severe parental illness and death in their kindergarten (see correspondence with NSD in appendix 2). In addition, in 2018 a new law was enacted in Norway, intending to secure personal information and implement the European Union's privacy regulation (GDPR). Among other things, the law made rules about consent more stringent than they were at the time when the first interview phase was conducted. The kindergarten teacher interviews therefore had to be conducted by first obtaining consent from the families that the kindergarten teachers were describing; hence, they did not have to anonymise or de-identify their stories. After conducting the kindergarten teacher interviews under different circumstances than with the health professionals, I realised that the interviews in the first interview round would have benefited from the same consent procedure. The practicalities surrounding this appeared challenging at first, but after having tried it another way during the kindergarten interviews, it appears at least *possible* to do it in a similar way with health professionals as well.

Informed consent

In the recruitment and participants sections above, I state that the participants received written and sometimes also oral or video-taped information about the research project, and they volunteered to participate and provided their written consent. During the recruitment phase of phase 1, however, I struggled with the degree to which I should inform the participants that I intended to analyse their accounts with the aim of locating transindividual meaning located in discourses. Discourse analysis may involve a reading of the participants' accounts as *text* (Parker, 2014), and hence discourse analysis can be criticised for objectifying statements rather than viewing them as subjective expressions inherent in a dialogue between two subjects (Skjervheim, 2002). In hindsight, I feel confident that I conducted a discourse analysis in which I considered statements both as made possible by transindividual, discursive resources and as speech acts—intentional and with a subjective dimension. Still, at that time I was afraid that I had deceived the participants by not informing them that I was going to conduct discourse analysis at the time of obtaining informed consent. This fear led me to elaborate on what should be considered *informed* consent.

Kleining (2010) defines consent as a communicative act that transforms the moral relation between A and B, here the relation between me as a researcher (A) and the participant (B). In this case, the moral transformation is that the participant makes it legitimate for me to do (at least) the five following acts, which would not have been legitimate without B's consent: 1) keep personal information about him or her that I otherwise would not have had access to (telephone number, full name, education, workplace etc.); 2) take his or her time, for the purpose of 3) asking questions that give me indirect access to his or her experiences, meanings, stories and views on minor children; 4) store files with data material from our interview; and 5) analyse the data material according to the aim and purpose of the project. To say that the consent was *informed*, the participants must have understood that they consented for me to perform the five acts mentioned above. This leads us further toward the concept of informed consent.

According to point 8 in the Norwegian National Research Ethics Committees' guidelines for research ethics in social sciences, law and the humanities (NESH, 2016), consent is informed if it meets both of the two following criteria: 1) The researcher discloses "general information about the project such as its purpose, the methods to be used, and the practical and other consequences of participation" (p. 12); and 2) "[t]he information [is] adapted to the recipient's ability to understand it" (p. 12). These criteria are in line with the definition of truthfulness, taken from Bok (2010a, 2010b), and with Beauchamp and Childress' (2013) elements of informed consent. Beauchamp and Childress state that "disclosures should generally cover the aims and methods of the research, anticipated benefits and risks, any anticipated inconvenience or discomfort, and the [participant's] rights to withdraw, without penalty, from research." (p. 125). Should I inform them that reading the results of the study might lead to inconvenience or a feeling of discomfort because they might feel alienated from their own statements and meanings? And, if I did, would that influence the participants' awareness of what they said in the interview in a way that yielded poor quality data?

Ultimately, I was content with only providing general information about the aims and methods (see information letter in appendix 3). My conclusion based on this elaboration was that, as long as the interview participants were professionals—they were being interviewed by virtue of their profession and not by virtue of their person—they are not particularly vulnerable individuals and should expect critical evaluation from a researcher. This critical evaluation might be experienced as uncomfortable in confrontation with the results presentation, but if this is a productive feeling that contributes to reflection upon practice and with learning processes, it might be legitimate. In fact, it will not only be legitimate but also have the potential to change practice by challenging and destabilising established knowledge, which is one of the aims of the present study. The potential of research to contribute to changing the professional practices that are being researched is one of the topics in next section as well.

The research interview as an intervention

In line with the retroduction logic presented in the methods section (pp. 31-33), inviting participants to talk about the minor children of their patients or children in the kindergarten that have had a severely ill and dying mother or father contributes to producing the phenomena at hand. The mere initiative of the interview communicates something, and the researcher may not have access to what it communicates to the interviewees before having conducted analysis of the data material (and not even then). For example, in interviews with young people in residential care performed by Anne Jansen in her PhD work, the initiative of the research interview signalled an interest in the young people's own narratives, as experienced from their perspective. In this way, the research interview seemed to have the power to position the young people in more liveable positions than the stereotypical troublemaker or victim positions that were regularly offered (Jansen, 2015). This is not necessarily the same message that I communicated. What did *my* initiative communicate?

During the first phase of interviews, I experienced that the health professionals had certain expectations about what my research endeavour was. These were sometimes explicitly stated, but mostly implicitly. For example, one nurse demonstrated how clever she was in her efforts to support and follow up on children as next of kin as well as in her efforts as a child-responsible personnel (ref. ASHS §3-7a). Another nurse at the end of the interview stated that she “had to be so honest” to admit that they “did not always have the time and resources to follow up on children as next of kin as much as they probably should have done”. These interview experiences told me that the participants had a particular notion of what I wanted them to say in the interview, and my initiative to interview them might have strengthened this notion. It is also possible that health professionals who were invited to join in did not want to participate because they felt that they were not good enough in supporting and following up children as next of kin, and they did not want to be “revealed”. Did my interview invitations and initiative function as an intervention, where I signalled to the health professionals that it was their responsibility to *talk to* and follow up on the child? What the further consequences of this might be for society and the individual is not clear to me. One possible critique toward me is that I contribute to reproducing knowledge that might have an oppressive function by focusing exclusively on individual psychological therapeutic interventions (more about this in the discussion).

In phase 2, I did not experience that I was contributing to the same type of construction upon initiating interviews with kindergarten teachers. Here, the initial contact was made through the families, which they personally knew. This might have contributed to adding another meaning behind the research participation for the kindergarten teachers compared to the health professionals. Is it possible that it led them to feel that they did it *on behalf of* the family and the child? Further analyses of the interview data could illuminate how the research interview functioned to position the kindergarten teachers and the health professionals.

Another aspect of the interview as an intervention was that the interview provided an opportunity for the professionals to reflect upon own practice. The interview represents an arena where the interviewer provides time and space as well as joint interest in the stories, views and experiences of the interviewees. However, reflecting upon own practice creates the potential for changing practice. There was many examples of this during the interviews, particularly for the life-mode interview, and hence they were most evident in the second phase. During the interviews, several kindergarten teachers commented about realising that it was about time to talk to the parents about involving the child more etc. One of the leaders came to me after I had interviewed her and two of her staff to ask me if it sounded to me as if they had handled the situation in the kindergarten in a good way. It appeared the kindergarten teachers were “hungry” for more supervision and guidance about how to handle the situation in the kindergarten. The interview questions and general focus of the interview potentially gave direction to and intervened in the kindergarten teachers’ ways of encountering the child and his or her family in the everyday life of the kindergarten.

A dimension worth illuminating here is that the interview function as an intervention in different ways depending on whether the child or patient in question is still in the kindergarten or ward. In both cases, the interview might intervene in professionals' practices through reflective practice, which can provide new understandings and ways of doing things, which in turn may have an impact on the working environment. In situations where the child is still in the kindergarten or the patient is still in the ward or on the health professionals' list, the intervention potentially has consequences for the individual child as well.

5 Summary of results

The overarching research question of this thesis has been the following: How do professionals encounter young children experiencing parental severe illness and death? How do the three papers answer this question?

Summary of paper 1

Hogstad, I. & Jansen, A. (2020) Smart, vulnerable, playful or just disturbing? A discourse analysis of child involvement in palliative care. *Childhood, 27*(4), 468–482. doi:10.1177/0907568220918910

The article theoretically departs from the idea that professionals' encounters with young children experiencing parental severe illness and death will be dependent upon socioculturally shared systems of meaning that are relevant within the specific situation. The paper analysed patterns of discourse to tap into these socioculturally shared systems of meaning and found patterns of four ways of talking about the child that form four discernible lines of argument about child involvement. These lines of arguments, or interpretative repertoires, are Children as individual thinkers and interpreters, Children as belonging to their parent, Children as playful and full of life and Children as disturbing elements. These interpretative repertoires give direction for moral positions for both parents and health professionals. Even though the analysis cannot say anything about the "underlying truth" about how the health professionals "actually" encountered the young children, it provides insight into legitimate arguments for different child involvement practices, hence giving insight on *possible ways of acting* for the health professionals.

The first repertoire argues that, since children understand more about illness and disease than the parents sometimes are aware of or capable of understanding, it is legitimate and desirable for health professionals to intervene by talking to the children and exploring their subjective experiences and views about the parent's disease and correcting misconceptions they might have. The second repertoire argues that, since (young) children are dependent on their parent, and the parent knows them best, health professionals are in no position to encounter young children. Other persons might be emotionally closer to the child and will be better suited to take care of the child's needs for comfort and care. The third repertoire argues that, since children by nature are resilient and have their child-specific way of going in and out of play and grief, health professionals must encounter young children in the ward by facilitating time and space for play. Health professionals could legitimately allow children to play and "be in their child world", free from illness and death. The fourth repertoire argues that, since children do not fit into the hospital ward, either because of their young age or if they are not properly adapted or deviant and do not behave in an acceptable manner, they should be there for only very short visits and should then be released so that the doctor may do their work. The repertoire legitimates doctors leaving the children to the nurses, and hence it points to profession-specific ways of encountering young children within the health system context. In the discussion, we point to how discourses of “the good death” and of individualist psychology provide overarching meaning structures that impact professionals’ practices.

Summary of paper 2

Hogstad, I. J., & Leer-Salvesen, K. (2020). Going against patients’ will? A qualitative study of how palliative health-care professionals handle competing considerations when children are excluded from parental illness and death. *European Journal of Oncology Nursing*, *49*, 101839. doi:https://doi.org/10.1016/j.ejon.2020.101839

The article concerns health professionals’ encounters with patients *about* the involvement of their children when the patient wants to withhold information about illness and prognosis from their child. The paper analyses which considerations come into conflict in the professionals’ practice and how these conflicting considerations limit the health professionals’ possibilities of involving the child (not limited to the youngest children). Two main considerations for the professionals were working for trust in the professional–patient relationship and retaining the patient’s hope. These two considerations are well known within nursing theory and practice. Still, the papers adds another dimension to these considerations when the patient is also the parent of a minor child, as the professional considerations may come into conflict with the child’s right to be involved.

The paper points to the primacy of the patient within the health care system, and with that the fact that health professionals’ access to the child is *through* the patient. This means that the health professional working in a ward or an outpatient clinic will not encounter a child that is being excluded from the health care context from their parent. For health professionals working ambulantly, the situation is different. They might encounter the children during visits but are still dependent on the trusting relationship with the patient to be able to fulfil their prioritised medical tasks. Still, the highly valued patient autonomy makes it difficult for health professionals to directly counter the patients’ wishes and personal choices, even though it involves not allowing their child to see them when they are ill or even to know that they are going to die. The health professionals reported encountering the moral problem between meeting the children’s right to information and securing the patient’s autonomy by adopting different positions on a continuum between these considerations. The position they took up seemed dependent on conditions such as available time, illness progression and whether they were working closely with the patient and alone in the municipal health service, in teams or in a ward. There seems to be a bias among health professionals toward securing patients’ right to patient autonomy above securing children’s right to be involved. The paper concludes by proposing that procedures for initiating collaboration with the professionals from the children’s everyday life context may help health professionals to involve the children without threatening the trust in various interpersonal relationships.

Summary of paper 3

Hogstad, I. J. & Jansen, A. (under review in *Early Years*) Parental death in young children's everyday lives: Health professionals' and kindergarten teachers' contributions in meaning-making.

The article concerns health professionals' and kindergarten teachers' direct encounters with young children (below school age) experiencing parental illness. The transcripts from the interviews with health professionals contained detailed descriptions of encounters with children where they made meaning about death together with the child and the dying or dead body. Together with established knowledge from previous research on children's intuitive understanding of death, which relies on concrete and explicit visual signs of death (Hogstad & Wold, 2016), these detailed descriptions made me aware of how the physical (dead or dying) body constituted a material resource for making meaning of death in a way that did not rely on language skills and *talking* activities. This made me want to look more into professionals' different ways of interacting with children to make meaning of parental death.

We utilised detailed practice descriptions in both phases of the interviews, first with health professionals and then with kindergarten teachers. The analysis focused on how the professionals contribute in meaning-making processes about parental death and looked for forms of interactions and resources used to make meaning. The study indicates that the two groups of professionals encounter children through different forms of dialogues, relying of different resources, both materially and discursively. The health professionals engaged in meaning-making dialogues that were centred on death as a biological phenomenon and dying as a biomedical process, relying on medical equipment and the dying or dead body as a meaning-making resource. The kindergarten teachers mainly engaged in meaning-making centred on parental death as an emotional and relational phenomenon. Peers in the kindergarten were important contributors to the meaning-making dialogue.

The article discusses how the professionals' contribution to meaning-making about death may open up or limit the child's possibilities of developing ways of taking part across contexts when a mother or father is severely ill and dying. First, involving children in dialogues is, in itself, to acknowledge them as participants, and this equips them with possibilities, for example, of rejecting and resisting or of expressing themselves. Second, involving children in dialogues provides them with discursive resources, which opens up their possibilities to share their experiences with others in other contexts. Knowledge about context-specific ways of making meaning of death illuminates professionals' contribution to children's development of ways of taking part, as children's participation in meaning-making dialogues develops their understanding towards (multiple) sociocultural concepts of death. Kindergarten teachers and palliative health care professionals have their context-specific ways of engaging in meaning-making processes about parental death together with the child, hence both groups have contributions that cannot be secured by the other group of professionals. However, their possibilities to provide meaning-making support is partially dependent on the collaboration and communication between health professionals and kindergarten teachers.

6 Discussion

This thesis has taken a critical sociocultural psychological-inspired approach to studying professionals' encounters with young children experiencing parental illness and death. In the introduction of this synopsis, I criticised previous clinical-directed research on children experiencing parental illness and death for applying theoretical models and methodological approaches that do not capture the complexity of the processes involved and the developmental processes following the loss. Further, I claimed that the state of the art *enforced* this thesis' critical approach because, in order to produce original knowledge situated in the young child's everyday life, it has been necessary to destabilise dominating normative conceptions in the research field. The present study's theoretical approach contributes contextualised knowledge about children experiencing parental illness and death and professional practices of child involvement.

The first section in the discussion-chapter take a macro-perspective on professional encounters as culturally and historically situated. The second section discusses three reasons why the youngest children have been excluded from studies of parental illness and death and presents an alternative theoretical approach that considers preverbal children as well. The third section discusses limitations by the methodological approach. The fourth and final section explains how the theoretical model of the child as a social participant enables child involvement practices that are directed toward the child's developmental conditions rather than to the individual child or family as isolated entities.

How may we understand professional encounters with young children as cultural-historically embedded?

Contextualisation is one of the basic principles of sociocultural developmental psychology and means that child development must always be understood as processes embedded in social, historical and cultural contexts. Professional child involvement practices must also be understood as contextualised within the "wider sociohistorical and cultural institutional practices and constraints" (Burman, 2018, p. 1602), as these contribute to regulating the possibilities and conflicts in the professional encounters. The three papers in the present thesis contextualise the knowledge about professional encounters to some degree. Paper 1 pointed to the dominant medical discourse, individualist psychology discourse and the discourse on the "good death" as discursive conditions for the professional encounters. Paper 2 related the professionals' dilemma to patient autonomy as a self-evident value in Western societies today, and paper 3 shed light on different sociocultural conceptions of death and dying. I want to take the contextualisation a step further here and argue for an understanding of professionals' encounters with young children in Norwegian welfare services today as embedded within a culture characterised by neoliberalism and individualism—with their accompanying technologies of psychologisation, medicalisation and professionalisation (Ekeland, 2019; Graven et al., 2013). This contemporary culture offers socially constructed meaning structures that function as discursive resources for the negotiation and distribution of rights and duties regarding the care, follow-up and involvement of young children. I will go into three aspects of this: first, how psychologisation may produce an expectation that professionals engage in therapeutic dialogues; second, how professionalisation may produce a feeling of insufficiency in parents; and third, how contemporary culture provides a meaning structure to distribute rights and duties of child involvement according to who is *emotionally closest* to the child.

Therapeutic psychological dialogues as a neoliberal technology

The language in §10a in the Health Personnel Act (2010) does not explicitly oblige health professionals to engage in direct encounters with children or to secure the child's need for information alone (only to *contribute to*). However, in the procedures outlined by BarnsBeste and in the circular accompanying the legal regulation (Helsedirektoratet, 2010), we do find professional–child conversations as one of the delineated interventions. In these documents, the legal obligation has been interpreted as a stronger obligation for health professionals in direct encounters with minor children. How do these documents relate to what is found in the present study and in previous research?

The present study and previous research draw an ambiguous picture regarding professionals' engagement in direct encounters. On the one hand, professionals within health, school and kindergarten contexts make references to "child talks" and making children "open up". In papers 1 and 3, we pointed to how professionals, both the health professionals and kindergarten teachers, engaged in therapeutic psychological dialogues with adolescents and children. A review of the approaches used to support bereaved pupils in schools by Duncan (2020) refers to a tendency among teachers to become counsellors rather than educators. On the other hand, the present study as well as previous research (e.g. Golsäter et al., 2016) indicate that professionals also seem to avoid engaging in direct encounters and dialogues with children. Some collaborate with others (parents or other professionals) and supervise them in how they should support the children, while others seem to avoid completely to engage themselves with minor children as relatives (Golsäter et al., 2016). Together, the incidence of references to psychological dialogues in the health professionals interviews in the present study, regardless of whether they actually had these conversations or simply expressed being guilty for not having had them, indicate that the health professionals *feel an expectation to* have "child-talks" and child-directed therapeutic interventions. Where does this expectation come from?

Nikolas Rose (1998) has argued that the growth of therapeutic disciplines must be understood as related to liberal democracies' rationality of governing as "governing souls" (Ekeland, 2019)—individuals must be governed based on individual autonomy instead of authoritarian exercise of power (Farsethås, 2009). Within this view, governing involves leading individuals to make the right choices with "free choice", and different *technologies* make this governing rationality possible (Miller & Rose, 2008). From this view, therapeutic dialogues can be seen as technologies aiming to help children to manage their feelings and to develop emotional self-control and regulation (Ekeland, 2019).

The analysis of the three lines of argument in the previous research section supports this interpretation. The first two lines argue that children need to be involved in open communication about illness and death to be able to cope with the emotionally overwhelming situation that they are in, and children at risk of pathological development following the death of a parent must receive professional support to alleviate these effects. Thus, the technique of therapeutic dialogues is fuelled by developmental psychological discourses about risk and resilience (Gladstone et al., 2006). Still, the professional medical logic and the structural frame of the health care system not only limits health professionals' possibilities to engage in direct encounters with children (Karidar et al., 2016) but also defines it as a task that is "outside" of the responsibility of the medical care of the patient. Why do still some nurses and doctors engage in therapeutic dialogues?

One obvious answer is that they do it because they think it is necessary for the patient and the child, and it accords with their code of ethics (Davis, 1991). However, it might be more than an altruistic concern for children's development. One way of understanding it is that the health professionals actually develop a self-understanding and professional identity that makes them *want to,* making it feel meaningful for them to engage in psychological dialogues with the children[14]. Another way of understanding it is that emotionally regulated children are "better fit" within the palliative context. As we pointed out in paper 1, this concerns both how "active, unregulated" children disturb the doctor from doing her job and conflict with the aim of a peaceful death and how the "natural and calm child" may accord with it (Hogstad & Jansen, 2020).

Health professionals as providers of expert knowledge—and parent blaming?

