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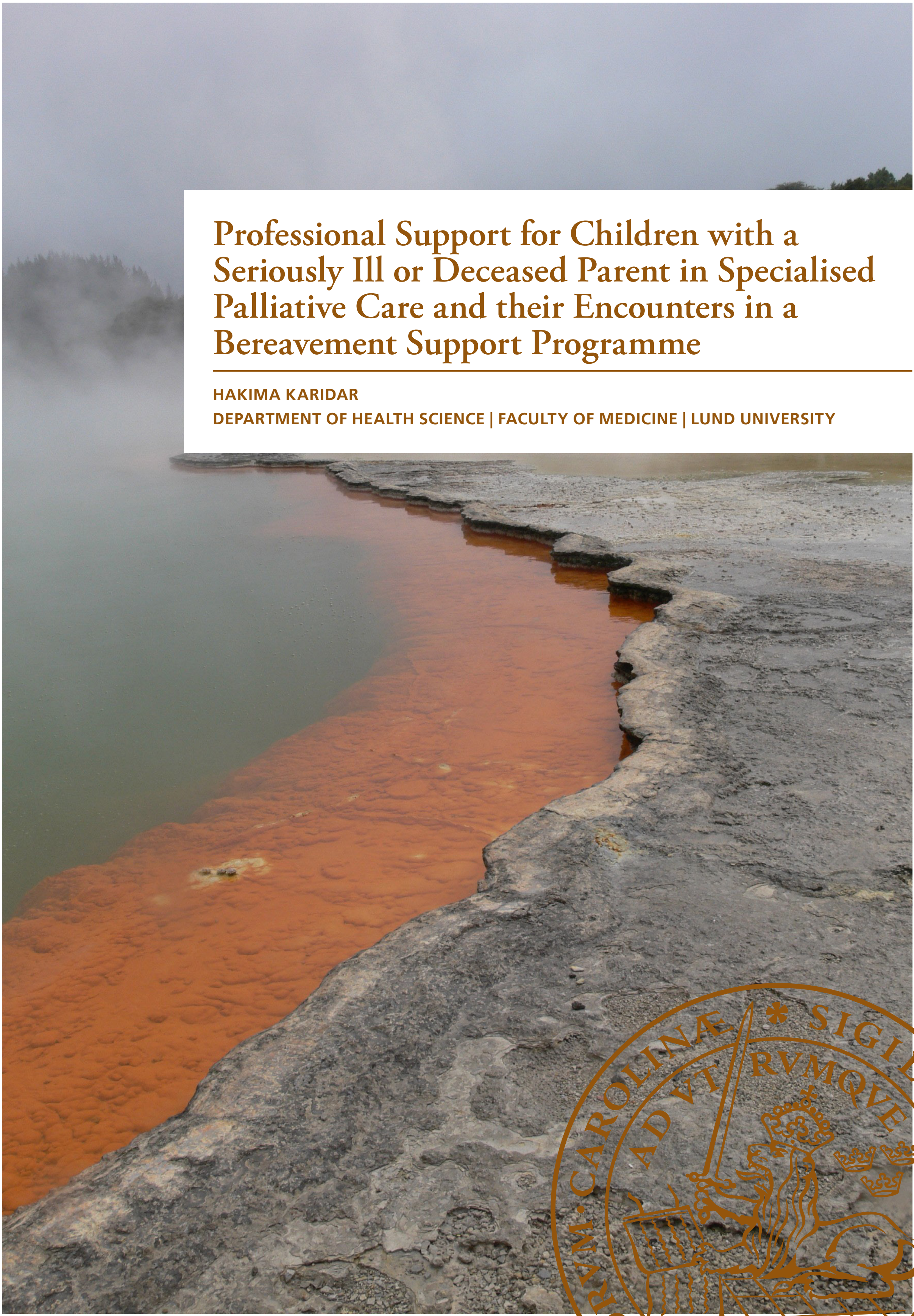

Professional Support for Children with a Seriously Ill or Deceased Parent in Specialised Palliative Care and their Encounters in a Bereavement Support Programme

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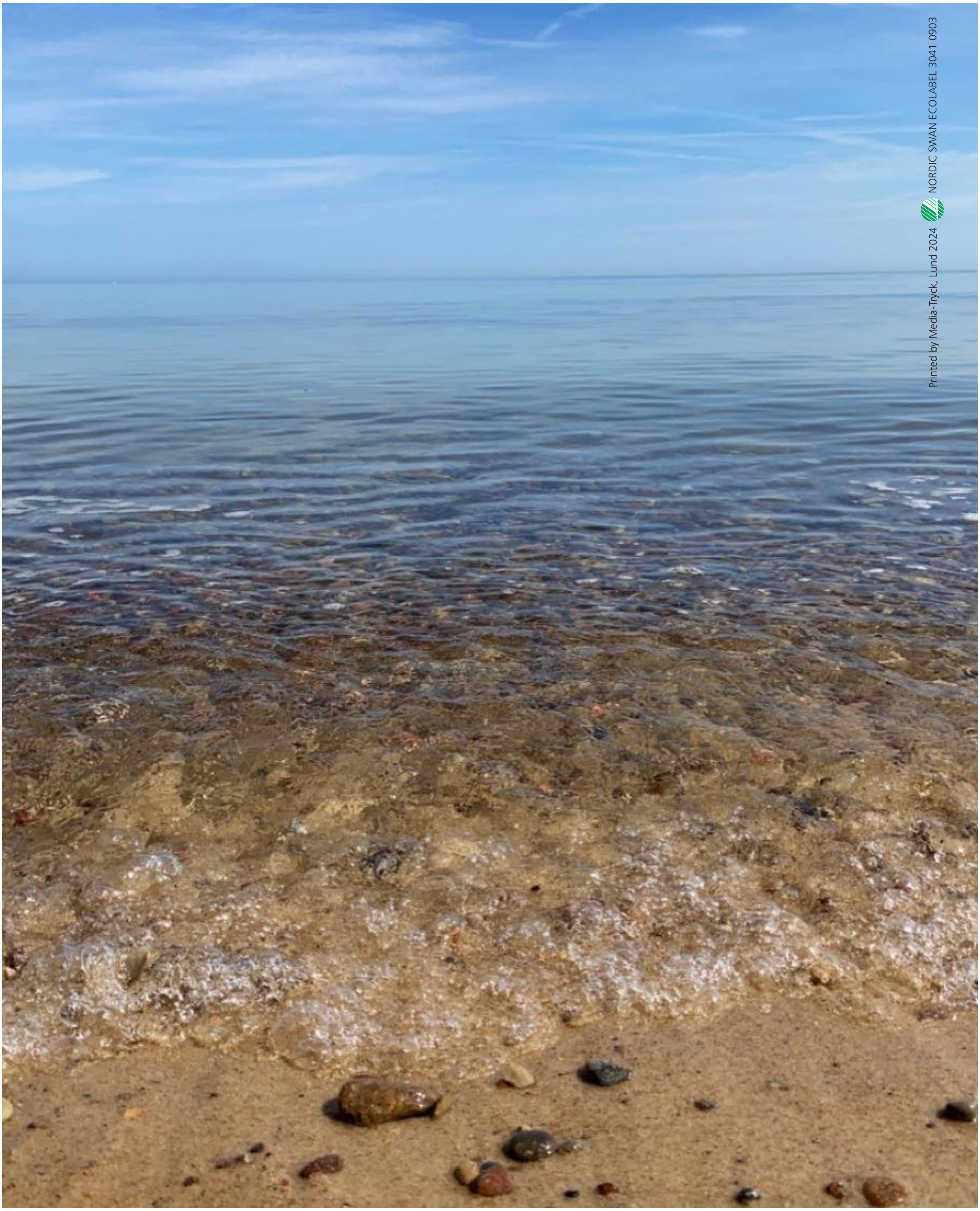

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Abstract

A parent's life threating illness and death can significantly affect their children's wellbeing in both the short and long term. Support from professionals is recommended when parents lack the ability to help children cope with loss, bereavement, and grief. The overall aim of this dissertation was to illuminate professionals' encounters with children of a seriously ill or deceased parent and to explore, from contextual and relational perspectives, the underlying logics and execution of a bereavement support programme for children.

The empirical material for Studies I and II was collected through individual semi-structured interviews with nurses, physicians, and social workers in specialised palliative care units in Southern Sweden. In Study III, an ethnographic field study was conducted within a support programme for children and their surviving parent. The empirical material was analysed using latent content analysis and thematic analysis, respectively, through a theoretical framework inspired by Bourdieu.

The findings revealed that, based on their symbolic position and power, both professionals and parents acted as gatekeepers in providing support to children during a parent's severe illness and after the parent's death. Professionals had limited direct contact with children in their daily work. Due to a lack of time and expertise, responsibility for supporting the children was often shifted between professional groups, with the result that no one actually took responsibility for supporting these children. This highlighted an absence of family-centred care. In both palliative care settings and the studied support programme, confidentiality played a key role, both facilitating and limiting the possibility of support and involvement of children. It also influenced interactions between children, parents, and professionals. In the support programme, open and verbal communication between children during sessions was limited. Instead, informal conversations during breaks and social mingling, unrelated to bereavement, connected the children more effectively than the organised discussions on loss, bereavement, and grief.

This dissertation highlights the importance of family-centred care in supporting children of severely ill parents and advocates for child-centred approaches in the development of future support programmes.

Key words: Children**,** Parental death, Illness, Professionals, Specialised Palliative Care, grief, support programme, Bourdieu

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“To everyone who made this dissertation possible”

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Abstract

A parent's life threating illness and death can significantly affect their children's wellbeing in both the short and long term. Support from professionals is recommended when parents lack the ability to help children cope with loss, bereavement, and grief. The overall aim of this dissertation was to illuminate professionals' encounters with children of a seriously ill or deceased parent and to explore, from contextual and relational perspectives, the underlying logics and execution of a bereavement support programme for children.

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This dissertation highlights the importance of family-centred care in supporting children of severely ill parents and advocates for child-centred approaches in the development of future support programmes.

Populärvetenskaplig sammanfattning

I Sverige förlorar varje dag cirka nio barn (under 18 år) en förälder genom dödsfall. Livssituationen förändras för hela familjen och många barn som har förlorat en förälder kan hamna i en utsatt situation och har behov av stöd från professionella. I svensk lag fastställs att professionella särskilt ska beakta barnets behov av information, råd och stöd när en förälder, eller annan vuxen som barnet bor hos, blir svårt sjuk eller avlider. Barnkonventionen är lag i Sverige sedan 1 januari 2020 och den fastställer bland annat att barnens bästa ska beaktas vid alla beslut som rör dem och att alla barn har samma rättigheter, inklusive rätt till lika värde, och rätt att få uttrycka sin mening och få den respekterad. Med denna bakgrund var syftet med avhandlingen att, ur ett professionellt perspektiv, utforska mötet med barn till svårt sjuka eller avlidna föräldrar. Vidare att utifrån relationella och kontextuella perspektiv undersöka hur ett befintligt stödprogram för barn och efterlevande förälder presenteras, planläggs och genomförs, samt vilken betydelse det har för barn och föräldrar i deras sorgehanteringsprocess.

Avhandlingen består av tre delstudier och två av delstudierna (artikel I och II) fokuserar på olika professioners perspektiv på mötet med barn som anhöriga inom specialiserad palliativ vård. I delstudie I genomfördes nio individuella intervjuer med sjuksköterskor och intervjuerna analyserades genom en kvalitativ innehållsanalys. I delstudie II intervjuades fem läkare och fem kuratorer och en tematisk analys inspirerad av Bourdieus begrepp: fält, makt, position och kapital användes. I delstudie III (artikel III och IV) användes en etnografisk metod, vilket innebar att empiriskt material samlades in genom observation, individuella intervjuer med barn och föräldrar samt en fokusgruppintervju med volontärer i ett gruppstödprogram för barn som förlorat en förälder. Även dessa intervjuer och fältanteckningar analyserades tematiskt och teoretisk inspirerad av Bourdieus begrepp fält, doxa, position, makt och kapital.

Resultaten visade att sekretess var ett centralt element som både öppnade och stängde möjligheten till att ge stöd åt och involvera barnet i en förälders sjukdomssituation. Kommunikationen och interaktionerna mellan barn, föräldrar och professionella, både i kontexten av specialiserad palliativ vård och stöd-programmet påverkades av rådande sekretess (artikel I, II, III och IV). Föräldrar hade en avgörande roll vad gällde barnens delaktighet i möten med professionella. En del föräldrar ville inte oroa sina barn och ville därför inte involvera dem i sin sjukdomssituation. Professionella var lyhörda och respekterade förälderns beslut, men samtidigt blev barnens rätt till information, råd och stöd inte tillgodosedd. Detta innebar att både föräldrar och professionella hade symbolisk makt och position att inkludera eller exkludera barnen från en förälders sjukdomssituation under vårdtiden inom specialiserad palliativ vård (artikel I och II). Inom ramen för stödprogrammet upprättade volontärer en sekretessregel, som förbjöd alla involverade att diskutera innehållet av sina samtal och erfarenheter utanför programmet. Syftet med denna regel var att barn och föräldrar skulle känna sig trygga med att dela sina känslor och erfarenheter av sin förälders/partners sjukdom, död och sorgen som fanns i efterförloppet. Samtidigt hade barn, föräldrar, volontärer och författaren av denna avhandling olika förutsättningar för sekretessåtagandet. Volontärer i positionen och rollen som professionella stödgivare hade avsatt tid i programmet för informell handledning där de öppet diskuterade sina erfarenheter med en handledare som vägledde dem i hur man hanterar olika situationer med barn och föräldrar. Vidare hade författaren av denna avhandling ett legitimt forum för att uttrycka sin erfarenhet inom ramen för forskningen. Som forskare var uppgiften att göra stödprogrammet synligt bortom sin egen ram och kontext, med godkännande från alla deltagare genom informerat samtycke. I kontrast hade barn och föräldrar, som var mottagare av stöd, inte samma möjlighet som volontärerna och författaren att dela sina erfarenheter utanför stödprogrammet. Å ena sidan erbjöd stödprogrammet barnen ett exklusivt utrymme för att prata om sin sorg och förlust men å andra sidan gjorde sekretessen att barnen inte fick berätta för andra vad som hände i programmet. En följd av rådande sekretess kan ha varit att barnen fick uppfattningen att man inte ska prata om sin egen och andras sorg med människor som inte har erfarenhet av en förälders död. Det är dock oklart för volontärerna och forskarteamet hur barnen och de efterlevande föräldrarna hanterade sekretess-reglerna utanför programmet (artikel III och IV).

Resultaten från delstudie I och II visade att sjuksköterskor, läkare och kuratorer hade begränsad direktkontakt med barn till föräldrar med palliativt vårdbehov. Den specialiserade palliativa vårdens strukturella ram och medicinska logik påverkade interaktionen mellan professionella och barn. I det dagliga arbetet prioriterades patientens vårdbehov framför familjens behov av stöd. Vidare hade de professionella olika perspektiv på vem som skulle ge stöd till barn. På grund av tidsbrist och brist på expertis/kompetens hade de professionella en tendens att skjuta ifrån sig ansvaret att ge stöd till barn till en annan professionsgrupp. Efter en förälders död avslutades kontakten mellan barn och de professionella inom specialiserad palliativ vård. Familjen hänvisades till andra professionella inom primärvård och skola (artikel II). Resultatet gav en antydan om att professionella inom primärvård och skola hade svårt att ge stöd till dessa barn eftersom de i sin tur hänvisade efterlevande förälder och barn till andra stödfunktioner, som till exempel att delta i ett stödprogram (artikel III).

Resultaten i delstudie III (artikel III och IV) visade att efterlevande föräldrar och volontärer i stödprogrammet hade en symbolisk position och makt till inkludering av barn i programmet. Efterlevande föräldrar och barn kunde ha olika inställning till att delta i programmet. Vissa barn accepterade omedelbart sin förälders förslag på att delta i programmet, medan andra barn var tveksamma. När barnen var tveksamma fick föräldrarna antingen förhandla, muta eller övertyga sina barn om att delta i stödprogrammet. Vissa föräldrar deltog i programmet för sina barns skull, eftersom programmets regler var att de skulle delta som familj. Det framkom att barn som inte behärskade det svenska språket eller som hade någon form av neuropsykiatrisk diagnos, såsom autism eller ADHD, inte fick delta i programmet. Gruppmötena i stödprogrammet liknade skolans miljö både till innehåll och struktur vilket innebar att de var tid- och temabaserade som en lektion i skolan. Programinnehållet utgick från en medicinsk-psykologisk förståelse av förlust, sorg och sörjande, och barnen fick lära sig hur man hanterar sin situation enligt denna logik. Under gruppmötena instruerade volontären barnen att skriva eller teckna/måla sina känslor, och sedan ställde volontären frågor till varje enskilt barn, baserat på deras text eller teckning/målning. De övriga barnen satt då tysta och lyssnade och ställde inga frågor till varandra.

Under pauser och mingel ökade den aktiva interaktionen mellan barn och vuxna. Deras gemensamma intressen var snarare ämnet i deras konversation än deras erfarenhet av att ha förlorat en förälder/partner. Konversationen handlade om det vardagliga i livet, som till exempel musik, sport, husdjur, skolbyte och semesterplaner inför sommaren. Barnen skrattade, pratade och strålade av energi när deras konversation inte handlade om sorg och förlust utan om deras vardagliga livs utmaningar och deras källa till glädje.

Sammanfattningsvis bidrar avhandlingen med kunskap och förståelse för den komplexitet som kan uppstå vid utformning av stöd till barn vars förälder är svårt sjuk och till barn i sorg. Maktrelationen mellan barn, föräldrar och professionella var i högre utsträckning en avspegling av den strukturella makten i samhället. Lagstiftning sätter ramar och förutsättningar för ett fungerande samhälle. Samtidigt kan professionella och föräldrar hamna i konflikt, och etiska dilemman kan uppstå i valet av vems rättighet och behov av stöd som ska ha företräde: barnens eller föräldrarnas. Det är därför av betydelse att vuxna ska beakta barnens individuella behov och att deras perspektiv på stöd ska vägleda vuxna och inte tvärtom. Avhandlingen framhäver också vikten av ett familjecentrerat förhållningssätt för att stödja barn till svårt sjuka föräldrar och förespråkar ett barncentrerat perspektiv i utvecklingen av framtida stödprogram.

List of papers

I. Karidar, H., Åkesson, H., & Glasdam, S. (2016). A gap between the intensions of the Swedish law and interactions between nurses and children. *European of Oncology Nursing, 22*, 23-29. https://doi.org/10.1016/j.ejon.2016.01.005.

II. Karidar, H., & Glasdam, S. (2018). Inter-professional caring for children who are relatives of cancer patients in palliative care: Perspective of doctors and social workers. *The British Journal of Social Work, 49*(3),595-614. https://doi.org/10.1093/bjsw/bcy080.

III. Karidar, H., Lundqvist, P., & Glasdam, S. (2023). Inclusion and participation in a support programme for bereaved adolescents – Relational perspectives from an ethnographic field study in a Swedish context. *OMEGA-Journal of Death and Dying*, 0(0). https://doi.org/10.1177/00302228231185802

IV. Karidar, H., Lundqvist, P., & Glasdam, S. (2024). The influence of actors on the content and execution of a bereavement programme: A Bourdieu-inspired ethnographical field study in Sweden. *Frontiers in Public Health*, 1395682. https://doi.org/10.3389/fpubh.2024.1395682

Introduction

The death of a parent is a life-changing event that can have both short- and long-term implications for a child's wellbeing (Farella Guzzo & Gobbi, 2021; Hiyoshi et al., 2021). A child is defined as a person under the age of 18, recognised as a legal subject and rights holder, perceived in the present (United Nations, 1989). Previous studies show that children's support needs are not always addressed when a parent suffers from a life-threatening illness or has died (Cockle-Hearne et al., 2019; Hanna et al., 2021). This lack of support can negatively affect children's health and wellbeing and increase their feelings of worry and uncertainty about the future (Faugli et al., 2021; Marshall et al., 2021). Furthermore, family dynamics, relationships, and roles often change for all members, both during the course of an incurable illness and after the death of a parent. Children often need adult support to navigate these changes (Cranwell, 2007; Farella Guzzo & Gobbi, 2021; Hsu et al., 2002). While many parents involve their children in matters related to their life-threatening illness, some choose not to, aiming to protect them (Cockle-Hearne et al., 2019; Marshall et al., 2021). However, an integrative literature review study shows that many children want to be involved in their parent's illness, care, and treatment (Bergersen et al., 2022). After the death of a parent, some children experience isolation and grief, and are often left to cope alone (Lytje, 2018; Vedder et al., 2021; Walter, 2020; Wray et al., 2022). Involuntary isolation is associated with experiences of depression and anxiety (Loades et al., 2020; Walter, 2020). Furthermore, the surviving parent's ability to support their children may be compromised due to their own grief and the increased responsibilities resulting from their partner's illness or death (Fasse & Zech, 2016; Glezar et al., 2010).

External support from healthcare professionals and teachers is regarded as essential for helping children cope with loss and grief (Alexander et al., 2020; Dimery & Templeton, 2021; Duncan, 2020). Children often experience a lack of support from professionals in healthcare and schools (Fearnley & Boland, 2017; Guzzo & Gobbi, 2021; Levkovich & Elyoseph, 2021). Some children express a desire for information and support from healthcare professionals, with the expectation that it is continuous and tailored to their individual needs (Bergersen et al., 2022). However, the support provided is not always in line with children's actual needs and wishes (Berg et al., 2016; Franklin et al., 2019; Lytje, 2018).

In western societies, various psychological interventions have been developed to prevent and identify psychopathologies such as anxiety and depression (Chris et al., 2005; Sandler et al., 1992, 2003, 2010). Literature reviews highlight that evaluations of evidence-based interventions show positive impacts on children's coping processes, particularly for those with symptoms of complicated grief (Bergman et al., 2017; Rosner et al., 2010). However, relatively few children participate in such support programmes. Children's own perspectives and involvement in bereavement strategies are often overlooked by those around them (Berg et al., 2016; Franklin et al., 2019; Lytje, 2018). In Sweden, since 2010, healthcare professionals have been required to support children during the course of a parent's severe illness and after their death (Swedish Patient Safety Act, 2010). Healthcare organisations are also obligated to create conditions within the healthcare structural framework that enable professionals to support children. (Swedish Health Care ACT, 2017). However, there is limited knowledge in Sweden regarding how healthcare professionals provide support to children during the course of a parent's illness and after their death, both in general and within the context of specialised palliative care settings. There is also a lack of knowledge about the interactions between children and professionals in organised support activities.

Background

Children with a seriously ill or deceased parent

Globally, in 2020/2021, at least 5.2 million children lost a parent or custodial grandparent (Unwin et al., 2022). In Sweden, approximately 3,500 children experience the death of a parent every year (Hjern & Manhica 2013; Swedish National Board of Social Affairs and Welfare, 2013). The availability and accessibility of support for bereaved children varies across countries, as does their possibility to access formal and informal support systems (Unwin et al., 2022). Studies show that serious parental illness and death can have a profound negative impact on many aspects of a child's life, including stunted personal development, poor physical and mental health, lower educational achievement, reduced socio-economic status, decreased overall quality of life, and strained relationships with family and friends (Chen, 2017; Faugli et al., 2021; Høeg et al., 2019; Liu et al., 2022; Serratos-Sotelo et al., 2021; Simbi et al., 2020).

Bereavement can be defined as the period of grief and mourning experienced after the loss of a loved one, typically due to death (Stroebe & Stroebe, 1987). It encompasses the emotional, physical, and psychological responses a person goes through while coping with and adjusting to the loss. Bereavement can vary in duration and intensity depending on the individual's relationship with the deceased, personal coping mechanisms, and cultural or social factors (Worden, 2018). Grief can be defined as the primary emotional and affective process that occurs in response to the loss of a loved one (Stroebe & Stroebe, 1987; Worden, 2018). The way children experience and manage parental death, bereavement, and grief depends on several different factors, including age and cognitive developmental stage (Piaget, 1964). Piaget's cognitive development theory focuses on how children's thinking and understanding evolve as they grow. For example, children in the sensorimotor stage (0-2 years old) are in the initial phases of comprehending their environment through sensory experiences and motor activities. Their understanding of complex concepts, such as death, remains rudimentary, potentially manifesting in more immediate and sensory perceptions, such as sensing the absence of a parent.

At the preoperational stage (2-7 years old), children are acquiring language skills and engaging in symbolic thinking. However, they have not yet attained a fully developed understanding of concepts such as permanence and abstraction. As a result, they may struggle to grasp the permanence of death, potentially believing that a deceased parent will return or misinterpreting the reason for their absence. Their grief may be expressed through play or behaviour changes, rather than through verbal communication (Piaget, 1964). During the concrete operational stage (7-11 years old), children begin to understand logical operations and the concept of permanence. They begin to comprehend the irrevocability of death and may develop a more nuanced understanding of its implications. Nevertheless, their comprehension is still largely based on concrete experiences, and they may not yet fully integrate the emotional and existential dimensions of grief (Piaget, 1964).

At the formal operational stage (12+ years old), children demonstrate the capacity for abstract thought and the ability to consider hypothetical scenarios. They are increasingly adept at grasping the abstract concepts associated with death and grief. This enhanced cognitive ability allows them to process the permanence of loss and its profound implications on a deeper emotional level, often resulting in a more complex range of feelings and reflections about the deceased (Piaget, 1964). According to Piaget (1964), children's understanding and management of bereavement are closely tied to their cognitive development. As children advance through the various developmental stages, their capacity to comprehend and cope with the concept of death evolves, becoming more sophisticated and nuanced (Kane, 1979; Piaget, 1964). Moreover, it is essential to consider that children's gender, family, religion, values, attitudes, culture, school, technology and mass media, emotional factors, and prior experiences with death impact in shaping children's understanding and perception of death (Krepia et al., 2017).

Children's daily lives in institutions

In western societies, children spend much of their daily lives in institutions from an early age, such as kindergarten and school, and many participate in organized activities after school. These daily institutional environments require children to operate under specific conditions, often involving monitoring, following specific rules and norms, self-control and disciplinary practices (Gansen, 2021; Lago & Elvstrand, 2021; Li et al., 2021). Children's relationships with their peers and teachers often affect their social and emotional wellbeing, as well as their academic performance (Endedijk et al., 2021). Furthermore, parental death is associated with lower grades and an increased risk of school failure (Berg et al., 2014; Burrell et al., 2020). In the school context, children with seriously ill parents often prefer to avoid being seen as different from their peers (Sheehan et al., 2016). During their parent's illness, many children divide their daily lives into two distinct worlds: the 'well world' (comprising school, friends, and extracurricular activities) and the 'ill world', which revolves around their parent's illness and the family's bereavement and related (inter)actions. However, many children have difficulty maintaining the separation between these two worlds (Sheehan et al., (2016). Studies highlight the important role that school professionals play in supporting these children (Holen et al., 2018; Maelan et al., 2018). However, teachers often report feeling unprepared and experiencing emotional distress when supporting children with a seriously ill or deceased parent (Levkovich & Elyoseph, 2021; Lytje, 2018). After the death of a parent, children often feel isolated and struggle to reconnect with classmates. Many children want school professionals to discuss their support needs with them (Hader et al., 2023; Lytje, 2018). According to de la Herrán Gascón et al. (2021), adolescents generally have positive attitudes toward including death education in school.

Supporting families through serious illness and bereavement is a primary goal for healthcare professionals such as nurses, physicians, and social workers. While they strive to provide support for all family members, they face various challenges, such as time constraints, lack of competence, and their own emotions and insecurities, which are identified as obstacles to establishing empathetic relationships with parents, partners, and children (Franklin et al., 2019; Levkovich & Elyoseph, 2021). Other studies show that healthcare professionals do not always consider relatives, including children, as a central aspect of care and support in clinical practice, as the focus is often on the patient's diagnosis and treatment, which define the scope of their work (Alam et al., 2020; Glasdam, 2003; Glasdam & Oute, 2019; Golsäter et al., 2016; Holst-Hansson et al., 2017; Molassiotis & Wang, 2022; Syse et al., 2012; Taylor et al., 2021; Tragantzopoulou & Giannouli, 2024; Tranberg et al., 2021).

Studies indicate that nurses sometimes overlook patients' children in clinical practice and may fail to provide support to them. This is often due to a lack of guidelines, time constraints, insufficient training, emotional barriers, and structural obstacles (Dencker et al., 2017; Granrud et al., 2022; Golsäter et al., 2016). Moreover, nurses are often more involved in the practical medical care of patients, which makes it difficult for them to prioritise the psychosocial needs of a patient's children (Ewens et al., 2022; Tafjord, 2020; Holmberg et al., 2020). This challenge is also seen in specialised palliative care contexts (Glasdam et al., 2020).

Physicians often focus on the patient during consultations, which can be explained by a lack of competencies and insufficient training in discussing a parent's serious illness with children (Gullbrå et al., 2014; Hafting et al., 2019; Osborn et al., 2015). A recent

Swedish study highlights the significant challenges that physicians face in oncology care when discussing patient' illnesses, poor treatment outcomes, and imminent death. Barriers such as time constraints, limited communication skills, and a lack of continuity in patient encounters impede effective communication (Tranberg & Brodin, 2023). Additionally, physicians often do not view supporting children as a part of their primary responsibility (Dencker, 2017).

In clinical practice, social workers are designated to address psychological issues and support both patients and their children (Afzelius et al., 2017; Hultman et al., 2015). However, studies show that social workers, in general, are often stressed due to competing demands from both parents and the organizational system, which limits their ability to engage with children on their own terms (Ferguson, 2014; Gillingham & Humphreys 2010; Winter & Cree, 2016; Winter et al., 2017). Overall, healthcare professionals often have differing perspectives and encounter challenges in collaboration, both within the healthcare system and with other professionals in kindergarten, schools and primary care. These obstacles may affect their ability to support children coping with the loss of a parent (Franklin, 2019; Hogstad & Jansen, 2023; Oja et al., 2021).

Children's wellbeing when families in change

Individuals within a family are interconnected and interdependent, meaning that their relationships and interactions with immediate family members have a mutual impact on each person's wellbeing (Sameroff & Fiese, 2000). Studies show that children of all ages have their health and wellbeing closely connected to their parents' overall health and wellbeing. Factors such as parents' physical and mental health, available resources, stress levels, education, income, and social support, are all linked to children's general health outcomes (Buehler, 2020; Bronfenbrenner, 2013; Newland, 2015). Furthermore, when parents are affected by severe illness, children may face various challenges in their daily lives. Some children may take on the role of main contributors for the functioning of their family's daily life, for example by providing emotional support to their ill parent, caring for younger siblings, and/or doing housework (Nuttall et al., 2021; Oja et al., 2019).

Losing a parent between the age of 6 months and 18 years is associated with an increased risk of mortality in children (Li et al., 2014). A Swedish nationwide study demonstrates a correlation between the loss of a parent to cancer and weakened family cohesion among children aged 13-16 years (Birgisdóttir et al., 2019). Poor family cohesion before and after the loss of a parent is often linked to an increased risk of self-injury and long-term decreased psychological health among bereaved children

(Birgisdóttir et al., 2023; Bylund-Grenklo et al., 2014). Furthermore, studies of children aged ten and older show parental illness can lead to anxiety, depression, sleep problems, and overall functioning and wellbeing decrease (Berg et al., 2016; Faccio et al., 2018; Haukan et al., 2018). Involuntary physical separation from parents due to hospitalisation can also be stressful for children of all ages (Berg et al., 2016; Bylund-Grenko et al., 2016; Farella Guzzo & Gobbi, 2021; Simbi et al., 2020).

Most children aged 2-18 get emotional and communicative support from their parents (Bergersen et al., 2022). Strong parent-child relationships and open communication can serve as protective factors in children's coping strategies (Jiao et al., 2021). Children aged 2-18 who engage in open communication with their parents tend to suffer less during serious parental illness and after a parent's death, as indicated by lower levels of anxiety and depression (Bylund-Grenklo et al., 2015; Falk et al., 2022; Weaver & Wiener, 2020). Caregiving contexts play a significant role in facilitating healthy bereavement processes (Alvis et al., 2020; Hoppe et al., 2024). Furthermore, research shows that young adults aged 13-29, who experienced the death of a parent while coming from divorced families, have a significantly higher risk of prolonged grief symptoms, lower wellbeing, and increased mental health problems compared to young adults from non-divorced families who lost a parent (Marcussen et al., 2021). Approximately five to ten percent of bereaved children aged 8-17 experience depression, posttraumatic stress disorder (PTSD), and/or prolonged grief disorder (Melhem et al., 2013). Prolonged grief disorder (PGD) is characterized by persistent and intense grief that is disabling and impairs daily functioning (American Psychiatric Association, 2013).

Parents' handling of illness and bereavement impacts children's ability to cope with challenges

Studies show that many ill parents express concerns about the practical impact of their illness on their child(ren), including various aspects such as maintaining daily routines, family traditions, childcare, transportation, meals, and finances (Fugmann et al., 2023; Whisenant et al., 2023). Psychological distress and depression are common responses among parents diagnosed with cancer, which can diminish their parenting capacity and negatively impact their children's health (Götze et al., 2017; Holst-Hansson et al., 2017; Parker et al., 2017). Studies also show that ill parents are often overwhelmed by chaos, anxiety, and uncertainty about the future and their life span, which heightens their concerns for their children's future and wellbeing. This indicates that children's support needs cannot always be fully addressed by the ill parent (Lundqvist et al., 2020; Zhu et al., 2022).

Throughout the course of a patient's illness, the role of being partners and parents also may change within the family. Parental responsibilities often increase, sometimes resulting in difficulties in maintaining a balance between the needs of the children, the ill partner, and themselves (Aamotsmo & Bugge, 2014; Tranberg et al., 2021). To support their children, parents often neglect their own support needs, which negatively impacts their phycological health and overall wellbeing (Yopp et al., 2015; Tranberg et al., 2021). Moreover, a parent's life-threatening illness places a significant emotional burden on the healthy partner, which can, in turn, affect their children's wellbeing (Götze et al., 2017; Lo et al., 2013).

Children primarily rely on their parents for a sense of security and emotional support (Hanna et al., 2019; Semple & McCaughan, 2019). However, parents facing severe illness may encounter major challenges in fulfilling this role, which can have a negative impact on their children's wellbeing. The lack of adequate support for children is often associated with the parents' own emotional struggles related to their incurable illness, the challenges of treatment, poor prognosis, and the anxiety of impending death (Holm et al., 2024; Semple & McCaughan, 2019). To address their children's need for support, some parents seek professional help. However, they often express dissatisfaction with the assistance they receive from professionals, often referring to the limited time spent discussing their concerns about their children with their physicians (Chien et al., 2022; Hanna et al., 2021; Strand et al., 2023).

Research shows that the support needs of surviving parents are often overlooked by healthcare professionals following the death of a partner (Holmgren, 2021; Park et al., 2021). Surviving parents often express that even friends and family members were not always able to provide the necessary support (Morrigan et al., 2022). Surviving parents have a central role in how their children cope with life after the death of a parent (Jiao et al., 2021). Parenting after the death of a partner is complex, and surviving parents often feel overwhelmed by the situation, and at times, unable to fully support their children (Fasse & Zech, 2016; Glezar et al., 2010; Jiao et al., 2021). Although children aged 2-18 generally prefer to receive support from their surviving parent, they often do not want to burden them with their needs (Bergersen et al., 2023). However, according to Andersson et al., (2022), after the loss of a partner, some surviving parents find that their children provide them with a sense of purpose in life and help them to cope with bereavement. Often, parents perceive mutual dependence with their children, where both parties rely on each other to navigate the bereavement process.

Bereaved children perceived as potentially ill in health-care settings

In contemporary societies, the experience of death, dying, and grief has largely moved from a family and community context to becoming primarily the domain of the healthcare system (Sallnow et al., 2022; Walter, 2020). Professionals in healthcare settings have become the primary resource for helping individuals through death and grief, which has led to the marginalisation of families and communities in these processes. The traditional reliance on interpersonal relationships and community networks seems to be increasingly replaced by professionals and protocols (Conrad, 2007; Brinkmann, 2020; Sallnow et al., 2022; Walter, 2020). In recent decades, there has been a societal tendency to view grief primarily from a medico-psychological perspective (Granek, 2016). In line with this, studies on children's bereavement mostly focus on assessing grief reactions, stress/distress levels, depression, and somatization (Wilson et al., 2017). The diagnostic culture of grief, including its interventions and treatments, contributes to the medicalisation of grief in society (Brinkmann, 2016; Conrad, 2007). This diagnostic approach to grief can be observed in diagnostic tools and manuals, which have provided a scientific foundation for extensive psychological research aimed at exploring grief reactions and developing psychological and pharmacological treatments (Rosner, 2015). Furthermore, 'prolonged grief disorder' has been added as a diagnosis in the International Classification of Diseases (ICD-11) and the Diagnostic and Statistical Manual for Mental Disorders (DSM-5), both of which are used to identify and diagnose prolonged grief reactions in children (American Psychiatric Association, 2013; Melhem et al., 2013; World Health Organization, 2019).

However, some researchers emphasize preserving the social and cultural experience of loss and grief, arguing against its medicalisation (France, 2013; Granek, 2010; Walter, 2020). Moreover, studies show that children have the capacity to develop resilience and cope with their circumstances. Many even experience positive personal development despite the life-changing experience of losing a parent (Arslan et al., 2020; Asgari & Naghavi, 2020; Fu et al., 2023). In other words, many bereaved people, including children, neither need nor benefit from grief therapy or counselling, as they can adapt to their loss without the involvement of professionals (Bonanno et al., 2004; Schut & Stroebe, 2010).

Palliative care

In contemporary Western societies, palliative care has become an integral part of the formal healthcare system, shaped by neoliberal, organisational ideas (Glasdam et al., 2023). The concept of palliative care is typically based on four key elements: symptom management, teamwork, communication and relation, and support for families. These elements work together to provide comprehensive care focused on improving the quality of life for patients and their families (Swedish National Board of Health and Welfare, 2018). Person-centred care is important in palliative care (Kmetec et al., 2020). The concept of person-centred care emphasises developing a partnership with the patient/person, respecting their autonomy, rights, and dignity in decision-making, while maintaining trust and a strong professional-patient relationship (Ekman et al., 2011; McCormack & McCance, 2011). Furthermore, palliative care consists of general palliative care and specialised palliative care. General palliative care can be provided by healthcare professionals who may not specialise in palliative care but possess fundamental knowledge and training in its principles and practices. This form of care is usually provided in community settings, such as in patients' homes, primary care facilities, or hospitals, and often serves as the basic level of palliative care offered (Swedish National Board of Health and Welfare, 2018; World Health Organization, 2020).

Specialised palliative care provides an additional layer of support for patients who require more intensive or expert-level care. Specialised palliative care is provided by healthcare professionals with advanced training and expertise in palliative care. These specialists focus on managing complex symptoms, providing comprehensive support, and addressing more complicated physical, psychological, social, and spiritual needs. Specialised palliative care is delivered by a multidisciplinary team of palliative care specialists, including physicians, nurses, social workers, chaplains, and other professionals specifically trained in palliative care. Furthermore, specialised palliative care can be provided in a variety of settings, including specialised palliative care wards, hospices, hospitals, and home-based palliative care for patients of all ages (Swedish National Board of Health and Welfare, 2018; World Health Organization, 2020).

Seriously ill parents with children under 18 years old are found across all hospital departments, primary care settings, and specialised palliative care units (Ewens et al., 2021; Laugesen et al., 2021; Lyu et al., 2024; Oja et al., 2021; Osborn et al., 2015). Providing support to the patient's family is one of the main pillars of the specialised palliative care approach (Swedish National Board of Health and Welfare, 2018; World Health Organization, 2020). Literature reviews indicate that nurses in palliative care have various roles and responsibilities, including caring for patients and their families, coordinating care for patients and their families, and collaborating with other healthcare professionals. Nurses, however, have limited legitimacy, are often required to handle ethical dilemmas, face demanding situations, and frequently have to deal with time and resource constraints (Moran et al., 2024; Sekse et al., 2018). However, other studies show that nurses often face challenges related to the work environment, such as insufficient physical space in patients' homes to carry out care tasks (Alvariza et al., 2020). Additionally, working in a home setting and being positioned as a guest in the home can complicate efforts to meet the needs of anxious or frustrated patients and their family members (Alvariza et al., 2020; Beyermann et al., 2023; Glasdam et al., 2020). Moreover, studies highlight that the working conditions of nurses often suffer due to organizational resource constraints when providing specialised palliative care in a private home settings (Becqué; 2021; Beyermann et al., 2023; Seke, 2018).

A recent Swedish cohort study shows that most patients receiving specialised palliative care prefer to die at home, with 80% of them doing so (Nilsson et al., 2023). However, in contrast, only about one-fifth of the overall Swedish population die in their own homes (Larsdotter et al., 2024). While many patients prefer home as the place of death, this preference presents challenges. Patients' homes become mini hospitals, filled with medical equipment and occupied by professionals, which can intrude on family privacy and disrupt their daily lives (Beyermann et al., 2023). The shift in end-of-life care from clinical settings back to home environments (Walter, 2020) requires a deeper understanding of how multi-professional teams in specialised palliative care manage the challenges of caring for dying patients with minor children.

Bereavement support programmes for children and their families

Over the past few decades, children's experiences of bereavement and grief have received increasing attention from both academic and clinical perspectives, leading to the establishment of bereavement support programmes. In the 1980s and 1990s, evidence-based psychological bereavement support programmes tailored for children and their surviving parents began to emerge. These included the Family Intervention Programme in the UK (Black & Urbanowicz, 1987), Group Intervention Programme for children in the US (Schilling et al., 1992), and the Family Bereavement Programme in the US (Sandler et al., 1992). These programmes were grounded in the theoretical framework focused on psychological coping with grief (Black & Urbanowicz, 1987;

Schilling et al., 1992), and the identification of risk and protective factors (Sandler et al., 1992). Programmes were organised into multiple sessions, for instance, the programme for children described by Schilling et al. (1992) included 12 theme-based weekly sessions with 6 to 8 children aged 6-12 years participating in five separate groups. Each session was led by two facilitators, and children expressed their grief-related emotions through drawings and verbal explanation. Additionally, pretests and posttests were conducted to assess children's symptoms of depression, their perceptions, and their understanding of death (Schilling et al., 1992).

Since then, the development of various intervention programmes has continued to evolve, such as the Parent Guidance Programme in the US (Chris et al., 2005), the Family Support Programme in Norway (Bugge et al., 2008), and a Weekend Camp for children in the US (McClatchey & Wimmer, 2012). These programmes have similar approaches and have shown positive effects in reducing children's symptoms of anxiety, stress, and depression, while improving their self-esteem, communication skills, and healthy coping strategies for both children and their surviving parent. However, these programmes were primarily targeted at school-aged children, ranging from 6 to 17 years old. Most of these programmes were evaluated through interviews and had short follow-up periods. The Family Bereavement Program, designed as a randomized controlled trial, is the only intervention that has been evaluated multiple times with different outcomes measured. It included long-term follow-ups at 11 months, 6 years, and 15 years, and showed improvements in parenting and coping among surviving parents, as well as reduced symptoms of depression and anxiety in children (Sandler et al., 1992, 2003, 2006, 2010, 2023).

In Sweden, evidence-based support programmes for children who have lost a parent are limited, and their availability varying across different parts of the country. A Swedish study by Carlsund et al., (2017) identified forty-seven non-profit organisations offering voluntary support programmes for children whose parents are dealing with physical or mental illness, substance abuse, and/or bereavement. All of these organisations were invited to participate in the study, which aimed to explore their group activities for children and assess their follow-up on the effects of the interventions. However, only ten organisations participated, revealing significant variation in follow-up practices and highlighting the need for improved education and financial support to enhance programme evaluation (Carlsund et al., 2017). There seems to be a lack of knowledge about how these support programmes function to help children, as well as how children respond to these forms of support. To date, there is no conclusive evidence regarding their effectiveness (Hanauer et al., 2024; Hewison et al., 2020; Wilson et al., 2017). Research tends to primarily highlight the effect of interventions based on various theories, such as grief theory, coping theory, social cognitive theory, and attachment theory, without fully exploring the underlying mechanisms behind their success. In other words, researchers tend to focus on ‘what‘ works, rather than investigating ‘why’ it works. This approach overlooks the impact of different mechanisms, such as relational and contextual aspects, as well as the role of actors in influencing the measured effect of the interventions (Glasdam et al., 2015; Inhester et al., 2016; Walczak et al., 2018; Wilson et al., 2021).

Theoretical framework

In this dissertation, Pierre Bourdieu’s relational concepts of field, capital, doxa, power, and position were used as the theoretical framework (Bourdieu, 1991). Bourdieu defined a field as a structured space of positions and a system of relationships between these positions that are relational. He emphasised that any social space or context, where concrete human activities take place, is always a pre-structured context as it is coded with specific rules and values. Moreover, Bourdieu demonstrates that every field possesses its own distinct doxa, which can be defined as an unspoken belief system shared by actors within that field. This doxa is readily apparent to those involved yet remains unarticulated and unexamined. Doxa arises organically and is inherent within the field or the broader social sphere (Bourdieu, 1977, 1988). In the current dissertation, the concept of the field refers to the structural and contextual analysis of specialised palliative care and the studied support programme, and its impact on different actors (parents, children, healthcare professionals) encounters and (inter)actions in relation to their different positions, power, and capital.

According to Bourdieu, there are different types of capital: economic, social, cultural, and symbolic (Bourdieu, 1977, 1996). Capital is a relational concept, meaning that someone must recognise it in order for it to be valuable. For example, professionals have cultural capital, defined by their medical and psychological knowledge, which places them in a higher position than patients and their children. While patients, partners, and their children have social capital through their support for the ill patient and each other, this capital may have limited value in the medical field where they are positioned as patient or relatives with limited medical knowledge. In addition, parents have social and symbolic capital in relation to their children as guardians in various contexts. In this dissertation, the concept of capital is used as an analytical tool to explore how different actors’ behaviours and strategies are shaped by their access to valuable and recognised forms of capital.

Power can be found at the heart of all social interactions and often takes the form of symbolic power, and the successful exercise of power requires legitimation and the belief of those subjected to it to legitimise the power and legitimacy of those who wield it (Bourdieu 1991, 1996). Bourdieu (1991) uses the term ‘symbolic power’, which is routinely deployed in social life. When power is exercised through symbolic exchange, it always rests on the foundation of a shared belief. This means that symbolic power functions as a structure in a social field where related people have accepted what is right or wrong about any phenomenon such as things, thoughts, behaviours, traditions, or actions (Bourdieu, 1990). Additionally, symbolic power appears in families, workplaces, and schools, often requiring legitimacy but also often ‘invisible’. The state and institutions as delegated holders of symbolic power have the right to exercise pedagogic action through pedagogic authority. In this way, the symbolic order helps reproduce the social order (Bourdieu & Passeron, 1990). In this dissertation, the concept of power was used to explore how power-relationships between different actors occur explicitly and implicitly in various contexts, including specialised palliative care, advance homecare, and the studied support programme. The objective was to understand the impact of power-relationships on their interactions and possible influences in the outcomes of the provided support and interventions.

Furthermore, Bourdieu (1999) states that the real is relational, meaning that social reality consists of power relationships between different objective positions and dispositions, which unfold through dialectical processes. Understanding people means understanding their inherent properties, attributes, or essences in relation to the objective structure or practices of the social field in which they exist (Bourdieu, 1999). This means that, within a social context, different actors fight for something that is both common and valuable to them. Actors’ social positions, education, upbringing, and habitus – defined as schemes of perceptions, conceptions, and actions – are part of the structure and have significance for the actors’ behaviours in a social context (Bourdieu, 1991). In a social context, actors or groups of actors assume different positions and act differently depending on their access to different forms of valuable capital, such as economic, social, cultural, and symbolic capital. These capitals are part of the social structure and impact actors’ behaviours in specific physical spaces (Bourdieu, 1977, 1991, 1996, 1999).

In this dissertation, Bourdieu’s relational sociological theory subsequently serves as an analytical lens to illuminate the dynamic power relationships between different actors’ social positions, capitals, and dispositions within the context of the support programme. Factors such as age, role, professional background, and parental authority as guardian influence the possibilities for shaping the actors’ interactions in predefined and organized social contexts and situations. In dialectic processes, as Bourdieu argues, actors influence the context, and vice versa. Furthermore, Bourdieu's theoretical framework is used to explore the relational aspects of power and position in specialised palliative homecare, as well as the structural, political, and administrative framework that governs palliative care practice.

Rationale

Various forms of psychological bereavement programmes claim to support children through their situations. However, the relational and contextual aspects of these programmes and their impact on the effectiveness of the interventions are underexplored. Such perspectives include examining how the structure of support programmes impact individuals' possibilities for inter(action), and how their positions shape these (inter)actions and influence the interventions (Glasdam et al., 2010; Choby & Clark, 2014). Furthermore, previous research indicates that the support provided often does not align with children's needs and wishes. This dissertation aims to address knowledge gaps from a relational and contextual perspective by examining children's involvement, positions, and influence in the decision-making process regarding support strategies.

In Sweden, in recent decades, the care setting of dying people has gradually shifted to their private homes. There is a lack of research on how professionals such as physicians, nurses, and social workers support children when their parents receive palliative care at home or in specialised palliative care wards. To develop effective support for these children, it is crucial to understand the conditions that enable professionals to assist them within the context of the organisational structure of specialized palliative care. This involves examining relational and contextual factors and understanding the challenges and facilitators that influence professionals' support strategies in different specialised palliative care units. This dissertation strives to address the research gap concerning hierarchical positions and power dynamics among professionals within specialised palliative care settings, as well as between professionals, parents, and children in the context of a voluntary bereavement programme.

Aim

The overall aim of the current dissertation was to illuminate, from a professional perspective, encounters with children with a seriously ill or deceased parent, and to examine, from contextual and relational perspectives, the underlying logics and execution of a bereavement support programme for children.

Specific aims of the four original papers in this dissertation:

I. To explore the interactions between nurses and children of patients with incurable cancer - from the nurses' perspective.

II. To explore how physicians and social workers met children as relatives of a parent with cancer, in order to understand the possibilities and difficulties in supporting children in specialised palliative homecare in Sweden.

III. To explore how adolescents who had lost a parent were included, acted, and interacted in a support programme, focusing on relational and contextual aspects.

IV. From relational and contextual perspectives, to explore different actors' influences on the content and the proceeding of a support programme in a Swedish context.

Material and methods

Design

This dissertation had a qualitative design. The empirical material was collected through semi-structured interviews in Studies I and II (Papers I and II) and through an ethnographic field study in Study III (Papers III and IV). In the ethnographic field study, data was collected through various methods such as observation, semi-structured interviews, focus group interviews, photographs, and the collection of written documents and drawings, as suggested by other researchers (Malterud, 2001; Patton, 2008). Furthermore, the ethnographic methodology facilitated gaining knowledge through direct encounters with participants, observing their actions and interactions in 'real life' situations (Fangen, 2004). Semi-structured interviews were used to explore complex phenomena in depth, providing rich and detailed insights. Furthermore, these interviews provided opportunities for participants to express their experiences, emotions, and perspectives in their own words (Malterud, 2001; Patton, 2008). An overview of the studies is presented in Table 1.

Table 1. Overview of the studies

Study	Methods for collection of empirical material (Years)	Sample	Place; duration	Data analysis	Paper
1	Semi-structured interviews (August – September 2013)	Nurses n=9	At workplaces; 28-71 minutes (average 57 minutes)	Latent content analysis	I
2	Semi-structured interviews (August – October 2016)	Physicians, n=5 Social workers, n=5	At workplaces; 56-70 minutes (average 63 minutes)	Thematic analysis inspired by Pierre Bourdieu's theoretical framework	II
3	Ethnographic field study, consisting of observations, semi-structured interviews, on-the-spot interviews, a focus group interview, photographs, drawings, and materials used in the intervention programme (February – June 2019)	Children, n=11 Parents, n= 8 Volunteers, n=8 Supervisor, n=1	Individual interviews conducted in private homes and at the location of the support programme; 40 to 167 minutes (average 68 minutes). Focus group interview with professionals conducted at the location of the programme; 120 minutes. Field observations conducted at the location of the programme; 82 hours	Thematic analysis inspired by Pierre Bourdieu's theoretical framework	III and IV

The context of the studies

All three studies were conducted in the southern part of Sweden. Studies I and II were performed in four specialised palliative care units. Study III was conducted within a voluntary bereavement support programme for children and their surviving parent. The programme was organised and conducted according to the guidelines established by Swedish psychologist Gyllenswärd (1997). To gain access to the programme, parents applied via email or phone. A contact person within the programme responded by phone and assessed whether the family met the programme's inclusion criteria. The inclusion criteria required that the family participate for a minimum of six months after the death of a parent and have proficiency in the Swedish language. The exclusion criterion was that children with cognitive or psychological disabilities, such as autism and attention deficit hyperactivity disorder (ADHD), could not participate. After this initial screening, a meeting was scheduled where the family and volunteers met to exchange information about the programme and discuss mutual expectations. Following this meeting, the volunteers made the final decisions regarding inclusion and exclusion of participants in the programme. The programme was structured into seven sessions, each focusing on predefined themes, schedules, and content. For more details, see Table 2. Furthermore, parents, children, and volunteers met half an hour before the start of each session for mingling time with refreshments provided at every occurrence. The studied programme course consisted of four groups: two for parents, one for younger children (ages 8-10), and one for older children (ages 11-14). Each group had two volunteers serving as group leaders. The field observations during the sessions were conducted in the group of older children, which consisted of six children.