In paper 2, we focused on the professional–patient communication when the patient does not want to involve the child in the way that the professional think is the right way. The specific formulation "the way that the professional think is the right way" points to the fact that the different actors may have different views on what is the right way to involve the child. The Swedish researchers Karidar et al. (2016) highlighted the same issue: parents often want to protect their child from matters related to illness and forthcoming death. These findings are consistent with the interpretative repertoire "Children as individual thinkers and interpreters" in paper 1, where the health professionals positioned parents as overprotective and unaware of their own children's competencies. Who has the power to define and decide what is the best way of involving a child? On the one hand,

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[14] Two of the participants from one of the large hospitals, were Child-responsible personnel. Both of them were overtly prone to proudly report on their initiatives to talk to and relate to the young children that they encountered. One of them also referred to how she previously was afraid of the minor children of her patients, but that she had grown through practice and become more skilled and secure in her role.

parents (with custody) have the indisputable legal right to make decisions on behalf of their children. On the other hand, an evidence-based practice movement and increased professionalisation may have the power to challenge the parent's moral position.

The Scandinavian countries' recent law changes and guidelines for professionals to secure the child's right to be informed about their parent's disease and prognosis may be understood as a professionalisation: the scientific knowledge about "best practice", owned by the professionals, has hegemony above the particular knowledge that the patient has about his situation, his child and his family. At the same time, the neoliberalist rationality about individual freedom dominates, and the health professionals seem overtly aware of not challenging the patient's autonomy. The health professionals' obligation is thus to provide expert knowledge about what is in the child's best interest, but without coercion or paternalism. Rather, they must provide information about the benefits of involving the child and the risks of not doing so. This could be exemplified by the position "Presenting a realistic picture" in paper 2, where some professionals referred to research on the potential risks of not involving children and cited this knowledge as an authority to challenge patients' views. This reference to research could be tied to the evidence-based practice movement, whereby evidence is privileged over clinical judgement (Ekeland, 2009; Lipworth, Carter, & Kerridge, 2008).

One example of professional advice from experts is open communication in the family. Previous research on children's and families' experience of severe parental illness has focused on open communication in the family as beneficial (e.g. Hanna et al., 2019). A myriad of psychosocial family interventions provide evidence-based support to families aiming to enhance their parenting competence and facilitate open communication in the family system (Bugge, Helseth, & Darbyshire, 2009; Eklund, Alvariza, Kreicbergs, Jalmsell, & Lövgren, 2020; Kühne et al., 2012). Erica Burman's (2008, 2018) critique about the normative effects of individualised, neoliberal definitions of families, what she calls the "textbook model of family", might well apply here to contextualise the quest for open communication. The textbook model of a family is the nuclear family, consisting of heterosexual couples with their genetic children, and I will add, based on the previous research review, a family environment characterised by open communication, emotional warmth and psychological support. In the present PhD project, open communication within the family seemed to be a compass for the health professionals and the kindergarten teachers. The professionals talked about "open" families as resourceful, easy to collaborate with and making it easy for the professionals to "do their work". "Open communication" seems to be a "buzz-word" that is impossible to disagree with.

At the same time, free choice informed by expert knowledge places the responsibility on the individual patient/parent, with the accompanying moral blaming of parents who do not choose to do what is best for their children according to professional advice. Further, the risk-resilience discourse about child development, where early childhood experiences, particularly those tied to the parent–child relation, are given weight as a cause of undesirable psychological consequences in adulthood (Gladstone et al., 2006), contribute to the blaming of parents for their children's development of pathology in adulthood (Burman, 2018). The precedence of putting the emotional, interpersonal bond between parent and child as explanation of and cause for delinquency and psychopathology, before structural conditions that make some individuals and groups privileged and others marginalised (Burman, 2008, 2018), contributes to what Burman (2018, p. 1600) calls *parent blaming*. Whereas some families in the present PhD project were categorised as "resourceful", others could be categorised as "not resourceful" and hence in need of supervision and help to be open about illness and prognosis in the family and with their child. The research literature, particularly within the parental loss field, abounds with categorisations of families according to norms and standards (such as "family functioning" "communication patterns"). For example, Christ and Christ (2006) distinguish between "adequately resourced and stable family relations" and "less stable backgrounds or under-resourced family environments" in their research. Open communication about illness and prognosis becomes a *moral* obligation and a criterion by which it is possible to delineate normal families from deviant ones, or risky childhood environments from those not representing risk.

Against this background, it is interesting to look at previous research emphasising parents' experience of feeling insufficient in their parenting capacity (Aamotsmo & Bugge, 2014; Semple & McCance, 2010; Tavares et al., 2018) and that support from professionals does not meet their individual needs sufficiently to be able to fulfil their responsibilities as parents (Golsäter et al., 2019). From a child development perspective, it seems important that parents perceive themselves as competent in their parenting to remain stable and secure in their parenting practices. However, a question remains of whether the family interventions solve the problem or actually contribute to producing it. The stated need for family interventions, expert knowledge and help from professionals to be able to feel competent as a parent and to be able to talk to one's child about illness and death may contribute to producing a feeling of insufficiency in parents, hence reproducing the problem.

The Hierarchy of Closeness

A central theoretical point in the present thesis is that health professionals, kindergarten teachers and parents discursively negotiate child involvement: What is the morally right way of involving children in matters relating to parental illness and death, to what degree and by whom? In this section I start out with a short recap to the dominating cultural discourses about childhood and family delineated in this thesis before I present a construct, "*The hierarchy of closeness*", developed through the retroductive reasoning process of this PhD project, which explains the relation between the dominant neoliberal discourses of childhood and family and the distribution of moral positions, rights and duties in relation to children experiencing parental illness and death.

The dominating cultural discourses about childhood and family delineated in this thesis, constitute background knowledge toward which health professionals, kindergarten teachers and parents negotiate child involvement. In paper 1, we discerned four interpretative repertoires that functioned as discursive resources for the health professionals in their legitimation of child involvement practices. In the theory section, I outlined the "textbook model of family" and the individualised "early 2000 version" of attachment theory (Burman, 2008, 2018), which constitute cultural narratives; the storyline "parenting", with the complementary pair of positions "parent" and "child", tells a story about the responsible and protective parent and the vulnerable child in need of protection, with accompanying rights and duties. Or a cultural narrative about the caring, attentive and loving caregiver that takes responsibility for her children so that the child is "allowed to be a child" and live in his or her untroubled "child world", free from negative, unpleasant feelings, worries and responsibilities that belongs to the adult world. These dominating discourses provide storylines and make subject positions available to take up and position others within. They also provide troubled subject positions, such as "inattentive mother" or "selfish mother", with the accompanying "poor child" and "child in need" (Burman, 2008; Van Langenhove & Harré, 1999).

Related to the individualised "early 2000 version" of attachment theory is the positivistic idea about a linear, causal relationship between the mother–child relationship in childhood and the development of psychopathology in adulthood (Burman, 2018). This idea places more weight on the importance of early childhood development (also visible in the previously mentioned "early intervention" trend, see more p. 24). A central point is that these discourses make it morally praiseworthy to be an emotionally attentive caregiver (mother) who succeeds in achieving a secure attachment[15]. Together, these make up socioculturally dependent and transindividually located discursive resources that make negotiation of child involvement practices possible.

The specific meaning structure that I present here constitutes a taken-for-granted transindividually located meaning structure that health professionals and kindergarten teachers draw on when negotiating child involvement and their particular position in the specific context or episode. It concerns what is in the child's best interest and who is best able to provide for the child's needs. I have called this meaning structure *The hierarchy of closeness* for two main reasons. The right to distribute rights and duties is hierarchically structured, and the hierarchy is structured according to emotional closeness to the child. The hierarchy is continually discursively and socially produced, reproduced and

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[15] Even more, it is praiseworthy to succeed in breeding the child to become an autonomous, economically efficient adult with good mental health, in line with the neoliberal ideal.

negotiated through people’s communicative acts as well as social and institutional practices (Harré & Van Langenhove, 1999).

It is a point that it is hierarchically structured: the emotional, interpersonal bond to the child defines who is on top of the hierarchy. He or she who is on top is “number one”, the most important person for the child, and has the right and duty to know and act upon what is in the child’s best interest, to make decisions on behalf of the child and to distribute others’ rights to closeness with his or her child. At the next level of the hierarchy is the “second best”, that is, the next best person to provide for the child’s needs. When the owner of the top position is temporarily away, the second best/number two has the duty to distribute other persons’ (who are lower in the hierarchy) rights.

When a mother or father become severely ill and is dying, their position closest to the child is threatened. The clusters of rights and duties tied to the position of being a “a good mother” in the contemporary hegemonic narrative is that she is sensitive and emotionally available, she places her child’s best interests in front of her own and she ensures that the child’s needs are met appropriately and that nothing harms the child emotionally or physically. Being unsuited or incapable of adhering to a mother’s duties (because of illness etc.) may challenge her position on top of the hierarchy. This opens up a space for negotiating who is the “next one in the hierarchy” and hence closest to the child.

Such negotiations regard not only the *right* to be closest to the child but also the duty. They involve both positioning acts of taking up the position on top and of *rejecting* a position high up or on top of the hierarchy. As an example of the former, of taking up a position, the health professionals applied the interpretative repertoire “Children as individual thinkers and interpreters” (presented in paper 1) to conduct a first-order positioning of parents as “ignorant”, with limited ability to move beyond the misconception that everything is fine with their child due to the severe illness in the family. They blamed parents for not being good enough in their parental task of talking to and understanding their child’s inner thoughts and feelings. This discursive positioning of parents challenged the parents’ position on top of the hierarchy as the one who knows their child best. With their second-order positioning, health professionals have the opportunity to “see” the child’s thoughts and worries, and the position further legitimises that the health professional should take steps to involving the child, sometimes against the patient’s will, as exemplified in paper 2. Being challenged in the top position of the hierarchy as a parent may be experienced as being positioned in a “troubled subject position” (Wetherell, 1998). This troubled subject position may be rejected by the parent, which at the same time may involve rejecting the support offered by the professional, hence again positioning oneself in the top position as the one who is closest to the child and knows the child best. Conflicts between parents and professionals regarding what is in the child’s best interest may be understood against this background.

As an example of the latter, rejecting a position higher up in the hierarchy, health professionals positioned themselves as “not-parents”, having little to offer when it comes to contributing to meeting the child’s needs and that it was therefore not their business (Hogstad & Jansen, 2020; Hogstad & Leer-Salvesen, 2020). I suggest that these positioning acts also took their productive power from attachment theory and the importance of the emotional bond for the possibility to act in relation to the child. Some of the health professionals did position kindergarten teachers above themselves in the hierarchy, with the “opportunity to meet the child’s need for security, safety and comfort” (Hogstad & Jansen, 2020, p. 476), placing themselves with the duty of supervising kindergarten staff about the particular situation of parental illness and death in the family. The interviews with kindergarten teachers suggested that they agreed with being in a position above the health care professionals in the hierarchy. Several of the kindergarten teachers talked about kindergarten staff as being “a good number two” (placing mother and father together as number one)[16].

Another aspect of the hierarchy of closeness is that it has the power to define some feelings as illegitimate and others morally commendable. It is morally commendable for parents to have deep emotional bonds to their children. A mother’s rejection of her children’s right to say goodbye to her, as in the “It’s the child’s right” position in paper 2, may challenge the mothers’ position on top of the hierarchy. “Elisabeth’s” securing of the children’s right to say goodbye to their mother could be understood as an intervention that simultaneously reproduces the meaning structure that defines mothers in line with the narrative of attachment theory and the “textbook model of family”, as delineated above.

Summary

To understand the possibilities and conflicts of professional encounters, it is important to include culture-historical conditions in the analysis. First, contemporary culture’s penchant for interpreting “support” and “meet the needs” within a therapeutic discourse regulates the expectations of health professionals, both from themselves and others, regarding the steps they should take to involve young children experiencing parental illness and death. I suggest that this psychologisation and the appurtenant psychosocial family interventions might have the power to reproduce the worries experienced by caregivers regarding not being good enough parents, rather than simply providing help that alleviates these worries. Second, recent Scandinavian studies emphasise the emotional distancing among health professionals working with seriously ill patients and tie this distancing to the predominant structural conditions within the hospital (Dencker et al., 2017; Karidar et al., 2016). According to the analysis in this chapter, an alternative explanation is that the possibilities for health professionals in encountering the children

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[16] It is possible to imagine that a loving grandmother would be prone to challenge and negotiate that position.

are limited as a result of the hierarchy of closeness, making it illegitimate and conflictual in many cases to emotionally connect with the children.

Directing attention toward the youngest children

The attention now turns toward the youngest children (0–6). As pointed to in the previous research-section (p. 17), the research focus on children below 6 years old is limited. To the best of my knowledge, there are no peer-reviewed studies on kindergarten teachers' encounters with these children. In the present section, I will first discuss three potential explanations for why the youngest children have been ignored within previous research.

The inclusion of kindergarten teachers and exploration of their perspective in phase 2 of this PhD project direct attention toward the youngest children and adds new knowledge. However, the present project could be subject to the same criticism that I direct toward previous research: not involving the youngest children directly but rather taking the professionals' perspective. In the second part of this discussion section, I suggest that focusing attention on the youngest children demands new approaches that transgress the poststructuralist discursive focus and include embodied, material forces as co-constitutive in subjectivation processes.

Why has the research field ignored the youngest children? Three explanations.

The first explanation relates to methodological issues tied to researching children's perspectives (Greene & Hogan, 2005; Juhl, 2019; Sommer et al., 2010). One such issue is that children's language competency limits the use of research interviews and other methods that demand writing or reading skills etc, such as filling out self-report schemata. The challenge is to choose an approach and method appropriate for young children's competence (Greene & Hill, 2005), and sometimes it may be convenient to simply avoid involving the youngest children to go around this issue. This explanation does not say anything about the involvement of young children in practice, only within research.

The second explanation for the lack of attention toward the youngest children in research does assume that there is a connection between research and general practice, and that this connection is a dominant view of the young child as immature and in need of protection, which may contribute to why the youngest children are excluded from arenas in which death is present, both as a (research) topic and as a physical reality. A dominating folk theory representing this view was found among American parents[17] in a study of parental reports of 3–6-year-old children's experiences of death and family practices surrounding death (Rosengren et al., 2014). This folk theory considered young children as not "developmentally advanced enough to handle death nor the fortitude or coping skills to deal with the powerful emotions that death evokes. Therefore, young children need

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[17] Rosengren et al. (2014) refer to the group under study as "European Americans", in contrast to Mexican American immigrants.

parents and other adults to prevent or filter their exposure to death" (Rosengren et al., 2014, p. 38). The interpretative repertoire "Children as belonging to their parents" in paper 1 (Hogstad & Jansen, 2020) aligns with this dominating folk theory. The ideas presented in the folk theory were present in the kindergarten interviews as well, appearing in negotiations between kindergarten teachers and parents about how much the children should be involved in illness- and death-related topics[18].

The third explanation suggests that the ignorance of the youngest children in research relates to a general tendency in contemporary Western culture to ignore people who are not "fully" autonomous and rational and skilled in using verbal language. This explanation takes its inspiration from posthumanist and postcolonialist perspectives and their critique of the Western world's dominant humanistic, individualised models of the child and humanist approaches to subjectivity (Burman, 2018; Viruru, 2001). According to Erica Burman in her book chapter "Towards a Posthuman Developmental Psychology of Child, Families and Communities", the humanist conception of the self presumes modern rationality and full access to consciousness and thus offers a fixed and closed model of the subject. Hence, the child cannot be accorded subject status within this humanist conception of the self, as children are not "fully" autonomous and rational and become "minor or insignificant, the fleeting and the non" (Burman, 2018, p. 1616). Together with the previously mentioned dominance of the therapeutic ethos and related psychologisation (Ekeland, 2019; Madsen, 2010), these individualised, neoliberal conceptions of subjectivity give language and verbal communication excessive importance, as radical postcolonialist Radhika Viruru (2001) argues. Relying on conceptions of fully rational selves and prescribing "open communication", family talks and child talks as "medication" excludes certain groups of people, particularly preverbal children and other people who do not use verbal language. How do you engage in open communication about illness and death with a toddler who mostly expresses herself through singular words, sounds and embodied expressions? The excessive importance of language may repress other modes of communication.

Transgressing the poststructuralist's discursive focus

The use of the interview methodology and clinical advice about open communication, "child talks" and "family talks" presuppose that children have the possibility to participate using verbal communication. Preverbal children and people with other modes of communication have other *ways of taking part* (Højholt & Kousholt, 2018) and other ways of *being in the world* (Juhl, 2019) than what is presupposed in interventions directed

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[18] Competing views about children's competence in understanding death do exist, in the empirical material of the present study, and correspondingly, in the study by Rosengren et al. (2014). A competing, subordinate folk theory held by a few parents and clinicians (within the same population) considered young children as having the psychological resources to cope with open and honest explanations of death "delivered in a safe context that allows children to air their concerns" (Rosengren et al., 2014, p. 41).

at talking. Directing attention toward the youngest children and other groups of people applying other modes of communication requires transgressing the discursive focus both in terms of theoretical and methodological approaches.

First, we need theoretical approaches that involve material and discursive forces to explain how subjectivity is constituted for the youngest preverbal children. According to Højgaard and Søndergaard (2011), poststructuralist analyses contribute to understanding subjects' (limited) possibilities to take up subject positions but "stop short of understanding how for instance (…) matter in terms of bodies, clothing, and school environment (…) as co-constitutive forces create(s) and shape(s) strategies and subjectification processes" (p. 5). The poststructuralist-inspired discourse analytic concept interpretative repertoire helped me discern four competing lines of argument about child involvement in paper 1 (Hogstad & Jansen, 2020). Notably, however, it took some time before I was able to discern the repertoire "Children as disturbing elements", but when I did, it was as if it had another ontology than the three other repertoires. Children as disturbing elements was a subject position that became available for the health professionals to position the child in, which seemed to be *given by* or *dependent on* or produced by the force of the architectonical, material conditions of the palliative context as well as the material, bodily movements of the young children. Still, the discursive resources enabled the production of children as disturbing.

Posthumanism and its associates (e.g. agentic realism and new materialism (Barad, 2007; Højgaard & Søndergaard, 2011; Søndergaard, 2019) transgress the boundary of singular individual subjectivity and move toward multiple, collective subjectivities, where subjectivity crosses bodies and minds (Burman, 2018). One posthuman move is "to attend to and explore affect, as a necessary corollary to embodiment" (p. 1605) and "as a relational effect of multiple and complex interactions" (Burman, 2018, p. 1616). This move has been called taking an affective turn and involves challenging the privilege accorded to rationality (Burman, 2018).

Second, taking the affective turn and involving embodiment and material forces in the analysis of subjectivity, demands methodological approaches that do not only rely on verbal communication. The Danish psychologist Pernille Juhl (2019) argues for multimodality in researching children's subjective experiences. She bases her position on Osterkamp-Holzkamp's (1991) definition of the concept *Befindtlichkeit* as "situated emotional evaluation of how one feels in relation to the concrete situation one is participating in" (p. 56). She argues for the importance of including emotions as a research modality and for understanding the "child in the world" rather than "the child's world" (Juhl, 2019).

In paper 3, we included embodied and affective responses and initiatives from children (body movements, singular words or sounds, silence, listening) as contributions to joint meaning-making. This approach provided insight into relational, affective and embodied dimensions in interactions, but most importantly it allowed us to include also interactions with the youngest children. If the inclusion criteria had required the child to contribute verbally in communication, most interactions with the youngest children (below 3–4 years of age) would have been excluded from the selected data material. Undoubtedly, even with this focus on embodied and dialogic ways of participating, the analysis for paper 3 was dependent on the health professionals' and the kindergarten teachers' initial recognition of these embodied and affective ways of taking part—or else they would not have referred to them in interviews. There is reason to believe that the kindergarten teachers and health professionals differed with regard to their awareness of the children's affective and embodied ways of taking part. The shortcoming of relying on interview material became evident, as it only gave access to professionals' stories without the ability to understand more about the range of co-constitutive forces within the kindergartens, palliative wards or oncology clinics that shapes the professionals' encounters with the youngest children. Conducting participatory observations in addition to interviews would have provided data material that, to a greater extent, could have described embodiment and affect as part of the professional encounters, both the professional's and the child's embodied ways of taking part in the interaction.