Table 2. Content in the seven group sessions

Sessions	Themes	Content
1	My family and my loss	Introduction of the support group, content, tasks, rules, and rituals. One ritual was to light an electronic candle for the deceased parent/person at the beginning of each session and extinguish it at the end of the session. Participants introduced themselves to each other and described the circumstances of their parent's death
2	Psychological reactions and changes in everyday life after the death of a parent	Descriptions of and reflection on the grief process and identification of changes that had occurred
3	Emotional changes after the death of the parent	Reflection on and identification of changes in emotions
4	Coping strategies	Description, and identification of and reflection on activities that could provide coping strategies in grief
5	Memories of the deceased person	Explanation about and reflection on strategies to keep the memory of the deceased parent/person
6	Support- networks	Identification of and reflection on supportive networks
7	Farewell	Closing ceremony of the programme, writing a letter to the deceased parent, which is then attached to a balloon and released. Evaluation of the programme

Recruitment strategies and samples

Study I-II (Paper I-II)

In Study I (Paper I), the participants were nurses, while Study II (Paper II) involved physicians and social workers, all working at four different specialised palliative care units in Southern Sweden. Participant characteristics for both studies (Papers I, II) are presented in Table 3. Inclusion criteria required that the nurses, physicians, and social workers had at least two years of experience in specialist palliative care and had worked with patients' children. There were no exclusion criteria. Contact with the participants was established through two head managers and their respective unit managers. The unit managers informed the nurses, social workers, and physicians about the research and encouraged those who expressed interest in participating to submit their names, telephone numbers, and email addresses. In Study I (Paper I), a total of nine nurses expressed interest in the study and were contacted by the author of this dissertation and a co-author to provide detailed information about the study. The unit managers reported that five out of six social workers and 12 physicians were interested in participating in Study II (Paper II). The objective of the research was to achieve a balanced representation of social workers and physicians, so seven out of the 12 physicians were randomly selected by the author of this dissertation and invited to participate via e-mail. Of these, two physicians did not respond, while the remaining five consented to take part in the study. All participants were provided with information about the study, both orally and in written form, and they subsequently provided written informed consent to participate.

Table 3. Demographic characteristics of participants in Study I-II (Paper I-II)

	Study I	Study II
Number of participants	9	10
Age (years)	33-62 (average: 46)	Physicians 46-63 (average: 55) Social workers 37- 62 (average: 44)
Gender	9 females	7 female and 3 males
Professional	Nurses	Physicians and social workers
Work experiences (years)	2,5-13 (average: 8)	Physicians 2,5-15 (average: 8) Social workers 5-13 (average: 5)

Study III (Paper III-IV)

In Study III, the participants included 11 children, eight parents, eight volunteers, and one supervisor. The observational part of the study was conducted in the group of children aged 10 to 14 years, involving a total of six children (Papers III-IV). Participant characteristics are presented in Table 4. Inclusion strategy was that all volunteers and families were invited to participate in the study. If the parent or the related child chose not to participate in the study, both were excluded. There were no exclusion criteria for volunteers and their supervisor. The volunteers received verbal information about the upcoming study from the author of this dissertation prior to the pilot field study in spring 2018. Furthermore, during the initial meetings with families in February 2019 and planning meetings with volunteers, both verbal and written information about the study was provided. The supervisor also received both verbal and written information at the start of the programme. At the initial screening meeting, the volunteers informed the parents about the study and asked if they were interested in receiving further information. Upon acceptance, the author of this dissertation entered the meeting and orally informed the parents and their children about the study and handed over written information in two versions: one for adults and one age-appropriate for children. During this meeting, the author collected the parents' telephone numbers and e-mail addresses for subsequent follow-up concerning their participation in the study. After one to two weeks, allowing parents and children time to think about and discuss their participation with each other, the author contacted the parents to ascertain their interest in participating in the study. They then gave oral consent to participate in the study. The study included eight out of the ten families who participated in the studied support programme. One family opted to participate only in the observation part and refrained to be interviewed. Seven families agreed to participate in all parts of the study. One family declined to participate, while another was excluded due to the child's refusal to take part. All participants over 12 years old (children, parents, volunteers, and their supervisor) gave informed written consent to participate in the study. Children under 12 years old provided informed oral consent, while their parent gave written consent for their participation. Furthermore, before the interview, children were informed repeatedly about their voluntary participation, confidentially, and their right to refuse participation in the study at any time, without needing to give a reason. Additionally, the children, parents, and volunteers had the opportunity to ask questions to the author of this dissertation before the interviews and during mingling sessions and breaks in the support programme.

Table 4. Demographics of participants in Study III (Papers III-IV)

	Study III
Children, n=11	
Age (years)	8–14 (average: 11)
Gender	
Girls	2
Boys	9
Included in Papers III & IV	
Age (years)	10-14 years (average: 12 years)
Gender	
Girls	2
Boys	4
Parents, n=8	
Age (years)	40-72 (average: 48)
Gender	
Male	3
Female	5
Volunteers, n= 8 and supervisor, n=1	
Age (years)	34–69 (average: 61 years)
Gender	
Male	2
Female	7
Experience of working as a volunteer in the support programme (years)	0–15 (average:7)

Development of guides and pilot studies

As recommended by Kvale and Brinkman (2009) and Brinkman (2014), interview guides were developed for each study (Appendix I-V). The themes in Studies I and II focused on the participants themselves, including aspects of their life histories and socio-demographic factors such as age, gender, place of residence, education, and employment. Furthermore, the themes centered on the experiences of professionals and the challenges they encountered when interacting with children of ill parents in the context of specialised palliative care (Appendices I-II).

In Study III, the themes in the first (individual) interview guide aimed to explore each participant's life history and socio-demographic information (age, gender, residence, education, work), as well as how they got access to the programme, and the families' experiences related to the parent's illness and death. The themes in the second (individual) interview guide were about their experiences of participating in the programme and how or if it helped them in their bereavement process (Appendices III-IV). The themes in the focus group interview guide included volunteers' demographic data, professional background, their thoughts regarding the structure of the programme, positive or negative experiences in relation to the children and their parents, challenges encountered with the families, and what they would like to change in the programme (Appendix V).

Two pilot interviews were conducted with nurses in Study I by the first and second authors of Paper I. In Study II, the author of this dissertation conducted a pilot interview with a physician specializing in palliative care. In Study III, the author of this dissertation conducted two pilot interviews with children aged 10 and 14 years, alongside one interview with a surviving parent. The participants were recruited from a specialised palliative care unit. All pilot participants were provided with comprehensive information about the study, and they subsequently gave their verbal informed consent to participate in the pilot interviews. The pilot interviews helped train the interviewer, assess the functionality of the technical equipment, and made it possible to evaluate the interview guides. The author of this dissertation transcribed the pilot interviews verbatim. The interviews were subsequently discussed within the research team to develop the interviewers' competencies. No adjustments were needed in the interview guides. The pilot interviews were not included in empirical material, as promised to the participants. It was not possible to conduct a pilot focus group interview due to difficulties in finding participants with experience working in a support programme.

In the spring of 2018, two pilot field observations were conducted during an earlier course of the studied programme. Prior to the observations, the volunteers agreed to participate in the pilot phase of the study. Both the volunteers and the author of this dissertation informed the parents and children involved, who subsequently granted verbal consent to being observed during the sessions. The primary aim of these observations was to gain an understanding of the context surrounding the support programme and to identify any potentially sensitive situations or reactions from the children. The observations were documented as field notes, which served as a foundation for the development of a guide for subsequent field observations in Study III. The guide served as a tool to help the author note with whom participants engaged, the nature of these interactions, the roles they adopted, and the physical contexts in which these exchanges occurred (see Appendix VI).

Data collection

Semi-structured interviews

In Studies I, II, and III, each interview started with a description of the study and details regarding the recording of the interview. Participants had the opportunity to ask questions pertaining to the study prior to its initiation and during the interviews. In Study I, the interviews were conducted by the two authors of Paper I; all other individual interviews were conducted by the author of this dissertation. Both Studies I and II began with questions about the participants themselves, including age, gender, place of residence, education, and employment. This approach was intended to foster a comfortable atmosphere for the participants during the interview process. The interview guides supported the interviews. Follow-up questions were posed to participants to elucidate their narratives and clarify their perspectives (Appendices I-II). The interviews were conducted at the participants' workplaces, according to their preferences. For more details on the interview durations, see Table 1.

In Study III, two semi-structured interviews were conducted with the children and their parents, respectively. The first interviews took place either before or at the very beginning of the support programme. The final interviews were conducted after the programme had finished. More details about the interviews can be found in Table 1. Seven out of eight families chose their home for their interview, which is also recommended by researchers (Danby et al., 2011; Eder & Fingerson, 2001). The author of this dissertation paid attention to children feeling comfortable during the interviews. Four children chose to have their parent present during the interview. Furthermore, the initial interaction between the author and the families during the introduction meeting of the programme likely contributed to a sense of safety. Children seemed comfortable during the interviews as they had already met the author (Danby et al., 2011; Eder & Fingerson, 2001). Each interview started with a description of the study, and how and why the interview was being recorded. Children were given the opportunity to ask questions before and during the interview. Additionally, to help children feel at ease, the interview started with simple questions about themselves, such as their age, hobbies, friends, and school. The author also engaged with children by talking about their favourite toys and games, drawing pictures, or using family photos to facilitate storytelling during the interviews (Danby et al., 2011).

Focus group interview

In Study III, a focus group interview was conducted with volunteers to explore their perceptions, ideas, opinions, and experiences of the support programme, both in general and specifically in relation to the recently completed programme (Glasdam et al., 2023). Seven out of eight volunteers participated, and one could not participate due to personal matters. The interview started with a description of the study, including details regarding the recording of the interview and the roles of the moderator and observer (Krueger & Casey, 2000). Participants had the opportunity to ask questions pertaining to the study prior to and during the interview. To help volunteers feel comfortable in the interview situation, the author of this dissertation started with questions about participants' demographic data. As the moderator, the author led the interview, aiming to facilitate an open dialogue, while ensuring that the discussion remained focused on the study's aim. Follow-up questions were asked to prompt further discussion and clarify responses. Furthermore, the last author of all four papers observed the session, took field notes and asked additional questions at the end of the interview (Krueger & Casey, 2000). For more details about the focus group interview, see Table 1.

Field observation

In Study III, field observations were conducted from February to June 2019 within the studied support programme. These observations took place when participants mingled before the start of the programme sessions, during all seven sessions, during breaks, and at volunteers' planning meetings and group meetings for supervision and reflection. Observation as a data collection method was particularly relevant for examining participants' activities across the different physical settings of the support programme, providing valuable insights into how individuals and social groups interacted with each other (Fangen, 2004; Kaijser & Öhlander, 2011). Ethnographic field observations are highly recommended for studies involving children as they are more effective than interviews (Christensen, 2004; Eder & Fingerson, 2001).

During the field observations, the author of this dissertation was engaged in both passive and active participant observations (Fangen, 2004; Kaijser & Öhlander, 2011). In the first three sessions, the author was invited by the volunteers to participate in the name game. However, during the remainder of the sessions, the author adopted a more passive role and refrained from verbal communication with both the children and the volunteers to minimise disruptions in their interactions. Furthermore, participant observation was carried out during mingles, breaks, and volunteer meetings, where spontaneous interviews were conducted when deemed relevant. These spontaneous interviews facilitated direct interaction with participants, thereby permitting inquiries concerning discussions or observations that arose during the sessions. Parents, children, and volunteers could also pose questions to the author. This brief and spontaneous interview format facilitated more personal and informal interactions, as conversations were not restricted by a predetermined set of questions (Kvale & Brinkman, 2009; Brinkman, 2014). These spontaneous interviews were documented as field notes (Fangen, 2004; Kaijser & Öhlander, 2011).

A dairy was used by the field researcher for reflection and as a means to challenge preconceptions during and after observations. Furthermore, photographs were taken during the field study to supplement the field notes and help to accurately remember locations and events. The photographs also supported the researcher in recalling important details in the fieldwork (Gradén & Kaijser, 2011). The photographs captured only the furnishings and materials used in the support programme or activities, for example, the balloon ceremony during the last session. Other kinds of empirical material, such as children's drawings, written reflections, and evaluations of the support programme, were also collected (Fangen, 2004; Kaijser & Öhlander, 2011).

Strategies of Analysis

All interviews were transcribed as closely to verbatim as possible and read several times to gain a comprehensive understanding and to form an overall view of the transcribed interviews (Brinkman, 2014). All observations and spontaneous interviews were documented as handwritten notes, which were subsequently transcribed into Word files (Kaijser & Öhlander, 2011). For more detailed information, see Table 1.

Latent, content analysis

In Paper I, the analysis was conducted using latent content analysis, inspired by Graneheim and Lundman (2004). Latent content analysis involves interpreting the text at a deeper level than what is explicitly stated in the initial manifest analysis. The first and second authors read the transcribed interviews several times to gain an overall understanding of the content. The text was then systematically organised and analysed in a step-by-step process inspired by (Graneheim & Lundman, 2004). The text was divided into meaning units based on the aim of the study. These meaning units were condensed into shorter sentences while preserving their original meaning. They were then coded and sorted to identify patterns, similarities, and differences. The two authors discussed their findings to resolve any discrepancies in the coding. Furthermore, this collaborative approach provided an opportunity for the authors to share insights and perspectives on the content to gain consensus. Codes with similar content were grouped into subthemes to generate potential themes. The last author engaged in discussions regarding the identification and construction of subthemes and themes, focusing on interpreting underlying meanings. Quotes from the empirical material were included to illustrate and provide transparency in the analysis.

Theory-inspired thematic analysis

Latent thematic analyses were conducted in Papers II, III, and IV, methodologically inspired by Braun and Clarke (2006) and theoretically inspired by Bourdieu's concepts of field, doxa, capital, position, and power (Bourdieu, 1977, 1988, 1991, 1996, 1999). Initially, the author of this dissertation thoroughly reviewed both field notes and transcribed interviews multiple times to gain familiarisation and a comprehensive understanding of the entire empirical material (Braun & Clarke (2006). The initial coding process for the field notes and interviews was conducting by using a matrix for each of the three papers (II, III, and IV, see Appendix VII, VIII). This matrix functioned as a multidimensional map, organising initial codes by asking theoretically constructed questions to the texts. For example, in the matrix used for Paper III, the horizontal rows contained information about the support programme's context (structure, content, place, and environment), the different positions of the actors (volunteers, parents, children), and how power relationships between the actors appeared in the different physical spaces. The vertical columns contained information about the actors' strategies—namely what, when, where, with whom, and how these strategies influenced the content and proceedings of the programme. In the next step, the author sorted the initial coded extracts into groups to capture similarities and differences, which led to the construction of initial sub-themes and themes. All authors involved in the papers were engaged in refining the identified themes and carefully analysed and reviewed the initial themes in conjunction with the coded extracts to verify that each theme was both unified and unique. This process ensured that each theme captured the essence of the study's aim in defining and naming themes (Braun & Clarke, 2006). Furthermore, the research team adopted a reflective approach (Bourdieu and Wacquant, 1992) throughout the analysis process and discussed their own preunderstandings and initial interpretations to ensure that the analysis was conducted objectively and that it was grounded in the actual empirical material and inspired by the theoretical framework. Quotes from the empirical material were included to illustrate and provide transparency in the analysis.

Ethical considerations

Ethical considerations were carefully addressed throughout the research processes. All three studies were conducted in accordance with the ethical guidelines of the Helsinki Declaration (The World Medical Association, 2013). Since Studies I and II did not involve sensitive personal data, psychological or physical interventions, or vulnerable individuals, ethical approval was not required under Swedish law governing the Ethical Review of Research Involving Humans (Swedish Act on Ethical Review, 2003).

Study III was approved by the Swedish Regional Ethics Board in Lund (Dnr. 2018/618; Dnr. 2019–01061) and was conducted in accordance with Swedish legislation. Participation in all three studies was voluntary, and participants were assured of their right to withdraw from the study at any time without consequences, including in Study III, where their withdrawal did not affect their participation in the support programme, according to the autonomy principle (World Medical Association, 2013). All participants were informed about the study both orally and in writing, with age-appropriate versions provided for adults and children to uphold the principles of justice and autonomy (Beauchamp & Childress, 2013). In all three studies, participants decided dates and places for interviews. Furthermore, results were presented at a group level to ensure participant anonymity (World Medical Association, 2013).

In Study III, the research team was aware of the potential impact of the author's presence on the children and volunteers during the sessions. To minimise disruption, no verbal communication occurred between the author, children and volunteers after the introduction games in the sessions. Furthermore, during the planning phase of Study III, when writing the application for ethical review, the research team discussed and reflected on the principle of non-maleficence (World Medical Association, 2013). This reflection was especially important regarding children's participation in this study, with regard to the balance between benefits and risks, with an awareness that children might experience discomfort during the sessions in the support programme, and as well as during the interviews when recalling stressful memories related to their deceased parents' illness and death. Therefore, an action plan was established to refer any child in need to a social worker for assistance, although this plan was never needed in the study.

Overall, there was no direct beneficence for participants in the three studies. However, all participants had the opportunity to engage in dialogue with the author of this dissertation, allowing them to share their experiences and emotions. This process can be therapeutic in itself, leading to a sense of relief and liberation. Furthermore, by participating in the studies, the participants contributed their knowledge and experiences, which might provide beneficence to professionals, patients, and relatives in clinical practice. Additionally, their insights contributed knowledge to the research community and may inspire ideas for future research.

Moreover, the empirical material, in the form of interviews, field notes, and photographs, is stored in a password-protected external hard drive, kept in a locked cabinet at Lund University, in accordance with the Swedish Archives Act (1990), and the General Data Protection Regulation (Swedish Authority for Privacy Protection, 2024). Other forms of empirical material from Study III, such as drawings and evaluations of the programme written on paper, are stored in a locked, fireproof room at Lund University. Furthermore, in 2020, the Swedish Appeal Board for Ethical Review selected Study III for ethical control and asked for additional inquiries concerning the ethical considerations, as children acted as research subjects. The purpose of the inquiry was to ensure that the study was carried out in accordance with the approved ethical application. The board concluded that ethical considerations were carefully addressed throughout the research process.

Findings

The main findings from the four included papers are integrated, summarised, and presented under the following themes: '*Symbolic power and position defined and shaped support strategies*', '*Confidentiality opened and closed the condition of possibility for communication*', and '*Social contexts influenced children and adults interactions and vice versa*'.

Symbolic power and positions defined and shaped support strategies

According to professionals – including nurses, physicians, social workers, and volunteers – parents bear the primary responsibility for supporting their children due to their symbolic power and position as guardians (Papers I, II, III, IV). However, within the context of the studied support programme, both parents and volunteers held positions of symbolic power to shape and create support strategies for children (Papers III, IV). From the parents' perspective, seeking support from professionals was a good way for their children to cope with parental loss and bereavement, such as through participation in a support programme. However, children reacted differently in the prospect of joining the support programme. Some children accepted their parent's invitation immediately and joined the programme, while others initially showed a willingness to participate but later hesitated. Nonetheless, parents persuaded them to continue participating in the programme.

Based on the volunteers' symbolic power, capital, and position, they held the authority to decide which children and parents could participate in the programme. Children with special needs and those who were not proficient in Swedish were systematically excluded. From the volunteers' perspective, children with special needs could potentially disrupt the programme for others. Furthermore, volunteers reported facing challenges in managing children with psychological diagnoses or those who spoke a native language other than Swedish. Such challenges were deemed to fall beyond the scope of the programme's framework and could not be accommodated (Paper III).

This power dynamic illustrates how adults – specifically parents and professionals, including professional volunteers – play a crucial role in assessing children's support needs and determining the strategies for providing that support (Papers I, II, III). Additionally, children expressed their views on their parent's support strategies by accepting them, sometimes after negotiation, or indicating their unique and individual needs of support (Papers III, IV).

The findings in Papers I and II showed that professionals in specialised palliative care had different perspectives on who should provide support to children. Healthcare professionals working in palliative care units argued that those who had interacted with the children earlier in the course of the parent's illness bore the responsibility of offering information and support to the children (Papers I, II). Nurses in palliative units expressed that professionals involved in specialised palliative homecare were responsible for supporting children, as they had the opportunity to engage with them in their home environment while caring for the ill parent (Paper I). However, nurses in specialised palliative homecare identified challenges in supporting children who frequently spent time in institutions, while teenagers often opted for self-isolation in their rooms or chose to be absent during the nurses' visits. In such instances, the nurses assessed that it was the teenagers' responsibility to initiate contact (Paper I). According to the nurses, teenagers acquired information about their parent's diagnosis from digital resources, which meant that the nurses had no control over teenagers' knowledge regarding their parent's illness and treatment. It meant that they had the power and opportunity to seek information independently. Moreover, some nurses noted that it was easier to interact with younger children, noting that encounters with teenagers were more challenging.

Some physicians also expressed their inability to provide support to children, as they were often not present at home during consultations, typically attending school or participating in extracurricular activities at the time of the physician's visit (Paper II). Moreover, from the nurses' perspective, the responsibility for professionally supporting children primarily rested on physicians and social workers. Physicians were viewed, based on their cultural capital, as possessing the necessary medical expertise, while social workers were also regarded as specialists in therapeutic communication with children based on their own cultural capital (Paper I). However, physicians tended to delegate the responsibility of supporting children to social workers, who expressed that physicians should engage more actively in supporting children (Papers II).

After the death of a parent, contact between children and professionals in specialised palliative care typically ended. Social workers made one to two follow-up calls, after which the families were referred to other professionals in primary healthcare and schools (Paper II). However, according to children and their surviving parents, social workers at schools referred them to the support programme (Paper III). According to the rules of the support programme, children could participate a maximum of twice, and if they needed more support, they were referred by volunteers to other healthcare professionals, such as psychologists in primary care or to child psychiatric clinics (Paper III). This meant that professionals and volunteers provided time-limited support to children in accordance with their organisational rules and guided them to other professionals for further assistance. In other words, depending on their symbolic position and power, professionals and parents acted as gatekeepers, organising support and guiding children on how to navigate grief and bereavement. Simultaneously, some children helped themselves by seeking information through digital resources (Papers I, II, III).

Confidentiality opened and closed the condition of possibility for communication

From a professional perspective, confidentiality was a core element governing communication between children, parents, and professionals in the context of specialised palliative care (Papers I, II) and in the studied support programme (Papers III, IV). According to nurses, physicians, and social workers, some ill parents deliberately excluded their children from their discussion about their illness to protect them (Papers I, II). This societal norm, or doxa, of shielding children from suffering was common among many parents, as perceived by professionals. Consequently, professionals were obligated to respect the parents' wishes, as confidentiality rules prevented them from sharing information about the patient's illness without the patient's permission. Some professionals found this to be a dilemma, as they recognised children's legal rights to receive information, advice, and support (Papers I, II). Nurses, physicians, and social workers had the opportunity to support children in families where parents chose to include them in the situation. In other words, parents acted as gatekeepers for professionals' contact with their children, and professionals respected parents' autonomy as patients, as well as their symbolic power and position as guardians with the mandate to include or exclude their children in discussions about their situation (Papers I, II).

In the context of the support programme, confidentiality was a key element that both opened and closed communication and interactions between different adults and children (Papers III, IV). Within the structural framework of the support programme, volunteers established rules of confidentiality, prohibiting anyone involved from discussing the content of their conversations outside the programme. This obligation also applied to both the volunteers and the author of the current dissertation as a private individual. From the volunteers' perspective, confidentiality was perceived as a protective shell that allowed children and parents to speak freely about their loss, bereavement, and grief. However, the positions and cultural capital of children and adults (parents, volunteers, author of current dissertation) defined the premises of the confidentiality commitment. Volunteers, positioned as professional support providers, had allotted time in the programme for informal supervision for the group of volunteers, where they openly discussed their experiences with children and parents, and the assigned supervisor guided them on how to manage different situations. Furthermore, positioned as researcher, the author of this dissertation had a legitimate forum for expression in the context of the research. As a researcher, the task was to make the support programme visible beyond its own framework and context, with approval from all the participants through informed consent. Nonetheless, the author followed ethical research laws, including the Helsinki Declaration, to ensure participants' integrity and confidentiality throughout the research process. In contrast, children and parents, positioned as recipients of support, did not have the same opportunity as the author and volunteers to share their experiences outside the support programme. On one hand, the support programme provided children (and parents) with an exclusive and legitimate place to talk about their emotions and experience of the loss of a parent or co-parent. On the other hand, the rule, or doxa, of confidentiality was imposed on the children and surviving parents, who, as recipients of support, were required to adhere to this rule to participate in the programme. However, it is unknown to the volunteers and research team how the children and surviving parents managed the rule of confidentiality outside the programme (Papers III, IV).

Social context influenced children's and adults' interactions and vice versa

The organisational and structural frameworks of specialised palliative care and the studied support programme had an essential role in shaping conditions under which professionals could interact with and support children (Papers I, II, III, IV). These frameworks encompassed various elements, including the working conditions of professionals, their responsibilities, time management, the content and focus of the studied programme, and the physical spaces where these interactions occurred.

Overall, the findings showed that professionals in specialised palliative care had limited interactions with children during their working hours. The working conditions, particularly the planning of time and content of work, were explored from the professionals' perspectives (Papers I and II). The working hours of physicians and social workers were dominated by administrative duties, attending a variety of meetings, research activities, clinical development projects, consultations with external care providers, social services, and coordinating appointments with patients and their families (Paper II). Furthermore, some nurses expressed that during the last stages of palliative care, patients often had a multitude of severe symptoms, which restricted their capacity to engage in conversation with the children. From the nurses' perspective, the structural framework and doxa were shaped by the medical field's logic, and necessitated that they prioritised the needs of the patients over those of the children (Paper I).

Professionals identified time as a considerable obstacle in various ways, leading to diminished interaction with children. One time-related obstacle was the planned time allocated for home visits, while another was finding optimal moments to engage in communication with the children (Papers I, II). During office hours, which coincided with school hours for children, physicians and social workers coordinated home visits with patients. Some physicians reported that this scheduling impeded their ability to engage effectively with the children. Additionally, physicians encountered difficulties in determining the appropriate time during a parent's illness to disclose the impending death to the children. This was most evident in families where the children were not actively involved in the ill parent's situation, particularly in cases where the parent's condition deteriorated rapidly and led to a sudden death. Nurses and physicians noted that children who were excluded from such situations and unprepared for the loss of a parent often exhibited intense reactions, including loud screaming, aggression, and panic upon the death of the parent (Papers I, II).

The studied support programme was based in a medico-psychological understanding of grief and bereavement, reflecting the dominant doxa within the medical field. The structured physical environment, session and content mirrored the organisational structure of a typical school setting (Papers III, IV). Moreover, the roles of children, parents, and volunteers varied across the distinct physical spaces of the programme, influenced by their symbolic power, positions, and designated roles (Papers III, IV). During the sessions, both children and their parents held the position of support recipients. The volunteers assumed the roles of experts and facilitators, based on their cultural capital, which included professional training, education, and experience working with bereaved families both within the context of the support programme and in their professional roles within healthcare and pedagogical settings. Additionally, like the context of a classroom, the volunteers led the communication during sessions, providing guidance and instruction to children who accomplished the tasks in line with the defined themes and content of the programme. Consequently, the structural framework positioned volunteers as teachers and children as pupils, who were expected to listen to instructions and engage with various tasks throughout the sessions. The children typically spoke aloud only when responding briefly to questions posed by the volunteers (Papers III, IV).

The lack of open discussions among the children during the sessions emerged as a major source of concern and frustration for the volunteers. From the volunteers' perspective, verbal expressions of feelings and emotions were deemed essential to the sessions and, therefore, highly valued. However, it was observed that the children primarily communicated non-verbally with one another during the sessions, utilising their cell phones and body language. Such behaviours went largely unnoticed by the volunteers. Like restrictions in a school classroom, the use of cell phones was prohibited during the sessions, however, the children found ways to bypass this rule (Papers III, IV).

Mingles and breaks before and during sessions were essential components of the support programme, fostering meaningful interactions among children, parents, and volunteers. Children interacted with each other during these social events, and the volunteers noticed this. These interactions were appreciated by the volunteers, who demonstrated flexibility by changing the planned time structure and content of the sessions, providing children with more free time to develop connections and engage in interactions (Papers III, IV). Furthermore, during mingles and breaks, interactions and connections also took place between children and volunteers, as well as among parents. In these informal settings, participants behaved differently and were free to interact with whomever they wanted. Volunteers assumed the role of hosts, and the conversations between children, volunteers, and parents shifted away from loss or bereavement-related subjects such as vacations and summer plans, hobbies, pets, and sports. In contrast to the structured sessions, where children often appeared as recipients of information, these breaks and mingles provided a lively atmosphere in which younger children could run, play, and laugh, while the older children engaged in conversations with their peers or with volunteers. Additionally, parents were able to connect with other parents who shared similar interests or whose children had formed friendships. This indicated that the different physical spaces and contexts facilitated by the support programme created distinct conditions that influenced their interactions. Specifically, shared interests during leisure time, common gathering places such as schools, and conversations about non-bereavement topics connected children more than the organised sessions focusing on the loss of a parent (Papers III, IV).

Discussion

Methodological considerations

To ensure the quality of the research, Lincoln and Guba's (1985) concepts of *credibility, dependability*, *confirmability,* and *transferability* were applied to discuss the strengths and limitations of the studies, enhancing the trustworthiness of the findings presented in the current dissertation (Lincoln & Guba, 1985).

Credibility

According to Lincoln and Guba (1985), credibility refers to the relevance of the methods used for data collection, the strategies for analysis, the context of the study, and the characteristics of the participants. These elements must align with the intended focus of the study to bolster the believability of the findings. Credibility can be achieved through data and material triangulation, which involves the use of multiple referents to draw conclusions about what constitutes truth (Lincoln & Guba, 1985). The findings in the current dissertation were based on the utilisation of a wide range of data collection methods, including individual interviews, focus group discussions, observations, and photography, which contributed to increasing the trustworthiness of the findings. Furthermore, the application of method triangulation allowed for a more nuanced exploration of the support programme, thereby enhancing the credibility of the research (Fangen, 2004; Lincoln & Guba, 1985). Additionally, examining the same phenomenon from multiple perspectives, known as participant triangulation, further strengthened the credibility of the findings (Lincoln & Guba, 1985). A thick description of the studies' context, the content of the programme, and the characteristics of the participants was presented during data collection to enhance the credibility of the findings (Lincoln & Guba, 1985).

Dependability

Dependability refers to the stability and consistency of the research process and its findings (Lincoln & Guba, 1985; Polit & Beck, 2020). To establish credibility in qualitative research, dependability must be demonstrated throughout all research processes, ensuring that the study could be replicated with similar findings (Lincoln & Guba, 1985). In Studies I and II, unit managers were involved in the recruitment process, which presents a potential limitation due to the risk of hidden inclusion or exclusion of participants. However, data triangulation involving time triangulation (the collection of data at different times and years) and space triangulation (exploring the same phenomenon across multiple sites) enhanced the trustworthiness of the findings (Lincoln & Guba, 1985). The professionals in Studies I and II worked at four different specialised palliative care units, further strengthening the trustworthiness of the findings regarding stability and consistency, as the same subject was explored from multiple perspectives and settings. In Study III, the author of this current dissertation personally informed and invited all children, parents, and volunteers to participate in the study, thereby strengthening the trustworthiness of the recruitment process. Although the sample size in Study III could be seen as a limitation, small sample research can still be valuable, especially when studying rare populations or when the availability of intervention is limited (Graneheim & Lundman, 2004; Polit & Beck, 2020).

Interview (and observation) guides were developed, and pilot interviews were conducted. The guides ensured that the interviews and observations were conducted systematically, enhancing the credibility of the findings. In addition, the length, time, and description of the physical location of the interviews and observations were described to assure the dependability of the findings. Participants were allowed to choose the location of their interviews, which supported their comfort during the interview situation and also balanced the power dynamics between participant and interviewer (Christensen, 2004; Eder & Fingerson, 2001; Glasdam, 2005). Individual interviews, involving one-on-one interactions, facilitated an in-depth exploration of participants' experiences, perceptions, and interactions. However, interviews rely solely on participants' narratives and cannot verify information about their actual actions within the narrated situations (Bourdieu, 1999; Kvale, & Brinkmann, 2009). Unfortunately, some of the interviews with children were not rich in content, perhaps due to the interviewer's lack of experience in interviewing children. However, the observations were rich in content, compensating for the lower quality of some interviews. For this reason, the interviews with the children were used to a more limited extent in Papers III and IV.

The focus group interview provided valuable insights and served as a dynamic platform for discussion, where different perspectives were explored (Krueger & Casey, 2000). The moderator observed the group dynamics and made sure that all participants actively engaged in the discussions (Krueger & Casey, 2000).

To observe actions and interactions between the individuals in ‘real life’ situations, the ethnographic method employed in Study III facilitated opportunities to obtain knowledge through first-hand experiences (Fangen, 2004). The use of an observation guide enhanced dependability by providing a thick description of the physical space and participants’ actions and interactions on the spot. A limitation of observation is that the observer can solely perceive participants’ bodily communication and expressions, but not what they thought or felt during the observed situations (Fangen, 2004). However, the spontaneous interviews conducted during field observations provided additional insights into participants’ inner thoughts and emotions, contributed to data triangulation, and strengthening the study’s dependability. Furthermore, in Studies II and III, the author of this dissertation conducted all individual interviews and performed all the field observations, which further strengthens the dependability of the overall view of the empirical material and its consistency.

Confirmability

Confirmability refers to the objectivity of research findings, emphasising the importance of ensuring that the data represent participants’ viewpoints rather than the researcher’s predispositions or personal beliefs (Lincoln & Guba, 1985; Polit & Beck, 2020). The author of the current dissertation has an educational background as a nurse and experience in caring for bereaved children, as well as collaborating with nurses, social workers, and physicians in palliative care units. This background called for an ongoing consciousness and reflection regarding potential medical or psychological preunderstandings related to children’s loss and grief, as well as the roles and functions of professionals in specialised palliative care. To address these habituated preunderstandings, and to enhance confirmability, a reflection diary was used throughout the research process, serving as a valuable tool during field observations (Fangen, 2004). Moreover, the author of this dissertation had no prior familiarity with the studied support programme or the volunteers, parents, or children involved, which enhanced the confirmability in the findings. While preunderstanding is a necessary condition for knowledge development, it can function as both a limitation and a benefit in the qualitative research process (Alvesson & Sandberg, 2022; Nyström & Dahlberg, 2001). In interview situations and during observations, the positive impact of the author’s professional experience may have helped establish connections with participants regarding their work conditions and in narrating a family member’s life threatening illness and a parent's death.

Another way to break with the current author's preunderstanding was achieved by seeking and utilising a theoretical perspective. This approach involved questioning one's own pre-structured perceptions, understanding, experiences, and assumptions to obtain a comprehensive understanding of the phenomenon under investigation (Alvesson & Sandberg, 2022; Bourdieu, 1977). To gain an outsider's perspective on one's own workplace or field, one should adopt a different way of viewing the field or area to uncover the implicit structural elements within the medical field that shape actions and interactions (Bourdieu, 1977). The selected theoretical framework assisted in minimizing the researchers' preconceptions, shifting the focus from preunderstandings to a theoretical perspective, thereby enhancing transparency and confirmability. However, it is important to note that no theoretical framework can claim to represent the absolute 'truth' of an analysis, as different frameworks can reveal varying 'truths' (Glasdam et al., 2024).

However, the studies inspired by Bourdieu carry the risk of reproducing theoretical pre-assumptions, which calls for critical reflection throughout the research process. Bourdieu emphasises for a double break approach, which has been a major point of attention for the research team. This involves ongoing discussions and reflections on both the methodological and theoretical aspects of the studies. The double break involves distancing from both the spontaneous experiences of the actors the spontaneous theorising of the researchers. On one hand, the theoretical perspective helps researchers get behind what materialises as the participant's subjective intentions or interpretations, as expressed during interviews or field studies. On the other hand, researchers must constantly strive to detach with their own immediate understandings of reality (Bourdieu & Wacquant, 1992). This has proven to be an ongoing and difficult challenge in the studies, ultimately strengthening the studies' confirmability.

In Study III, the presence of parents during some interviews with children could have potentially influenced how these children articulated their viewpoints and responded to questions, which might impact the confirmability of the findings (Gardner & Randall, 2012). However, it was the children's own choice to have a parent present. Researchers argue that children's perspectives must be taken seriously throughout the research process to acknowledge and respect the agency of the child (Coad et al., 2015; Danby et al., 2011; Eder & Fingerson, 2001). Moreover, parents also helped the children's contribution as they made the situation safe for the children and made sure the children felt comfortable (Coad et al., 2015; Danby et al., 2011; Eder & Fingerson, 2001; Gardner & Randall, 2012).

Furthermore, confirmability can be achieved through researcher triangulation (Lincoln & Guba, 1985; Polit & Beck, 2020). To ensure confirmability and trustworthiness, all authors had access to the original empirical material, including field notes and transcribed interviews. They collectively reviewed the initial coding and defined themes to ensure transparency and confirmability throughout the analysis process (Papers, I, II, III, IV). Furthermore, all authors were engaged in continuous discussions using a reflective approach to enhance the credibility of the analysis process (Bourdieu & Wacquant, 1992). Quotes were selected and presented in the papers to support the analysis, which also enhances the confirmability of the findings (Lincoln & Guba, 1985).

Transferability

Transferability refers to the extent to which the findings can be applied to settings beyond the specific conditions under which the original research was conducted (Lincoln & Guba, 1985). To promote transferability, the studies provide a transparent description of the context, the support programme, participant characteristics, and the processes of participant recruitment. This approach not only strengthens the study's dependability but also enhances its transferability. Furthermore, data collection methods, the use of interview and observation guides, analysis strategies, and the application of the theoretical framework further facilitate the potential for transferability to other contexts (Lincoln & Guba, 1985).

General discussion of findings

The discussion focuses on three main findings. Firstly, adults acted as gate keepers for the support opportunities available to children. Secondly, the confidentiality obligation both facilitated and hindered the possibility of support for children. Finally, the organisational structure and the various physical settings for encounters influenced the possibilities for support and shaped the interactions between children and adults.

One overall finding was that adults (parents, volunteers, and professionals) acted as gatekeepers and had an essential role in defining and shaping the support possibilities for children. From the professionals' perspective, parents held a central role in providing and initiating support for their children, which is in line with other systematic review studies that highlight the essential role parents play in supporting their children (Hanna et al., 2019; Wray et al., 2022). The findings showed that in some families, children and their parents had contradictory views on receiving support from the programme. However, the current findings showed that some parents assessed that their children needed this support and convinced them to participate in a programme. This finding corresponds with Uprichard's (2008) observation that adults primarily view children as ‘becomings’ rather than as ‘beings’. The term ‘becoming’ implies that children lack the competencies associated with the ‘adult’ that s/he will ‘become’. In other words, children lack the capacity to make logical and rational decisions, and therefore parents have the authority to make key decision on behalf of their children. The ‘being’ perspective implies that children are active participants in their societal role and can shape their own experiences of childhood (Uprichard, 2008). Moreover, the findings also showed that children actually acted as ‘beings’ and were active in the decision process of being included in the programme in various ways. Ahmadi et al. (2019) also showed that children possess the capacity to evaluate and articulate their own ideas and desires towards provided support. Venkatesan (2022) argues that there is a misconception among some adults regarding children’s ability to manage their emotions related to grief and bereavement, which can lead to a reliance on adult intervention and guidance. A recent study points out that children’s own preferences and approaches must be considered by adults when providing bereavement support (Joy et al., 2024; Stevens et al., 2024). This calls for adults to perceive children as active beings capable of choosing how to handle life’s challenges, including grief and bereavement (Chowns, 2013; Hogstad & Jansen, 2020; Joy et al., 2024; Uprichard, 2008).

Furthermore, volunteers in the support programme acted as gatekeepers, establishing specific inclusion and exclusion criteria that prevented children with psychological disabilities and linguistic limitations from participating. It could be seen as problematic and stands in contrast to the principles outlined in the United Nations Convention on the Rights of the Child, which has been law in Sweden since 2020 (Government Offices of Sweden, 2020; United Nations, 1989). The legislation mandates that all adults in decision-making roles must consider the implications of their decisions on children, ensuring that such decisions do not cause harm and do not discriminate against children’s legal rights in any context (Government Offices of Sweden, 2020; United Nations, 1989). Furthermore, the programme’s inclusion and exclusion strategy highlight what Bourdieu describes as ‘selecting the elect’, meaning that children’s social origins, as well as their cultural and economic capital, determine their destiny and lay the foundation for social inequalities (Bourdieu & Passeron, 1979). This means that children may encounter inequalities and may not receive the support they need due to language barriers or psychological disabilities.

Another key finding revealed that professionals could not support some children due to confidentiality obligations imposed by their parents. The obligation of confidentiality constitutes a fundamental principle of medical ethics, which professionals regard seriously in their encounters with parents and their children (Demirsoy & Kirimlioglu, 2016; Karasneh et al., 2021). The professionals’ strategy of being responsive to the parents' decisions regarding their children's participation was in line with the approach of person-centred care (Ekman et al., 2011). However, other researchers argue that the support needs of family members are often overlooked when person-centred care prevails (Byrne et al., 2020; Gaudio et al., 2012). There is a growing acknowledgment of the necessity to support families as collective entities during palliative care, often referred to as family-centred care (Gaudio et al., 2012). Although there is a general agreement on the importance of family support, which is also one of the four key elements in palliative care (Swedish National Board of Health and Welfare, 2018), there remains a paucity of clinically based guidelines to direct professionals on the implementation of support for all family members (Kissane et al., 2006; Petursdottir et al., 2019). Review studies show that the family-centred care model established in the context of paediatric care is highly recommended for application across all populations and care contexts to facilitate information sharing, collaboration, involvement, and support for all family members (Kokorealias et al., 2019; Krajnc & Berčan, 2020). Furthermore, children's best interests seem to be dismissed when parents' wishes are prioritised over children's need for support. Thereby, this is in contrast to Swedish law and the United Nations Convention on the Rights of the Child, which declare that adults in decision-making positions must consider the potential impact of their decisions on children to prevent any harm (Government Offices of Sweden, 2020; United Nations, 1989). Like the findings in the current dissertation, other studies showed that healthcare professionals take their commitment to confidentiality very seriously, and often face difficulties in balancing children's legal rights to support with the need to prioritise patients' privacy and autonomy (Demirsoy & Kirimlioglu, 2016; Hansson et al., 2022; Hogstad & Leer-Salvesen, 2020; Soikkeli-Jalonen et al., 2023). Moreover, the findings showed that in the context of the support programme, confidentiality obligations aimed to facilitate open communication among children actually hindered their ability to share information with others outside of the programme. However, it seems that this requirement for confidentiality from children is in conflict with the principles outlined in the UNCRC regarding children's right to freedom of speech and is at odds with Swedish law (Government Offices of Sweden, 2020; United Nations, 1989). Other studies have highlighted that professionals often lack the expertise and face challenges in ensuring children's best interests and legal rights in healthcare, including in paediatric care contexts (Quaye et al., 2021; Sahlberg et al., 2020). This is particularly pertinent in light of the well-established approach of family-centred care and within the Swedish child protection system (Leviner, 2018). This calls for future reflections on how the rules of confidentiality both enable and restrict the possibility for communication and influence support strategies for children.

The dissertation's third main finding showed implicit power relationships within the organisational structure of specialised palliative care, particularly among professionals, which influenced their possibility to provide support for children. Physicians in palliative care settings set the agenda for the workday, with a predominant emphasis on the management of patients' physical symptoms. The psychological needs of patients and families were discussed once a week during psychological rounds. Other studies also point out that standardised medical routines, such as rounds, along with dominant positions and conversation patterns among professionals, reinforce hierarchical power dynamics within inter-professional settings. This is especially pronounced when key medical issues are perceived as being 'owned' by physicians. This perception of ownership remains largely unchallenged and does not necessitate justification, thereby hindering progress towards the establishment of integrated interprofessional teamwork (Lokatt et al., 2023; Rogers et al., 2020).

The findings showed that the organisational structure, characterised by constraints such as insufficient time, lack of competencies, focus and content of their working day, was identified to significantly influence the support provided to children. While nurses provided care to patients around the clock, they faced significant challenges in providing emotional support to children. This is in line with another Swedish study conducted in the context of specialised palliative homecare, which highlighted the difficulties nurses encounter while supporting the families of patients in a home environment (Beyermann et al., 2023). Other studies highlight the necessity for training and support to enhance the communication skills of nurses, social workers, and physicians, particularly in navigating challenging conversations with patients and their families (Franklin et al., 2024; Soikkeli-Jalonen et al., 2023; Tranberg et al., 2024). To assist professionals in supporting children, the Swedish Palliative Care Guide (SPCG) has been developed to facilitate the documentation and identification of children's support needs, as well as the provision of support both during and after the death of a parent (Birgisdóttir et al., 2021).

The findings showed that professionals working in specialised palliative wards perceived that those working in specialised palliative homecare had better opportunities to provide support to children within the patient's home environment, as home settings were associated with greater chances for interactions with children. However, children were not always at home during professionals' visits to the ill parent during office hours. According to Michel et al., (2023), the accessibility of support and psychological care for relatives are perceived to be more integrated within specialised palliative care units compared to specialised palliative homecare, primarily due to the availability of professionals around the clock. Moreover, the findings also showed that contact between children and professionals ended upon the parent's death. A similar finding was reported by Soikkeli-Jalonen et al., (2023), which noted that after the death of a patient, professionals in specialised palliative care typically refer families to other professionals for support.

Finally, the findings in the current dissertation showed that interactions between children and volunteers varied across different physical settings of the studied support programme. A review by Legros & Cislaghi (2020), highlight that the norms and regulations of any social context can impact individuals' behaviours. Social contexts influence how individuals act, often leading them to conform to the rules even if they personally do not agree with them. For instance, the findings showed that in the time-structured sessions, children did not engage in open discussions with one another but instead they socialised informally. During the breaks and informal mingling time, there were more interactions among children, volunteers, and parents, as there were no formal rules to follow. These mingling opportunities and breaks were essential for developing connections and friendships among the children and their surviving parent. The content of their conversations during these informal interactions often centred on daily life, hobbies, music, pets, and sports. It is obvious that both formal rules and informal norms within a social context play a significant role in shaping individual behaviours, influencing personal decisions interactions with others, and overall social cohesion (Legros & Cislaghi, 2020; Veenstra, 2022). This underscores the need to explore how to actively engage and involve children in future support programmes. It is essential to apply democratic processes and promote collaborative efforts among researchers, professionals, and children, thereby acknowledging children as active collaborators in the conception, development, and implementation of support programmes (Olsen, 2023; Suleiman et al., 2021). It seems important that researchers, professionals, politicians, and other decision makers recognise the significance of daily activities, such as leisure and school activities, in facilitating coping strategies and connecting people. These activities have the potential to improve children's quality of life and health (Fancourt et al., 2021), even in bereavement situations.

Conclusion and Clinical Implications

Supporting children during a parent's illness and after their death is a challenging and complex task for professionals. Power dynamics emerged between professionals, parents, and children in the process of planning and providing support. Parents often acted as gatekeepers, which meant that professionals could only support children if their parent allowed contact. Confidentiality obligations impeded communication about illness and death, shaping the possibilities for involving and supporting children within the medical field. The findings indicated that, despite having a legal right to information, some children did not have access to support and details about their parent's severe illnesses. At a structural level, children, parents, and professionals had different conditions of possibility for inter(actions), ruled by different laws such as confidentiality obligations, guardians' legal rights, and children's legal rights. Professionals often encountered ethical dilemmas and challenges when trying to balance the legal rights and support needs of patients with those of their children. Confidentiality obligations also appeared in the studied support programme, where the actors' social positions, cultural capital, and the related symbolic power defined the premises for confidentiality. This meant that children and parents did not have the same opportunities as volunteers or the author of this dissertation to share their experiences with others outside the support programme.

Some children and their parents had contradictory views on joining the support programme. While some children willingly accepted and joined, others either negotiated or were convinced by their parents to participate. Children's own perspectives on support were significant for shaping their coping strategies. The support programme was embedded in a medico-psychological understanding of loss, bereavement, and grief. The sessions mirrored the structure of a school class, where the volunteers acted as the 'expert' and conveyed facts about loss and grief to the children, who were expected to absorb and benefit from this knowledge. In other words, the positions of children and volunteers within the programme provided them with different conditions and opportunities for interaction and support. Interactions between the children were influenced by the various physical settings of the support programme. During breaks and informal mingling, children interacted and developed friendships freely. Children's daily activities, common meeting places like school and neighbourhoods, and mutual interests in music, sports, and pets not only helped children to cope with parental bereavement but also facilitated connections with other children. In other words, bereavement experiences alone did not appear sufficient to foster connections among children in the studied support programme. This dissertation calls for a focus on democratic processes, involving children in designing the concepts and implementation of future support programmes.

The organisational and structural frameworks of specialised palliative care and the studied support programme were identified as key mechanisms influencing how professionals, depending on their positions, power, and cultural capital, either facilitated or hindered support for children. Professionals operated within the constraints of their working environment in terms of time, resources, and the medical logic that ruled the priorities nurses, social workers, and physicians during their daily work. Their opportunities to provide support to children of patients were limited, and professionals often delegated the responsibility of supporting children between themselves. Although professionals were responsive to the wishes of ill parents and provided person-centred care, the dissertation calls for extending this focus to include patients' children, in line with a family-centred care approach. This approach could be further developed in specialised palliative care and the studied bereavement support programme to better address the needs of the children.

Further research

The findings of this dissertation highlight the necessity of viewing children as active 'beings', calling for the integration of democratic processes in bereavement support. This calls for future studies on the development and evaluation of child-led support programmes, as well as studies on how professionals in palliative care settings can incorporate a focus on patients' children in their daily work.

Future research is needed to explore children's coping strategies following the loss of a parent and related adult support strategies. Moreover, organisational policies related to the development and implementation of guidelines to support professionals in assisting children need to be outlined. Additionally, it is important to examine the roles, experiences, and perceptions of staff in leadership positions, along with professionals involved in supporting severely ill patients and their families. This includes interdisciplinary studies examining collaboration between professionals in schools and healthcare to facilitate support for children. Finally, the dissertation calls for research focusing on children's resilience in coping with life after the death of a parent. It is essential to explore how they navigated life's challenges and the strategies they used to overcome difficulties during the bereavement process.

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A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology — The perspective of nurses

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ABSTRACT

Purpose: Children who have a parent with incurable cancer are in a vulnerable situation and the Swedish law tries to protect them. This article aims to explore the interactions between nurses and children of patients with incurable cancer from the nurses' perspective.
Method: Semi-structured interviews with nine nurses in palliative oncology in Southern Sweden. Latent content analysis was carried out, inspired by Lundmann and Graneheim.
Results: Parents are gatekeepers to the children's involvement and meetings with the healthcare professionals. Therefore the nurses were dependent on the parents for contact with their children. Additionally, nurses were subject to the structural frame of their working environment in terms of time, economy, resources and the medical logic ruling the priorities for nursing during their daily working day. The opportunities to pay attention to the children of patients were limited, despite good intentions, willingness and a favourable legal framework. Teenagers were regarded as a challenge, and *per se* they challenged the nurses' opportunities to gain control of the meetings and situations around the families.
Conclusions: Often nurses did not see and acknowledge the children of the palliative patient. They knew that the children were there and that it was important that they were there, but they challenged the order in the working environment in relation to time-allocated tasks and working flow. In the working environment patients were prioritised over relatives. From the perspective of nurses, there is a gap between the intentions of the Swedish law and the interactions between nurses and children.

1. Introduction

Every day about nine children lose a parent in Sweden and in 40% of these cases it is because of cancer (Regional Cancer Center in collaboration, 2012). The life situation changes for the entire family when a parent becomes ill (Elmberger and Hedstrom, 2004). A cancer diagnosis in a parent has a major impact on many aspects of the life of both the patient and other family members, especially for children who are still dependent on their parents (Huizinga et al., 2011). Psychological reactions such as anxiety, depression, sleep problems, bad concentration and difficulty in school are seen in the child through all stages of disease and treatment of the parent, and forced physical separation from a parent can in itself be stressful for a child (Kornreich et al., 2008; Huizinga et al., 2011; Sutter and Reid, 2012; Syse et al., 2012). Teenagers are described as being in a particularly difficult situation when a parent gets cancer because they are in a life situation dominated by secession and at the same time dependence on parents. When a parent has cancer it may mean that the teenagers have nobody to support them during the parent's illness and death. Some teenagers are not even informed about their parent's disease and impending death (Huizinga et al., 2005; Bylund-Grenklo, 2013).

Several studies demonstrate the importance of advice, support and information to children to facilitate their handling of and grief reaction to the parent's illness and death (Lewandowski, 1996; Clarke, 2000; Helseth and Ulfsaet, 2003; Gabriak et al., 2007; Osborn, 2007; Thastum et al., 2008; Kennedy and Lloyd-Williams, 2009; Syse et al., 2012). Further, studies show that

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some parents may be afraid to inform their children about illness and death, and may not have the strength to be the necessary support for the child in the situation (Elmberger and Hedstrom, 2004; Dyregrov, 2007; Forinder, 2007; Thastum et al., 2008; Kennedy and Lloyd- Williams, 2009; Sutter and Reid, 2012). The dominating professional understanding is that children need to participate in the emotional community that is created in a family or circle of friends through grief and loss. They need to be involved to understand what death means and it is important that their grieving process can begin. Grieving can be more difficult when adults are hiding things and not talking about the circumstances surrounding the death. Embellished descriptions of death can lead to anxiety and confusion in children. Rituals and ceremonies may reduce feelings of unreality, prevent fantasies and help the child to express the loss, and it seems to be important that the child is prepared for what they will see and what is going to happen with their ill parent (Dyregrov, 2007; Forinder, 2007; Dencker, 2009).

According to the Swedish Society of Nursing, a nurse should take the initiative and conduct difficult conversations with patients and their families and be able to communicate about life, dying and death (Sektionen Sjuksköterskor för palliativ omvårdnad (SFPO) & Swedish Society of Nursing, 2008). It seems to be important that nurses can identify the individual child's needs for support and information (Clarke, 2000). Studies show that some nurses are unaware of the children of the patients in their meetings in clinical practice (Helseth and Ulfsaet, 2003; Dencker, 2009; Huizinga et al., 2011; Syse et al., 2012). This is in contrast to the intention of Swedish law. In 2009, it was established by law that healthcare professionals should consider the needs of children for information, advice and support when a parent or another adult with whom the child lives becomes seriously ill or dies (Hälso-och sjukvårdslag, 1982; SFS, 2009). In order to understand how the intention of the law is put into clinical practice, this study aims to explore what happens in the physical meetings and interactions between nurses and children of patients in the field of palliative oncology, from the perspective of nurses.

2. Method

This was a descriptive qualitative study using semi-structured interviews (Kvale and Brinkmann, 2009). The interviews are analysed by latent content analysis inspired by Graneheim and Lundman's (2004) model of analysis.