A well-known reservation regarding the interpretation of children (that has become particularly relevant when affect and non-verbal signals are included) is the fear of "over-interpreting" a child's response to mean something more than the child might have intended. All human communication and meaning-making relies on transindividual discursive and material conditions constituting and preceding communication, and this is as true for adults as it is for children. Hence, there is no such thing as a neutral interpretation. The awareness that we interpret and make meaning together, always imposing meaning, should be a reservation in all human communication, but it cannot stand in the way of communicating. Rather, as Juhl (2019) suggests, by relating to the embodied orientation of each other, we may "use the shared situation as a starting point for asking questions, not as a means to ascertain what children feel or experience but rather as a reminder of not knowing in advance" (p. 61).

Summary

Professionals may have difficulties in taking the child perspective with the youngest children, particularly preverbal children. The contemporary neoliberal discourse focuses on verbal communication, "open communication", child talks and family talks, and this focus serves to exclude preverbal children and positions them as minor, irrelevant objects that are present but not participating as rational subjects. Posthumanist perspectives offer theoretical approaches to researching preverbal children that provide some methodological tools that include affect and embodiment in addition to discourse.

Implications for professional child involvement practices situated in the young child's everyday life

One of the aims of this thesis has been to produce knowledge needed for developing professional child involvement practices that are situated in the young child's everyday life. Here I first present a theoretical, descriptive, non-normative definition of professional child involvement practices that acknowledges children as social agents. Then, as a practice implication of this definition, I suggest moving from individual interventions relying on verbal communication toward interventions targeting the child's everyday life system and the developmental conditions therein.

A non-normative definition of professional child involvement practices

One of the main contributions of the present work is that it challenges "the dominating professional understanding (…) that children need to participate in the emotional community of a family or circle of friends and/or professionals through grief and loss" (Karidar & Glasdam, 2018, p. 596). It does not challenge the importance of participating, but, by taking participation as a preceding ontological premise, instead asks how children's possibilities of different *ways of* participating are regulated (Højholt & Kousholt, 2018). This is a theoretical understanding of professional practices of child involvement that extends beyond the normative claims and general recommendations for practice about "open communication". A descriptive, non-normative definition of professional child involvement practices enables analysing professional encounters contextualised within a continuous discursive negotiation of children's participation in versus segregation from certain cultural practices and situations (Rogoff, 2003a) as well as the continuous discursive negotiation of cultural conceptions of death, death rituals and the management of death and dying.

This view considers professional child involvement practices as *all actions by professionals that function to regulate the child's possibilities of participating in social activities related to parental illness and death* and includes actions that constrain, limit or forbid certain ways of taking part. It involves actions as directed not only to the individual but also toward the systems within which the child participates (e.g. informing the child group in kindergarten about the illness). This view is in line with Foucault's concept of power as actions upon actions:

> [The power] acts upon their actions: an action upon an action, on existing actions or on those which may arise in the present or in the future…it incites, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely. (Foucault, 1983: 220, cited in Gallagher (2008))

This way of understanding professional involvement practices also includes professional encounters where professionals may "freeze" and not know what to say when a child raises the topic of the parent's death and children's welcomed *silent* presence in a hospital ward. While a normative conception of child involvement could categorise these acts as working *against* child involvement, the above definition allows an analysis of how the act functions to regulate the child's possibilities of participating.

Including children's agency acknowledges the possibility that professional practices of child involvement may have different "effects" on children in different positions, as they may act in different ways in relation to the same type of initiative (Højholt & Kousholt, 2018; Juhl, 2019). For instance, opening up children's possibilities to take part in different ways also opens the possibility for *resistance* (rejecting visits in hospital, *not* talking about the death etc.) (Øksnes & Samuelsson, 2017).

Child involvement practices directed towards the individual, family or system

In line with the three main interventions for health professionals in the procedures delineated by BarnsBeste[19], professional practices of child involvement may be directed toward the individual child, toward parents, the patient or family and/or toward the whole system or parts of the system that the child participates in during their everyday life (school/kindergarten). In this thesis, I have pointed out that individual- and parent-directed child involvement practices are dominant in contemporary culture and how this might be tied to current neoliberal processes of psychologisation. Involvement practices at the system level seem to be repressed by the dominating individual models of child development. A view that essentialises children's views, thoughts, worries, grief etc. as isolated, individual phenomena frames the interpretation of behaviour and individual mal-adaptions so that what is seen is "individual reactions" to parental illness. Implicated from this is help directed toward the individual child to alleviate reactions. This study points to two ways of changing this view.

First, considering humans as fundamentally communicative and interpretative enables an interpretation of the child's "individual reactions" as constituted in (dynamic) encounters and embedded in relationships with others and their personal histories. This understanding implicates interventions directed toward relationships and encounters, for example, towards the professional's contribution to meaning-making, as we studied in paper 3.

Second, situating the study of professional practices of child involvement in the child's everyday life helps us to see the child's "individual reactions" in relation to—and as part of—the social activities the child participates in, which carry a plurality of demands, possibilities, contradictions and conflicts (Højholt & Kousholt, 2018). Living with a severely ill and dying mother or father, and later, after death, living without this mother or father, affects the child's everyday life by dramatically altering the child's developmental conditions. Cancer illness trajectories often involve rapid, unforeseen changes. The child has to develop his or her ways of adapting to these changed conditions and find new ways of conducting everyday life with them (Højholt & Kousholt, 2018). This is not done by

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[19] https://sshf.no/helsefaglig/kompetansetjenester/barnsbeste/

the child in isolation, but through participation in social activities and in relation with peers and professionals across the everyday life arenas of kindergarten and family. In the following, I point to two main practice implications: first, the need for interprofessional collaboration initiated by health professionals, and second, the kindergarten's responsibility in working with the developmental conditions tied to the child's everyday life system (the dual socialisation butterfly, p. 27) to close the gap between the anticipating or grieving child's individual prerequisites and the demands from the environment.

Health professionals' responsibility to initiate interprofessional collaboration

This thesis has highlighted the limited possibilities of health professionals to engage in professional–child conversations when it concerns the youngest children (Hogstad & Jansen, 2020). This limits health professionals' ability to consider the child's needs for follow-up and the family's need for support to what the patient shares in professional–patient conversations about the children. This is problematic, as patients may not have the surplus energy to relate to their children's perspective and because they may tell health professionals that their children are well informed about the disease, but the health professionals may suspect that they have not actually informed the children (Hogstad & Leer-Salvesen, 2020; Karidar & Glasdam, 2018). It is therefore of great importance for the child's possibilities to participate that health professionals establish interprofessional collaboration with the child's kindergarten so that the kindergarten teachers receive supervision, information and at the same time are positioned with the right and duty to take steps toward child involvement.

Establishing interprofessional collaboration is particularly important in cases where the patient withholds information about illness and death from their child (Hogstad & Leer-Salvesen, 2020). In these cases, the parent will probably not inform the kindergarten about the severity of the illness and the anticipated death, making it more difficult for kindergarten teachers to understand the child in the world in which he or she participates in a situation of parental illness and death. These are, however, also the cases where the health professionals may find it particularly difficult to obtain consent from the patient to establish interprofessional collaboration. A procedure that applies to all patients may function as a discursive resource (Hogstad & Leer-Salvesen, 2020) that positions the parent as just *one of all patients* rather than in a troubled subject position as *a parent in need of help*, hence avoiding a challenge to the parent's top position in the hierarchy of closeness.

Previous research on interprofessional collaboration about minor children as relatives in palliative teams in Sweden has emphasised the practice of referring children to further follow-up in the school or for mental health care *after the parent's death* (Karidar & Glasdam, 2018), but references to contact between the professionals and school during the illness span are few or non-existent. This thesis has provided knowledge about context-specific resources as well as multiple discursive resources for making meaning of parental illness and death, and this knowledge will prove useful for health professionals and kindergarten teachers in their interprofessional collaboration about the child. For example, the palliative context provide exclusive opportunities for health professionals to contribute to meaning-making about death as a biological phenomenon and dying as a biomedical process (Hogstad & Jansen, Under review).

Kindergarten teachers coordinate the whole group of children's individual needs, ideas, plans and priorities

The developmental processes of children in a kindergarten are intertwined with each other (Sommer et al., 2013), and the kindergarten is an arena in which children's personal needs, ideas, plans and priorities have to be continually coordinated with those of others (Højholt & Kousholt, 2018). Let me use an example to illustrate this. "Harriet" is a fictitious name, and the example is constructed based on empirical examples from the analysis in paper 3 (Hogstad & Jansen, Under review) as well as examples from my own experience from kindergarten and bereavement groups. When Harriet's peers heard (from her, a sibling, their own parent or in the kindergarten) that Harriet's mother was ill and going to die, the other children started their process of adjusting to and figuring out how to understand, deal with and live with the threat of parental illness and death. A part of this process for some children might be to ask Harriet about her mother's disease ("Is she going to die?") or simply state that "Your mother is going to die". In paper 3 we comment upon how the "everyday life of the kindergarten offered situations where the bereaved or anticipating child stood out for peers as different" (p. 14). Peers make comments on what appears different with Harriet; for example, "your mother cannot pick you up in the kindergarten because she is dead/in the ground/in the hospital" or "you don't have a mother" or "your mother is dead". The way in which the kindergarten teachers approach these questions and comments, as well as their worries and emotional responses, will affect Harriet and her social relations in the kindergarten, regardless of whether the questions and comments are directed toward the kindergarten teacher or directly toward Harriet. The social activities and relationships constitute contexts in which the young child's subjective experiences of parental illness and death are being formed.

Changing the conditions of the context have the power to change the child's subjective experiences. This is not to say that the child's subjective experiences of loss and grief are not real or that they will disappear if the contextual conditions changes. The individual child will always engage in the world with his or her personal, embodied prerequisites. Still, the individual child's prospects of developing ways of conducting his or her life without a mother or father are being constituted in the encounter with others. When there is a large gap between the child's individual prerequisites and the demands of the situation, the child's possibilities to develop their ways of conducting their life become limited. When the kindergarten teacher has to make arrangements to coordinate the whole group of children's individual needs, ideas, plans and priorities, including those of the anticipating or bereaved child, she has to do it within the demands of the institutional order of the kindergarten, with limited adult resources per child and the related need for children to follow rules, routines and to be competent, physically independent and self-controlled (Franck & Nilsen, 2015). Working with the child group in the kindergarten and their parents, securing extra personnel resources and, with that, changing the demands from the environment contributes to closing the gap between the child's individual prerequisites and the demands of the situation.

Limitations and directions for further research

Many topics has been raised in this thesis, and only a few of them have received the attention they deserve. I want to highlight some areas of research that could be pursued further, and I also need to make the reader aware of the limitations of the present thesis. I have already mentioned some of the limitations of the theoretical and methodological approach: my insider and outsider position with regard to conducting interviews with the two groups of professionals (pp. 37, 40); that the professionals in the first phase of interviews were bound by confidentiality, but not the professionals in the second phase of interviews (see pp. 46–47 in the synopsis and pp. 18–19 in paper 3); that the poststructuralist concept interpretative repertoire was unsuitable for capturing affect and embodied ways of participating (p. 65); and shortcomings related to conducting interviews to capture non-verbal contributions (p. 66). In this section, I will discuss five more: limitations tied to conducting interviews in researching professional practice, how my researcher position may have contributed to producing the results, how the sample provided partial perspectives, gender issues and generalisability to other contexts.

Interviews as data

I started out in this project being interested in preconceptions about children and socioculturally shared discourses of the child and how they may function in exclusion processes. Conducting interviews is a suitable method for collecting data material to conduct discourse analysis. However, I became increasingly interested in *practices* from a critical psychological perspective (Axel, 2011; Kousholt, 2018), and particularly the connection between knowledge, power and practices from a Foucauldian perspective of knowledge (Foucault, 1969/2002, 1970/1999). The interview material provided limited insights on practices—understood as what people actually do—and mainly provided insights on justifications for practice, legitimate practices and meaning structures supporting practices, by adhering to what people say that they did, will do or would have done. This is interesting, but particularly regarding the embodied dimension of taking part and of acting, as a *situated* practice, the interview methodology falls short. Further research is needed on professional child involvement practices and professional encounters with children experiencing parental illness and death that includes observational or video data.

Researcher position

"Theoretically informed analyses" (Bøttcher et al., 2018) are not only informed by theory but also rely on my interpretations as a researcher situated in a particular sociocultural context, being gendered and with privileges and experiences that make me particularly aware of some things and leave me with blind spots regarding other dimensions or aspects (Bøttcher et al., 2018; Gadamer, 2003/1959; Glynos & Howarth, 2007). In addition to the substantial commentary provided earlier regarding the insider and outsider positions, being a woman and a mother is worth mentioning. Being a woman and a mother might have contributed to me engaging in "gendered dialogues" and elicited other responses in the dialogues than I would have received if I was a man and a father or not a mother myself. Of course, this is difficult to test. I make some more comments on gender issues below.

Based on previous experience and research, I was aware of how caregivers' and professionals' conceptions about children's limited ability to understand death legitimise excluding children from information-sharing and from other forms of shared meaning-making about illness and death in the family (Hogstad & Wold, 2016; Mahon, 2011). With this as a preconception, I began the present PhD project more afraid of being wrong in according children lower competence and less understanding than they "actually" have than of being wrong in the other direction and overestimating their skills and competences.

My background from working with children experiencing death and not directly with death and dying contributed to the child being more in the foreground than death in the present study. I was more concerned with contextualising the results within discourses of the child than within discourses of death. Engaging more with discourses about death and cultural and religious conceptions of death and dying through history (Amundsen et al., 2019) as well as in the modern world (Walter, 2020) could have opened up other dimensions and understandings of the professionals' practices.

Gender issues

Gender is an issue that I have become increasingly aware of during the work on this thesis, but which I have not had the opportunity to give the attention that it deserves. Women are dominant in all positions: in samples of professionals in the current project as well as in previous research, in samples of parents in previous research and among researchers in the field (and I am a woman myself!). Previous research has considered mothers' experiences or father's experiences or delineated the gender of the parent as a variable in the analyses to test whether the gender of the parent has an impact on the development of pathology. Still, I cannot find any *critical* gender perspectives anywhere in the field.

The two samples of the present study are both dominated by women participants. The samples' gender distributions are representative of the gender distribution within the arenas of palliative care and kindergarten, as these arenas are dominated by female carers and health workers. A dimension here, which is not raised in the article, is that this means that ill mothers will most often be cared for by a female nurse (who is often experienced as a mother herself) and that ill fathers also will be cared for by female nurses. During interviews with municipal nurses, in at least two cases, I could sense a female fellowship between the nurse and an ill mother. This was just a feeling and not a finding, but it made me aware of what it could mean for inclusion and exclusion processes, particularly tied to possible ways of taking part—for fathers, men and boys but also for women girls—limited by gendered constructions about ways of taking part (e.g. preconceptions about men not being expected to talk about things). There are some interesting findings related to gender, particularly in paper 2, which found that a majority of the stories where the health professionals experienced a moral problem when the parent withheld information about illness and death from their child were about mothers.

I became particularly aware of gender issues in relation to the development of "The hierarchy of closeness", where I found attachment theory to be a central part of the meaning-making structure. Burman (2008) discusses how the story of attachment theory as a cultural, chronological narrative "has found particular resonance within policy and service provision" and that "attachment can be seen (in Butler's 1997 sense) as the trope, lynchpin or turning point around which" (p. 130) we are mothers and how we are evaluated and regulated as mothers. It could be interesting to explore the gendered distribution of tasks in the family, such as developing and upholding the family's and the children's social networks and activities in leisure time and examining how professional helpers relate to mothers compared to fathers. Most importantly, employing *critical* gender perspectives that also involve embodiment (e.g. Butler, 2011) is necessary in further research on mothers, fathers and professional helpers within palliative care.

Sampling and partial perspectives

In the previous research-section (p. 17), I pointed to that the recruitment strategy in qualitative interview studies in previous research utilised convenience samples, where some voices might not be represented while others are over-represented. This criticism could be directed toward the present study as well. First, I have reason to believe that the recruitment procedure in phase 1 with health professionals led to a sample skewed toward professionals who felt secure in their role regarding minor children as relatives (see more on pp. 18-19 in paper 3 and in footnote 14 on p. 57 of the synopsis), even though this was not necessarily true for those recruited from smaller hospitals. Second, the kindergarten teachers were recruited based on the families' consent, which might have led to a sample of kindergartens skewed toward those that had positive experiences tied to home–kindergarten collaboration during illness and death. The recruitment problems that I experienced tied to the patients' reservation about viewing themselves as "dying" (see more on p. 38 of the synopsis) underscore the point in the previous research section that interview studies from the patients' perspective will represent only some particular voices and not others. Patients who are "in denial" and uncomfortable with talking about their experiences and who have difficulty coping with the situation will not volunteer to participate in interviews (Tavares et al., 2018). However, involving health professionals' perspectives does capture stories about parents who, for various reasons, withhold information about their illness and death from their child (Hogstad & Leer-Salvesen, 2020).

Context-dependent results

There are two points I want to make regarding the study context. First, the first phase of the present study did not initially pay attention to the differences between palliative home care and hospitals as contexts. Second, the results are dependent on the contextual conditions in the macro culture.

The present study highlights differences between the home and hospital contexts with regard to children's possibilities to participate. The nurses and doctors talked about home as the child's arena and, accordingly, that children do not feel comfortable in hospitals. They also reported reservations about home deaths for parents with young children, either from the surrounding family (husband and parents in law), from the patient herself or from health professionals. However, the data material is not robust enough to conduct analyses regarding potential differences. Two of the nurses included in the sample worked within municipal health care, and several of the other participants had extensive experience with home visits, but the interview guide was not focused on particularities within the home context, and the empirical material remains very limited and random regarding home deaths.

Policy documents about palliative care in Norway explicitly state the goal of increasing the time that the palliative patient spends at home before death (Ministry of Health and Care Services, 2020). Home deaths are replete with conflicting considerations and demands for a family with young children, and little is known about how these conflicting considerations and demands impact decision-making processes regarding where to die: at home, in a hospital ward or in a nursing home? More research is needed on family life and home deaths. Further research could explore the experiences of parents and children regarding the complexity of home deaths. One way of conducting such a research project could be a close-up study of the family life of a couple of families in which the mother or father is severely ill and (still) at home. A participatory observation following a child's movements during day and night across family and institutions combined with life-mode interviews with the parents could provide insights into these conflicting considerations and demands from an everyday life perspective.

The study was conducted in Norway in the period 2015–2020, and the results are tied to the Scandinavian context, which has a strong welfare state, high kindergarten attendance from 1 year of age, high gender equality, high female work attendance and public health care for all. In addition, the Scandinavian countries’ recent legal changes regarding minor children as relatives also mean that the results of the present thesis might not be generalisable to other sociocultural contexts. As noted in the presentation of “the hierarchy of closeness”, this meaning structure is context-dependent. However, I still suggest that this theoretical construct is generalisable to other contemporary cultural contexts, such as child protection cases and negotiations about fathers’ and mothers’ rights to parental leave in relation to child births.

7 Concluding remarks

Overall, the results point to a problem inherent in the practice of positioning health professionals with the formal, main responsibility of taking care of the needs of children as next of kin. Health professionals have limited opportunities to consider children's needs and to contribute to meeting these needs, but it is still essential that the responsibility is placed on the health professionals, as they have primary access to the information about the parent's illness and disease. In cases where the patient denies his or her illness and prognosis, or for other reasons rejects telling his or her child or family about it, the child's possibilities to participate and be involved depend on the establishment of collaboration between health professionals and kindergarten teachers or other significant carers in the child's everyday life. The negotiations between patient and health professional about establishing this collaboration may be conflictual, and the results of the present thesis point to the importance of professionals' awareness of how they discursively position themselves in these encounters.

Experiencing parental illness and death consists of a wide range of shifting subjective experiences, all of which are situated in particular places, positions and relationships as well as within historical and cultural contexts. The child's possibilities to develop their ways of conducting their life and adapting to and arranging their developmental conditions when a mother or father is severely ill and dying are not only related to individual characteristics and competencies, their parents' parenting capacity or the availability of professional support. Children's possibilities are deeply embedded in cultural-historical conditions that are inherently contradictory and come into conflict, such as children's individual rights versus human embeddedness and social participation in communities or neoliberalism's ideal of autonomy versus palliative care's four-dimensional care. Conflicting lines of argument, conflicting considerations and contradictory values will inevitably contribute to regulating children's, parents' and professionals' possible ways of acting.