2.1. Recruitment of participants

Nine nurses, who worked at specialised palliative care units in Southern Sweden, were interviewed. Three of the nurses worked at a palliative care inpatient ward and six of them worked with advanced medical homecare. Inclusion criteria were that the nurses would have at least two years working experience in specialist palliative care and experience of meeting with children of patients in oncological palliative care. There were not any exclusion criteria.

Contact with the informants was through two head managers and their unit managers. The unit managers informed the nurses at the working places about the research and interested nurses left their names, phone numbers and email addresses. The researchers then called up the nurse informants with verbal information about the study, and went on to mail information and consent form to the informants. The consent forms were signed before interviews took place. All the nurses who expressed an interest and received the written information agreed to participate in the study; it is not known how many other nurses in these institutions met the inclusion criteria.

2.2. The interview process

The interviews were supported by an interview guide consisting of themes for the interview, tested by pilot interviews. The themes were: professional background and palliative experiences; description of a typical working day; description of experiences of meeting children of patients in the working day; challenges in meeting children of patients in the working day. The nurses seemed comfortable with the interview situation where the interviewer pursued their narratives and used follow-up probing, specifying, structuring and interpretive questions to clarify what the informant said (Kvale and Brinkmann, 2009). The interviews were recorded and saved on a USB stick. The interviews lasted 28–71 min and took place at the nurses' working places in undisturbed rooms.

2.3. Ethical consideration

All participation was voluntary. Interviewees were informed about the aim of the project both orally and in writing and they gave informed consent. All data was anonymised and kept inaccessible to anyone other than the research team. In publication, the study seeks to maximize anonymity and names, person-specific job names and toponyms have been removed (The World Medical Association, 2013). The study has been approved by the Advisory Committee for Research Ethics in Health Education (VEN) at Medical Faculty, Lunds Universitet (J.no. VEN 92-13) and obeys Swedish Legislation.

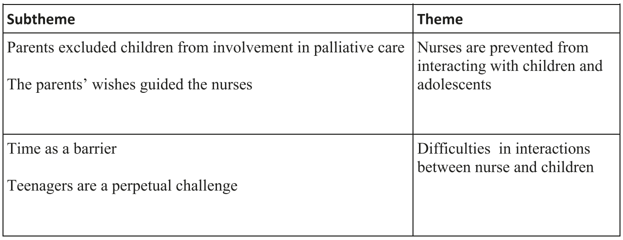
2.4. Analysis strategy

The interviews were transcribed verbatim (Kvale and Brinkmann, 2009). First, empirical data was read through in its entirety several times by all researchers to get an idea of its contents and to get an overall picture of all the interviews. Secondly, the interviews, first one by one and then across the entire empirical material, were analysed by two of the researcher through constructing meaning units, condensed meaning units with description close to the text and condensed meaning units with interpretation of the underlying meaning, inspired by (Graneheim and Lundman, 2004). This was discussed and challenged by the third researcher. Thirdly, in view of this all three researchers constructed two themes with each two sub-themes (see Fig. 1), within the analysis as it unfolded. The analysis presented quotes from informants to underpin the analysis and clarify the content of the text.

3. Findings

It was immediately clear that, from the nurses' point of view, parents related in different ways to children as relatives in the palliative oncological field. Some 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.

> "*If we just get permission to talk to the children then it is easy, but sometimes parents can make it very difficult*".



Subtheme	Theme
Parents excluded children from involvement in palliative care The parents' wishes guided the nurses	Nurses are prevented from interacting with children and adolescents
Time as a barrier Teenagers are a perpetual challenge	Difficulties in interactions between nurse and children

Fig. 1. Constructed sub-themes and themes.

3.1. Nurses are prevented from interacting with children and adolescents

3.1.1. Parents excluded children from involvement in palliative care

The possibility of a physical meeting between nurses and children of patients in oncological palliative care occurred only if the parents gave their permission. The relationship between the family and the children and their way of communicating had significant impact on how the meeting between the nurse and the children developed. Some parents' strategy was to protect their children by partially or completely excluding them from all matters related to the illness and forthcoming death, including the healthcare system. There were situations where nurses never met the children in the family. Consequently the nurses did not have the opportunity to get insight into how the children and the family reacted to the situation around the parent with serious illness, which meant that s/he could not support the family as whole. The nurses expressed the view that because families often found themselves in a difficult and stressful situation, the nurses were not always successful in communicating their view of the importance of openness within the family to the parents. From the outset, the nurse implicitly believed that s/he knew what was best for the children regardless of the parents' point of view and philosophy of life. The nurses had found through experience that excluded children reacted more strongly when a parent died than did children who were informed and took an actively part in different matters related to the parent's illness and forthcoming death. From the nurses' perspective, the situations where children were excluded from matters related to a parent's illness and forthcoming death seemed more stressful for the remaining parent, the children and other significant people after the death. The situation became more disorderly and chaotic, and the nurses found it more difficult not being able to control and/or restore the order in the family. The children reacted, for example, with loud screams, aggression and panic, when the parent died; they were inconsolable. The nurses felt frustrated and had difficulty in accepting these chaotic situations because they thought that it in a way it was the parents' fault. If the parents had accepted the nurses' strategy of including the children in the situation, the nurses concluded that the children would have been better prepared for the upcoming death and probably would not have reacted so strong when death occurred. Parents often had not experienced similar situations in their lives and chose the strategy they thought best for their children and family; but the nurses thought they knew better as they had experience of similar cases. Consequently the nurses felt powerless.

> "*When he died, it was total chaos in the family; they were not ready even though we had tried to talk about it many times*".

From the perspective of nurses, children often noticed and knew when someone in the family was seriously ill. However, younger children could not express this verbally in the same way as older children. Nonetheless, if adults tried to avoid something children knew it. Nurses in general found that children knew more than parents realized. The nurses thought that it was important to talk about the situation with the children, and considered that they had both the knowledge and experience with children to do this. Despite this the nurses rarely talked with the parent about the dilemma that the children probably already knew what the parent tried to keep secret.

> "*You see it in the entire body language. Children are cleverer than we think. They do not need long explanations. They just understand the situation quickly*".

3.1.2. The parents' wishes guided the nurses

The nurses described how they and other healthcare professionals tried to change parents' decisions on non-involvement of children in the situations around the illness of the parent by informing parents of 'the importance of information and participation of children'. Some nurses found it difficult when parents were persistent in their determination to protect their children from matters related to their illness and forthcoming death, and in these cases relied on the parents to take responsibility for their children. Parents had the final decision in relation to children's involvement, and nurses' wishes and knowledge always had to yield to parental right. Nurses indicated that they knew that by law, children have the right to professional advice, support and information, but at the same time the nurses knew they could not defy the wishes of the parents. This meant that children of patients in oncological palliative care were only in contact with healthcare professionals if the parents allowed it.

> "*It has been decided that you should not talk about it. Then we of course accept it. I have great respect for the parents- it's still the parents who know their children best*".

There was a notion among nurses that later in life the children would respond to the lack of involvement and lack of information about the parent's illness and prognosis. They were aware of the risks to the child but the problem was postponed. The nurses felt split between the parents' wishes and their own professional responsibilities, but they declined to enter into any discussion of this potential conflict in order to maintain a good relationship with the patient.

> "*On the one hand, I will not force patients to hear that they are going to die, and that they should tell their children about it. Conversely, I see what happens if they do not*".

Sometimes nurses were in a dilemma when parents asked them not to tell the truth to the children. Some nurses then chose to respond to the parents that they would not lie to the children if they asked direct questions, but the nurses could promise not to inform the children on their own initiative.

> "*One is instructed by the parents to lie to the children*".

Some nurses thought that their primary responsibility was the patient and not relatives, whether child or adult. Deep conversations with relatives, including children, were in principle, a task belonging to other professions such as doctors and social workers.

> "*It's still the one who is ill that we are meant to care for. That's it*".

> "*I try not to take on too much responsibility. You have to use the whole team, all have their specific competences which are there to be used. The social workers do a fantastic job [in relation to children]*".

3.2. Difficulties in interactions between nurse and children

3.2.1. Time as a barrier

'Time as a barrier' can be understood in two ways. On the one hand nurses needed the 'right time' to interact and intervene with children and adolescents. On the other hand the nurses' needed 'more time' allocated to the children in the family, since their time was already consumed by the medical care of the dying parent.

From the perspective of the nurses, when children were involved in the parent's illness and were allowed to ask questions, a good relationship between the children and the nurse developed. The children were mostly calm, curious and interested in what happened in oncological palliative care. Some nurses found it important to invite the child into the nursing situation by explaining what she was going to do and showing what she did. It was easier for the nurses to get in touch with the children when the parents had a permissive attitude. The atmosphere in the family meant that nothing would be kept secret and the nurse felt free to act. From the nurses' perspective, it created a space for the children to decide whether they wanted to participate in the care or not. But the responsibility for the children's participation in the physical meeting with the nurse was placed on the children themselves. The nurses did not register the children who quietly remained in the background.

> "*My experience is not to force the children; open up the situation so they feel they are allowed to be there; if they want to go away, it is ok*".

The nurses found it relatively easy to deal with younger children because they made few demands on the nurse, which made the nurses feel confident and competent in interactions with them. When there was openness in the family, the nurse was allowed to communicate freely with everyone in the family at the nurse's own views about the best way of managing the situation. Consequently the nurses could devote themselves to the relief of symptoms and perform tasks that they themselves considered to be good. This created a sense of security, order and control over the situation for the nurses. The standard plan for good palliative care was accepted and followed by all participants in the situation. The doctor and the social worker had already informed and supported the children, if necessary.

Regarding the idea of a 'right' time for the information to be provided to the children, the nurses found that it was sometimes too late to inform the children, when death was imminent. The information should have been given earlier in the continuum of care when the cancer was diagnosed and not when the ill parent was in a late palliative phase. The nurses in palliative care did not consider it to be their duty to inform the children in the late stage. There was a tendency among nurses to push responsibility for children's involvement to other colleagues; such as those who had met the children earlier in the course of the patient's illness.

> "*How can it [overlooking the child] pass through the entire system of the oncologist, school and palliative homecare?*"

In the late palliative phase, patients often had many severe symptoms to address, which created a lack of time for the nurses to talk to the children from the nurse perspective. The top priorities of the nurses were practical, medical issues around the patient. The nurses found they had to prioritise patient over children. The economic system affected resources in the medical context and constituted a framework which led to medical data and patient's physical symptoms often being the nurse's first priority.

> "*Nurses are very busy and time-bound to do all the practical and medical tasks and do not have much time to devote to family and the children*".

> "*Having the time and allocating time, as a nurse, there's never really time set aside for such things*".

3.2.2. Teenagers are a perpetual challenge

Nurses found that teenagers were difficult to connect with and usually were not as spontaneous in their contact pattern with the nurses as younger children. Teenagers often excluded themselves and isolated themselves in their rooms or chose not to be at home when the nurse came to visit the parent. The nurses found that the teenagers were already in a complicated life situation just because of being teenagers, and parents' illness and upcoming death distressed them further. The nurses often chose not to initiate contact, or asked parents how the teenager felt. Often the nurses never had a real contact with the teenagers. The nurses' attitude was that they had to accept the teenagers' own exclusion from the illness situation; they did nothing to include them in the name of a person's 'free choice'.

> "*I have not had a conversation with them [teenagers], but they are just passing through the rooms; nobody [amongst the teenagers] has taken the time and asked questions*".

The teenagers were seen as a challenge because the nurses seldom met them and therefore were not able to advise, assist and inform the teenagers as the nurses actually wanted to. According to the nurses, teenagers found information about diseases on the internet. It meant that the nurses were unable to control the teenagers' information, which meant that the nurses had no control in the situation, and this was seen as a challenge for some nurses.

> "*A teenager, a guy who just sat there with his cap. When he spoke with the doctor it turned out that he had 'Googled' all about cancer and found help himself from the Cancer Society, where he chatted with other teenagers*".

The nurses found that teenagers might be erratic and unpredictable. It was not always transparent to the nurses how the teenagers reacted and handled the situation. Some nurses found them generally to be difficult to reach.

> "*Teenagers often stay happy on the outside. They often excluded themselves from the actual situation and the nurses' visit*".

Those nurses explained and rationalised their feelings of inadequacy, lack of experiences and education in relation to dialogues with teenagers.

> "*I do not think I have enough education and I feel that I am not always skilled enough: I try my way. I am quite careful, and I rather take a step backwards.*"

While other nurses found that it was not difficult to meet teenagers *per se*, it was difficult to schedule time to meet them individually. The nurses expressed the view that the best conversations occurred in spontaneous situations that were not planned and booked in advance. In these situations the nurses could catch the teenagers on the spot.

> "*So you have to find an entrance … you must see a hint*".

Nurses' previous experience with teenagers had significance for the upcoming interactions with the teenagers whether or not they were perceived as difficult. From the perspective of nurses, some of the teenagers took a lot of responsibility for the family and were forced to grow up too soon. Teenagers who took responsibility for their parents participated full time in the parent's illness situation. These teenagers did not want to leave the ill parent alone and were accessible and available for the parents on a full time basis. According to the nurses' point of view, these teenagers paid a high price as they neglected their friends. The teenager's involvement in the parents' situation was regarded by the nurses as a balance between 'too much' and 'too little' involvement where the 'right' dose appeared as an unknown parameter.

> "*Unfortunately, some teenagers may take too much responsibility for the care of their parents*".

4. Discussion

The main findings of this study are that the parents were gatekeepers of the children's interactions and physical meetings with the healthcare professionals when a parent was seriously ill. Therefore the nurses were dependent on the parents for contact with their children. Additionally, nurses were subject to the structural frame of their working environment in terms of time, economy, resources and the medical logic ruling the priorities of nursing in their daily working day. The opportunities to pay attention to the children of patients were limited, despite good intentions, willingness and a favourable legal framework. Teenagers were regarded as a challenge, as they *per se* challenged the nurses' possibilities of gaining control of the physical meetings and the situations around the families. In this section of discussion, we choose to focus on: the parents' role as a gatekeeper in physical meeting between nurses and children of cancer patients; the issue that teenagers were perceived as a challenge for the nurses; and the importance of a structured, organisational frame for physical meetings and interactions between nurses and children of patients.

The findings show that if there was ever to be a physical meeting between nurse and children, the parents would have to give their permission for it. From the nurse perspective, the parents related in different ways to children. Some parents excluded their children from matters related to the illness and forthcoming death, which has also been shown by Phillips (2014). Those parents often believed that successfully maintaining normalcy and not communicating about the illness would protect their children from the emotional impact of cancer (Phillips, 2014). Some parents included their children from the beginning to the end of the illness, and some parents included their children after persuasion by the nurse. This meant that from the start the nurses were subject to the parents in whether they could have contact with their children. Overall, the nurses did not find it difficult to meet the children but the parents could make it more difficult. Therefore 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. According to Swedish law the child's need for information, advice and support should be considered especially when a parent or other person responsible for the child is seriously ill, dying or dead (Hälso-och sjukvårdslag, 1982; SFS, 2009). On the other hand the National Care Programme for palliative care states that it is the parents who have the ultimate responsibility and it is they who know their children the very best (Regional Cancer Center in collaboration, 2012). This means that parental responsibility weighs heavily, just as the nurses in our study noticed. This remains the case, despite many studies show that involving and including children through advice, support and information help them to handle and cope with the situation and the grief reaction to the parent's illness and death (Lewandowski, 1996; Clarke, 2000; Helseth and Ulfsaet, 2003; Gabriak et al., 2007; Osborn, 2007; Thastum et al., 2008; Kennedy and Lloyd- Williams, 2009; Syse et al., 2012). Teenagers especially seem to in a vulnerable life situation (Huizinga et al., 2005; Bylund-Grenklo, 2013). Problems arise for the nurses when they find that the parents do not include children in the situation in what the nurses consider to be 'the right way'. As long as parents have custody of their children they have the ultimate right to make decisions about these children. It is an indisputable legal premise. Studies on children as relatives and as cancer patients show the same patterns, where parents managed and controlled what and how their children could decide and were told about their illness (Young et al., 2003; Dencker, 2009; Coyne et al., 2014). In other words, the patients/parents act as gatekeepers to their children for healthcare professionals and the parents have the right to privacy, dignity and autonomy, despite the nurses' knowledge and wishes for her professional work. This premise forms the opportunities for the nurses and their actions; they are subject to the will and wishes of the parents.

In this study, teenagers were regarded as a challenge by the nurses and the nurses had a tendency to ignore and overlook teenagers. The nurses found that teenagers in general were often difficult for adults to get contact with and socialise with, and they often excluded themselves from the family situation. It has been shown in another study how teenagers pulled away when the parent was ill and did not want contact and support from the professionals for their own sadness and despair (Dehlin and Mårtensson, 2009). However, those views are in contrast to the findings of a literature review, namely that a consequence for teenagers of a parent's cancer was spending more time with their parent and 'a sense of becoming closer to their family' (Phillips, 2014). By categorizing teenagers as difficult the nurses did not attempt to seek out these teenagers; in this way the nurses stigmatized a group of children and consolidated teenagers feelings of 'otherness' in general in the society; the teenagers were in a time of transition, learning the balance of taking chances and being safe (Wickman et al., 2008). Elsewhere, it has been shown that parents did not receive guidance or support from healthcare professionals on how to talk to their children about advanced cancer where the healthcare professionals avoided discussions about advances cancer and death. Teenagers were often aggressive in seeking information about the disease from various sources such as parents, healthcare professionals, books, etc., and in reality many teenagers desired more communication about the illness, either factual or emotional (Phillips, 2014). Apparently, by teenagers mere presence, they *per se* challenged nurses' understanding of and their opportunities to gain control of the interactions and the situations around the teenagers and the families, and the nurses often reacted and responded by ignoring or overlooking the teenagers. The same pattern was found in other studies when nurses met other so called ‘deviants’ or difficult patients or relatives in the medical clinic (Glasdam, 2003; Järvinen and Mik-Meyer, 2003; Mik-Mayer and Villadsen, 2007; Michaelsen, 2012; Wright and Stickley, 2013). The literature on teenagers with cancer shows that nurses have a stated focus on teenagers and try to include them actively in care practice (Olsen and Harder, 2011; Weaver et al., 2015) which can be an eye-opener and inspiration for nurses working with teenagers as relative to cancer patients.

It would appear that some obstacles in the interactions between nurses and children are created by are medical, administrative, and political structures. The current socio-economic priorities and efficiency measures in health care may be a contributing factor to why nurses are unable to meet the children to the extent that is needed. There are many different tasks and responsibilities imposed on the nurse but the economic resources are limited. This means that nurses must prioritise their tasks and then, according to past traditions, prioritise patients and their medical issues. From an economic perspective, the interaction between the nurse and the children can be regarded as a secondary priority; all professional tasks are defined and allocated through the needs of the patients (Glasdam, 2003; Glasdam et al., 2013). The medical logic in the palliative, oncological field also requires that medical issues have first priority, and then the psycho-social issues. The same logic produces an order where in principle the doctor informs the patient and family about diagnosis, treatment and changes in the prognosis, and the nurse takes care of the patient and family after the doctor's work. Clearly, nurses have less autonomy in relation to medicine, as they are subordinate and under greater surveillance than physicians in the medical field in general (Glasdam, 2003; Brante, 2013). Primarily, the nurses must be alert to the patient's symptoms and carefully observe, document and describe these symptoms (Engstroem, 2012). It means that the nurses first duty is to observe and perform medical tasks, and have a coordinating function in practice: therefore they are not always able to carry out difficult conversations with patients and family, including children, which means that this task might be delegated to other professions - in our study often to doctors and social workers. In this way, the nurses are subject to firstly the parents in relation to getting a contact with the children and secondly to the structural frame of their work which leaves little time and little space to taken care of the children of the patients; the same pattern is found in the opportunities of healthcare professionals for interactions with all kind of relatives in the oncological field (Glasdam, 2003; Northfield, 2010; Engstroem, 2012). Meanwhile, the nurses have visions and goals in oncological palliative care to engage in comprehensive care and to see the whole person and their family. In reality, care on these terms does not always exist because nursing always take place in a context framed by medical, economic and political structures. Nurses in our study and in other studies found that specific education and training are of great importance when it comes to taking care of children to parents with cancer (Dencker, 2009; Sutter and Reid, 2012). However, an urgent question is whether education *per se* is *the* solution to a seemingly complex, historical and structural problem in the health system? Looking at other challenges in nursing, (more) education is often the first answer to solve problems, for example when nurses experiences difficulties in caring for dying patients (Nielsen and Glasdam, 2013), or difficulties related to including the family of the cancer patients in the nursing practices (Pinkert et al., 2013). The idea of more education and training is a responce to the dream that the interactions between the children of parents with cancer and the nurses will be better in the future. Qualification of nurses through education and training will only address the issue of the individual nurses' skills, while historical and structural conditions for the nurses' opportunities to act do not change. One question is whether contextual simulated training (Bibila and Rabiee, 2014) can challenge historical and structural conditions over time by through increasing awareness of their presence and their impact on nurses' acting options.

Finally, the methods of this study should be discussed. The selection process of the informants seems problematic because information and the invitation to participate were passed through the nurses' managers. But this does not seem to have affected the informants' narratives in a limiting sense; it seems as if the interviews were characterized by honesty and sincerity in the narratives. The obvious weakness of the study is that it does not take on board the children's or the parents' perspectives on these physical meetings and interactions in the medical field. This could have illuminated the complexity of these meetings and interactions in a more nuanced way.

5. Conclusion

Often nurses did not see and acknowledge the children whose parents had cancer in the palliative phase. Teenagers were regarded as a special challenge for the nurses due to the fact that they are in a secession phase of their life and at the same time dependent on their parents. The nurses knew that the children were in the families and that it was important they were included in matters related to the illness and forthcoming death, but the needs of the children implicitly challenged the usual order of the working environment in relation to time allocated tasks and work flow. There were different factors that affected the interaction between nurses and children as relatives to palliative cancer patients such as the parents' willingness to include their children in the illness and specific life situation, and the structural frame of medical, economic and political logics and priorities. The nurses were subject to the structural frame which limited their interactions with the children of the patients and what they were able to do together in these physical meetings. The structural frame overruled the good will and intentions of the nurses to meet the children of the patients, despite the laws demanding that nurses pay attention to those children. From the perspective of nurses, there is a gap between the intention of the Swedish law and the interactions between nurses and children.

5.1. Clinical and research implications

The results of this study call for clinical attention to be paid to the conditions of nursing practice and the historical and structural frame within which nursing is practiced in order to understand – and be able to change – those important, often invisible, factors for action. Further, they call for clinical attention to be paid to focus also on child inclusion at the point of the parent's diagnosis to mitigate need to introduce the serious illness for the child at a very vulnerable time in the family's life. In addition, this study calls for continuous training of the nurses in how to include and meet children of parents with cancer so that nurses feel comfortable in the different kind of interactions with parents with cancer and their children. Such training demands that the contexts of the physical meetings also are incorporated into the concepts taught in order to avoid problem that the issue of children of parents with cancer only is considered to be purely a matter of individual nurses' skills and competencies.

In order to develop and challenge this study's findings, it would be interesting to investigate parents' and the children's experiences of support by and interactions with healthcare professionals so that a relational perspective on the interactions could emerge in oncology palliative care.

Ethical approval

The study has been approved by the Advisory Committee for Research Ethics in Health Education (VEN) at Medical Faculty, Lunds Universitet (J.no. VEN 92-13).

Conflicts of interest

There are no conflict of Interest in the study ‘A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology - the perspective of nurses’.

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Paper II

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Inter-Professional Caring for Children Who Are Relatives of Cancer Patients in Palliative Care: Perspectives of Doctors and Social Workers

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Abstract

A palliative cancer diagnosis in a parent has a major impact on many aspects of patients' children. This article aims to explore how doctors and social workers met children as relatives of a parent with cancer in order to understand the possibilities and difficulties in supporting children in specialised palliative homecare in Sweden. Qualitative, semi-structured interviews of doctors and social workers were conducted, inspired by Bourdieu. The findings showed that professionals had limited contact with patients' children. Mono- and inter-professional meetings were organising structures for working days of doctors and social workers. Due to hierarchy positions, doctors often set the agenda in inter-professional teamwork. Doctors seldom met patients' children, only when information about parents' cancer diseases were needed. Social workers were responsible for psycho-social issues, but mostly only special vulnerable families and their children were prioritised. Meetings between children and professionals were conditional on the parents' permission and, even if permission was given, meetings seldom took place. Doctors and social workers were subject to the structural frame and a medical logic, which limited their interactions with children of the patients. Children were dependent on both their parents and professionals, who had the power to include or exclude them from parents' illness situation.

Keywords: Bourdieu, children as relatives, doctors, interview study, palliative oncology, social workers

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Introduction

Every day, about nine children under the age of eighteen experience the death of a parent in Sweden, of whom 40 per cent have cancer (Regional Cancer Center in Collaboration, 2016). A cancer diagnosis in a parent has an impact on many aspects of the life of both the patient and other family members, especially for children who are still dependent on their parents. Children can have both physical and psychological reactions (Sutter and Reid, 2012; Syse *et al.*, 2012).

Studies show that many parents include their children in the cancer disease. However, some parents may be afraid of informing their children about illness and death and may not have the strength to be the necessary support for the child in the situation (Sutter and Reid, 2012). At the time of decision, those parents often believe that successfully maintaining normality and not communicating about the illness will protect their children from the emotional impact of cancer. With hindsight, they would have involved the children more actively (Phillips, 2014; Karidar *et al.*, 2016; Möllerberg *et al.*, 2017). A further issue is that studies show that the surviving parent sometimes cannot provide enough support for the child. Some surviving parents are ill themselves and others are filled with their own grief after their partner's death. Those parents have to cope with the everyday problems of the family, when the child may get less attention, time and support (Pearlman *et al.*, 2010; Sandler *et al.*, 2010).

The medical understanding is that teamwork in palliative care is essential, in an interdependent team that works collaboratively, recognises shared expertise and appreciates the specialisms of each member, communicates well and is comfortable relying on and supporting one another (Stark, 2011). In palliative care, teams consist of several different professionals, such as nurses, doctors, physiotherapists and social workers, who are intended to work together to achieve the best care for cancer patients and their families (RCCC, 2016). Teamwork depends on the team's professional composition; attention is paid to patients' physical, psychological and/or social aspects (Stark, 2011). The dominating professional understanding is that children need to participate in the emotional community of a family or circle of friends and/or professionals through grief and loss (Dencker, 2009; Coscarelli, 2011; RCCC, 2016). Studies show that parents are gate-keepers of the children's interactions and physical meetings with professionals when a parent is seriously ill (Phillips, 2014; Karidar *et al.*, 2016). Often, children of cancer patients do not seem to be the focus for inter-professional teams (Dencker, 2009; Syse *et al.*, 2012; Karidar *et al.*, 2016). This is despite the fact that, for instance, Swedish law states that health-care professionals should consider children's needs for information, advice and support when a parent, or another adult with whom the child lives, becomes seriously ill or dies (Department of Social Affairs, 1982).