Therefore, I adhere to the lesson stated by Burman (2018) of attending to the dangers of overstating what our research does and remaining "modest and limited in our claims, to enjoy and celebrate 'immature' or limited research that helps slow down the societal over-readiness to apply and 'roll out' or 'scale up' such claims, in particular in instrumentalising early childhood development and education" (Burman, 2018, p. 1616). Hence, I caution against the psychologisation of childhood grief and individualised "early intervention" to prevent bereaved children from developing pathologies in adulthood as a consequence of childhood bereavement. This does not mean that we should not pay attention to children experiencing parental illness and death. Neither does it mean that interventions relying on verbal communication have no potential to help families and individuals. It is, however, a call to slow down and not push the "alarm clock" when a mother or father is severely ill and dying, even though "death" or "children" may really scare us. I want to challenge professionals both within kindergarten and palliative health care to *engage with* the youngest children. This engagement should not have the intention of helping, intervening, alleviating pain, educating or making the child “open up”, so it does not demand a particular competence. With the starting point of *not knowing*, we can jointly explore experiences of being in the world when a mother or father dies. Experiencing and understanding death is not something we are ever fully educated in or that we can reach a “full” or “mature understanding” of; here, are we all apprentices.

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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' (Alldred 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 *hyper*active. 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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Paper 2

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Going against patients' will? A qualitative study of how palliative health-care professionals handle competing considerations when children are excluded from parental illness and death

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ABSTRACT

Purpose: The Norwegian Health Personnel Act (HPA §10a) obliges health professionals to contribute to meeting minor children's need for information about their parents' illness and prognosis. Previous research has shown that many parents withhold information about illness and anticipated death from their children. This study explored main considerations for palliative health-care professionals in these situations, and how they negotiate conflicting considerations of confidentiality and child involvement.
Method: This qualitative exploratory study involved semi-structured interviews with 11 palliative health-care professionals. Hermeneutics informed the data analysis.
Results: The health professionals' main considerations were sustaining patients' hope and building trust in the professional–patient relationship. Both concerns were grounded in respect for patient autonomy. The health professionals negotiated patient autonomy and child involvement in different ways, defined in the present analysis on a continuum ranging from granting full patient autonomy to going directly against patients' will.
Conclusions: The professional–patient relationship is the primary consideration in the health care context, and decision making on the degree of children's involvement happens in a dialogical process between health professionals and patients. Close professional–patient relationships might increase the emotional impacts on health professionals, who consequently might give greater relative weight to patients' will. We propose that procedures for initiating collaboration with professionals in the child's everyday life context help health professionals involving the child without threatening trust.

1. Introduction

Communication about end-of-life issues presents complex challenges to health professionals (Parry et al., 2014). That complexity increases when patients are also parents of minor children. The Norwegian Health Personnel Act (HPA §10a) obliges health professionals to involve the children of their patients so they receive information about their parents' illness and prognosis.[1] However, the structural and organisational working conditions of palliative health-care professionals hinder rather than facilitate child involvement. Several studies in Scandinavian countries have shown that the dominant medical logic, time pressures and limited economic resources result in health professionals prioritising patients and medical issues over the patients' relatives and psychosocial issues (Dencker et al., 2017; Karidar et al., 2016). Nurses have reported that they are unqualified or insufficiently trained to support children (Golsäter et al., 2016). In a literature review, Franklin et al. (2018) confirmed the findings of several Scandinavian studies reporting that encountering children in close proximity to death in the workplace has emotional and existential effects on health professionals, creating a need for self-distancing and -protection.

Previous studies in European contexts, including Norway, have found that many parents want support and advice from health professionals on how and when to inform their children about their own condition (Fearnley and Boland, 2017; Semple and McCance, 2010).

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[1] The law states that health personnel shall contribute to meeting minor children's needs for information about their parents' illness and prognosis. Other Scandinavian countries mandate similar obligations (Danish Health Authority, 2012; Swedish Law of Health and Medicine, 2017).

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Many parents withhold information and keep their children away from the health care system (Asbury et al., 2014; Hailey et al., 2018). In a study of nurses' interactions with the children of patients in the field of palliative oncology, Karidar et al. (2016) found that "[s]ome parents excluded their children from being involved in matters related to the illness and forthcoming death and the physical meeting with healthcare professionals, some parents included their children from the beginning to the end of the illness, and some parents included their children after the healthcare professionals had persuaded them to do so" (p. 24). The nurses found it problematic when the parents did not involve their children in what the nurses considered the right way, and Karidar et al. (2016) claimed that "the parental strategy of inclusion or exclusion of their children is the biggest challenge for nurses' compliance with the [Swedish] law and for nurses to do what they consider to be a good job" (p. 27). These findings indicate that there are frequent conflicts between meeting children's need for information and maintaining confidentiality on behalf of the patient (Clark, 2006). In this paper, we call such morally challenging situations *moral problems*, a term that Clark (2012) prefers to *dilemmas* because the former implies that evidence and reasoned solutions can and should be sought and that there may often be more than just two alternatives.

Empirical evidence on health professionals' handling of moral problems to do with confidentiality is generally scarce and fragmentary (Clark, 2006). As a cornerstone of professional ethics and the professional–client relationship, confidentiality restricts how health personnel may share information about patients' health and other personal matters. According to traditional theory, one purpose of professional confidentiality is to secure patients' right to privacy and the general population's trust in health care providers to prevent treatment withdrawal due to fears about unauthorised sharing of personal information (Bok, 1988; Kipnis, 2006). As Clark wrote, "the basic idea of privacy follows quite naturally from the core principle of autonomy in liberal rights theory" (Clark, 2006, p. 130). Beauchamp (2010) defined the principle of autonomy as respect for "an autonomous agent's right to control his or her affairs in accordance with personal values and beliefs" (p. 62). This normative principle is based on common moral experience and socioculturally influenced. In Western societies, which stress individualism, patient autonomy in information-sharing decisions is important and seemingly self-evident (Rising, 2017).

In some cases, it may be legitimate to share information against patients' will (Bok, 1988). For instance, HPA §23–4 makes it clear that health professionals should take action if severely ill parents are inattentive to their children's needs. If children suffer serious neglect, health professionals have a duty to report it to Child Protective Services (CPS). Deciding when it is legitimate to share information against patients' will and when it is not, is a complex, challenging task where first principles, such as the principle of confidentiality, fall short in guiding health professionals (Clark, 2006, 2012). The decision-making process is a discretionary process in which health professionals need to handle the tensions between the abstract general rules of confidentiality and the conditions and circumstances of specific situations, requiring substantial interpretive work on several levels (Clark, 2012; Loyens and Maesschalck, 2010).

Clark (2012) outlined three interrelated principles from Gadamer's hermeneutics. First, all understanding is historically conditioned and inherently biographical. Second, the act of interpreting a text, a human act or another social phenomenon follows a circular, iterative movement (Clark, 2012). Interpretation and understanding are conditioned by preconceptions; what we already know contributes to establishing a frame of meaning that makes interpretation possible (Clark, 2012). The interpreter moves between, on one hand, projecting the meaning of the whole as a frame of reference to establish the meaning of the particularities and, on the other hand, using the achieved understanding of the particularities to revise the meaning of the whole. Third, professionals' search for understanding is a *dialogic* process that has two implications worth mentioning here.

First, language carries historical, social and cultural meanings, so palliative health-care professionals' way of talking functions to ascribe rights and duties to actors in episodes, which we call discursively assigned moral positions (Harré et al., 2009). Second, in dialogue, the professional tries to understand the other's *horizon*, defined by Gadamer as "the range of vision that includes everything that can be seen from a particular vantage point" (as cited in Clark, 2012, p. 125). Trying to understand another's horizon entails attempting to grasp the "conceptual apparatus that makes the individual's world intelligible to him or her self" (Clark, 2012, p. 130). This frame of meaning is then negotiated in a process of comparing, revising, discarding and replacing other frames of meaning and, ideally, moving towards a fusion of horizons and mutual understanding (Clark, 2012).

The present study investigates how palliative health-care professionals handle the moral problem of meeting children's need for information while maintaining patient confidentiality. The study aims to provide thinking tools for health professionals and to produce knowledge about the context-specific conditions that could inform policy-making procedures. We pose the following research questions:

1. What are the main considerations for health professionals in situations when parents withhold information about illness and anticipated death from their children?
2. How do health professionals negotiate conflicting considerations in these situations?

2. Method

2.1. Design

The study was a qualitative, exploratory interview study with purposeful sampling (Patton, 2015).

2.2. Participants

We recruited health professionals who had worked in palliative care for at least two years. We included doctors and nurses of both genders from four public hospitals of different sizes and two municipal health services, all geographically dispersed throughout Norway. The first author, who conducted the interviews, visited hospitals and presented the project, inviting professionals to make contact if interested in participating. This process obtained six participants, five of them were female. We recruited the other four participants through mediators, aiming to achieve a more balanced combination of genders and professions. In addition, we included one of two pilot interviews in the final data to ensure a gender balance that represented the gender distribution within palliative care. The Data Protection Official for Research in Norway was notified of and approved the research project. All participants volunteered and provided written informed consent.

A total of 11 professionals participated in our study. At the time of the interviews, the participants had 2–17 years of experience in palliative care, and their ages ranged from mid-30s–60s. The participants comprised three doctors and eight nurses (eight women and three men). Two participants came from municipal health services and nine from specialist health services. The nine professionals from specialist health services worked in palliative wards ($n = 2$), or multidisciplinary palliative teams ($n = 7$). One of these seven worked ambulant, one in a multidisciplinary hospital team and five worked in palliative teams that operated both in hospital and ambulant.

2.3. Interviews

The first author conducted the interviews. All but one took place in the health-professionals' workplaces during working hours, while the remaining interview took place in the participant's home at the participant's request. The interviews were conducted as open-ended dialogues that allowed the participants to talk freely about their experiences. An interview guide (Appendix 1) helped the interviewer focus the interviews towards producing data that consisted of 1) stories about the children whom the professionals encountered during their years of practice in palliative care and 2) the professionals' views on the needs and understandings of death and illness among the young children of palliative patients, as well as on the ideal ways to support such children. As a warm-up at the beginning of the interview, the interviewer asked about the participants' biographical information and, at the end, about their roles and competences. The individual interviews lasted 62–128 min and were audio-recorded. The first author transcribed the interviews verbatim, resulting in 315 pages of text. We de-identified the participants upon transcription, changing or deleting all personal names and place names.

2.4. Data analysis

Data analysis consisted of three theoretically informed phases: first, reading transcripts and separating a subset of the data, second, working with analytical questions and third, returning to the complete data set to analyse discursive positioning. *Theoretically informed* refers to how theoretical inspirations and concepts opened for interpretations of data. Preliminary findings in early stages functioned as analytical cues and generated analytical questions for further analysis, inspired by Haavind's (2019) interpretive analysis.

First, both authors read the transcripts and together discussed the preliminary themes and tendencies. Data contained stories about successful and unsuccessful support and stories about health professionals not having access to the children, as well as the participants' thoughts, views and meanings. As we wanted to explore the considerations that health professionals need to handle when patients exclude their children, we needed to focus the analysis on stories of exclusion as a subset of the data. Therefore, we identified the stories in the data in which the health professionals experienced a moral problem related to child involvement. This was done manually using Microsoft Word (Microsoft Office, 2013) and was guided by the following three inclusion criteria:

1. Children were not told that their parent was going to die until the last days or hours of the parent's life.
2. One or both parents wanted to keep the impending death confidential.
3. Children either knew about the disease but not the impending death or did not know about the disease at all.

Seventeen stories met the inclusion criteria (see Table 1) and formed the subset of the data used in the second phase of the analysis.

In the second phase of the analysis, we posed the following analytical questions:

1. How did the health professionals talk about what they did when the parents did not want to inform their children about their own impending death?
2. What did the health professionals say they would do in future or hypothetical cases?
3. How did the health professionals justify their actions?
4. What did the health professionals say about their discretional thresholds and turning points?

The first author systematically examined the stories to find answers to the questions listed above. Not all the stories were detailed enough to generate answers to all the analysis questions, but such stories still functioned to systematise the reading of the text, allowing us to constantly revise and discard our preliminary understandings instead of reproducing them (Clark, 2012). In addition, we reflected on which values and considerations (Clark, 2006) seemed to be in play within each story and across the stories in order to find patterns and

Table 1

	Children in the story	Who is ill?	Summary of story[a]
1	Boy, eight years old	Mother	Told by medical doctor: Single mother who have not accepted her prognosis. Fast progression of the disease after an operation and hence no time to prepare the boy for the imminent death.
2	Two children, approx. one and four years old	Mother	Told by nurse: The children were physically present in the hospital frequently and in longer periods, however the parents did not tell the children that mother was going to die before the day it happened.
3	Three children, the youngest twelve years old	Mother	Told by nurse: Health professionals did not encounter the children. The patient solemnly declared having a good dialogue with her children, whereas the health professionals experience that the mother do not accept her own prognosis.
4	Two girls, fourteen and sixteen years old	Mother	Told by nurse: The parents had known it in a year or more that the mother's disease was incurable, but did not tell before the disease progressed fast.
5	Four children, the youngest six years old	Mother	Told by nurse: Single mother haven't told her children about her cancer before she came to a point of no return at home. Came to the ward by ambulance. Did not want the children to see her. Died within a day and a night.
6	Four children, the youngest six years old	Mother	Told by nurse: Single mother that had told her children that she was going to make it, and live until the children had grown up. She was marginal when she came to the ward, died within 24 h.
7	Two girls, three and six years old.	Father	Told by nurse: The parents instructed the health professionals that the children should not be informed about the father's imminent death, until just a couple of days before he died.
8	Boy and girl, nine and eleven years old.	Mother	Told by nurse: Father did not want the children to know that mother was going to die.
9	Three children, six, nine and thirteen years old	Father	Told by nurse: Parents recently separated. Parents disagreed on whether to talk to the children about death or not, where the father was most restrictive.
10	Two children, eleven and fifteen years old	Father	Told by nurse: Father ill, did not tell his family about his disease (not even his wife).
11	Girl, ten years old	Father	Told by medical doctor: Daughter not present in hospital – the father did not accept the disease as palliative.
12	Boy and girl, eight and thirteen years old	Mother	Told by nurse: Disease far progressed when detected. Parents disagreed on whether to talk about death or not. The boy was kept away from the dying mother, and was not told the mother was dying.
13	Two children, three and six years old	Mother	Told by nurse: Mother was very closed off – did not even want to talk about talking with the children about the disease.
14	Three children (age span 2–7)	Mother	Told by med. doctor: Of African origin*. Mother did not want to talk about her disease. The children stayed at the hospital in long periods when no one else could look after them.
15	Five minor children	Mother	Told by medical doctor: The parents kept all the children physically away from the ill and dying mother and sent away to relatives. Member of a religious sect*.
16	Three children (age span 7-adolescent)	Mother	Told by nurse: Parents did not reject openly to telling the children about

(*continued on next page*)

Table 1 (*continued*)

	Children in the story	Who is ill?	Summary of story[a]
			death, but postponed it again and again.
17	One adolescent	Mother	Told by nurse: Mother from Russia*, did not want to talk about the seriousness in the diagnosis – rejected using the word cancer.

[a] The professionals made explicit that the patient had immigrant- or religious minority background, the other stories do not provide such information.

similarities.

In the third phase of the analysis, we returned to the complete data and read all transcripts again to see how the professionals discursively positioned themselves in the episodes (Harré et al., 2009). We categorised positions by how much weight the participants put on patient autonomy, and we created what Patton (2015) called an analyst-constructed typology: we placed the positions on a progressive continuum ranging from full respect for patient autonomy to violations of patient autonomy. We discussed the typology with health professionals in the field of palliative care to assess its credibility (Patton, 2015).

3. Results

All participants told at least one story about parents who withheld information from their children or excluded them in other ways. See Table 1 for an overview of the stories.

3.1. Main considerations

3.1.1. Sustaining patient hope

An important consideration in the stories was patients' hope. The health professionals described hope as a valuable, healthy and life-enhancing quality and stated that challenging patients' hope could be harmful. Cecilie (Story 3, Table 1) described her dialogue with a severely ill mother as follows: "I cannot tell her [the mother] that she is not going to live until her son celebrates confirmation, as she hopes. She will break down completely." The data indicated that working to sustain patients' hope was integral to professional conduct. However, this consideration seemed to compete with children's involvement. For instance, in four stories, a patient or the healthy parent withheld information from their children due to a deep hope that a cure would emerge or that the patient would still live for a long time.

The health professionals highlighted an unclear border between hope and denial. Andreas (Story 1), a medical doctor, spoke about a mother transferred from another hospital:

> She had a deep hope that everything was going to turn out well and that she would return to a better state again, but in reality, the prognosis was bad, and her expected lifetime was very short. The health professionals in [the previous] hospital said that she had not taken it in and did not accept it. She was divorced and had a child who lived with her father when she was hospitalised. It was dramatic as we could see how fast it went; it was within the night shift […]. Nevertheless, it was clear to us that we had to do something with that boy as no one had informed him that his mother was going to die within a very short time.

Andreas used the term "hope" when taking the patient's perspective as his frame of reference. When taking the health professional's perspective as the frame of reference, he and other health professionals described such patient behaviour as not "taking in" or accepting the prognosis. Still, both doctors and nurses expressed uncertainty about how precise the doctors' estimates of remaining life were, emphasising that they repeatedly turned out to be wrong. In many cases, this uncertainty seemed to prevent the health professionals from challenging a patient's potential denial or non-acceptance of anticipated death. The health professionals' active sustaining of patients' hope and the more passive refusal to take the patient's hope away led them to withhold information from children in some cases.

3.1.2. Building trust

The health professionals emphasised the importance of trust in multiple relationships. Story 4 from nurse Dina demonstrated that the professionals considered trust to be important in various relationships in addition to the traditional patient–professional relationship. In this story, the mother's disease suddenly progressed quickly, and the parents were in a hurry to tell their daughters about the impending death. When telling this story, Dina highlighted that she and her colleagues experienced difficulties forming trusting relationships with the daughters, who accused the health system of not doing enough to save their mother. Dina got the impression that the daughters consequently felt distrust towards the health system. She reflected that, despite this undesirable consequence, distrust in the parent–child relationship would be even worse, so she was prepared to take the blame. Dina's story involved three relationships of trust that were also discernible in other stories: the child–professional relationship, children's trust in the health system and the child–parent relationship. Dina's and several others' stories indicated that gaining trust in one relationship could compete with other considerations.

While Dina's example concerned trust in relationships involving children, the health professionals' main consideration seemed to be the patient–professional relationship. The nurses who worked in municipal health services and ambulant specialist health services told stories about patients who were mothers and who initially lacked trust in the health professionals. The nurses explained how through a wary, circumspect process, they stayed in line with the patients and got increasingly close to them. In this way, the nurses developed trusting relationships to the patients, making it possible to provide palliative care. In Story 13, municipal nurse Jenny recounted how she worked hard to establish a trusting relationship with a patient, who eventually let her into her home. Jenny stressed the following:

> You had to be extra careful as it had been so difficult to get contact with the patient. I, therefore, did not dare go into topics she did not want to discuss when I noticed she would not talk about them.

In this and similar stories, the nurses were reluctant to approach children or to talk about them with the patients after having worked hard to gain the patients' trust.

3.2. Patient autonomy versus child involvement: five positions

The identification of the two main considerations related to patient autonomy further made us aware that across the 17 stories, the participants negotiated and talked about patient autonomy in different ways. We established a continuum of five positions ranging from full respect of patient autonomy to violations of patient autonomy. These positions overlapped and were not mutually exclusive. The health professionals adopted several positions within the same interview and sometimes even within the same story.

3.2.1. "It is not my business"

On one end of the continuum, the health professionals did not take any steps to involve the children or to convince the parents that their children needed to be involved. The health professionals' stories gave sparse descriptions of such situations, indicating that they did not place themselves as responsible in these episodes, and so did not ascribe to themselves the duty to make the parents disclose their diagnoses or prognoses to the children. The health professionals explicitly stated that they could not do anything as "it is not my business," "I was not the closest one to the family" or they did not encounter the children. The professionals also used children's young age as a justification for doing nothing.

3.2.2. *"Stay in line"*

The health professionals frequently described how they followed or stayed in line with the patients during the progression of their illness. Rather than jeopardising patients' hope or trust in the patient–professional relationship by raising the topic of children's involvement, the health professionals seemed to let the right moments "appear" by themselves. After introducing the topic, the health professionals gave patients the time to process the information. Building trust and empathy with patients, the health professionals did not dispute the patients and parents' views, even when the health professionals favoured greater child involvement. Fanny stated the following: "I am afraid of saying that the parents are wrong. They know their own child." When illness suddenly progressed quickly or the disease's time span was short for other reasons, some parents died before information about their anticipated death reached their children.

3.2.3. *"Presenting a realistic picture"*

This position challenged patient autonomy more than the previous positions as the health professionals disputed patients' views by presenting their own perspectives. The health professionals most commonly did so by talking about what they generally did or would do in hypothetical cases. Some health professionals referred to research on the potential risks of not involving the children and cited this knowledge as an authority to challenge patients' views.

3.2.4. *"Make the opportunity"*

This position involved an element of disguise that challenged patient autonomy. In front of patients, the health professionals respected their views while actively creating opportunities to involve the children to a greater extent than their parents wished. In Story 1, Andreas asked a mother to allow her son to come to the hospital and intended to convince her to allow the son to see her once he arrived. However, she died while the son was present in hospital but before Andreas could convince her that the son should see her. In several stories, the health professionals sought opportunities to be temporarily alone with the children and ask them leading questions about their parents' illness and prognosis despite explicit parental instructions not to introduce the topic of death. In these cases, the patients most likely thought that the health professionals respected their autonomy.

3.2.5. *"It is the child's right"*

The fifth and final position favoured children's involvement over patient autonomy. This position was represented by only one story that came from nurse Elisabeth (Story 5), who worked in a palliative ward. When a single mother arrived at the ward, Elisabeth soon became aware that the patient had not told her children anything about her disease. When in the ward, the mother refused to allow her children to come see her. Elisabeth confronted her, saying, "They will see you. You are going to die, and it is the children's right to see you before you die." Going directly against the mother's will not to meet with her children, Elisabeth physically brought them to her, one by one. A special condition in this story was that the time constraints demanded an immediate decision and did not allow the health professional enough time to convince the patient to consent to the children's involvement.

4. Discussion

In this study, we have explored health professionals' ways of handling the moral problem of dying patients excluding their minor children from their illness and impending death. A main finding is the strength and impact of the health professionals' respect for patient autonomy, defined as patients' right to control situations in accordance with their own personal values and beliefs (Beauchamp, 2010) and concretised in the professionals' work to sustain patients' hope and build trust. The themes of hope and trust are not new to the field and have been thoroughly discussed in the clinical and palliative literature as fundamental considerations in health professionals' practice (see, e.g., Parry et al., 2014). However, our study points to an extra dimension when the patients are also parents of minor children. Although the health professionals often equated patients' hope with denial, the main pattern seemed to be that patients controlled situations in accordance with their perceptions of reality. The health professionals prioritised establishing trust rather than working to involve the children if there was any danger that the professional–patient relationship might be challenged.

The theme "Sustaining patients' hope" illustrates the importance of parents coming to terms with their own disease if their children are to be involved and informed about illness and prognosis. This point accords with the findings by Hailey et al. (2018), showing that the parents who have incurable advanced cancer but do not share prognostic information with their children commonly do not consider their own death to be either imminent or likely. Logically, as long as patients themselves do not think of their illness as incurable or life threatening, it makes no sense to tell their children that it is.

Interestingly, mothers were overrepresented in our sample of 17 stories. We do not know if the gender distribution in our data represents a tendency in the patient population; quantitative studies with larger samples are needed to investigate that. However, the findings from previous research suggest that the sick parent's gender affects children's adjustment to parental cancer (Tavares et al., 2018). Even in Scandinavian countries with high gender equality, mothers often have the primary responsibility to communicate with children about emotionally challenging topics. If the mother is in denial, there might be no one to replace her in talking to her children about illness and death. Confronting patients and telling them that their hope amounts to denial might facilitate children's access to the health care context and prognostic information. However, such truth-telling requires many considerations (Rising, 2017). Health professionals might think that patients will break down if confronted with their prognosis and consequently withdraw from treatment, leading to negative consequences for both the parents and the children (Kipnis, 2006).

The main pattern in the stories is that health professionals follow patients' will, practicing strict confidentiality. This is in line with findings from a study on the Norwegian health and welfare sector, which found that health personnel want or practice nearly absolute confidentiality. Health professionals in particular seemed to put special restrictions on themselves regarding information sharing (Stang et al., 2013). Stang et al.'s study further indicate that health personnel and other welfare workers do not have sufficient knowledge about the legal regulations in HPA §23–4 that trump confidentiality. Still, we found three positions that directly or indirectly challenged patients' view: "Presenting a realistic picture," "Make the opportunity" and "It is the child's right." The conventional precept of confidentiality as absolute (see, e.g., Kipnis, 2006) implies that these positions involve "breaching" confidentiality and are thus unethical. However, according to Clark (2006), a strict view on confidentiality falls short in complex clinical situations. Consequently, he proposed to discard confidentiality "as a first-order principle of professional ethics" (Clark, 2006, p. 121) and suggested, instead, paying attention to the following three classes of rights that confidentiality purports to serve (see Fig. 1): 1) the patient's right to privacy, 2) the patient's right to safety and 3) the well-being, welfare and interests of all individuals other than the patient (the public good). In practice, these classes of rights often conflict, creating a three-cornered contest.

Applying Clark's (2006) triangle to the study results shows that privacy trumps the public good, indicating a bias towards securing patients' rights over children's rights. This bias can be understood in light of the professional–patient relationship.

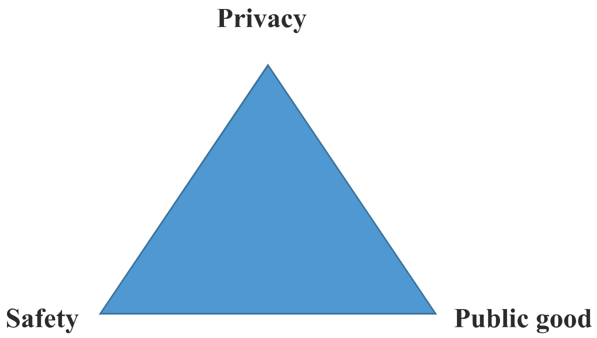

Fig. 1. Confidentiality as a three-cornered contest. Model adapted from Clark (2006).

4.1. Primacy of the professional–patient relationship

Previous studies have shown that time pressures and limited resources hinder health professionals from involving children and that the dominant medical logic contributes to this situation (Karidar et al., 2016). On the one hand, the medical logic in the palliative oncological field prioritises medical issues and treats psychosocial issues as secondary considerations. Thus, health professionals are trained to prioritise patients and the treatment of medical conditions. On the other hand, the dominant medical logic is *a discourse* that provides arguments that health professionals draw on to discursively position themselves (Harré et al., 2009). This discourse may provide shared and personal rationalisations in the working environment, both of which legitimise not involving children, making it easier for health professionals to deal with emotional stress.

Previous research has shown that such emotionally and existentially challenging encounters may create a need for protection and distance among health professionals (Franklin et al., 2018). Golsäter et al. (2016) studied how nurses perceive their roles when caring for the children of seriously ill patients and found that some nurses are convinced that the children are not their responsibility. These findings align with the "It is not my business" position (see Section 3.2.1), whereby health professionals adopt arguments as to why the patients' children are not their responsibility. Instead of viewing these utterances as individual nurses' and doctors' established perceptions or static beliefs about their roles, we suggest that these claims should be read as discursive positioning having as effect to create emotional distance and decrease distress (Franklin et al., 2018; Harré et al., 2009).

However, the health professionals who work in isolation might not have the same possibility to create emotional distance by saying, "It is not my business." A literature review by Franklin et al. (2018) indicated that professionals' opportunities to deal with stressful emotions depend on whether they work in isolation or have support from a team. In our data, the position "Stay in line," characterised by trust and empathy for the patients, is more frequently expressed by municipal and ambulant nurses working in isolation in patients' homes than by health professionals working with multidisciplinary teams. On one hand, emotional commitment and trusting relationships might contribute to securing patients' rights to safety and privacy by helping health professionals understand others' horizons—namely, to interpret and understand patients' beliefs, values and needs (Clark, 2012; Loyens and Maesschalck, 2010). On the other hand, the fusion of horizons and mutual understanding might also increase the severity and possible impact of stressful emotions in situations with conflicting considerations as well as increase the risk of not taking the child's perspective into account. Empathically tuning into the perspectives of children about to experience parental death is emotionally challenging (Sommer et al., 2013). When these encounters also involve challenging patients' values and beliefs, professionals often lack the parents' support in this challenging task. Consequently, close professional–patient relationships might impede health professionals' opportunities to act on behalf of the children whose parents do not want to involve them.

4.2. Going against patients' will

Positions challenging patients' will were associated with situations involving very limited expected lifetime. In an exception, the "Presenting a realistic picture" position was based on general statements about what health professionals have done or would do. The type of confrontation characterising this position centres on what is best for children according to general advice. This position can be aligned with a more paternalistic orientation whereby health professionals "own" the knowledge and know what is best, in line with Karidar et al.'s (2016) findings. The nurses in Karidar et al.'s (2016) study implicitly believed from the outset that they knew what was best for the children regardless of their parents' point of view and philosophy of life.

Although the "Presenting a realistic picture" position initially seems to help secure children's rights, it also risks implicitly conveying to parents that they are wrong about their children's needs. This may create misunderstandings and conflicts in the dialogue with parents (Hogstad and Jansen, 2020). Believing at the outset to know what is best according to general advice may also impede health professionals' discretionary interpretation of children's specific needs in concrete circumstances (Loyens and Maesschalck, 2010). In several stories involving families with cultural and religious minority backgrounds, the health professionals implicitly and explicitly expressed that they did not understand these families' decisions regarding end-of-life issues. When health professionals do not understand the patients' horizons, they risk being ignorant of situation-specific conditions important to discretionary judgement. General advice and research framed in Western individualist conceptual apparatuses might not always be intelligible to children and families from cultural and religious minority backgrounds with other conceptual apparatuses. These children might need to receive information and support in ways other than those generally prescribed by professionals within Western sociocultural contexts.

Health professionals going against patients' will to exclude the children and intervening to support the children's rights might threaten not only the professional–patient relationship but also relationships within families. If health professionals provide children with information essential to the parent–child relationship, such as news about death, this communication might violate trust, which risks harming the parent–child relationship. Instead of direct interventions by health professionals, especially young children should be involved via the relationships established in their everyday lives (e.g. healthy parents, grandparents and teachers) that have the prerequisites to take the young child's perspective (Sommer et al., 2013).

4.3. Methodological considerations

According to the hermeneutical inquiry framework applied in the present study, 'there is no such thing as a pure description; every communicative act involves interpretation' (Patton, 2015, p. 137). Consequently, the stories told in the interviews must be considered as representing the participants' perspectives rather than what *really* happened (Haavind, 2019; Patton, 2015). Readers might have noticed that Stories 5 and 6 in Table 1 appear similar, and we have reason to believe that both stories originate from the same episode. The fact that the stories differ – for instance, regarding how much information the mother had shared with her children – illustrates that the two nurses experienced, interpreted and communicated the same episode differently. We want to argue that pointing to this subjective dimension in the data does not take away the strength of our study in contributing to knowledge and informing practice. Discretionary processes are interpretative, and professional practice is shaped by professionals' lived experiences rather than objective criteria and theoretical conclusions explicitly worked out from first principles (Clark, 2012). Exploring individual health professionals' subjective and situation-specific knowledge may contribute to *practice validity* – that is, knowledge useful for the professional practices to do with handling moral problems (Clark, 2012).

4.4. Implications for practice

Reflective practice may help professionals become more engaged with ethical problems (Clark, 2012). Our discussions with the health professionals in the field of palliative care already revealed the usefulness of our analyst-constructed typology of the five positions because the typology allowed the professionals to reflect on their own ways of handling the moral problem between meeting children's need for information and maintaining confidentiality on behalf of the patient. The typology could thus be used for educational purposes.

Nonetheless, reflective practice does not in itself change the main considerations and contextual conditions that health professionals have to take into account and that limit their opportunities to take steps to involve children. The primacy of the professional–patient relationship seems to *inherently* challenge the involvement of children because it comes into conflict with the considerations tied to health professionals' prioritised tasks. Together with the fact that going against the patient's will to involve the children may also threaten the relationships within families, it may prove difficult to evade the conditions of the palliative context by, for instance, providing more training or education to professionals (Dencker et al., 2017).

We recommend that policy makers formulate procedures for health professionals working with children as next of kin that oblige health professionals to always establish interprofessional collaboration with the children's kindergarten or school when a patient that is a parent of a minor child is diagnosed with a life-limiting illness. Based on our findings, such a procedure may function as a discursive resource for health professionals, providing a convincing reason to ask for patients' permission as the procedures apply to all patients. Hence, it could help the professional to position themselves as "staying in line" with the patient while taking concrete steps towards child involvement without necessarily endangering the trust in the professional–patient relationship.

In cases when the patient still does not consent to involve the child, health professionals can seek assistance from CPS, which may access people with whom the children have established relationships and discursively position such persons with the legal and moral responsibility to involve the children (Harré et al., 2009). Professionals must report to CPS any suspicions that children are suffering serious harm or neglect. Knowing what constitutes possible harm is a difficult task, and professionals may overestimate or underestimate the probable risk of children's suffering – for instance, due to preconceptions such as sociocultural conceptions about children's needs (Hogstad and Jansen, 2020). In addition, when patients keep children away from the health care system, health professionals do not even have the opportunity to consider possible harm to the children. In these cases, professionals could consult CPS anonymously, and CPS could, situated closer to the children's everyday life perspective, assess the probable consequences of the parents withholding information.

5. Conclusions

The present study supports the findings from previous research about the contextual conditions that limit palliative health-care professionals' opportunities to involve children as relatives. Our study contributes to this established knowledge by deeply investigating the health professionals' ways of handling the moral problem that occurs when parents withhold information about their illness and impending death from their minor children. Our findings point to how the primacy of the professional–patient relationship in the health care context and the importance given to patient autonomy in the present sociocultural context result in health professionals giving greater weight to patients' will than to children's right to – and need for – information about their parent's illness and prognosis. We propose that procedures for initiating collaboration with the professionals from the children's everyday-life context may help health professionals to involve the children without threatening the trust in various interpersonal relationships.

CRediT authorship contribution statement

Ingrid Johnsen Hogstad: Conceptualization, Methodology, Investigation, Writing - original draft, Writing - review & editing. **Kjartan Leer-Salvesen:** Writing - original draft, Writing - review & editing.

Declaration of competing interest

None declared.

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Appendix 1. Interview guide

Make the participant aware not to identify persons in the stories told. There are no right or wrong answers, I am interested in what you have to tell, your thoughts and opinions. We conduct the interview as a dialogue. I might take notes during the interview for my own recollection on questions to follow up on.

1. *Introduction.* Tell me about yourself: **education, occupation, position,** your tasks and about **how long** did you work within palliative care?
2. Own experiences.
   a. Tell me about **your experiences** with the minor children of your patients. Successful support? No access or unsuccessful support? (Why? What could have been done otherwise?)
   b. Do you have stories about children with **special needs** (f.ex. disabilities, language challenges, minority background)? (What needs did they have? What adaptations did you do?)
3. Reflections upon the youngest children
   a. What do **kindergarten-aged children** (1–6) understand about: Severe illness? Death?
   b. How would you **present to a kindergarten-aged child** that mother or father is going to die?
   c. What is the **best way of taking care of- and supporting** kindergarten-aged children when mother or father is dying?
      i. What are their **needs**?
      ii. What is **important**? What is not so important?
      iii. **Who** should provide support?
      iv. What does supporting the child demand?
4. Professional role, competence and knowledge
   a. What is **your role in relation to patients' minor children**? What is expected from you? What is demanded from you?
   b. What is important for you **to feel prepared** to take care of and support the children of your patients?
5. *Thank you for your help!* How did you experience being interviewed? As expected? What did you expect? Did the information you received in advance suffice your information needs?

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Paper 3

Parental death in young children's everyday lives:

Health professionals' and kindergarten teachers' contributions in meaning-making

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Parental death in young children’s everyday lives:

Health professionals’ and kindergarten teachers’ contributions in meaning-making

The present study focused on professionals’ meaning-making support to young children (1–6 years old) anticipating and grieving the loss of a parent because of a severe, somatic disease. A two-phased interview study with palliative health-care professionals (11) and kindergarten teachers (18) provided data for a comparative analysis of professionals’ contribution in making meaning of parental death across the contexts of palliative health care and kindergarten. The analysis focused on forms of interactions and resources for meaning making. Dialogues in the health systems centred on death and dying as natural, biomedical processes and relied on the dead or dying body as a context-specific resource for meaning making. The dialogues in the kindergarten centred on trying to understand the affected child’s behaviour and emotional expressions together with the peer group.

A parent severely ill and dying: children’s everyday life contexts

A parent’s severe illness and death represents a complex developmental condition. It alters the everyday life of the family, and at the same time the young child’s possibilities for participation within and across other development contexts, such as school and kindergarten (Højholt and Kousholt 2018; Lytje and Dyregrov 2019). The present study compares kindergarten teachers’ and palliative health-care professionals’ ways of interacting with young children (1–6 years old) about parental death.

In Norway and other OECD countries, a majority of children live their life across the two societal institutions of family and kindergarten already from the end of the first year of their life (Bae 2010; Sommer, Pramling Samuelsson, and Hundeide 2013). When a mother or father falls ill with an incurable, somatic disease, palliative health care additionally becomes another societal institution in the child’s everyday life. These two institutional contexts provide different conditions for children’s participation.

The institutional contexts

As a result of medical progress in the late 19th century, death has been professionalized and moved from being handled by the community to being handled by palliative health-care professionals that provide inter-professional care at the location where the dying person is (in palliative wards in hospitals or nursing homes, or palliative care arranged and based in their own homes) (Graven, Lund, and Jacobsen 2013; Madsen, Meldgaard, and Henriksen 2013). Palliative care has as ideal to focus on the physical, emotional, social and spiritual suffering of both the patient and her relatives (Madsen et al. 2013), and recent changes in laws and recommendations for health professionals in Scandinavian countries oblige palliative health-care professionals to contribute to take care of patients' minor children's needs for necessary follow-up and individually adapted information about prognosis and diagnosis (Danish Health Authority 2012; HPA 2010; SFS 2009). However, the patient-centeredness and the medical code ruling within the health care system, seem to make health professionals prioritize medical tasks above psychosocial issues (Karidar, Åkesson, and Glasdam 2016) and limit health professionals' possibilities for involving children (Dencker et al. 2017; Hogstad and Jansen 2020). Several studies point to insufficient support from health professionals to minor children of severely ill patients and their families (Golsäter et al. 2016; Ruud et al. 2015). In addition, health professionals' opportunity to meet the child directly is limited to short visits during home-based care, or on occasions when the child is actively invited to visit in hospital, something that not all patients allow (Hogstad and Leer-Salvesen 2020; Karidar, Åkesson, and Glasdam 2016). Kindergarten teachers, on the other hand, are in a position where they have close, everyday contact with the children.

The Nordic kindergarten tradition is founded on social-pedagogical philosophy where free play and social interactions with peers are considered central in learning- and developmental processes (Alvestad and Berge 2009). Arranging weekly or daily gatherings in the kindergarten is a common pedagogical practice for educational purposes and to build a sense of community in the peer group. The Framework Plan for the Content and Tasks of Kindergartens (2017), mandates kindergartens to support children in coping with misfortunes, to deal with challenges and become familiar with their own and others' feelings. Still, to the best of our knowledge, there exists to date no peer-reviewed studies that have focused on kindergarten teachers' contribution in supporting affected and grieving children. Two master's degree theses report from small-scale qualitative interview studies with kindergarten teachers in Norwegian kindergartens, and point to the need to voice kindergarten teachers' professional theoretical and practical knowledge about children and grief (Røkholt 2010)—a knowledge that seems to be underestimated by other professional collaborating partners (Sandberg 2012).