Studies show that nurses do not offer much assistance to children of palliative cancer patients and nurses find that social workers have the best contact with these children (Golsäter *et al.*, 2016; Karidar *et al.*, 2016). At present, there are no studies on how doctors and social workers handle children as relatives of palliative cancer patients. Studies show how social workers handle children in other vulnerable life situations. Social workers in general spend little time with children on their own, and are often stressed by both the parents and the way in which the organisational system defines tasks and limits time in their meetings with children (Gillingham and Humphreys, 2010; Ferguson, 2014, 2017; Winter and Cree, 2016). Likewise, a study shows that general practitioners (GPs) try to pay attention to children as relatives but time constrains their practice. GPs' main focus is on the patient present in a consultation and, as the child is often not present, the child is outside the attention of the doctors. GPs may avoid bringing up the patients' children as a subject for discussion because they are afraid of hurting or losing their vulnerable patients (Gullbrå *et al.*, 2014). In general, professionals in the palliative field do not seem to offer relatives much attention (Glasdam, 2007; Glasdam and Oute, in press). The aim of this article is to explore how doctors and social workers handle children as relatives of a parent with palliative cancer in order to understand the possibilities and difficulties in supporting children in specialised palliative homecare in Sweden.

Method

This study is based on qualitative, semi-structured interviews with doctors and social workers, inspired by French sociologist Pierre Bourdieu's theoretical concepts of capital, position, power and field, with the objective of analysing strategies for supporting children from a relational and structural perspective (Bourdieu, 1991). Bourdieu's theoretical framework functioned as the background to the interview process and to the analysis of the empirical material.

Theoretical framework

Pierre Bourdieu's concepts of field, position, power and capital inspired this study. A field is a structured space of position and a system of relationships between positions. People and institutions fight for something that is common to them in a field. Social class, education, upbringing and past choices are part of the structure and determine the behaviour of actors in the field. Actors act differently depending on their position in the social space (Bourdieu, 1991). In this study, specialised palliative care at home is regarded as part of the medical field; different actors (e.g. parents, family, health-care professionals) have different positions and power in this area. The position of actors in the field is determined by the amount and importance of the capital. There are four types of capital: (i) economic capital, such as money, property and other valuable assets; (ii) social capital, such as relationship resources, friends and family; (iii) cultural capital, such as education and job; and (iv) symbolic capital, such as the person's status, prestige and honour (Bourdieu, 1977).

Power is not a separate domain, but stands at the heart of all social life, and the success of exercising power requires legitimation. Bourdieu uses the term 'symbolic power', which is routinely deployed in social life. It is an 'invisible' power, which has legitimacy. When power is exercised through symbolic exchange, it always rests on a foundation of shared belief. As a condition of its success, symbolic power requires those subjected to it to believe in it, to legitimise the power and legitimacy of those who wield it (Bourdieu, 1991). Bourdieu always thinks in relational perspectives, characterised by an interest in what is happening between people when they interact in social space. Relational concept means the analysis of the relation between social positions and dispositions (Bourdieu, 1999). This study examines the relational aspects of power and position in specialised palliative homecare and the structural, political and administrative frame that rules palliative care practice.

Data collection

The study took place in the specialised palliative homecare service in southern Sweden. The study was instigated by a university, but one of the researchers had an insider position in the homecare service and served as a gate-keeper to the informants. Inclusion criteria included that informants had at least one year of working experience; there were no exclusion criteria. The senior managers of specialised palliative homecare approved the project. At workplace meetings, unit managers informed the professionals orally about the study and supported the researchers by providing contact information of all doctors and social workers. The study wanted to include the same numbers of social workers and doctors as informants in order to balance the empirical material. Five out of six social workers in specialised palliative homecare accepted the invitation and were included. Seven out of twelve doctors were randomly asked by mail to participate in the study. Two doctors did not reply and the other five accepted participation. All participation was voluntary. All participants were informed about the aim of the project, both orally and in writing, by the interviewer and they gave informed consent.

A semi-structured interview guide with basic themes was constructed according to Bourdieu's theoretical concepts to support the interviews.

First, in order to know a little about the informant and to analyse his/her disposition and social position, it was important to highlight the underlying structures of educational and social status, such as the informant's age, education, job, children and social relations. To understand the informant's position and power in the medical field and the way they acted, another theme was constructed about how a normal working day was organised and handled. The informant was asked to focus on his/her latest working day. A third theme focused on how the informants acted and supported children as relatives from their respective positions. The interview did not focus on children's age, parent's illness trajectory or preferences of the patient themselves, but only on the child–professional relationship, from the professional perspective. All interviews were in Swedish. The interviews lasted fifty-six to seventy-six minutes, with an average duration of sixty-three minutes. A pilot interview (not included in the study) was made in order to test the interview guide. No changes were needed.

Data analysis

An inductive consent analysis, inspired by Bourdieu's theoretical framework, was made. First, the interviews were fully transcribed and the text was read several times by the first author in order to obtain an overall view of the whole text. Next, an inductive, theoretically inspired analysis was conducted, focused on how the doctors and social workers articulated that they handled children as relatives from their specific positions in the medical field. Bourdieu did not specifically advise how to perform analysis (Glasdam, 2005). Therefore, the analysing of interviews was a creative process: Bourdieu's concept of field, position, power and capital functioned as a perspective from which the empirical material was read, understood and interpreted (Glasdam, 2005, 2007). A matrix was constructed for each interview, horizontally containing information about: facts, viewpoints on facts (positioning) and how to act. The vertical column contained information about: who the person was from a sociological perspective, what s/he did on a working day, whom s/he met in a working day and what they did together, and contacts with families/children. Each interview had five to nine pages of the matrix, which helped to establish an overview of the empirical material. All interviews were analysed first separately and then across the interviews of respective doctors and social workers. Themes and sub-themes were constructed (see Table 1).

Ethical consideration

The study followed the principles of the Helsinki Declaration (The World Medical Association, 2013). The study has been approved by

Table 1 Themes and sub-themes

Themes	Sub-themes
Professionals had limited contact with children of cancer patients	Meetings as an organising structure for the working day' Doctors directed collaboration between doctors and social workers
Patients defined contact between professional and child	Parents had primary responsibility for their children Children were often not at home Patient's death meant sparse professional contact with children

the Advisory Committee for Research Ethics in Health Education (VEN) at Medical Faculty, Lund University (J.no. VEN 55–16) and is in accordance with Swedish legislation.

Findings

Professionals had limited contact with children of cancer patients

Meetings as an organising structure for the working day

In the medical field, different meetings among professionals were a basic part of a working day. In this study, professionals talked about the content of their latest working day, namely yesterday. Many of the doctors and social workers spontaneously reacted by saying that this was impossible to describe because 'yesterday' consisted of various meetings and administrative work and included no patient contact.

> Yesterday was a special day, so I could take the day before instead. It was a day with plenty of meetings, so I will tell you about the day before (Doctor).
>
> Yesterday, I attended so many meetings, so it's not the best example of a typical day (Social worker).

In a 'normal' working day, the doctors had a large amount of administrative work and various meetings. Research, administrative work and meetings seemed to be a high priority of doctors' working days and were closely connected to the doctors' position in the local hierarchy of clinic doctors and in the medical field in general. The higher the position, the more working days there were without direct patient contact. In that way, a doctor's meeting intensity functioned as symbolic capital in the clinic:

> I usually come to work at 7: 30 and start at the computer and I read emails and then I check my calendar. Then between 8: 00 and 8: 30, we

> have a meeting about patients. Then, 8: 30 to 8: 45 we plan the day. At 8: 45–9 we have a meeting and referral briefing when the team coordinates where we go with new referrals and plans the next days and weeks, and then 9–9: 15 we have the doctors meeting (Doctor).

Doctors' working days included an average one to two hours of direct contact with patients. Doctors' remaining time consisted of contact with external care providers for treatment advice, management of deviations such as investigating the cause of the anomaly report and driving in a car to meet patients. 'Hands on' and direct contact with patients and their families testified to relatively low positions in the hierarchy of doctors in the clinic and in the medical field. From the perspective of doctors, it was usual for the nurses to visit the patient and for the doctors to visit them only when the nurse assessed that a doctor was needed. A nurse could often be an excellent substitute for the doctor in the meeting with the patient. Such tasks could be delegated down in the position hierarchy in the field. Doctors' research meetings and administrative work were never delegated to nurses or other professionals. This indirectly stated something about the symbolic capital that was linked to the different working areas:

> 'It's the administrative system that organizes extra meetings and we have our weekly meetings with patients, as well, and I participate sometimes and sometimes not. The times I've been visiting [patients] are when the nurses ask me to' (Doctor).

Some social workers attended the daily medical round with other health-care professionals. Others did not, but instead had meetings with other social workers and did administrative work in the morning, contacting various authorities such as social services and the social insurance manager and booking meetings with patients and families. Social workers had the freedom to book their own meetings with patients independently of other health-care professionals:

> Usually, I start work around 8, the medical round starts at 8 and I am usually on, not always. My first visit is usually around 10 o'clock or 11. Beforehand, I usually read a journal, have authorities to contact, perhaps call someone who wanted contact with a social worker and schedule a time, so it is a bit of paperwork, you could say (Social worker).

Social workers were dependent on referrals from doctors to get in touch with patients but, once the referral was received, social workers were relatively autonomous in relation to the patients. Social workers were positioned under doctors in the clinic, as access to patients was conditional upon doctors. Doctors framed what social workers should do for patients, but social workers were relatively free to determine priorities in their mono-professional meetings with patients.

Doctors and social workers had a lot of flexibility in their working days. After all the meetings and paper work, they could drive to patients' homes for planned visits:

> It's very varied work, and it is clear that there are fixed times for some things and in between there is pretty good flexibility (Doctor).
>
> Usually there are one or two home visits in the afternoon and in between I try to get space to do other things, because social work is so much more than just dialogue, much of it is about working with authorities (Social worker).

The ability to allocate time to meetings and administrative work was relatively high symbolic capital for social workers, as it was also for doctors. Overall, meetings functioned as an organising structure for the working day, for both doctors and social workers. Participating in meetings had an imminent symbolic capital and functioned as a legitimate reason for not being in direct contact with patients and their families in the clinic.

Doctors directed collaboration between doctors and social workers

According to Bourdieu, professionals had different roles and positions in the medical field, which also determined their relative power and position in the inter-professional team. Doctors had the relatively highest cultural capital, understood as educational capital, and the relatively highest position among other professionals, due to their right to take key decisions about patients' treatment and care, with a focus on physical symptom management in palliative care. In this study, doctors had a marked informative role when they talked with patients and their families about disease, prognosis, treatment and changes in the situation. Social workers were supposed to handle social and psychological issues or reactions that occurred after receiving the doctors' information. The same pattern was seen in the inter-professional meeting with patients' children; doctors only met the children if they had explicit questions about the parent's illness and/or prognoses. This meant that doctors did not routinely meet the children. They only met children when other professionals such as nurses or social workers asked them to participate in these meetings:

> The conversations I have had with children have been of an informative character. I have never had a conversation with a child and then followed up without the follow-up care done by the social worker, and we have different roles and the doctors have the opportunity to inform on matters that other professionals cannot inform about (Doctor).
>
> The social workers cannot explain medical things, we have doctors who explain what the disease looks like, depending on the age of children (Social worker).

In the medical field, in general, patients' psychological issues had less priority than medical issues. Articulations on the medical round exemplified doctors' relatively high position in the clinic and the corresponding power by which doctors directed the agenda around the patients. The medical round was carried out every day and all professionals were supposed to attend. Those sessions primarily handled problems related to disease, physical symptoms and treatment. When it came to patients' and their families' psychological problems, time was limited. The psychological round took place only once a week for one hour when the inter-professional team discussed psycho-social problems of the patients (and families). The lack of parity between medical and psychological rounds also showed the priorities and hierarchy of position among professionals. From a perspective of Bourdieu, doctors were positioned relatively higher than social workers. Those medical rounds were an organised structure in a working day and demonstrated both doctors' and social workers' relative positions, priorities and power in the clinic. Doctors, more or less, directed and controlled the work of all professionals in the clinic:

> We have a psychosocial, once a week, and it's very important. There are doctors, nurses, physiotherapist and the social worker is chairman of the meeting, …, and we have a round of about 1 hour and then most often the children's perspective comes up (Doctor).

Inter-professional meetings were especially important to doctors, because they could put into motion actions by other professionals. Social workers did not have the same need for inter-professional meetings as did doctors. Most of the time, social workers worked alone, but sometimes they needed a doctor to be a part of meeting with children for a medical explanation about a patient's disease and treatment. Social workers often participated in meetings organised by a doctor when a patient would get bad news about the illness. The opposite was not always the case: some doctors refused to participate in a meeting with children as relatives, called by a social worker. This pattern also showed the relative positions of doctors and social workers in the clinic, where the doctor had the symbolic power to claim the social worker's time. The reverse did not seem to be the case:

> Sometimes we manage very well in the team when all the team members pull together to help each other with different things. Sometimes it fails and we do not reach [the children] because there is not enough time or too many problems due to the patient's disease (Doctor).
>
> Not all doctors want to have those conversations. I have received an answer from one doctor who said 'no, we've talked enough, I do not need to have multiple conversations', even though it was the child who desired the conversation (Social worker).

From the perspective of social workers, doctors and nurses worked closely together and spent a lot of time together. At the same time, the social workers preferred to work alone. Social workers found that other professionals' presence could disturb their conversation with the family, although, at other times, it was fruitful for the conversation. It meant that professionals included and excluded each other in order to help and support children as relatives of cancer patients:

> I think that doctors and nurses have more private time with each other. They make visits together, sit in the car together and have meetings (Social worker).
>
> It becomes a different conversation if there is someone else [there]. Sometimes the focus might be directed in another direction than originally planned ... you lose some fluency in the conversation (Social worker).

Inter-professional teamwork meant handling power and the right to define and rule the situations around the patients and the families. The relative positions of the professionals in the clinic framed the contents and frequency of and the participants in meetings, where doctors often set the agenda for inter-professional teamwork.

Patients defined contact between professional and child

Parents had primary responsibility for their children

Children of cancer patients could get support and information from professionals only if their parents allowed and approved contact between their children and professionals. First, professionals took into account the rights of parents as guardians before they supported children who were relatives of cancer patients, despite the law requiring children's right to information and support:

> Children have the right to information, but it is a difficult balance. We must always assume guardian responsibility first, and it is they who know the child best (Social worker).
>
> It is precisely about meeting the children; to be allowed to speak with them in ways that are good for the family. It is not written in the law when we should inform them, but only that we should be available and that children have the right to know (Doctor).

Professionals knew that parents had the right and power to decide how to handle the situation around their children. Professionals accepted tacitly when parents did not agree to professional contact with their children. Both doctors and social workers expressed the view that parents supported their children best, because they were the persons who knew their children best. Many professionals did not find it necessary to meet the children in order to support them; their opinions were that the parents should be able to face the spontaneous questions of their children and handle the situation on the spot and in general:

> I do not need to see the children; it does not depend on me. People in the children's environment must give the information. Often when you meet a child, you think 'at three o'clock we'll talk about feelings', but children do not behave in that way. …. the child can ask, for example when they brush their teeth, if their mother will die, and then the adults at home must deal with these issues. Afterwards, the parent can discuss the situation with me (Social worker).
>
> The idea is to give parents support to talk properly with their children and then provide further calls as a means of offering family counselling (Doctor).

Professionals also expected patients to support their children in parallel with handling their own life situation with a terminal cancer disease. According to professionals, it was the parents' choice whether or not, and how, their children should be informed about the parent's serious cancer disease. Consequently, professionals had a strategy to meet the children in the long run by supporting parents and building up relations with them.

At the same time, some professionals expressed the view that some parents did not talk with their children about their serious cancer disease, even though they had told professionals that they had talked with their children and informed them. Social workers and doctors reported that nurses often visited patients at home and apparently noticed that children were not included in or informed about the situation. In those cases, many social workers and doctors defended the choice of the parents because the parents knew their children best of all. Overall, their professional experiences were that children should be included in the situation and professionals felt badly in cases where children were excluded. Despite this, their attitude was to show respect for the parents' legal right as guardians:

> Parents say that the children have received adequate information but nurses could feel that the children did not understand the situation at all, and the discrepancy could be difficult to relate to. Then it can be a question of how much the child is suffering from not knowing (Social worker).
>
> He wanted the children to live as normally as possible. but then he became acutely worse … when he more or less slumbered at the end, all the children came. The children sat there and it felt lousy that we could not prepare them …. They were taken by surprise and it did not feel right for those children (Doctor).

According to professionals, some patients could not talk with their children about their cancer diseases and had even more difficulty supporting their children. In those cases, a professional understanding was that the other parent could support their children. It meant that the other parent had a double role, being loyal to her/his spouse and, at the same time, helping and supporting their children to handle an ill parent receiving palliative care. Sometimes the other parent was not healthy and had both psychological and physical problems:

> The patient had difficulty talking with his son, but the mother could do it a little better. So I think she could help her son (Doctor).
>
> Her husband was seriously ill and she has been alone in this; their son was 15 years old (Social worker).

Children were often not at home

According to professionals, some parents allowed them to meet their children, but other obstacles made it difficult for them to meet the children. Doctors expressed the view that they often did not meet children of cancer patients in the patients' home, particularly because the children were at school. If, by chance, the children were at home, the children were often in a hurry and on their way to different spare-time activities, so the doctors had difficulties in having conversations with them. Doctors planned their home visits during the day shift, at times similar to children's school hours, which can also be regarded as an organised structure in the medical field. The same pattern was seen for social workers. It meant that, if the children had to meet professionals, they had to take a day off from school:

> We had a patient who had three children, and the children were never home when we arrived at the home to visits the patient (Doctor).
>
> But it's really important to have the child's perspective, so even if I do not meet the child [which she seldom did], it is important that you talk about children with parents (Social worker).

Overall, children as relatives had a relatively low position in the medical field. The organisation of the clinic even framed meetings in a patient's home. It seemed as if the working conditions of the professionals had a relatively higher priority than the daily conditions for the children of the patients, and that the organisation of the clinic facilitated exclusion of patients' children as the focus area for professionals. Furthermore, when the clinic and the hierarchy of positions in the clinic moved into a patient's home, it meant that relatives per se were given a relatively low position and were often invisible to professionals. Children were dependent on both their parents and professionals, who had the power to include or exclude them from the illness situation.

Patient's death meant sparse professional contact with children

Doctors and social workers expressed the view that they could not prepare children for their parent's forthcoming death. Death was regarded as something that children could not be prepared for: even adults could not prepare themselves. Thus, professionals wished to prepare the children, in the hope of normalising and minimising reactions to their parent's death:

> I had clearly told him 'your mother will die.' …. But when his mother died and I met the boy, he said he did not believe the mother would die. ... 'I thought mom would be sick, sick, sick. Then it would turn and she would get well again'. . . . It is abstract even for adults (Social worker).
>
> The biggest problem is that neither we nor the social worker get the opportunity to prepare children (Doctor).

From the perspective of professionals, professionals had a lack of opportunities to support families psychologically. Time was regarded as a problem. Another issue was that, when the patient died, contact between professionals and families ended. Professionals did not know how the children reacted after a parent's death and lived in their future life without a parent. In some places, social workers had contact with families defined as the most vulnerable; they had no contact with most families. Often children were referred to other health-care providers or were left on their own. Generally, families and their children were referred to other care units such as schools or child and adolescent psychiatry. Doctors and social workers were aware of a lack of follow-up regarding children:

> Children as relatives, it's an important issue to get the opportunity to talk about. It raises a question for me and that's really where do they (children) go? For I have always thought that the social worker takes care of it, but I do not know if that is always the case (Doctor).
>
> We have a very short time so we wouldn't make children too dependent on us and then just disappear. The best thing is if we can strengthen the parent's own abilities instead of taking all the responsibility. You can sometimes weaken the family through your help (Social worker).

Social workers had some individual opportunities to allocate time for telephone follow-up after the death of a patient. Primarily, those follow-up calls were addressed to partners of patients. However, it must be reflected upon that these calls were to those families that social workers had already established contact with during the course of the patient's illness. Interests and preferences of the individual social worker and her/his relationship with the family had significance for whether or not these children received attention *post mortem*:

> We have a little rule of thumb to offer about five calls to survivors. When it comes to [already known families with] children, we are a little more generous, offering calls as needed. The goal is that when you see [from the partner's assessment of their own children] that the child's situation seems fairly stable then we end contact or if needed we contact other units such as child and adolescent psychiatry (Social worker).

In principle, there should be a patient—that is, a person with a diagnosis—in order to claim professional attention in the medical field. Such attention was sparingly addressed to the patients' children through the patients' palliative course of treatment. With the passing of the patient, and consequently following the release of the medical clinic, the doctor's attention ceased immediately, including for the surviving children. Social workers had an opening in their work that allowed them to extend the inclusion of the family within the medical clinic. However, interest in the children most often occurred through the surviving partner and her/his assessment of the children's situation.

Discussion

The discussion will focus on the main findings that: professionals have limited contact with children of cancer patients due to the logic and structural frame in palliative homecare in the medical field; the parents are gate-keepers to professional contact with their children; and, overall, there is limited professional focus on children.

Doctors' and social workers' working days are structured by different meetings and medical rounds, driven by a medical logic in which diagnoses and treatments are in focus as the agenda for the inter-professional team. Hierarchies in the medical field are constructed on doctor-oriented and institution-oriented rather than patient-oriented practices, with the result that psychological and social issues in patients, partners and children are low priorities in the teams' work and collaboration (Glasdam, 2007; Klitzman, 2007). In general, actors act differently in a field, depending on the actor's position and power in the concrete field (Bourdieu, 1991). In the medical field, doctors have the highest relative position and power among other professionals and tacitly rule the teamwork (Glasdam, 2007; Oute, 2017). In general, patients are included and are entitled to treatment and attention from professionals when they have a cancer diagnosis. Partners and children do not have a diagnosis related to palliative care and so they do not have the legitimate (medical) right to attention from a doctor or other professionals (Glasdam, 2007; Mik-Meyer, 2010; Glasdam and Oute, in press). This contrasts with the intentions of palliative care guidance, which includes the family as the unit of care (World Health Organisation, 2018). It is clear that historically rooted thinking and treatment of patients (and relatives) are difficult to change, despite numerous strategies and policy documents and actions.

Doctors and social workers spend most of their working day conducting administration on behalf of, and with, patients and colleagues. A recent study shows the same pattern for nurses (Karidar *et al.*, 2016). The inter-professional meetings conform to the hierarchical structure in the team whereby doctors have an overview of the patients and delegate tasks to other professionals in the team. According to Baker *et al.* (2006), such meetings define the hierarchical differentiation among professionals in an organisational structure: the system of hierarchy makes it difficult for teams to achieve a high level of co-ordination and cohesiveness on issues unrelated to diagnosis and treatment. This means that the team has an incorporated lack of attention to children as relatives in palliative care; all know the children are there, but only a few act and react to them.

Parents are regarded as gate-keepers between their children and professionals, which has also been shown in other studies (Semple and McCaughan, 2013; Phillips, 2014; Karidar *et al.*, 2016). Families, including children, can only be included in the medical field when patients allow it. Health-care professionals are bound to professional secrecy (Department of Health, 2009), unless the patient consents that relatives be involved in her/his situation. In general, professionals do not have time even for adult relatives. However, professional statutory secrecy does not prevent professionals from talking to relatives about relatives themselves. It is also possible to reveal general characteristics about the admission, disease or treatment without breaching confidentiality and sharing sensitive, personal information about the patient's situation (Glasdam, 2007; Oute *et al.*, 2015; Oute, 2017). This means that children as relatives are dependent on their parents' gate-keeper function in physical meetings with professionals in health-care. As shown in other studies, adult relatives of patients have a relatively low, if any, position in the health-care hierarchy (Glasdam, 2007; Laursen *et al.*, 2015; Oute *et al.*, 2015; Glasdam and Oute, in press). From the professionals' perspective of the patients' situation, some relatives with a relatively large amount of capital volume, according to Bourdieu's understanding of capital, are able to fight for a position in the field and manage to be included in the situation. When patients are dying, adult relatives tend to be included in patient care as semi-professionals, expected to care for the patient in the professionals' absence (Glasdam, 2007; Glasdam and Oute, in press). It is hard to imagine that children in general, and especially in this vulnerable life situation, can claim an included position in specialised palliative homecare services. There appears to be a gap between the intentions of Swedish law and interactions between professionals and children. Swedish law requires that professionals pay attention to those children (Department of Social Affairs, 1982) and gives parents the right to take care for and protect their children (Department of Justice, 1949).

Even when parents allow contact between professionals and their children, professionals seldom meet children of cancer due to the organised structure and framework of the clinic. Professionals often plan their visit in office hours when children are usually at school. This indicates that professionals and the medical unit are also gate-keepers to children's involvement in their parent's illness situation and indirectly the professionals exclude the children from the parent's illness situation, despite the possible negative physical, psychological and social effects on children (Chen *et al.*, 2015; RCCC, 2016). Several studies indicate that children and the rest of family should have access to professional support when a parent is diagnosed with cancer and also have further support after a parent's death (Henoch *et al.*, 2015; Inhestern *et al.*, 2016). The structural framework, to which the professionals are subject in their everyday work, gives them minimal opportunities to find time and space to support relatives, who, numerically, are at least as many as the number of patients, and perhaps even twice as many or more (Ferguson, 2014, 2017; Oute *et al.*, 2015).

Professionals do not seem to meet all children as relatives within teamwork but expect each other to do it. When social workers met children in the present study, they preferred to do it alone. This seems to contrast with the normative idea that social workers should facilitate processes of inter-professional teams, through role modelling, shared discussion and joint learning in team work (Stark, 2011). The preference for working alone can be regarded partly as a way to maintain order and control in an unpredictable communication situation, and partly as a way to conquer their own area of competence in the medical field and to define their own role in the inter-professional team (Mik-Meyer, 2010), which is normally defined by doctors.

Finally, the methods of this study should be discussed. A weakness of the method is that it is based on how doctors and social workers articulate their practices. The study says nothing about how clinical practice is handled within practical reality. Likewise, the study says nothing about the perspective of parents and children as relatives, which means that it is not possible to describe all the relational understandings of the complex reality and meetings in this study. The analytic strategy, using the lens of Bourdieu's concepts of capital, position, power and field, has an embedded risk of reproducing one's theoretical pre-assumptions, which have called for critical reflection throughout the research process.

Conclusion

Mono- and inter-professional meetings were organising structures for a working day of doctors and social workers. A working day included minimal time with children as relatives in palliative care and was seldom an inter-professional set-up—rather a hierarchical set-up where doctors overviewed, controlled and ruled the medical practices and the other professions. The doctors had the relatively highest position in the medical field; the medical logic was strong and ruled the agenda of what was important to handle, when, why and by whom. Doctors and social workers preferred to use the time they had to support the patient to support their children. Doctors seldom met children of cancer patients and, when they did, it was often to provide information about a parent's cancer disease and treatment. Meetings between children, doctors and social workers were possible only if the parents allowed it. Even if parents allowed the contact, meetings between doctors, social workers and children seldom took place because professionals visited the patient in office time when the children were in school, etc. Doctors and social workers were subject to the structural frame, which limited their interactions with the patients' children and what they were able to do together in these physical meetings. The structural frame overruled the goodwill and intentions of the professionals to meet the children of the patients, despite the law demanding attention to those children.

This study indicates that, despite having the legal right, some children who are relatives of cancer patients do not have access to information and support. Both parents and professionals in the medical field function as gate-keepers for the children into the medical field. The study calls for reflections and discussions by health-care workers in general, and social workers and doctors in particular. Further, this study calls for an observation study investigating interactions between professionals', parents' and the children's experiences of support and interactions, so that a relational perspective on the real interactions in oncology palliative care can emerge.