We need to consider professionals' contribution across contexts in relation to each other, to be able to understand children's possibilities in developing ways of conducting their life, and for the development of policy and practice for professionals. Two research questions will be addressed in this article:

(1) In which ways do professionals within the two contexts of palliative care and kindergarten interact with children to make meaning of parental death, and which resources do they rely on in their ways of making meaning?
(2) How does the professionals' meaning making work to condition children's possibilities to participate within and across everyday life contexts when a parent is severely ill and dying?

By conducting a comparative analysis of palliative health-care professionals' and kindergarten teachers' meaning-making practices and related resources, we bring to the fore knowledge about professional practices that might have remained implicit and taken for granted without the contrast created by comparison with the other context.

Dialogues that form and expand meaning

Developmental psychology has traditionally been concerned with the universal development of children's death concepts by age (Hogstad and Wold 2016). However, when a mother or father dies, the child's understanding of parental death involves more than just understanding death cognitively: children's subjective, everyday life experiences of parental death relates to how they together with others actively relate to- and continuously *make meaning* of parental death (Hundeide 2003; Højholt and Kousholt 2018).

By departing from sociocultural psychology, the present study relocates death concepts from the individual child to the *transindividual:* the meaning of death is socially constructed and already embedded in cultural practices, language, and other socioculturally shared symbol systems (Graven, Lund, and Jacobsen 2013). In situated encounters between people, multiple competing discourses of death are resources for making meaning about parental death and make available different possible ways of talking, thinking, feeling, and acting. A study of concepts and understanding of life and death among Norwegian 8-year-old pupils showed that they alternated between several discourses of death, depending on the conversational context and related to the overarching sociocultural context (Hogstad and Wold 2016). Two of these discourses were, first, death as a natural, biomedical process that happens to all living things, and that results from the cessation of bodily life functions; and second, death as the loss of—or a fundamental change in—an emotionally significant relationship (Hogstad and Wold 2016).

In a developmental perspective, children gradually, and together with others, develop their ways of drawing on socioculturally shared meanings in their conduct of life (Hundeide 2003; Højholt and Kousholt 2018). Caregivers or professionals contribute as interpretation partners by taking departure from shared knowledge (what is already known to the child), and they expand this by building bridges to something novel (Hundeide 2003). Engaging in such meaning-making work could be done through different forms of dialogues and with different aims (Ulvik 2015), but these practices have in common creating distance from the immediate by constructing a representation of the child's immediate experience (Hundeide 2003). To be able to depart with a basis in shared knowledge in dialogues with the young child (1–6 years old), professionals need to be conscious of the child's modes of communication and body language, and to listen, improvise, and interpret singular words or sounds and body language (Bae 2009; Sommer, Pramling Samuelsson, and Hundeide 2013).

Method

Participants

The present study focuses on interactions and dialogues in situated encounters where professionals engage as interpretation partners for young children in expanding the meaning of parental death, and it is part of a PhD project about professional support to young children who have a severely ill and dying mother or father. The PhD project has been approved by the Data Protection Official for Research in Norway, and it consists of two phases of interviews with professionals. In the first phase, three doctors and eight nurses from six public health institutions took part, and the second phase included participation by 18 kindergarten teachers from seven kindergartens. See Table 1 for an overview of participants.

Health professionals within palliative health-care services received written and oral information about the research project through information meetings arranged in the health institutions where they worked, or through a mediator within the health system.

Table 1

Profession (woman/man)	*Years of experience*	*Institutional affiliation*
3 doctors (1/2)	3–17 years of palliative care experience	1 in a small hospital 2 in university hospitals
8 nurses (7/1)	2–10 years of palliative care experience	From 2 different hospitals: - 2 palliative wards - 1 ambulant team - 2 ambulant/hospital teams From municipal health services: 2
18 kindergarten teachers (16/2)	4–36 years of experience as kindergarten teacher	From 7 different kindergartens: - 6 administrative leaders - 12 leaders in groups of children: - of mixed age (2) - 1–3 years old (4) - 3–6 years old (6)

Those who volunteered to participate contacted the first author directly by mail or telephone. All participants provided informed, written consent.

In the second phase, kindergarten teachers were recruited through families anticipating or recently experiencing the death of a parent because of a severe, somatic disease with at least one child in the family who attended or had attended kindergarten during the illness process. Information about the research project was distributed to families with the help of a university hospital-based bereavement support centre and a national health institution for cancer patients, as well as a municipal public health service.

Eight families with a total of nine children having attended kindergarten during illness processes (5 girls, 4 boys) contacted the first author by mail. Through written consent, they released the kindergarten teachers from their duty of professional confidentiality for the specific purpose of the interviews and at the same time provided contact information for the kindergartens. All 18 kindergarten teachers and their leaders volunteered to participate and provided their written consent.

Interviews

Both first- and second-phase interviews focused on professionals' experiences in encounters with minor children and their views and considerations regarding child involvement when a mother or father is severely ill and dying, but the interview guides differed from each other. Fundamental differences in the two professional groups' experiences relating to their access and relations to children for the scope of this study made different interview guides necessary. Whereas the kindergarten teachers (with one exception) each had experiences of providing support to only one child or pair of siblings, who all were 6 years of age or below, the health professionals' experience consisted of encounters with several children in a wider age range (0–18 years old). Health professionals' encounters were however more limited in time and closeness in their relations to the children compared to the kindergarten teachers, who followed the children from day to day before and throughout the illness process, and continued to follow some children also after the parent's death (five children). The health professionals' interview guide had four main questions; of these, two elicited the most responses relevant for the present study: one asked for stories from practice and the other focused specifically on children of kindergarten age (1–6 years old). The latter asked for these children's needs and understanding of illness and death, and how they ideally should be supported.

As a means to elicit detailed descriptions of practices of interaction that would provide knowledge about meaning-making work within the kindergarten, the kindergarten teacher interview guide was developed with inspiration from the life-mode interview (Haavind 2019). The interview started by asking about the time when the kindergarten got to know that the mother or father was severely ill, and continued by alternating between following and making a picture of the events chronologically, and lingering on specific events to explore and elicit detailed accounts of interaction sequences and justifications for practice. All interviews were conducted in Norwegian, and all except one were conducted in the professionals' workplace. Interviews lasted from 30 to 135 minutes and were audio recorded. The first author transcribed all the interviews verbatim, resulting in 850 pages of text.

Analysis

During the first-phase interviews, the first author became curious about the interactions between health professionals and young children next to the dying or dead body because of the way the body appeared as an essential, but also *context-specific*, resource for making meaning about death. This made us want to further explore- and systematically analyse context-specific patterns of forms of interactions. The first and second author then together developed the four-step process of analysis described below.

In the first step, the first author read the 850 pages of transcripts searching specifically for stories about and descriptions of interactions with children in making meaning about parental death. As expected, given the differences between the two groups and the different interview guides, the data from the two groups of professionals differ. Whereas the kindergarten teacher data contain many detailed stories with descriptions of interactions with the child in question, the health professional data contain references to detailed descriptions of practices that they claimed they used to do. These detailed practice descriptions, “we-used-to descriptions”, were more generalized in their form and were not necessarily tied to specific children. These were not found in the kindergarten teachers’ transcripts.

Text sections that consisted of detailed descriptions of concrete practices where the professionals interacted with children in particular ways, or detailed descriptions of specific interactions between the child and the professional, were marked in the text and given a code (hp for health professional/bl for kindergarten teacher), plus a number. After several rounds of thoroughly considering whether the text sections met the inclusion criteria, we ended up with 98 text sections—30 extracts from the health professional interviews and 68 extracts from the kindergarten teacher interviews. The codes referring to the text extracts were structured in a table for the second and third steps of the analysis. See a translated example in Table 2.

Table 2

Code and short description	*How does the professional describe:*				*Interpretation:*	
	- the initiative of the child?	- the child’s participation?	- the initiative of the professional?	- the professional’s participation?	What is the interaction about?	Which resources do they apply for making meaning?
HP-E-6/1 Concrete description of a situation from practice: a child (appr. 5–6 years old) comes along into the room to see her mother just after her death		Listen to the nurse’s heart first, then to her mother’s heart with the stethoscope. She hears the difference between the beating and non-beating heart.	Takes initiative to get the girl into the room of the mother just after she died. Suggests that the child may listen with a stethoscope.	Offers her own beating heart for the girl’s listening.	Helping the child in understanding what it means to be dead and that mum is dead now.	Medical equipment: the stethoscope. Bodies/hearts: the dead body of the mother and the healthy body of the nurse.
BL-V-37/4 Story from one of the regular weekly gatherings in the kindergarten where the boy’s (appr. 2 ½ years old) mother recently died. They listen to music—accidentally the instrument that the mother used to play.	The boy suddenly stands up when he hears the music, saying, “Mum”.	Responds by saying “Mum, mum” repeatedly. Sits down together with V and looks at the picture of the instrument mum played on the iPad.		Answers the boy: Yes, mum played music, do you want to come up here?” Continues by talking about his mother. Searches for a picture of the instrument she played (that they listen to) on the iPad and shows the children.	The boy seems to associate the sound of the music with his dead mum. V contributes to strengthen this association when she acknowledges it and expands it by adding another sensible element—a picture of the instrument she played—and by talking about what she interprets as the background of the child’s association: that mum played music.	Language Music iPad: picture, iconic representation of an object that is associated with mum. V’s knowledge about mum as a musician.

The second analytic step was descriptive and involved identifying the child’s and the professional’s initiative and participation in the interaction from each text extract, and structuring it in the table. Body movements and language, singular words or sounds as well as silence and listening were included as forms of participation, in line with Bae (2009). The third step of analysis involved interpreting the interactions described, built upon two analysis questions that were theoretically informed (Kousholt 2018) by Hundeide’s (2003) dialogues that expand and form meaning: What is the interaction about? Which resources do they apply for making meaning? Steps two and three were conducted twice: first for the health professionals, and then for the kindergarten teachers, revealing within-group differences and similarities.

The fourth step of analysis involved looking for patterns of forms of interactions and resources for meaning making within and across the professional groups, and it resulted in three main forms of interactions, with the two latter tied to context-specific resources within the institutional contexts. Finally, using the findings in the fourth step as a point of departure, we used Højholt and Kousholt's (2018) concept of participation to analyse how the professionals' various ways of conducting meaning-making work conditioned children's possibilities to participate across the contexts.

Results

Forms of interactions

The three main forms of interactions presented in the following—*prepared meetings with many involved participants*, *dialogues in encounters with the dying and dead body*, and *therapeutic, psychological dialogues*—are categorizations of the interactions that were most commonly referred to across the interviews. The categories do not apply to all participants within each context, or to all areas of the contexts. For example, even though gatherings to memorialize the dead parent was a frequently mentioned form of interaction, none of the kindergarten teachers in toddler groups (1–3 years old) did arrange such gatherings. In addition, four (of 29) professionals did not refer to any instance of meaning-making interactions in their interviews, while others' accounts consisted of up to 10.

Prepared meetings with many involved participants

Both groups of professionals organized well-prepared, structured meetings where information about illness and death was provided. In the health-care context, these took the form of information meetings and involved family as well as professionals from different institutions and of different professions. In the kindergarten, the prepared meetings were memory gatherings after the parent had died and gatherings informing the children's group that one of the parents of a kindergarten child was severely ill and might die. The gatherings involved the peer group and sometimes the remaining parent, and candles and a picture of the dead parent decorated the room. The purpose of the meetings within both contexts seemed to be to inform the child or children, and to help them understand that the parent was going to die or had died. Nurse "Jenny" told of an information meeting with two siblings of kindergarten age who were informed that their mother's disease was incurable and that the mother was going to die within a short time:

> I had brought a little teddy and a suitcase with doctor equipment, and I told them, "You know that mum has been sick for a while". I then opened the suitcase and picked up the hypodermic syringe and showed on the teddy, "She has gotten medicines". I let them try the syringe, before continuing, "If someone has been sick for a very long time, and the doctor has no more medicines to give…" and I showed them the book Chemoman Casper[1], and further built on that story to explain how the chemotherapy eventually stops working and the illness grows in the body. Moreover, the children asked, "Will mum die?" "Yes, she is going to die. Everybody dies eventually, we just do not know when. But your mum is not going to live very much longer."

The kindergarten teachers in the gatherings used very similar explanations to Jenny, about how doctors try to heal the parent, but that sometimes no medicine is working. Even though the purpose of the meetings within both contexts was to provide information, there was a difference regarding who was familiar with the knowledge before the information meeting. In the health-care context, the purpose was to provide the child with knowledge that was previously unknown to him or her, and in the

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[1] Chemoman Casper [Norwegian title: Kjemomannen Kasper] is a children's book about chemotherapy, published by the Norwegian Cancer Society.

kindergarten, the information was known to the bereaved (or anticipating) child but not necessarily to the other children in the group. Hence, whereas in the health-care context the information target was the child or siblings, in the kindergarten the peer group was as much the target as the bereaved child.

Dialogues in encounters with the dying and dead body

The most frequently referenced forms of interaction between health professionals and young children (approximately 8 years and below) were dialogues next to the dying and dead parent, where the professional supported the child in interpreting what they heard and saw. The professional used plain, concrete descriptions of physiological processes. For instance, nurse "Lavrans" recalled saying the following:

> "Your mother's breath sounds like this because she has water in her lungs. We will try to relieve her of this water."

They also had similar dialogues *prior* to encounters with the dying or dead body, where the nurses and doctors prepared the child for the fact that the dead body would be cold, about how the death process possibly could proceed, and how the breath sounds and changes in the death process. No kindergarten teachers told about engaging in this form of interaction. However, kindergarten teacher "Maria" related that when the recently bereaved boy in her group (same-aged children, 4 years old) came back to the kindergarten after visiting hospital, he told about having felt his dead father and that "he was cold, but not white".

Therapeutic, psychological dialogues

The doctors and nurses told about interactions with adolescents categorized as therapeutic, psychological dialogues, because they provided individual psychological support and comfort, but this type of dialogue did not happen with the youngest children. However, the kindergarten teachers did have such dialogues, some in private and some within the child group, like in this example from Maria:

> We have had a lot of good conversations, even though he doesn’t say much. However, he can initiate it by just a sentence, and I will talk around it while he listens. Recently, he was lying on his tummy across my lap. His mate complained about him having done something, and I said to his mate, “Maybe it is not so easy to be him these days; maybe he is angry or sad within. Maybe he misses his dad really much and is sad because of that.” Several children started asking, “Why did he get cancer?” and “Will he never ever come back?” We talked for a long time. He said nothing himself, just lay there on my lap listening. I was very well aware that he was listening.

Maria’s example is a conversation with the group that carries an individual therapeutic effect for the bereaved child. In addition, the kindergarten teachers referred to engaging in play situations as a narrative-dramatic form of therapeutic dialogue.

In private therapeutic dialogues, the kindergarten teacher took the child away from the children’s group to be alone in a private space. In one kindergarten, a picture of the deceased mother of a 3-year-old boy was placed in the staff’s break room, and the kindergarten teacher “Vilde” brought the boy there to talk about and memorialize the mother when he initiated talking about mum. In another kindergarten, when a 5–6-year-old boy anticipating the death of his mother showed signs of being emotionally overwhelmed while in the group of children, the kindergarten teacher “Belinda” immediately and discretely invited him out of the situation to the staff’s break room where he could cry in private.

Resources

The body and medical equipment in the health-care context, as well as *peers* in the kindergarten context, stood out during the analysis as context-specific resources. Again, not all health professionals seemed to utilize the possibilities for meaning making available through the medical context. Even though kindergarten teachers' accounts abounded with references to peers, peers as a resource were not equally evident in cases where the children attended 1–3 years old-groups. The kindergarten teachers in these groups did not tell about the same types of conversations, and the dialogues seemed mainly to concern the child painfully calling for or merely asking for the dead parent, and the professional replied that he or she was dead or in heaven. The other children in the group were not part of these interactions. In addition to these context-specific resources, we present *discursive resources* that have the potential to span across contexts.

Context-specific resources: the body and peers

The dying or dead body was a resource for meaning making exclusive for the health care context. Nurse "Lavrans" encouraged a pair of siblings to tickle their dead father under the feet to see that he did not respond. Nurse "Elisabeth" allowed children to borrow her stethoscope to listen for heartbeats, first in her own chest, and then in the dead mother's chest to see that her heart did not beat any more. Nurse "Jenny" told, from the same meeting as quoted from above, that she showed the children how the mother's hair was gone as an indication of severe illness. In these examples, the dying or dead body became objects of shared knowledge. In addition to the body, nurses and doctors applied medical equipment as interpretative resources, as with Elisabeth's stethoscope or Jenny's use of a syringe to visualize and expand on the children's knowledge about illness and medicines.

Kindergarten teachers made explicit references to peers as helpful and welcoming partners in joint meaning making. None of the health professionals did so. During the memory gatherings in kindergartens, peers asked questions about cancer as a cause of death and the irreversibility of death, and commented with their own death-related experiences. The everyday life of the kindergarten offered situations where the bereaved or anticipating child stood out for peers as different, for example the pick-up-situation at the end of the day. Peers contributed with statements that made death explicit, by stating that (name)'s mum or dad is dead or going to die; for instance, as kindergarten teacher "William" related, an older child said while 3-year-old "Carl" was present, "Carl's mum is dead".

Discursive resources

Even though the health professionals exclusively own the access to the body as a material resource in making meaning of death as a biological process, the related biomedical discursive resource is available for both groups of professionals. The kindergarten teachers draw on a biomedical discourse of death in their explanations within gatherings when explaining why the parent's illness might lead to or led to death. However, there are fundamental differences in the two groups' ways of approaching the emotional aspect of death experiences. The health professionals tended to explain death as a concept by drawing comparisons to other biologically similar instances of death that the child might be familiar with, like dead flies and animals. They generalized death as a naturally occurring phenomenon happening to all living things, regardless of the emotional significance of this specific death. The kindergarten teachers, on the other hand, tended to highlight the difference between a dead parent and a dead fish in the grocery store fish counter or a beloved dead pet. In the memory gatherings, candles and white tablecloth created an emotional atmosphere that contributed to convey the emotional meaning of death, in addition to deliberately showing facial and bodily expressions of grief, such as gentle weeping and sad faces. This meaning-making work seemed to draw on discourses of loss and bereavement and involved a dimension of socializing the peer group into socioculturally appropriate ways of behaving, such as comforting, showing sadness, and displaying a sense of care.

Discussion of possibilities for participation within the two contexts

In the following, we apply empirical examples to analyse how professionals' contribution in meaning-making dialogues may condition children's possibilities to participate across contexts when a parent is severely ill and dying (Højholt and Kousholt 2018). First, it is a theoretical point that involving children in dialogues at the same time is to acknowledge them as participants, which in itself contributes to equipping them with possibilities, for example of rejecting and resisting (Øksnes and Samuelsson 2017), as well as to express themselves in the dialogues (Bae 2009). Involving children in gatherings also opens an arena for participation, regardless of whether the aim of the gathering is to deliver information or to memorialize, and of whether the child participates verbally or just with their embodied presence. Even very young children may feel the emotional significance of parental death by merely being present. Towards this background, it is worth noting that the youngest children (1–3 years old) in mixed age-groups had other possibilities for participating than young children in same-aged groups where gatherings were not conducted.

Second, involving children in dialogues may increase their ability to apply discursive resources to talk about their experiences, which further opens up the possibility to share their experience with other people in other contexts of their everyday life. Maria's example, where the 4-year-old boy was able to tell the peer group and Maria back in the kindergarten about the feeling and vision of his recently deceased father, nicely illustrates this. Guidelines for support to children experiencing parental death recommend that professionals provide clear and concise factual explanations in concrete language about causes of death, using the words 'death' and 'dying' and avoiding euphemisms (Willis 2002), which is similar to how the health professionals in the present study contributed as interpretation partners in encounters with the dead and dying parent.

For health professionals, the dying or dead body permits the use of sensory cues (tactile, visual, smell) as shared knowledge to expand the meaning of death as a biomedical process and biological phenomenon. Plain, concrete descriptions of visual and tactile impressions are discursive resources that make available a distance to the immediate, intense experience of encountering the dead or dying body. Previous studies of children's developing understanding of death show that presenting visual cues in explanations of death support children's understanding of death as involving cessation of all body functions (Hogstad and Wold 2016), and that increased biological understanding of death seems to decrease the fear of death in young children (Slaughter and Griffiths 2007).

Third, peers' behaviours, reactions, utterances, and engagement in processes of making meaning of parental death can either limit or open up possibilities, and in this way they become part of the anticipating or bereaved child's developmental conditions. When peers hear that a parent has died or is ill and going to die, the other children start their process of adjusting to- and figuring out how to understand-, deal with- and live with the threat from parental illness and death. However, peers' contributions are conditioned by the kindergarten teachers' regulation of the peers' opportunities to take part (Højholt and Kousholt 2018), and in our study, the kindergarten teachers' ways of approaching and responding to initiatives by peers varied. William told about talking in a friendly manner to the boy who spoke of the death of Carl's mum, pointing out that it might affect Carl that he said so. Further, he talked about what it means to be dead. An important aspect here is that William implicitly acknowledged the peer as trying to come to terms with what it means that someone's mum is dead. Still, there appeared to be an element of moral judgement in William's way of talking to this boy, probably tied to sociocultural norms for behaviour when someone is dead, as he commented in the interview, "It is the unfiltered mind of the child talking".

The same correction of behaviour was not visible in the example from Maria. She responded to the efforts of the children's group in coming to terms with what it means that someone's dad or mum is dead, while simultaneously taking care of the boy's individual psychological needs. Hence, she conducted parallel dialogues with multiple purposes, both made possible by the mere presence of peers. Her way of incorporating into the peer group her understanding of the boy's behaviour as expressions of grief seems to have the potential to facilitate the boy's bereavement processes in the kindergarten group by making the peers understand him better. Belinda's responses, on the other hand, when she on one occasion "froze" and remained silent upon a peer's mention of the anticipated death of the boy's mother, because she was fearful of saying something wrong, potentially contributed to making death a taboo topic within the kindergarten. Creating or upholding taboos limits the peer group's opportunities to take part and to understand—not only what the anticipated death means to the child in question, but also what the anticipated death means to the peer group members, in their relationships and their everyday lives.

Discussion

The present study points to ways of making meaning accessible to professionals within the contexts of kindergarten and palliative care. It is a strength that it involves data from both kindergarten teachers and health professionals, primarily for two reasons. First, to our best knowledge, this is the first study to focus on kindergarten teachers' contribution in joint meaning-making work with children experiencing parental death because of a severe, somatic disease. With some exceptions (Bugge et al. 2014), previous studies within the field of childhood bereavement have focused on parentally bereaved children above 6 years old (Duncan 2020; Hanna, McCaughan, and Semple 2019). Second, involving two professional groups allows a comparison that could not be done in previous studies involving only health professionals.

The recruitment strategies of this study limit the generalizability of the results. The sample of health professionals may skew towards those professionals with above-average dedication to supporting children as next of kin, and it may therefore contain an unnaturally high amount of meaning-making interactions compared to a more representative sample. The process of recruiting kindergarten teachers involved difficulties in obtaining consent from the families, which may indicate a sample skewed towards kindergartens where the parent–kindergarten collaboration functions more satisfactorily than in other such situations.

Another aspect affecting the generalizability of the results is that only the kindergarten teachers were temporarily released from their adherence to strict confidentiality. The health professionals' abundant experience during years of clinical work made it possible for them to anonymize their stories, but in their efforts to anonymize their patients and their children they probably withheld details and made the stories more impersonal and general. The fact that the health professionals gave more "we-used-to" descriptions, while the kindergarten teachers gave more detailed descriptions, might derive from this, and this might have resulted in deeper insight into the meaning-making dialogues within the kindergarten. Some of these differences may however derive from actual differences on the basis of experience between the groups. A point of particular significance here is that *time* is a resource that the health professionals are in continual shortage of, overall and in encounters with children (Karidar, Åkesson, and Glasdam 2016), while kindergarten teachers follow the children in their everyday life during illness processes. More time with the child enables closer relations and results in a situation where the kindergarten teacher and the child share more background knowledge necessary for successful communication (Hundeide 2003).

An additional strength is that the research methodology involved in-group analysis, which allowed for insights regarding differences within the two contexts on how the professionals contributed to open or limit the child's possibility to engage in meaning-making dialogues. Worth noting is that these differences do not have to be tied to the individual professional but could relate to other circumstances, for instance communication patterns in the family system that affect the professional's possibilities to engage in meaning-making dialogues with the child, such as parents withholding information about illness and death from their child (Hogstad and Leer-Salvesen 2020). Further research is needed to better understand the conditions contributing to limiting and opening up possibilities to participate within and across everyday life contexts for children experiencing parental death.

Concluding remarks

The international literature provides guidelines for professionals directing them to support children experiencing parental death by engaging in open communication about illness and death (Duncan 2020; Hanna, McCaughan, and Semple 2019). The present study's findings show that such open communication may involve very different ways of engaging in dialogues with young children, depending on the availability of resources and the purposes of engaging in meaning-making work, tied to the societal institutions. Health professionals engage in meaning-making dialogues centred on death as a biological phenomenon and dying as a biomedical process, while kindergarten teachers mainly engage in meaning making centred on parental death as an emotional and relational phenomenon. Hence, the two groups of professionals have different perspectives on the development of children, resonating with their formal mandates through the Health Personnel Act (HPA) and The Framework Plan for the Content and Tasks of Kindergartens (2017). Their roles, responsibilities, and tasks in relation to these children, keeping in mind the knowledge of professionals' fundamentally different ways of attending to their obligation to support children in making meaning of death, should be distributed by developing interprofessional collaboration.

Health professionals could take steps to involve the kindergarten staff when new information about prognosis and diagnosis is shared, and with that they would signal a responsibility as well as provide a possibility for the kindergarten staff to engage in dialogues, with this information as background knowledge. In the present study, there was few references to interactions between health professionals and kindergarten teachers. Sharing information across the different contexts about what a child has experienced, enables the professionals' interpretation of the young child's singular words or sounds to expand on their meaning. For example, the information that a child has felt the coldness of a dead body in the hospital, provide kindergarten teachers the necessary background information so that they may take basis in shared knowledge – even though the concrete, physical meaning-making resource of the dead body is not present. This is especially important with the youngest children, who might not have the possibility to share this information themselves. Our findings point to the need for paying extra attention to the possibilities of toddlers, and especially toddlers in same-aged groups, to participate in meaning-making dialogues.

Acknowledgement

We are grateful to the families that provided their consent to let the kindergarten teachers share their stories with us. We would also like to thank the mediating institutions for their help in distributing information about the research project to health professionals and families. Thanks to Prof. Else Lykkeslet for her supervision on the development of the design of the PhD project and to Eline Grelland Røkholt for valuable comments in the writing process.

Declaration of interest statement

No conflicting interests.

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Appendixes

1: Letter from NSD

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Ingrid Johnsen Hogstad
Avdeling for helse- og sosialfag Høgskolen i Molde
Postboks 2110
6402 MOLDE

Vår dato: 08.10.2015 Vår ref: 44977 / 3 / LT Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 02.10.2015. Meldingen gjelder prosjektet:

44977	*Ivaretakelse av mindreårige barn som pårørende til en alvorlig syk og døende mor eller far*
Behandlingsansvarlig	*Høgskolen i Molde, ved institusjonens øverste leder*
Daglig ansvarlig	*Ingrid Johnsen Hogstad*

Personvernombudet har vurdert prosjektet og finner at behandlingen av personopplysninger er meldepliktig i henhold til personopplysningsloven § 31. Behandlingen tilfredsstiller kravene i personopplysningsloven.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 29.06.2020, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Lis Tenold

Kontaktperson: Lis Tenold tlf: 55 58 33 77
Vedlegg: Prosjektvurdering

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Prosjektvurdering - Kommentar

Prosjektnr: 44977

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Personvernombudet legger til grunn at forsker etterfølger Høgskolen i Molde sine interne rutiner for datasikkerhet. Dersom personopplysninger skal sendes elektronisk, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 29.06.2020. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette digitale lydopptak

Det kan bli aktuelt å benytte en transkriberingsassistent. Høgskolen i Molde skal inngå skriftlig avtale med assistenten om hvordan personopplysninger skal behandles, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: http://www.datatilsynet.no/Sikkerhet-internkontroll/Databehandleravtale/.

2: Letter from NSD, phase 2

NSD NORSK SENTER FOR FORSKNINGSDATA

NSD sin vurdering

Prosjekttittel

Ivaretakelse av mindreårige barn som pårørende til en alvorlig syk og døende mor eller far

Referansenummer

710887

Registrert

16.08.2018 av Hogstad Ingrid Johnsen - Ingrid.J.Hogstad@himolde.no

Behandlingsansvarlig institusjon

Høgskolen i Molde – Vitenskapelig Høgskole i Logistikk / Avdeling for helse- og sosialfag

Prosjektansvarlig (vitenskapelig ansatt/veileder eller stipendiat)

Ingrid Hogstad, ingrid.j.hogstad@himolde.no, tlf: 90919642

Type prosjekt

Forskerprosjekt

Prosjektperiode

02.11.2015 - 31.12.2021

Status

18.03.2019 - Vurdert

Vurdering (3)

18.03.2019 - Vurdert

Vi viser til endringer registrert i meldeskjema 15.3.2019. Endringene innebærer at deltakere i utvalg 2 i tillegg vil rekrutteres via barnehager eller andre som har kontakt med personer som oppfyller utvalgskriteriene. Den enkelte barnehage vil videreformidle invitasjon til potensielle deltakere, og forsker mottar ingen opplysninger om deltakeren før samtykke foreligger.

NSD vurderer at rekrutteringen fortsatt er lagt opp på en måte som sikrer at krav til konfidensialitet, taushetsplikt og frivillighet blir ivaretatt, og har ingen innvendinger mot endringene.

Det er dermed vår vurdering at behandlingen av personopplysninger i prosjektet fortsatt vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 18.3.2019 med vedlegg. Behandlingen kan fortsette.

Kontaktperson hos NSD: Lasse Raa
Tlf. personverntjenester: 55 58 21 17 (tast 1)

14.03.2019 - Vurdert

Vi viser til endringer registrert i meldeskjema 7.3.2019. Endringene innebærer at informasjonsskrivet til foreldre/tredjepersoner er omformulert noe.

Vi legger til grunn at det tilføyes opplysninger om rettigheter, lovlig grunnlag (samtykke) og kontaktinformasjon til personvernombud, tilsvarende i det opprinnelige informasjonsskrivet til foreldre. Vi har ellers ingen innvendinger mot informasjonsskrivet slik det foreligger.

NSD vurderer på dette grunnlag at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Det er dermed vår vurdering at behandlingen av personopplysninger i prosjektet fortsatt vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 14.3.2019 med vedlegg. Behandlingen kan fortsette.

Kontaktperson hos NSD: Lasse Raa
Tlf. personverntjenester: 55 58 21 17 (tast 1)

10.10.2018 - Vurdert

Prosjektet er en videreføring av prosjektnummer 44977, som ble vurdert av NSD 8.10.2015 etter personopplysningsloven av 2000. Herværende vurdering inkluderer i tillegg intervjuer med barnehagelærere (utvalg 2 i meldeskjema).

Det er vår vurdering at behandlingen av personopplysninger i prosjektet vil være i samsvar med personvernlovgivningen så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 10.10.2018 med vedlegg. Behandlingen kan starte.

MELD ENDRINGER
Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringer gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET
Prosjektet vil behandle alminnelige kategorier av personopplysninger frem til 31.12.2021.

LOVLIG GRUNNLAG
Prosjektet vil innhente samtykke fra de registrerte til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 og 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes samtykke, jf. personvernforordningen art. 6 nr. 1 bokstav a.

PERSONVERNPRINSIPPER
NSD finner at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen om:
- lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen
- formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke behandles til nye, uforenlige formål
- dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet
- lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet

DE REGISTRERTES RETTIGHETER
De registrerte vil ha følgende rettigheter i prosjektet: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15),

retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20). Rettighetene etter art. 15–20 gjelder så lenge den registrerte er mulig å identifisere i datamaterialet.

NSD vurderer at informasjonen om behandlingen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER
NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32).

For å forsikre dere om at kravene oppfylles, må dere følge interne retningslinjer og/eller rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET
NSD vil følge opp behandlingen av personopplysninger ved planlagt avslutning og underveis for å avklare om behandlingen er avsluttet eller i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet!

Kontaktperson hos NSD: Lasse André Raa

Tlf. personverntjenester: 55 58 21 17 (tast 1)

3: Information letter to health professionals, phase 1

Høgskolen i Molde
Vitenskapelig høgskole i logistikk

HØGSKULEN
I VOLDA

Tlf: 71 19 58 24
E-post **ingrid.j.hogstad@himolde.no**

Molde. 28.09.15

Forespørsel om deltakelse i forskningsprosjektet:

«Ivaretakelse av mindreårige barn som pårørende til en alvorlig syk og døende mor eller far.»

Bakgrunn og formål

(Navn på institusjon) har gitt meg tillatelse til å spørre deg og dine kollegaer i (palliativt team/palliativ avdeling) om dere kan tenke dere å delta i forskningsprosjektet. Forskningsprosjektet er del av en doktorgradsstudie ved Høgskolen i Molde som har som formål å legge til rette for oppfølging av mindreårige barn som pårørende til en alvorlig syk og døende mor eller far. Deres institusjon har blitt strategisk valgt ut på grunn av sykehusets størrelse og geografiske plassering.

Jeg er interessert i å høre dine historier om – og erfaringer fra ditt og dine kollegaers arbeid med mindreårige barn som pårørende. Forskningsspørsmålet som søkes besvart, er: *Hva fremmer og hemmer ivaretakelse av mindreårige barn som pårørende til en alvorlig syk og døende mor eller far?*

Hva innebærer deltakelse i studien?

Deltakelse i studien innebærer deltakelse i først et individuelt intervju og senere et gruppeintervju sammen med dine kollegaer. De to intervjuene vil bli holdt med ca. en måneds mellomrom. Det individuelle intervjuet forventes å vare i 45 min-1 ½ time, og gruppeintervjuet forventes å vare i ca. 1½ time. Intervjuene vil gjennomføres ved (navn på arbeidssted/institusjon) i din arbeidstid. I de individuelle intervjuene vil du bli spurt om å fortelle om dine personlige erfaringer og historier fra arbeid med barn som pårørende. Jeg er interessert i historier både om suksessfull og ikke så suksessfull oppfølging, samt om de tilfellene der man eventuelt ikke har fått «tilgang» til barna. Spørsmålene i gruppeintervjuene vil blant annet omhandle: erfaringer med tverrprofesjonelt samarbeid (både innad i institusjonen og på tvers av institusjoner og hjelpeinstanser) og hvilke rammevilkår som dere oppfatter som fremmende eller hemmende for oppfølging av barn som pårørende. Intervjuene vil bli tatt opp på lydfil og etter gjennomføring vil lydfilene bli skrevet om til skriftlig materiale.

Hva skjer med informasjonen om deg?

Alle personopplysninger vil bli behandlet konfidensielt. Personidentifiserende opplysninger brukes kun for å holde kontakt med deg som deltaker, og vil anonymiseres allerede i utskriften av intervjuet. Opplysninger om ditt arbeidssted, din stilling og utdanningsbakgrunn vil kunne finnes i datamaterialet, men det vil ikke være mulig å identifisere deg som person. Kun jeg som forsker vil ha direkte tilgang til personopplysninger, og mine veiledere vil kunne få tilgang til personopplysningene gjennom kontakt med meg (ved behov). Lydfilene slettes fra spilleren straks de er overført til sikkert nettverk, der de vil lagres med passordbeskyttelse. Navneliste og koblingsnøkkel vil lagres atskilt fra øvrige data.

Det vil ikke være mulig å gjenkjenne deg som deltaker i det publiserte materialet.

Prosjektet skal etter planen avsluttes i juli 2019. Personopplysninger og opptak vil bli slettet ved prosjektets ferdigstillelse. Det skriftlige datamaterialet vil bevares i anonymisert form og under passordbeskyttelse.

Frivillig deltakelse
Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn.

Dersom du ønsker å delta, skriv under på samtykkeskjema som ligger vedlagt.

Dersom du har spørsmål til studien, ta kontakt med Ingrid Hogstad på telefon 90919642 eller 71195824.

Studien er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og er villig til å delta (kryss av):
☐ i begge intervjuer (individuelt- og gruppeintervju)
☐ kun i individuelle intervju
☐ kun i gruppeintervju

(Signert av prosjektdeltaker, dato)

Vennligst oppgi ditt telefonnummer for nærmere avtale om tidspunkt for individuelt intervju:

Tlf: _______________

Samtykkeskjema puttes i ferdig frankerte og adresserte konvolutt som ligger vedlagt.

4 a: Information letter to families, phase 2

Høgskolen i Molde
Vitenskapelig høgskole i logistikk

HØGSKULEN
I VOLDA

Kan jeg få lov til å snakke med barnehagelæreren til ditt barn?

Dette er en forespørsel om du som forelder eller foresatt kan samtykke til at barnehagelærere i barnehagen hvor ditt barn går eller har gått, kan delta i et forskningsprosjekt.

Jeg, Ingrid Hogstad, er doktorgradsstipendiat ved Høgskolen i Molde og jobber med et forskningsprosjekt hvor jeg søker kunnskap om hvordan både helsepersonell og barnehagelærere ivaretar barn som kommer til- eller har mistet en mor eller far på grunn av alvorlig, somatisk sykdom.

For å kunne snakke med ditt barns barnehagelærer trenger jeg samtykke fra foreldre, siden barnehagelærere er bundet av taushetsplikt. Jeg er interessert i barnehagelærernes arbeid og betingelser for ivaretagelse av barn, og når vi snakker om dette vil også konkrete barn bli omtalt. Det er derfor jeg trenger samtykke fra deg/dere som foreldre.

Hva innebærer samtykket?

Samtykket innebærer at du fritar barnehagelærerne i din nåværende eller tidligere barnehage fra taushetsplikten, slik at han eller hun kan fortelle om ditt barn i det aktuelle intervjuet. Dette fritaket er midlertidig og gjelder kun dette intervjuet. Intervjuene tas opp på lydfil og transkriberes på en måte som gjør det umulig å identifisere hvem som omtales og hvem som snakker. Lydfilen oppbevares trygt og i et begrenset tidsrom.

Hvis du gir samtykke til at jeg kan snakke med ditt barns barnehagelærer kan du enten

a) kontakte meg på **telefon eller sms: 90919642**. Du kan også sende e-post til ingrid.hogstad@himolde.no. Jeg vil så kontakte deg for å få informasjonen som er nødvendig før jeg kan kontakte barnehagen deres, og du kan stille spørsmål om det er noe du lurer på.
b) bruke samtykkeskjema nederst i dette brevet. Signer, oppgi eget navn og kontaktinformasjon til barnehagen hvor ditt barn går, eller har gått. Samtykkeskjemaet sendes i vedlagte konvolutt som er ferdig frankert og adressert. Jeg vil så ta direkte kontakt med barnehagen.

Du kan trekke ditt samtykke tilbake uten å oppgi noen grunn og det vil ikke ha noen negative konsekvenser for deg. Hvis intervjuene allerede er gjennomført på det tidspunktet du melder at du vil trekke deg, vil lydfiler og transkripsjoner bli slettet og ikke brukt i det videre arbeidet.

Hvordan opplysninger oppbevares og brukes

Jeg som forsker har taushetsplikt. Opplysningene om ditt barn vil bare bli brukt til formålene fortalt om i dette skrivet. Opplysningene vil bli behandlet konfidensielt og i samsvar med personvernregelverket.

- Det er kun undertegnede som vil ha tilgang på lydfilene fra intervjuene. Lydfilene oppbevares under passordbeskyttelse.
- Intervjuene anonymiseres samtidig som de skrives om til skriftlig materiale slik at det skriftlige datamaterialet ikke inneholder personopplysninger som gjør barnehagelæreren, deg eller ditt barn direkte identifiserbare
- Mine veiledere og andre forskere som jeg samarbeider med får tilgang kun til anonymisert datamateriale.

Det vil ikke være mulig å gjenkjenne ditt barn, barnehagelæreren eller barnehagen i publisert materiale.

Prosjektet skal etter planen avsluttes innen utgangen av 2021. Personopplysninger og lydfiler vil bli slettet ved prosjektslutt. Det skriftlige datamaterialet vil bevares i anonymisert form og under passordbeskyttelse.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg,
- å få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

Opplysninger om deg og ditt barn behandles basert på ditt samtykke.