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Inclusion and Participation in a Support Programme for Bereaved Adolescents – Relational Perspectives From an Ethnographic Field Study in a Swedish Context

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Abstract
The death of a parent is a life-changing event, and different programmes are developed to support children. This study explored how parental bereaved adolescents were included and (inter)acted in a Swedish support programme. The conducted ethnographic field study included six adolescents, their parents, and eight volunteers. The empirical material was thematically analysed through a theoretical lens inspired by Bourdieu. Three themes emerged: '*Different strategies for adolescents*' *inclusion in the programme*,' '*Medico-psychological understanding of grief and suffering*,' and '*Reproduction of the logic of the school*.' Adolescents were included in the programme through different strategies, where adults functioned as gatekeepers. The programme reproduced the school logic and was based on a medico-psychological grief/bereavement understanding. Volunteers had pedagogic authority and concomitant symbolic power, ruling adolescents to do what they must do in the meetings, silently socialising them into the medical logic. The adolescents only interacted and communicated with each other during breaks.

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adolescent, Bourdieu, grief and bereavement, intervention/support programme, parental death, Voulnteer

Introduction

A parent's death is a dramatic event, and one of the most life-changing experiences that can affect a child (Farella Guzzo & Gobbi, 2021; McLaughlin et al., 2019). Globally, in 2020/2021, at least 5.2 million children lost a parent or custodial grandparent. The prevalence of bereaved children varies across countries as does their possibility to access formal and informal support (Unwin et al., 2022). In Sweden, about 3,500 children (aged under 18) lose a parent every year (Swedish National Board of Health and Welfare, n.d). Studies show that bereaved children want to be acknowledged as individuals with individual needs and not regarded as vulnerable children, even when they are in a vulnerable situation (Alvariza et al., 2017; Lytje, 2018; Fu et al., 2023). The current study focusses on an informal Swedish support programme and its functions and structural mechanisms, paying particular attention to power and relationship processes between bereaved children and adults.

A surviving parent is often the most important person to a child who has lost a parent. However, those parents' abilities to handle their child's needs can be limited as they are often also struggling with their own grief (Donohue, 2020). For this reason, children in such situations are often double jeopardised as they must manage their own grief as well as take their remaining parent's grief into account (De López et al., 2017).

Other adults, such as teachers, play an important role in helping children to understand death and communicate feelings and grief (Duncan, 2020). However, teachers report emotional distress, insufficient skills and training, and other concerns when supporting bereaved children in their classes. Teachers often regard this as a role that is beyond their competencies (Lane et al., 2014; Levkovich & Elyoseph, 2021), which can result in bereaved children experiencing limited support from their teachers (Lytje, 2018).

Healthcare professionals' skills and attitudes can significantly affect the support given to children (Beverley et al., 2021). However, it is also important that children are supported during a parent's illness as well as after their death (Dalton et al., 2019; Walczak et al., 2018). When a parent dies, contact between healthcare professionals in somatic care and families often ceases (Karidar et al., 2016; Karidar & Glasdam, 2018).

Research shows that evidence-based, psychological interventions can support children in bereavement processes by strengthening their ability to cope with the situation and preventing psychopathologies such as anxiety and depression (Christ et al., 2005; Sandler et al., 1992, 2003, 2010). Such claims are tested in randomised controlled clinical studies, with clear verdicts backing the effectiveness of interventions (Neimeyer, 2000). To our knowledge, evidence-based intervention programmes such as 'The Family Bereavement Program' (Sandler et al., 1992), 'Parent Guidance Program'

(Christ et al., 2005), and ‘Family Intervention’ (Black & Urbanowicz, 1987) do not exist in Sweden where only a limited number of informal programmes has been developed and offered to bereaved children and/or families. Moreover, informal programmes are run by volunteers with a range of different backgrounds, often receiving priori specific training (Ridley & Frache, 2020; Glasdam et al., 2023). A support programme can be regarded as a social practice, meaning that someone does something to/with someone in a certain situation, in a specific context. A context can be understood as the circumstances forming the setting for the support programme, such as the place, the environment, and the structural framework. A social practice is always relational as more than one person participates. According to Bourdieu (1999), the real is relational, which means that the social reality consists of relationships between different social interests, positions, and structures.

Research shows that several bereavement/support programmes have effectuated valuations of the interventions, and preliminary results show positive effects for children and their families (Miller et al., 2020; Ridley & Frache, 2020). Conversely, studies also show that only a few children take long-lasting advantage of intervention offers (Bergman et al., 2017; De López et al., 2017; Walczak et al., 2018). There is a lack of knowledge relating to which components of intervention programmes are decisive in effect. Often, the effects of interventions or support measures are presented with a focus on existing theories that emphasise ‘what’ works without consideration being given to ‘why,’ which mechanism of a successful concept works, and how structures and relationship processes influence children (Glasdam et al., 2010, 2015; Walczak et al., 2018). In addition, there is a lack of knowledge about children’s own perspectives on supportive strategies in the bereavement process (Bergman et al., 2017). This article aims to explore how adolescents who had lost a parent were included, acted, and interacted in a support programme focusing on relational and contextual aspects.

Theoretical Framework

Pierre Bourdieu’s concept of field, capital, doxa, and power functioned as the study’s theoretical framework (Bourdieu, 1991). Bourdieu defined a field as a structured space of position and a system of relationships between positions that are relational. Actor and institutions fight for something that is common to them in a field. Social class, education, upbringing, and the actor’s habitus, i.e., schemes of perceptions, conceptions, and actions are part of the structure and have significance for the actors’ behaviours in the field (Bourdieu, 1991). Actors act differently, depending on their position and access to valuable capital. According to Bourdieu (1977, 1996), there are different types of capital: economic, social, cultural, and symbolic capital. Capital is a relational concept in which someone must recognise it as valuable (Bourdieu, 1977; 1996). Further, Bourdieu shows that each field has its own specific doxa, understood as a tacit belief that actors share in a specific field, which is obvious to them but not discussed openly or spoken of. Doxa occurs naturally and is implicit in the field or in the social space (society) in general (Bourdieu, 1977; 1988).

According to Bourdieu, power can be found at the heart of all social interactions as the successful exercising of power requires legitimation. Bourdieu (1991) used the term 'symbolic power,' which is routinely deployed in social life. It is an 'invisible' power, which has legitimacy. When power is exercised through symbolic exchange, it always rests on the foundation of a shared belief. As a condition of its success, symbolic power requires those subjected to it to believe in it, to legitimise the power and legitimacy of those who wield it (Bourdieu, 1991; 1996). In addition, symbolic power also appears in families, workplaces, and schools requiring legitimacy, and is often 'invisible.' State and institutions as delegated holders of symbolic power have the right to exercise pedagogic action through pedagogic authority. In that way, the symbolic order reproduces the social order (Bourdieu & Passeron, 1990). In schools, primary, symbolic power appears, when pedagogic teaching occurs in an incomprehensible language and, at the same time, this linguistic misunderstanding, or more precisely the teacher's inability to transmit knowledge to the students, is accepted in pedagogic institutions. Pedagogical authority also appears through distancing techniques e.g., placement of the teacher's chair, and keeping a clear and respected distance between student and teacher (Bourdieu & Passeron, 1990).

In the present study, analysis of power relationships in the context of the support programme was inspired by Bourdieu's theoretical framework. Structures, strategies, and hierarchic positions can be analysed between different actors: adolescents, parents, and volunteers. Through the lens of Bourdieu, we focus on the interactions between actors in a specific sub-field, and how doxa influences the structure of a support programme, and the behaviours and strategies of the actors.

Methods

Study Design

An ethnographic field study (Fangen, 2004) was conducted from February to June 2019 in a bereavement support programme in Sweden. The overall empirical material consisted of 82 hours of observations of the programme, including 130 pages of field notes, 25 semi-structured individual interviews with adolescents and their parents, and one focus group interview with the voluntary programme facilitators. In addition, short and spontaneous interviews were conducted on the spot and photographs, drawings, and adolescents' written notes about their feelings and emotions were collected. This article focuses on a part of the empirical material, namely the interviews and field notes related to the aim of the current study.

Study Setting

The current study is based on an informal, non-evidence-based programme in Sweden. The development of this support programme was inspired by a Swedish psychologist's guidelines for bereavement (Gyllenswärd, 1997). The concept of this studied support programme consisted of three elements: 1. An initial screening meeting of 30–60 minutes where the adolescent, the parent, and a volunteer met to discuss expectations. Inclusion and exclusion of participants in the programme took place after this meeting, based on the volunteer's assessment, and suitable participants were invited to take part in the programme, 2. Seven consecutive support sessions for adolescents, consisting of 6–15 adolescents in total who were divided into groups according to age, and 3. Seven consecutive support sessions for parents. All these sessions were structured in time, content, and form where volunteers led the sessions. Each session had a specific theme, and both adolescents and parents worked with the same theme at the same time in their different groups (Gyllenswärd, 1997), see Table 1. The volunteers did not have specific formal training in the programme, but initially they read the related basis book (Gyllenswärd, 1997) by themselves.

Recruitment of Study Participants

Inclusion criteria for the current study included that 1) the family participated in the support programme, 2) the adolescents and their surviving parents would participate as families, and 3) the child was between 10 and 18 years old. There were no exclusion criteria.

Eight families were eligible for inclusion. One family declined participation, and one family was excluded from the study because the adolescent declined to participate. Six families with adolescents consisting of six parents (two fathers and four mothers, aged 40–72 years, average age 48) and six adolescents (four boys and two

Table 1. Content of the Support Programme.

Session	Themes	Content
1	My family – who has died? How did it happen?	Introduction about the content in the support programme and introduction of the participants
2	What happens inside of me when I'm grieving? What has changed in my life?	Description of and reflections upon grief and grief reactions
3	My emotions and how do they change when I'm grieving?	Description of and reflections upon emotions relating to a parent's death
4	Ways to relieve and help me in my grief	Description of and reflections upon relief and help strategies in bereavement processes
5	Memories - who was the person who died and how do you remember him/her?	Reflection on different ways to remember a deceased parent
6	Support – networks	Description of and reflections on how to identify support and supportive networks
7	Farewell	Farewell ceremony for the deceased parent and evaluation of the programme

girls, aged 10–14 years) were included in the current study. One family only participated in the observation part of the study, while the other five families participated in all parts of the study. Eight volunteers (aged 34–69 years, average age 61) participated. They all had professional backgrounds as either a nurse, priest, teacher, deacon, or leisure educator (8–44 years of working experience). The volunteers' experience in the support programme varied (0–15 years). Two of them were facilitators for the first time and were paired with an experienced facilitator during the group sessions for training.

Data Collection and Material

A self-constructed, semi-structured interview guide (Brinkmann & Kvale, 2014) based on open and supplementary questions was used for the interviews. The initial interviews with all the included adolescents and their parents were conducted before the start of the support programme. This interview focused on the person's life history, sociodemography (age, gender, residence, education, work), description of their path to the programme, and the families' experiences of illness associated with the parents' death. All interviews were performed in each family's private home, except for one family who was interviewed at the location of the programme. All parents and three adolescents were interviewed individually. Two adolescents chose to have their parent with them during the interview. The interviews lasted for 40–167 minutes (average 68 minutes). Spontaneous interviews with the participants were also conducted on the spot before and after each support session, aiming to gather information about the participants' experiences of each session. These interviews were documented as field notes.

Participatory observation was conducted in the group of adolescents aged 10–14 years and was carried out in all seven sessions as well as when the participants mingled. This involved observing the participants' behaviours, (inter)actions, and activities. The first author observed whom they (inter)acted with, from which positions, and in which context (Bourdieu, 1977). These observations also included the volunteers' other activities relating to the programme, e.g., initial meetings before the programme started and two meetings for supervision and professional guidance led by a social worker specialising in family therapy.

Finally, a focus group interview was conducted with seven of the eight included volunteers after the last session, at the location of the programme. One volunteer could not participate due to personal matters. The interview focused on their opinions, perceptions, ideas, and experiences of the support program in general and in relation to the programme studied. The focus group interview was led by two researchers, where HK conducted the interview and SG observed, made field notes, and asked questions at the end of the interview. The focus group interview lasted 120 minutes (Glasdam et al., 2023). All interviews and field observations were conducted in Swedish, recorded by an audio recorder, and subsequently transcribed verbatim. To support the researchers' reflexivity (Bourdieu & Wacquant, 1992) as ways to be aware of own emotions and influence on the participants/situations and to break with the field researcher's preunderstandings, a field diary was written in continuation with every field visit and interview. The diary reflected on interior, inter/actions, what happen in the situations, under which circumstances, how did the researcher react (e.g., emotionally, mentally), etc. All those reflections functioned as a preparation for the researcher for the next meeting with the studied field. The field researcher had no previous experience of the studied support programme but had years of experience of working with bereaved children positioned as a nurse in specialised palliative care units. The field researcher had an ongoing awareness of possible medical/psychological preunderstanding regarding children's loss and grief, where the diary helped to spot and break with this preunderstanding during the field study process.

Analysis Strategy

A latent, thematic analysis was conducted, methodically inspired by Braun and Clarke (2006) and theoretically inspired by Bourdieu's concept of doxa, capital, position, and power (Bourdieu, 1977; 1988; 1991; 1996; 1999). Firstly, all field notes and transcribed interviews were read several times by the first author to get an overall view of the whole empirical material regarding inclusion, actions, and interactions among participants in the support programme. This process facilitated familiarisation with the empirical material (Braun & Clarke, 2006). Secondly, a coding process for field notes and interviews was drawn up using a matrix, inspired by Bourdieu's theoretical concepts.

The matrix's horizontal rows contained information about each participant's position, disposition, action, and interactions in the context of the support programme. The vertical columns contained information about the inclusion process in the support programme, what role the participants had, with whom and when they interacted, and what they did together. The next analytical step was to construct initial themes based on differences and similarities of the coded material in the matrix. Those initial themes were developed and reviewed in a consensual analysis process among the authors, going back and forth between the empirical material and constructed themes to ensure that the themes reflected the empirical material and answered the study's aim. The initial themes were refined by identifying where some primarily defined themes collapsed into each other and needed to be broken down into separate themes (Braun & Clarke, 2006). Ongoing, the authors discussed the analytical process with focus on and guidance by the theoretical framework. At the same time, the researchers constantly tried to break both with each other's preconceptions and the constructed themes. This reflexivity was strengthened through the researchers' different professional and academic traditions, which gave the opportunity for new thoughts, views, and breaks along the analytical process. Finally, three themes were constructed: *'Different strategies for adolescents' inclusion in the programme', 'Medico-psychological understanding of grief and suffering',* and *'Reproduction of the logic of the school'.* The themes were developed from relational perspectives where positions, dispositions/capital, and (inter) actions of the participants were considered in each theme, focusing the power relationships and logic of practice. Quotes were used to illustrate the findings and enhance transparency of the analysis process and the researchers' interpretations of the empirical material.

Ethical Consideration

The study was conducted in accordance with the ethical guidelines of the World Medical Association (2013) and was approved by the Swedish Regional Ethics Board. Firstly, at the initial meeting, parents were informed of the present study by the volunteers and asked if they were interested in getting further information. Once parents asked for more information, the first author informed them orally about the study and handed over written information in two versions, one for adults and one age-appropriate version for adolescents. Subsequently, parents talked with their children about the study and gave consent to the researcher to invite their child into the study. Before the interview, parents and adolescents were separately informed repeatedly about participation being voluntary and confidential and that they had the right to discontinue participation in the study at any time, without needing to give a reason. Furthermore, adolescents had the opportunity to ask the researcher questions before the interviews and during all sessions of the support programme. Also, the volunteers were informed about the study orally and in writing. All participants over the age of 12 years signed a written, informed consent form.

Results

Different Strategies for Adolescents' Inclusion in the Programme

Adolescents who had lost a parent accessed the support programme in different ways. The first step of the inclusion strategies for adolescents took place before a formal screening meeting, which preceded the start of the programme. Parents were convinced and guided by social and healthcare professionals to join the support programme. Further, parents and professionals in schools collaborated by introducing adolescents to the programme and encouraging them to take part.

> "I called the social worker at school, talked to her about the children, and met her twice. However, the children did not want to meet with her. I offered them meetings and I offered that they could go somewhere else, but none of them wanted to. It was just like they totally refused." (Interview, Parent 4)

> "Volunteer: How did you get information about this support programme?
>
> Adolescent 5: From a social worker at school.
>
> Adolescent 6: My parent told me." (Evaluation of the support programme)

Another way of being included was that adolescents who had previously participated in a similar support programme wanted to join the programme again and their parents also supported their request for further external support. However, it was a basic premise that the parents should be positive towards the support programme before the offer could be an option for their adolescent, which meant that parents were the primary gatekeeper for adolescents' inclusion in the programme.

> "(Adolescent who participated in the programme 2 years ago) I really don't need it but I'm participating for X's sake." (Interview, Parent 1)

The next step of the inclusion strategies for adolescents took place during the formal screening meeting before the start of the programme. Volunteers functioned as secondary gatekeepers for adolescents' inclusion in the programme. One inclusion strategy was to support parents in persuading their adolescents to participate and they also guided parents to use their parental authority and take parental responsibility and decide on behalf of their children. One way was to suggest a trial period for participants. This strategy was often used when adolescents refused to participate in the programme.

> "(Adolescents) don't want to participate. [....] We advise parents to take them [the adolescents] twice (to the programme) and make a deal with them. Be an active parent, take responsibility, and decide on their behalf that they will come twice and then they can stop [...] It's better than letting the children decide, because they don't know what [the support programme] will give them [...]. (Then they attend and) they don't stop, and they come and make their own friends and think that it was really fun." (Focus group interview, Volunteer 1)

Parents seemed to trust the advice from volunteers, which resulted in adolescents joining the programme despite their initial resistance. However, volunteers in the support programme only had access to adolescents whose parents gave them this access.

> "In the beginning, they (adolescents) didn't want to participate in this support programme, but I was quite determined and said: 'Now, we're going to do this' and took them with me, you could almost say." (Interview, Parent 4)

In principle, volunteers had two interests, namely, to support bereaved adolescents and their families *and* to run the support programme, which meant helping enough participants to obtain financial support and documenting that the support programme was effective.

> "Volunteer 1: We started running the programme in 20XX in collaboration with (a child organisation) and from 20XX, we received project money, but then we broke off the collaboration with (the child organisation). In 20XX, we received expansion and regional funding." (Field notes, volunteers meeting)

According to volunteers, parents initially joined the support programme for the sake of their children. However, they experienced that the programme also helped the bereaved parents. Volunteers acknowledged that parents participated in the support programme to help their children and some adolescents participated to please their parents. From the perspective of volunteers, handling these adolescents was always a challenge.

> "Volunteer 7: Then an adolescent didn't want to come to the group meeting today and (the parent) took on his parent role and made him come.
>
> Volunteer 1: (The parent) said 'even if the (adolescent) doesn't come, I intend to come." (Field notes, supervision of volunteers)

The support programme had hidden exclusion criteria and was therefore not available to all bereaved adolescents. In the initial screening meeting, volunteers excluded children and adolescents with psychological diagnoses and children (and their families) who could not speak Swedish. According to volunteers, children with special needs could disturb the other children in the programme. They found it challenging to deal with children with a psychological diagnosis or a native language other than Swedish. These issues fell outside the framework of the programme and could not be supported. It meant that children or adolescents who also suffer from issues other than having lost a parent or those who were not able to speak Swedish per se were excluded from the programme.

> "It's a balancing act (with non-Swedish speaking adolescents) [...]. (Participants) must be able to understand what the others are saying […]. If you are in a group and do not even speak Swedish, they (the others) get tired and can't bear it [...]. Further, I think also it feels like a challenge if someone comes with a mental diagnosis. How should we handle it?" (Focus group interview, Volunteer 1)

Some adolescents supported and accepted unconditionally their parent's and volunteers' suggestions for participation in the programme as they approved of the idea and wanted to be included in the support programme.

> "(What do you think about participating in this programme?) It actually seems fun." (Interview, Adolescent 6)

Other adolescents first refused participation in the support programme but joined it conditionally. However, some adolescents participated due to the initiatives of the adults, albeit with explicit resistance.

> "Adolescent 2: I don't really want to take part in the support programme, but mom is pretty much forcing me.

> Parent 2: What? Now it sounds like I've really forced you to come here, but I haven't.
>
> Adolescent 2: I will come if I get sweets." (Field notes, session between volunteer, parent, and adolescent)

Although, some adolescents participated voluntarily and benevolently, some participated due to adult persuasion, and some wanted to withdraw after the trial period had expired. However, adolescents had to deal with their parents still wanting them to continue and complete the programme.

> "Adolescent 1: I want to quit this.
>
> Parent 1: No, we can't.
>
> Adolescent 1: I was stressed a month ago and I'm not stressed now. Can't we quit?
>
> Parent 1: Hmm, no.
>
> She was busy on her mobile phone and trying to get her dad to go home. They sat there by themselves. The father was determined and did not change his mind." (Field notes, third meeting)

As recommended by volunteers at the screening meeting, parents used different strategies to ensure their adolescents' continued participation. They could, for instance, bribe their children with nice activities together such as shopping or visiting a restaurant to encourage them to participate in the programme as a gift exchange with something for something. These gift exchanges occurred even between siblings.

> "Parent 2: They (the adolescents) didn't want to come today, but I've bribed them. [....] It was mostly the little brother today. I suggested a visit to a restaurant nearby, and the big brother was immediately keen and persuaded his little brother to come along." (Field notes, social mingle before group meeting).

Adolescents clearly expressed their dissatisfaction. Parents and volunteers were aware of adolescents' reluctance to participate in the programme but they ignored it. However, parents and volunteers supported each other, and adolescents had no choice other than to participate. This meant that adolescents were subjected to the will and power of adults.

> "He's been difficult. [...] He's a bit more introverted, so every time he has asked, 'Mom, do I have to go today?', but he has usually been happy afterwards, so I think it has been good for him and I think that he thinks it has been good, even though he has been strongly resistant." (Interview, Parent 4)

Medico-Psychological Understanding of Grief and Suffering

From the perspective of volunteers, grieving processes in adolescents were perceived as potentially pathological, and the best way to both prevent them getting stuck in their grief and help them recover was regarded to be reflection and the sharing of emotions through the support programme or similar set ups. According to volunteers, unsupported adolescents might never recover, and they risked facing psychological problems later in life.

> "The loss makes you reflect. Narrative has healing power." (Field notes, observation of supervision of volunteers)

Even though the support programme represents the medical logic, according to the volunteers it was difficult to find a place and to be recognised in the formal treatment system that treated and cared for the deceased parent. Not all volunteers believed that bereavement could be treated through support programmes, some considered the support programme to be in competition with healthcare professionals' work.

> "I think of those [families] who have been looking for us. It has not been so easy to find us. I know that it (information about the support programme) was sent out to the counsellors, in the schools and hospitals and hospices, ASIH. [...] who doesn't take their task seriously to pass it on?" (Focus group interview, Volunteer 1)

Parents apparently supported the medical logic of understanding grief and suffering in adolescents, this could be seen both explicitly and through the fact that they participated in the support programme. Parents appreciated the way the programme functioned and supported their bereaved adolescents. They considered it as being a good way to manage their bereavement.

> "I like therapy, because I believe a lot in being able to talk like this, then you can move on. So that's why I thought this might work, because he needs someone to talk to as well." (Interview, Parent 3)

Some adolescents also represented the medical logic of understanding grief and suffering, which was associated with the emotional expression of grief. In the current study, it was revealed that adolescents knew or learned that they could and should talk with adults around them, such as teachers, social workers, sport leaders, and school nurses.

> "Volunteer 3: What adults do you think you can talk to?
>
> Adolescent 2: Social workers and teachers. […]
>
> Adolescent 5: I've talked to the social worker.

> Volunteer 3: Did it work?
>
> Adolescent 5: I think it was good.
>
> Volunteer 3: Has anyone talked to a psychologist?
>
> Adolescent 4: No.” (Field observation, sixth group meeting)

In many ways, adolescents demonstrated different views on grieving such as being completely silent, not being active during meetings, or not initiating contact or interacting with the others in the group. From the perspectives of volunteers, these adolescents’ behaviour was regarded as disruptive and was a cause of frustration. This lack of engagement in the medical logic astonished volunteers who lacked understanding of other ways of dealing with grief and loss.

> “Volunteer 3: (Name) is very kind and describes grief as a signal that is sent from the brain, etc. Does not talk much about his feelings. He would rather not be part of the group. He has promised his mother to come two to three times, and then he will drop out.
>
> Volunteer 4: It’s hard for him to feel the loss. (Name) barely says more than a few words […] (Name) was not here today. He’s gone. He was also silent [….]
>
> Volunteer 3: They are closed, silent, invisible, and having a facade that you can’t break down.” (Field observation, supervision for volunteers)

However, adolescents understood that adults thought it was important for them to talk with professionals and other adults about their situation. According to volunteers, adolescents in the current support programme were reluctant to talk about how they really felt regardless of how hard volunteers tried to make them to talk in the hope that it would help them cope with their bereavement.

> “Volunteer 3: Today’s theme is about emotions; I think that is very difficult. It is difficult with teenagers who don’t talk or want to tell us about their feelings. Whatever you ask they just say, I don’t know, I don’t know.
>
> Volunteer 8: Yes, it can be difficult to get the [adolescents] to open up.” (Field observation third group meeting)

Parents had symbolic capital as guardians, and volunteers had cultural and symbolic capital in the support programme, which placed both in dominant positions in relation to adolescents. Adults had legitimate power over adolescents in the support programme, which meant that adults could take action to socialise adolescents into the medical logic of the grieving process through trumping these action strategies in relation to grief management and thus suppress the adolescents’ different understandings of and ways of living with grief.

> "Volunteer 3: The purpose of this support group is to meet others who have similar situations and experiences, to be able to feel connected […] A former research study (compared) one group that was allowed to talk about their feelings and situation with another group that didn't get any help or talk to anyone, and the results showed that those who weren't allowed to talk to anyone had a tougher time because they had to process what they had been through by themselves. So, try to talk to someone, (even) with your dog or cat. Even if you don't get a response from them, talking helps you." (Field observation, sixth group meeting)

Reproduction of the Logic of the School

The structure and context of the support programme resembled the school environment in many aspects: assembly hall, 'mingling' before the sessions, breaks between sessions, different groups according to participant age, etc. Volunteers functioned as class teachers, and parents were excluded from participating in the same classes as their children.

> "There were 14 adolescents, 10 parents, eight volunteers, and me: 33 people in the large room. A volunteer called out to everyone and said, 'Now we are starting'. All parents should be down here, and all adolescents should go upstairs with their respective group leader'. Everyone went to the different rooms. Upstairs, all adolescents stood in a large circle so they could see each other. A volunteer explained that they would be divided into two groups according to age." (Field observation from first group meeting)

The logic of the pedagogical actions was well known to all participants, both adults and adolescents. Volunteers instructed, taught, and prescribed, and adolescents listened and performed, more or less, the activities requested of them.