NSD – Norsk senter for forskningsdata AS har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Har du spørsmål eller innvendinger?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt direkte med undertegnede, eller:

- Høgskolen i Moldes personvernombud: Karl Yngvar Dale (telefon: 71 21 40 57)
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Ingrid Johnsen Hogstad

Prosjektansvarlig

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet, og har fått anledning til å stille spørsmål.

Jeg samtykker til at Ingrid Hogstad tar kontakt med ____
(Fyll inn navn på barnehagen)

Jeg samtykker til at barnehagelærere i denne barnehagen midlertidig fris fra taushetsplikten slik at han eller hun kan fortelle om ditt barn i det aktuelle intervjuet - selv om det medfører å dele informasjon om personlige forhold.

Jeg samtykker til at mine opplysninger (lydopptak av intervjuene) behandles frem til prosjektet er avsluttet, innen utgangen av 2021.

(Navn på forelder)

(Signatur og dato)

Kontaktopplysninger til barnehagen (* må fylles ut):

Barnehagens navn*: ____

I kommune*: ____

Barnehagens adresse og/eller telefonnummer: ____

4 b: Information letter to kindergarten teachers, phase 2

Høgskolen i Molde
Vitenskapelig høgskole i logistikk

HØGSKULEN
I VOLDA

Vil du delta i et forskningsprosjekt om ivaretakelse av barn som har en mor eller far med alvorlig, livstruende sykdom?

Dette er et spørsmål om du som er barnehagelærer vil delta i et forskningsprosjekt. Du kan delta hvis et barn på avdelingen hvor du jobber har eller har hatt en mor eller far med en alvorlig sykdom med kronisk forløp.

Jeg, Ingrid Hogstad, er doktorgradsstipendiat ved Høgskolen i Molde og jobber med et forskningsprosjekt hvor jeg søker kunnskap om hvordan både helsepersonell og barnehagelærere ivaretar barn som har en mor eller far som er alvorlig syk og døende.

På grunn av taushetsplikten trengs samtykke fra foreldre for at jeg skal kunne snakke med deg om dine erfaringer.

Hva innebærer det for deg å delta?

Deltakelse i studien innebærer at jeg intervjuer deg en gang i et individuelt intervju. Intervjuet forventes å vare i 1 til 1 1/2 time. Intervjuet vil bli lagt opp som en uformell samtale hvor du får fortelle mest mulig fritt og uhindret om dine erfaringer, imens jeg kommer med oppfølgingsspørsmål fra en intervjuguide der det er nødvendig. Du vil bli bedt om å fortelle om dine erfaringer, om ditt og barnehagens arbeid og vurderinger i situasjonen. Jeg er interessert i alle typer erfaringer, ikke bare om de gode vurderingene og «suksesshistoriene», men også erfaringer med å være usikker, komme til kort eller ikke vite hva man skal gjøre. Jeg er interessert i det *du* har å fortelle, og det er ingen fasitsvar på spørsmålene mine.

Intervjuene vil bli tatt opp på lydfil og etter gjennomføring vil lydfilene bli skrevet om til skriftlig materiale.

Hvis du er interessert i å delta

Hvis du er interessert i å delta, ber jeg deg først og fremst om å be foreldre eller foresatte til det aktuelle eller de aktuelle barnet/a om samtykke. Vedlagt ligger et informasjonsskriv og skjema til å innhente samtykke. Om foreldre/foresatte samtykker, ringer du meg eller sender meg en SMS på telefon **90919642,** eller du sender en e-post til **ingrid.j.hogstad@himolde.no**. I sms-en eller e-posten oppgir du ditt navn og telefonnummer, så ringer jeg deg. Per telefon får du mulighet til å stille meg spørsmål, og om du ønsker å delta, avtaler vi tid og sted for intervjuet sammen.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Hvis du velger å delta, kan du når som helst trekke samtykke tilbake uten å oppgi noen grunn. Alle opplysninger om deg vil da bli anonymisert. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Hvordan opplysninger oppbevares og brukes

Jeg som forsker har taushetsplikt. Opplysningene om deg vil bare bli brukt til formålene fortalt om i dette skrivet. Opplysningene vil bli behandlet konfidensielt og i samsvar med personvernregelverket.

- Det er kun undertegnede som vil ha tilgang på lydfiler fra intervjuene. Lydfilene oppbevares under passordbeskyttelse.
- Intervjuene anonymiseres samtidig som de skrives om til skriftlig materiale slik at det skriftlige datamaterialet ikke inneholder personopplysninger som gjør deg eller barnet direkte identifiserbare.
- Det vil ikke være mulig å gjenkjenne deg eller barnet i publisert materiale.
- Mine veiledere og andre forskere som jeg samarbeider med får tilgang kun til anonymisert datamateriale.

Prosjektet skal etter planen avsluttes innen utgangen av 2021. Personopplysninger og lydfiler vil bli slettet ved prosjektslutt. Det skriftlige datamaterialet vil bevares i anonymisert form og under passordbeskyttelse.

Dine rettigheter
Opplysninger om deg behandles basert på ditt samtykke. Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg,
- å få utlevert en kopi av dine personopplysninger (dataportabilitet), og
- å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger.

NSD – Norsk senter for forskningsdata AS har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Har du spørsmål eller innvendinger?
Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt direkte med undertegnede, eller:

- Høgskolen i Moldes personvernombud: Karl Yngvar Dale (telefon: 71 21 40 57)
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med vennlig hilsen

Ingrid Johnsen Hogstad

Prosjektansvarlig

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet *Ivaretakelse av mindreårige barn som har en alvorlig syk og døende mor eller far*, og har fått anledning til å stille spørsmål.

- Jeg samtykker til å delta i et individuelt intervju

- Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet, innen utgangen av 2021.

(Signert av prosjektdeltaker, dato)

5: Interview guide phase 1

Intervjuguide, individuelle intervjuer

Gjør deltakeren oppmerksom på at han/hun ikke må si noe i intervjuet som kan identifisere enkeltpersoner i historiene som blir fortalt. Det er ingen fasitsvar, jeg er interessert i det du har å fortelle, dine tanker og dine meninger. Intervjuet har dialogform. Jeg noterer underveis for å huske.

1. *Vil du først fortelle kort om deg selv*: om din **utdanning**, **stilling, arbeidsoppgaver**? Alder?
2. *Mitt prosjekt handler om de mindreårige barna (u 18 år) som er pårørende til en mor eller far som er uhelbredelig syk og skal dø, altså palliative pasienter.*
    a. Kan du fortelle meg om **dine erfaringer** med disse pasientenes mindreårige barn?
        i. Interessant – fortell meg mer om…/hva tenker du om det?
        ii. Kan du si noe mer om dette barnet? Hvordan ville du beskrive barnet?
    b. Har du historier om familier med minoritetsbakgrunn eller hvor barn har hatt **spesielle utfordringer**, som utviklingshemming etc.?
3. *Jeg er spesielt interessert i de minste barna, barn i barnehagealder (1-6 år)*
    a. Hva tenker du om hva **barn i barnehagealder** forstår om: Alvorlig sykdom? Døden?
    b. Hvordan ville du **formidlet til barn i barnehagealder** at mor eller far skal dø?
    c. Når mor eller far skal dø - **hvordan ivaretas barnehagebarn best?**
        i. Hvilke **behov** har de?
        ii. Hva er **viktig**? - Hva er ikke så viktig?
        iii. **Hvem** skal følge opp?
        iv. Hva kreves? Av ressurser, kunnskap, kompetanse, deg – andre?
4. *Egen rolle, kompetanse, kunnskap.*
    a. Hva er **din rolle overfor pasienters barn**? Hva er forventet? Hva er krevet?
    b. Hva er viktig for at **du skal føle deg rustet** til å ivareta din rolle overfor pasienters barn?
5. *Takk for hjelpa!* Hvordan opplevde du dette intervjuet? Var det som forventet? Hva forventet du? Syns du at du fikk nok informasjon i forkant?

6: Interview guide phase 2

Intervjuguide, individuelle intervjuer med barnehagelærere

Du er med i denne studien fordi du har opplevd at et eller flere barn på avdelingen der du jobbet har eller har hatt en alvorlig syk mor eller far som vet at de kommer til å dø av sykdommen. Intervjuet har dialogform. Det er ingen fasitsvar, jeg er interessert i det du har å fortelle, dine tanker og dine meninger. Jeg noterer underveis for å huske.

1. (Tegn opp tidsakse.) Start fra begynnelsen: hvordan var det da dere første gang fikk vite at mor/far var syk?
    a. Hva gjorde dere? overfor barnet? overfor foreldrene? overfor barnegruppa?
    b. Hvorfor gjorde dere det? /Hva var bakgrunnen for å gjøre det?
    c. Hva skjedde da?
    d. Hvordan ble barnet involvert?
2. Hva skjedde videre? Hvordan fikk dere vite at sykdommen var uhelbredelig?
    a. Fikk barnet vite at sykdommen var uhelbredelig?
    b. Fortell om dine møter med barnet i barnehagen i denne perioden
3. Skjedde andre viktige hendelser underveis? hvilke?
    a. Hvorfor gjorde dere som dere gjorde?
    b. Hva skjedde da?
    c. Hvordan ble barnet involvert?
    d. Hva gjorde barnet? Hvordan møtte du barnet?
4. Hvordan endte det?
    a. Hva skjedde da mor eller far døde?
    b. Fortell om dine møter med barnet i barnehagen
5. Hva tenker du om hva barn i barnehagealder forstår om: Alvorlig sykdom? Døden?
    a. Hvordan har du snakket om sykdom og død i barnehagen?
    b. Hvordan ville du formidlet til barnet at mor eller far skal dø?
    c. Når mor eller far skal dø - Hvilke behov har barna? Hva er viktig? - Hva er ikke så viktig? Hvem skal følge opp? Hva kreves? Av ressurser, kunnskap, kompetanse, deg – andre?
6. Egen rolle, kompetanse, kunnskap. **Hva er din rolle overfor barnet og familien når mor eller far er syk?**
    a. Hva er forventet? Hva er krevet?
    b. Hva er viktig for at du skal føle deg rustet til å ivareta din rolle?
7. *Takk for hjelpa!* Hvordan opplevde du dette intervjuet? Var det som forventet? Hva forventet du? Syns du at du fikk nok informasjon i forkant?

7: Detailed analysis plan study 3

Molde, 26.11.19

Analyseplan

Målet med analysen er å få innsikt i hvordan de profesjonelle inngår i samspill som veiledere i dialoger hvor de *skaper og utvider mening* om foreldredød som konsept og som fenomen i barnets hverdagsliv, det jeg på engelsk velger å kalle *interpretation partners*.

STEG 1: Lete etter praksisfortellinger

Hva: Lese gjennom transkriptene etter praksisfortellinger eller konkrete beskrivelser fra praksissituasjoner hvor helsepersonell eller barnehagelærere er direkte involvert med barn *i samspill*. Hver beskrivelse gis et datanummer, som består av kode HP/BL for profesjonsgruppe, en bokstav (korresponderende med koden for deltakeren) og et nummer (løpende). Kontinuerlig noteres inklusjons- og eksklusjonskriterier i et eget dokument.

Hvorfor: jeg ønsker konkrete beskrivelser av praksiser for å komme forbi de tatt-for-gitte sannhetene og generelle rådene som først og fremst gjenspeiler det som er sosiokulturelt legitimt.

STEG 2: Analysere praksisfortellingene

Ny lesning av det utvalgte datamaterialet – disse spørsmålene stilles til hver enkelt praksisfortelling ved bruk av en tabell:

1. Beskrivende nivå:

Hva: Søker etter beskrivelser av initiativ og deltakelse hos både den profesjonelle og barnet ved å benytte analysespørsmål:

Barnets bidrag:

– hvordan beskrives barnets initiativ?

– hvordan beskrives barnets deltakelse?

Den profesjonelles bidrag:

– hvordan beskrives den profesjonelles initiativ?

– hvordan beskrives den profesjonelles deltakelse?

Hvorfor: Det gir indirekte kunnskap om voksen-barn-samspill, i tråd med slik det er beskrevet i Hundeide (2003)

2. Fortolkende nivå:

Hva: Søker etter å forstå hva hvert enkelt beskrevne samspill handler om ved å benytte analysespørsmål:

2.1. Hva handler samspillet om?

Hva: Undersøker hvilke ressurser (begreper, historier, andre personer/relasjoner, konkreter/objekter, fysiske rom/landskaper) samspillet er avhengig av eller involverer ved å benytte analysespørsmål:

2.2. Hvilke ressurser gjør de nytte av for å skape mening?

Hvorfor: Det gir kunnskap om innhold i og rammer for samspillet.

Kode	Hvordan beskrives:				Fortolkende nivå:	
	barnets initiativ?	barnets deltakelse?	den profesjonelles initiativ?	den profesjonelles deltakelse?	Hva handler samspillet om?	Hvilke ressurser gjør de nytte av for å skape mening?

STEG 3: Oppsummere

Hva: søke etter mønster på tvers av historiene når det gjelder former for samspill, innhold og ressurser. Kategorisere former for meningsarbeid eller meningsutvidende dialoger (Hundeide, 2003) ut fra likhet på disse tre parameterne. Legge merke til tilfeller som er unike eller som ikke lar seg kategorisere – spare på disse for å bruke dem som moteksempler i diskusjon – en slags validering og belysning

Hvorfor: for å skaffe oversikt og å få kunnskap om det som er felles og det som er unikt

STEG 4: Sammenligne de to gruppene profesjonelle

Hva: søke etter tema og ressurser som synes å være knyttet til den enkelte arena? er det tema og ressurser som synes å gå på tvers av de to arenaene?

Hvorfor: for å få kunnskap om betingelser for meningsskaping ved de to ulike arenaene. Ved å tydeliggjøre hvilke muligheter for meningsskaping som finnes innenfor de ulike kontekstene kan hjelpe profesjonsutøverne i forståelse av hverandres oppgaver, noe som er sentralt for å få tverrprofesjonelt arbeid til å fungere.

Hundeide K. (2003) *Barns livsverden. Sosiokulturelle rammer for barns utvikling. [Children's life world. Sociocultural frames of children's development],* Oslo: Cappelen Akademisk forlag.

8: Example of text sections in Norwegian

Example of text sections in Norwegian

Elisabeth, paper 1, p. 474:

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.

Noen barn at de har skjønt det, men aldri har spurt fordi de enten ikke har turt, eller at det ikke er kommet som tema. Men, barn er jo smarte. Det må være veldig vondt, hvis de går og er redde for det, og ikke tør å spørre om det, og kanskje ikke får de svarene de trenger.

Elisabeth, paper 1, p. 475:

It is a misunderstanding not to let the children know the realities.

Det er en veldig misforstått sak og ikke skulle la barna få vite realiteten.

Cecilie, paper 1, p. 476:

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.

Så små unger er jo sterkt avhengige av foreldrene sine. Det kan føles skremmende hvis de er mye på sjukehuset og besøker mor eller far at det blir mye nye folk å forholde seg til, og i hvite frakker.

Jenny, paper 1, p. 476:

I 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.

Barn er veldig sånn ut- og inn av sorgen. Jeg tror de er mer beskyttet på den måten. Mens vi voksne, vi har det med oss hele tiden, vi kjenner klumpen i magen selv om vi holder på med noe annet. Det er med oss.

Cecilie, paper 1, p. 477:

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.

De var jo overalt og veldig travelt og faren orka omtrent ikke at de var der, for det var… ett og to år, da er de jo ganske aktive da, styrer på.

Andreas, paper 2, p.4:

She had a deep hope that everything was going to turn out well and that she would return to a better state again, but in reality, the prognosis was bad, and her expected lifetime was very short. The health professionals in [the previous] hospital said that she had not taken it in and did not accept it. She was divorced and had a child who lived with her father when she was hospitalised. It was dramatic as we could see how fast it went; it was *within the night shift […]. Nevertheless, it was clear to us that we had to do something with that boy as no one had informed him that his mother was going to die within a very short time.*

Hun hadde stort håp om at ting skulle gå greit, og at tilstanden hennes skulle bli bedre igjen, men det var egentlig veldig dårlig prognose med kort forventet levetid. Og det ble også sagt fra (forrige sjukehus) at pasienten hadde ikke tatt det inn og ikke akseptert det heller. Hun var skilt og hadde et barn som bodde hos sin far i den tida da hun var på sykehus. Det var dramatisk, for vi kunne se at det gikk veldig fort, og det var innenfor vakttida […]. Men det var klart at vi måtte gjøre noe med den gutten, for han hadde ikke fått beskjed om at mora skulle komme til å dø om veldig kort tid.

Jenny, paper 2, p. 4:

You had to be extra careful as it had been so difficult to get contact with the patient. I, therefore, did not dare go into topics she did not want to discuss when I noticed she would not talk about them.

Du var jo ekstra forsiktig i og med at det hadde vært så vanskelig å komme inn. Så jeg turte jo ikke gå inn på emner hun ikke ville, og som jeg merket at hun ikke ville prate om.

Elisabeth, paper 2, p. 5:

They will see you. You are going to die, and it is the children's right to see you before you die.

De skal inn og se deg. Det er barnas rettigheter, at de får komme her, og se at du er dødssyk, for nå skal du dø fra barna dine.

Jenny, paper 3, p. ?:

I had brought a little teddy and a suitcase with doctor equipment, and I told them, "You know that mum has been sick for a while". I then opened the suitcase and picked up the hypodermic syringe and showed on the teddy, "She has gotten medicines". I let them try the syringe, before continuing, "If someone has been sick for a very long time, and the doctor has no more medicines to give…" and I showed them the book Chemoman Casper, and further built on that story to explain how the chemotherapy eventually stops working and the illness grows in the body. Moreover, the children asked, "Will mum die?" "Yes, she is going to die. Everybody dies eventually, we just do not know when. But your mum is not going to live very much longer.

Jeg hadde med en liten bamse og vi hadde med doktorutstyr i kasse. Så forteller jeg dem: «dere vet jo at mamma har vært syk en stund.» Også åpnet vi kofferten og begynte liksom å: «også har du fått sprøyter, og..», og viste på bamsen hele tiden, og, så de fikk prøve selv. «og hvis man har vært syk veldig lenge og legen ikke lenger har medisin», også viste jeg dem Kjemomannen Kasper-boka om cellegift, og så bygger jeg på den for å forklare at når cellegifta ikke virker lenger, så vokser sykdommen i kroppen. Og da spør ofte barna selv: «jammen, kommer mamma til å dø?» «ja, det gjør hun. (…) Alle dør jo en gang. Men vi vet ikke når. Men deres mamma kommer ikke til å leve så veldig lenge.»

Lavrans, paper 3, p. ?:

Your mother's breath sounds like this because she has water in her lungs. We will try to relieve her of this water.

Nå strever mamma med å puste, for nå har hun litt vann på lungene. Og det skal vi prøve å tappe.

Maria, paper 3, p. ?:

We have had a lot of good conversations, even though he doesn't say much. However, he can initiate it by just a sentence, and I will talk around it while he listens. Recently, he was lying on his tummy across my lap. His mate complained about him having done something, and I said to his mate, "Maybe it is not so easy to be him these days; maybe he is angry or sad within. Maybe he misses his dad really much and is sad because of that." Several children started asking, "Why did he get cancer?" and "Will he never ever come back?" We talked for a long time. He said nothing himself, just lay there on my lap listening. I was very well aware that he was listening.

Vi har jo hatt mye fine samtaler, selv om ikke han sier så mye. Han kan dra i gang samtalen med en setning, også kan jeg prate litt rundt det, også lytter han. Så en dag her så lå han på magen over fanget mitt, også var det et eller annet han hadde gjort som et barn [vennen hans] klagde på. også sa jeg: kanskje det er vanskelig å være han om dagen, kanskje han er mye sint eller lei seg inni seg. også snakket vi om, kanskje han savner pappa veldig og er veldig lei seg. og da… begynte jo disse barna å spørre: «hvorfor fikk han kreft?», og «kommer han aldri tilbake?» og vi fikk en ganske lang samtale. Men han sa ingenting selv, han bare lå helt sånn slapt på magen, liksom, på fanget mitt og hørte på samtalen. Jeg var veldig klar over at han lyttet.

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