> "I thought that (the group support) felt very safe. [..] At first, I thought it was a bit like school and one of the children once commented that this is almost like a school. Nevertheless, at the same time, I think she liked it. It felt quite safe after all." (Focus group interview, Volunteer 8)

Volunteers had the pedagogic authority and the concomitant symbolic power in the meetings, where their pedagogic authority functioned in an invisible manner and led adolescents to do what they should do in the meetings. In this way, the support programme reproduced the social order of the school. In the first session, volunteers informed them about the rules, conditions, and content of the programme. Adolescents received a clear and detailed picture of why they were there and how they were expected to act and cooperate to cope with their bereavements. It was like a first day in a new school class, and adolescents understood and accepted without negotiation that they had the role of pupils, and they paid attention to their teacher's instructions and lectures.

> "All adolescents looked a little tense and listened to Volunteer 3. They sat around a table.
>
> Volunteer 3: You are all here because you have lost a parent and we will help you process the grief. […] Here you can talk about what happens in your grief and how it feels or where in the body you feel the grief. We have some rules that everyone must follow, e.g., what we are talking about must stay here and not be repeated to anyone else. We respect each other and listen to each other. You are allowed to go outside if it gets difficult or you get sad. You should have your mobile phones on silent." (Field observation from first group meeting)

Communication between volunteers and adolescents was led by volunteers and was one-way communication most of the time. In all sessions, conversation was initiated by volunteers. Adolescents were asked questions related to the session's theme actively and constantly, and they responded by answering, often giving very short answers. Adolescents never took initiatives to ask questions. They appeared as a passive audience contributing only when their teacher demanded it of them and waiting their turn to answer. Adolescents talked only when they were invited into the conversation by a volunteer; sequentially one by one they 'answered the question' they were supposed to, and consequently group conversations and dialogues never occurred among the participants during the sessions.

> "Volunteer 3: What has changed in your family?
>
> Adolescent 5: We don't do the same things, like going boating.
>
> Volunteer 3: Did you sell the boat?
>
> Adolescent 5: Yes.
>
> Volunteer3: Do you miss going boating?
>
> Adolescent 5: Yes.
>
> Volunteer 3: Maybe you might get your own boat in the future?
>
> Adolescent 5: I don't know.
>
> Volunteer 3: Do you talk about dad at home?
>
> Adolescent 5: Not so often." (Field observation' second group meeting)

According to volunteers, the younger child group participated more actively than the older group during the sessions. Thus, they found it disturbed them when they talked too much, as such behaviour was regarded as undesirable and not appreciated. Apparently, volunteers tried to correct and socialise the maladapted participants into adopting the right 'school behaviour', such as being quiet and being like the pupils who followed the rules and instructions from a teacher. Furthermore, volunteers also expressed difficulties with the participating adolescents who had trouble expressing themselves verbally or who could not focus on the task in the sessions.

> "Volunteer 8: We have a boy who talks so much. I asked him if he talks as much at school. He said 'Yes'. Then he said: 'I should practice listening'. I told him 'I'm an experienced schoolteacher [...] it's good to talk, but we can get tired of you'. Then X, he's careful and doesn't take up much space. A and Z, you must be aware of them. They can't concentrate." (Observation of supervision of volunteers)

In mingling sessions and breaks, participating adolescents interacted and communicated with each other. In the beginning of the course, they were reserved and shy towards each other but as time went on most of them developed friendships. In their 'free time', out of the earshot of adults for content definition and management, adolescents found the opportunity to unfold and develop among peers.

Discussion

The discussion focuses on two main findings. Firstly, adults act as gatekeepers to adolescents' adult support. Secondly, how the medico-psychological understanding of adolescents' grief and suffering rule a support programme, reproducing the logic of the school. In addition, the study method used is discussed.

The results show that volunteers and parents, i.e., adults, are crucial and important regarding adolescents' grief and bereavement strategies with the power to open or close external support possibilities, such as the studied support programme. Adults have the legitimate right and symbolic power in relation to children per se, which, according to Bourdieu (1991), is routinely deployed, often invisible, and found in all social life such as in families, schools, and workplaces. The adults' perspective is based on a cognitive psychological understanding of bereavement strategies with an implicit understanding that if people cognitively know how to handle a situation, they are also able to transform this knowledge into actions in their lives and living. In other words, the structures and processes within the individuals' minds affect their behaviour (Cantor & Kihlstrom, 2017). Many voluntary and professional support programmes work in extension of and in line with this cognitive psychological understanding (Christ et al., 2005; Van Agteren et al., 2021), which guide adolescents into this world of understanding to cope with their grief as the right way to behave in contemporary society. Foucault (1977) shows how the medical way of thinking infiltrates all thinking in modern society like a web, as seen in the current study, also in bereavement support. In Bourdieu terminology, the medical doxa functions as an overarching doxa for adults in the current study, where they shared a tacit belief of what is normal and abnormal. Such beliefs appear 'culturally' and are implicit in society (Bourdieu, 1977; 1988).

Studies show that children and adolescents who have lost a parent are sensitive to and conscious that their remaining parent is suffering and grieving for their spouse and co-parent, so they try to protect them or the other significant people around them (Bergman et al., 2017). A way to protect their parent is to obey them, e.g., to agree to participate in a support programme. In addition, children develop a concrete logical way of thinking between the ages of seven and eleven (Piaget, 1964), which also allows them to follow their parent's arguments and thereby be able to accept the premises for the parent’s suggestions and choices. Nevertheless, it is shown that the parenting responsibilities of the surviving parent increase after the death of a co-parent. Bereaved parents/spouses typically have difficulties with their own bereavement and try to suppress their grief in front of their children (Donohue, 2020). Ridley and Frache (2020) argue that external professional help for bereaved adolescents is necessary when parents are overwhelmed by their own grief and struggling to provide for the emotional needs of their children. However, the current study’s result challenges this understanding as the support programme can function as a substitute for a parent’s bad conscience about their own inadequacy but is no guarantee that the adolescent will feel supported in their grief.

The study’s results show that support programmes were not available to all bereaved adolescents. Volunteers selected adolescents who met the inclusion criteria of the support programme. It was necessary for adolescents to have a good command of the Swedish language, the ability to follow instructions, and for them to know how to behave in a group. Adolescents who did not meet the criteria were preconceived as not being able to deliver the desired result of the programme. This inclusion and exclusion strategy of the programme highlights what Bourdieu describes as ‘selecting the elect,’ which means that adolescents’ social origins and cultural and economic capital determine their destiny, and inequalities in the education system lay the foundation for social inequalities (Bourdieu & Passeron, 1979). This is in line with the results of the current study, which show that inequalities not only appear in the education system but also in bereavement support programmes.

Furthermore, the results show how the medico-psychological understanding of adolescents’ grief and suffering were embedded in the structure and content of this studied support programme. The reproduction of school logic was recognised in the structure and context of the programme, for instance assembly hall, ‘mingle’ before the sessions, breaks between sessions, different groups for children according to their age, volunteers as class teachers, the adolescents as pupils, etc. Through pedagogical action and authority professionals socialised adolescents into the ‘right’ grief behaviour by teaching them facts about grief and bereavement and strategies to cope in line with medical logic. The results show how symbolic power through pedagogical actions appeared in communication between volunteers and adolescents as an interrogation technique or style. In general, school is a space where socialisation occurs according to a purpose and of the educational activity. Risnoveanu (2010) shows how children, through educational activity, learn in a social apprenticeship of interaction, exchanges of mutual adaptation and negotiation with other people. In addition, they learn student-teacher interaction that is socially shaped by child-adult relationships, where the teacher has a higher position and thus also has more power than children in the school. In other words, as Bourdieu and Passeron (1990) describe, school as a social space has the power and possibility to shape graduates with the aim of getting them ready to integrate in the macro-social plan, with focuses on becoming a ‘productive individual’. In European countries, themes about grief and bereavement are not a ‘cultural’ part of school education systems and curricula (Stylianou & Zembylas, 2016), and this can be regarded as a prolongation of the taboo of being open about death and grief, which still exists in Western societies (Bauman, 2013; Glasdam et al., 2020; Jacobsen, 2017). Thus, in dedicated programmes, individuals are allowed to talk about their feelings of, for instance, sadness and despair (Granek, 2015; Stylianou & Zembylas, 2018). However, grief is embedded in sociocultural practices and different perspectives promote different morals and values regarding grief and bereavement, which either provide or limit different strategies and understanding of the processes (Holte Kofod, 2017). From the medical understanding, grief is perceived as a potentially pathological condition from which one should recover, by treatment and therapy with the goal to be 'cured.' However, from the sociological point of view, grief is perceived as a social emotional response to e.g., the loss of a loved one and not a condition to be treated (Jakoby, 2012). This challenges the result of the current study showing how adults handle adolescents' bereavement according to adults' own perceptions and with the power to socialise children to go back to 'normal' life or 'act normally' by participating in a support programme. Adults may need to change their thinking from the desire to do something *for* children to the desire to do something *with* children, letting the children be frontrunners and guides through vulnerable bereavement life situations, and support these strategies. The current study points to the necessity of developing children-led programmes in the future, by listening to, acknowledging, and taking the children's voices, resources, and creativity as a starting point in such vulnerable life situations (Lindquist-Grantz & Abraczinskas, 2020; Suleiman et al., 2021).

The ethnographic method used in this study provided opportunities to gain knowledge through first-hand experiences, and empirical material was collected through multiple methods, which contributed to increasing the trustworthiness of the study (Fangen, 2004). The process of the study design (description of the context and content of the support programme, demographic information about participants, and interview guide) is presented transparently to the readers, which strengthens the study's transferability. Quotes were selected to support the analysis, which also enhances the findings' trustworthiness. Further, the researchers had no previous experience of the studied support programme or the included professionals, parents, or adolescents, which increases the credibility in relation to an analytical distance. A limitation in the participatory observation part of the study was that the researchers could only observe participants' bodily communication and expressions but not what they thought or felt in the actual situations. In the interviews, the researcher only gained narratives from the participants and not what they actually did in the narrated situations. Also, the parent's presence during some interviews with adolescents might have influenced adolescents' responses and expressions of their own perspectives, which might have had implications on the results. Another limitation is that the results did not consider volunteers' professional backgrounds, their personal experiences with loss and grief, their level of the experience in working with the support programme, or their pairing and training, all of which might have influenced their performance and the outcome of the current study. The field researcher only observed two volunteers during the field observations so such factors cannot be considered in the field observations in the current study. The process of coding can also be discussed as the initial coding was performed only by the first author who also collected all empirical material. However, all researchers had access to the original empirical material (field notes, transcribed interviews) and checked the initial coding to ensure transparency, consistency, and trustworthiness in all processes of the study. Using the lens of Bourdieu's theoretical concepts has an embedded risk of reproducing one's theoretical pre-assumptions, which calls for critical reflection throughout the research process. Bourdieu calls for a double break, which has been a major point of attention for the research team with a lot of discussion and reflection on both the methodological and theoretical work throughout the process. The double break consists of breaks with the spontaneous experiences of the actors and breaks with the spontaneous theorising of the researchers. That is, on the one hand, the theoretical perspective helps researchers get behind what materialises as the participant's subjective intention/interpretation, as it is declared in an interview or expressed during a field study. Otherwise, researchers must constantly break with their own immediate understandings of reality (Bourdieu & Wacquant, 1992), which has been an ongoing and difficult challenge in the study but has strengthened the study's trustworthiness.

Conclusion

Adolescents' need of bereavement support was assessed by adults who had the symbolic power to decide, shape, and create support strategies. Adults' perspectives and perceptions dominated the bereavement support and adolescents' own wishes were not always taken into consideration. The studied support programme was embedded in a medico-psychological understanding of adolescents' grief and suffering and lacked consideration regarding the impact of objective structures on adolescents' subjective experience of loss and bereavement. Further, the support programme was not available for all adolescents due to inclusion and exclusion criteria of the programme and lack of resources. That meant inequality existed in the distribution of support opportunities for bereaved adolescents. Adolescents were selected by adults based on expectations of their being able to understand the content of the programme and follow instructions. By reproducing the logic of the school setting, both in the content and structure of the support programme, selected adolescents were socialised through pedagogical action on how to cope with their loss according to a medico-psychological understanding of grief and bereavement. There was a lack of interaction between adolescents during the sessions who behaved in a similar way to how they would in school as a pupil, following the programme according to instructions, meaning that interaction and communication among adolescents occurred during breaks and mingle sessions. The results of this study raise questions regarding how "school" structured support programmes help, who is offered support in such programmes, and who is not. This study calls for further research exploring other support programmes for adolescents to further understand the complexity of grief and bereavement processes among adolescents and the societal systems in place designed to support these adolescents.

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Author Contributions

SG Conceptualisation, methodology, conducted focus group interview, analysing, writing - original draft preparation, writing - review & Editing. HK Conceptualisation, methodology, conducting interviews and field observations, transcription, analysing, writing - original draft preparation, writing - review & editing and project administration. PL contributed to writing-original draft preparation, writing - review & editing. All authors red and approved the final version of the manuscript.

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Paper IV

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The influence of actors on the content and execution of a bereavement programme: a Bourdieu-inspired ethnographical field study in Sweden

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Introduction: The death of a parent can have profound negative impacts on children, and a lack of adequate support can exacerbate negative life experiences.

Aim: To explore the influences of various actors on the content and execution of a bereavement programme within a Swedish context, considering relational and contextual perspectives.

Methods: An ethnographic field study involving six children, their parents, and eight volunteers. A theory-inspired thematic analysis was conducted, methodically inspired by Braun and Clarke, theoretically inspired by Bourdieu's concepts of position, power, and capital.

Results: Confidentiality obligation was an essential element in the programme, however, the premisses varied depending on actors' positions. Volunteers and researchers had different outlets to express their experiences in the program. The programme offered the children an exclusive space for talking about and sharing experiences and feelings. Simultaneously, the programme restricted the children by not allowing them to share their experiences and feelings outside the physical space. The physical settings shaped the different conditions for interactions among the actors. The sessions adopted loss-oriented approaches, where communication between volunteers and children was guided by the volunteers. However, children created strategies for additional, voiceless communication with their peers or themselves. During breaks and mingles, shared interests or spaces connected children (and adults) more than their common experience of parental bereavement.

Conclusion: The participants in the programme were significantly influenced by the structural framework of the programme, and their positions within the programme provided them with different conditions of possibility for (inter)acting. Children's daily activities and interests were both ways to cope with parental bereavement and connect them to other people.

KEYWORDS

bereavement support programme, Bourdieu, children, ethnographic field study, parental death, volunteers

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Introduction

The death of a parent during childhood can have detrimental consequences in a child's life, and a lack of support can potentially increase some children's vulnerability to negative life experiences (1). Previous research shows that parental death is associated with an increased risk of depression and psychological disorders (2, 3), subsequent poor school performance, decreased socio-economic conditions (4, 5), criminality (6), self-inflicted injuries (7), mortality in childhood, and suicide later in life (8, 9). However, research also shows that distressing experiences of losing a parent during childhood's formative years can pave the way to personal development, and that children have remarkable resilience and an ability to navigate through the complexities of life (10–12). Lund (13), argues that grief should be viewed as a natural emotion of loss. In many ways, experiences of loss have significance for people's self-understanding, self-relation, and relationships with others in society (13).

The management of death and grief is influenced by culturally mediated experiences and social norms (13). In western societies, bereaved individuals can find themselves isolated and struggle to navigate their new life situation due to a lack of communication with people close to them, which may impact their well-being and ability to cope with their loss and the bereavement they are experiencing (14–16). Other studies show that some children perceive a taboo around death, due to adults perceiving death and bereavement as difficult subjects to talk about (17, 18). According to Wray et al. (19), some remaining parents avoid open communication with their children regarding loss and grief in an attempt to protect them. However, children are often more aware of death than is expected by adults. Thus, some of these children suppress their emotions, withdraw from social activities, and the support offered by adults does not always align with the children's needs (17, 19). Some children face difficulties finding legitimate ways to cope with parental bereavement and the associated grief (20).

Research highlights childhood bereavement as a public health issue that requires engagement not only from professionals but also from communities to gain a deeper understanding and provide appropriate support for bereaved children (19). Nevertheless, professionals in healthcare settings and schools frequently express feelings of emotional strain, inadequacy in their abilities and training, and various other challenges such as lack of time and poor collaboration with other professionals when it comes to supporting children in their grief. Often, professionals perceive such tasks as falling outside the scope of their expertise, leading to them referring grieving children to other professionals and/or bereavement support programmes (21–24).

In western societies, individuals' experiences, including the handling of bereavement and grief, have become both a personal and professional matter (16, 25). It is a personal matter in the sense that experiences of disease and bereavement are handled by individuals, maybe shared with some close family members (16). It is a professional matter as grief reactions are often regarded as potential pathological conditions, which may require psychological and/or pharmaceutical interventions to support the individual's recovery. The primary objective of professional interventions is to facilitate people in their recovery from bereavement as quickly as possible, so they can resume their lives as if nothing significant has happened to them (13, 26). At the same time, professionals claim that the guardian parents are responsible for providing support both during and after a parent's death (22, 27). Some parents seek support for their children from professionals such as teachers, social workers, and professional led support programmes, either through their own initiatives or at the request of others (16, 23). This is often because the capacity of the remaining parents to address their child's needs may be constrained since they are also experiencing a loss, namely of their co-parent (28). However, it is important to consider that some children do not prefer professional support, and some of the parents ignore children's wishes. This can force the children to accept parents´ decisions such as participating in support programmes (23, 29).

During the last 6 decades, the professionalisation of bereavement and grief management has manifested itself in the development of various individual and group support programmes, aiming to support self-help (16). During the 1980s, different psychological programmes were developed to support bereaved children and their families [see, for example, (30–36)]. Evaluations of different programmes show different positive outcomes, significantly impacting children's behaviour, sleeping patterns, anxiety, and depressive symptoms (30, 34), and positive impacts on children's self-esteem and improved communications skills between children and parents (31, 36). All in all, these cognitive psychological-inspired programmes have similar structures, consisting of different sessions with themes for reflection, including problem identification and the articulation of children's feelings and emotions. Moreover, during the last decade, new concepts of support programmes have come about, considering children's own perspectives, and involving them in the development of future programmes. Consequently, researchers have argued for the value of democratic processes and cooperation with children, where children are regarded as active co-actors in the designing, planning, and implementation of bereavement programmes (37–39). Overall, the primary focus and outcomes of intervention programmes are often presented based on existing theoretical approaches, with the emphasis being placed on uncovering 'what' works. Few studies have focused on the 'why' or 'how' behind what works (40, 41). Basically, all different kinds of group interventions are performed in social contexts. However, research often lacks consideration of the importance of contextual influence and the relational dimension, understood as how different actors impact the content and implementation when evaluating the outcomes of any intervention programme (40). To the best of our knowledge, previous research has not explored how and in which ways different actors can perform and impact in a support programme. Therefore, from relational and contextual perspectives, the current study aims to explore the influences of different actors on the content and execution of a bereavement programme in a Swedish context.

Theoretical framework

In the current study, Pierre Bourdieu's concepts of power, capital, and position serve as the theoretical framework (42–44). According to Bourdieu (44), the real is relational, which means that social reality consists of power relationships between different objective positions and dispositions, unfolding through dialectic processes. Understanding people means understanding their inherent properties, attributes, or essences in relation to the field of objects, practises, or activities in which they exist (44). Power is central in all social interactions, especially symbolic power. Symbolic power functions as a structure in a social space where related people have accepted what is right or wrong about any phenomenon (things, thoughts, behaviours, traditions, and actions). Symbolic power exists among people in different social contexts, e.g., families, workplaces, and schools (45).

In a social context, actors or groups of actors assume different positions and act differently depending on their access to different valuable capitals, such as economic, social, cultural, and symbolic capital. These capitals are part of the social structure and impact on actors' behaviours in a specific physical place (42–44, 46).

The physical context of the current study consisted of a physical setting with a specific interior, where different meetings between different actors took place, framing the conditions for their (inter)actions. (43), emphasises that a social context, where concrete human activity takes place, is always a pre-structured context as it is coded with specific rules and values. In the current study, the authors focused on how the structural framework of the support programme—consisting of seven consecutive support sessions with different themes, pre-defined content, and activities—guided and shaped the conditions for possible (inter)actions and vice versa. Hence, the concept of power was employed to illuminate its multidimensional aspects during actors' (inter)actions in the specific physical setting. Subsequently, the concepts of positions, power, and capitals served as an analytical lens to illuminate how actors' different social positions and capitals, such as age and roles, might have significance for the conditions of possibility to act in the programme. In the current study, Bourdieu's relational theoretical framework was used to inspire a focus on symbolic and structural power, capital, and position. Bourdieu's theoretical concepts highlight the dynamic power relationships between different actors' positions that influence the possibilities to shape the content and proceedings of the programme, which, in dialectic processes, further influenced the actors' (inter)actions.

Materials and methods

Study design

The current study is a part of a larger ethnographic field study (10, 23), conducted within a Swedish support programme for bereaved children and their families from February to June 2019. Empirical materials were collected through multiple methods, totalling 82 h of observations that led to 130 pages of field notes, 29 semi-structured individual interviews with children and their parents, and one focus group interview with the volunteers. Additionally, short, spontaneous interviews were conducted during mingle sessions and breaks, and these were also documented as field notes. Photographs, drawings, and written notes used during sessions regarding emotions and feelings were also included in the empirical material. Thus, the current study exclusively built on field notes from the observational part of the larger study that is related to the aim of this investigation.

Structural framework of the programme

The studied support programme, developed and inspired by Swedish psychologist Gyllenswärd (47), was structured based on three key elements: (1) The remaining parents applied through email or phone to join the support programme, and then the remaining parent, their children, and volunteers had a planned initial meeting lasting 30–60 min where they exchanging information about the programme and discussed expectations. (2) Seven sessions were held where children were grouped according to age and parents had a separate group. (3) All seven sessions were structured in terms of time, themes, content, and activities (47). For more details, see Table 1, also presented in another article (23).

TABLE 1 Content of the support programme.

Session	Themes	Content
1	My family and my loss	Introduction about the content in the support programme and introduction of the participants.
2	Grief and grief reactions	Description of and reflection on grief and grief reactions.
3	Grieving and emotions	Description of and reflection on emotions relating to a parent's death.
4	Relieve and coping strategies	Description of and reflection on relief and coping strategies in bereavement processes.
5	Memories	Reflection on different ways to remember a deceased parent.
6	Support – networks	Description of and reflection on how to identify support and supportive networks.
7	Farewell	Farewell ceremony for the deceased parent and evaluation of the programme.

Participants and data collection requirements

In total, 10 families participated in the support programme and all of them were informed and invited to participate in the study. Inclusion criteria required that children and their surviving parents participate as families, and the children's ages ranged between 9 and 18 years. One family declined to participate, and one family was excluded due to inclusion criteria. Eight families, consisting of eight parents (three fathers and five mothers, aged 40–72 years, with an average age of 48) and 11 children (nine boys and two girls, aged 9–14 years), were included in the study. One of the included families only participated in the observational part of the study, while the other seven families participated in all parts of the larger study (10). All eight volunteers (aged 34–69 years, with an average age of 61) participated and had various professional backgrounds such as nursing, priesthood, teaching, deaconry, and leisure education with work experiences ranging from 8 to 44 years. Furthermore, the volunteers had varied experience as facilitators in the programme, spanning from 0 to 15 years. Two of them were beginners and were paired with experienced facilitators during the group sessions (10).

The field study observations were conducted during mingle sessions/breaks and in the seven group sessions for children. The first author conducted the field study with a focus on understanding with whom participants (inter)acted, and how, from the positions they assumed, and in which physical settings these interactions occurred. Furthermore, observations were also conducted during the volunteers' other activities related to the programme, including initial meetings before the programme started and two planned group meetings on supervisions and reflections, which were led by a social worker specialising in family therapy.

All field observations were conducted in Swedish, and a field journal was written during field work and after all interviews to provide reflexivity support for the field researcher, following the approach of Bourdieu and Wacquant (48). The journal functioned as a reflection tool partly to challenge the field researcher's preunderstandings but also to guide attention to the researcher's own emotions in relation to the participants and situations. The journal documented what happened in various situations, what was captured in the observations and why, and how the researcher reacted, both emotionally and mentally. All these reflections supported the preparation and strategies for the next meeting within the studied field.

Analysis strategy

A latent thematic analysis was conducted, methodically inspired by Braun and Clark (49), and theoretically inspired by Bourdieu's relational concepts of power, position, and capital (43, 44, 46, 48). Firstly, fieldnotes were read repeatedly by the first author to gain familiarity and get an overall understanding of the empirical material (49), with focus on contextual and relational perspectives regarding actors' influences that shape the content and proceedings in the studied programme. Secondly, to generate initial codes (49), a table was inspired by Bourdieu's relational theoretical concepts to carry out the analysis of features in the fieldnotes. The table's horizontal rows contained information about the support programme's context (structure, content, place, and environment), the actors' different positions (volunteers, parents, children, and the researcher), and how power relationships between the actors appeared in the different organised physical spaces. The vertical columns contained information about the actors' strategies—namely what, when, where, with whom, and how these strategies influenced the content and proceedings of the programme. The table functioned as a multidimensional map, organising initial codes within relational and contextual perspective (43, 44, 46, 48).

Thirdly, the initial coded extracts in the table were sorted in groups to capture both similarities and differences in the empirical material to construct initial sub-themes and themes. Forth, the initial themes were reviewed by all authors in relation to the coded extracts to ensure that the themes were not only cohesive but also distinct from each other, capturing the essence of each theme within the study's aim (49). Furthermore, the process of defining and naming themes involved thorough discussions among all authors. This ensured a reflective approach (48), which meant that the authors consciously and continuously tried to break with preunderstandings and perceptions during the dialectic analysis processes. Finally, three themes were constructed '*Positions defined the premises for confidentiality obligation*', '*Visible and invisible communication patterns in the classroom*', and '*Free time and non-bereavement-related interfaces connected people*'. Moreover, the themes were developed from a relational perspective, focusing on the power relationships within the context of the studied support programme. Additionally, the actors' different social positions based on cultural capital were considered in each theme. Quotes from the empirical material were used to illustrate transparency in the analysis process. All names have been changed.

Ethical consideration

The study was approved by the Swedish Regional Ethics Board and conducted in accordance with the ethical guidelines of the World Medical Association (50). Participation was voluntary, and all participants were informed about confidentiality and their right to withdraw at any time without facing any consequences regarding their participation in the support programme. The first author informed all participants orally about the study and provided written information in age-customised versions, with one version for adults and another for children. All participants aged 12 years and above signed a written, informed consent form, and children below12 years gave oral consent. Moreover, children had the opportunity to ask the field researcher questions before and during mingles/breaks regarding their participation in the current study.

Results

Positions defined the premises for confidentiality obligation

Six children, two volunteers, and one fieldwork researcher participated in the seven weekly meetings in the support programme. All actors were bound by an obligation to maintain the rule of confidentiality within the programme. The confidentiality obligation functioned as an essential element in the structural framework of the programme, however, the demands of confidentially obligation differed among the three groups of actors: children, volunteers, and the researcher. The volunteers, who had cultural capital as support providers, saw confidentiality obligation as a major part of their role, ensuring that information about the included parents and children was not spread outside the programme. Their confidentiality commitment also functioned as a trust-builder between the volunteers and programme's participants.

> Sam explained the content of the programme to the family and said: '*One must participate in the programme to know, and we [the volunteers] follow rules of confidentiality. No one else will know what you say in the group*' (Field observation during the initial meeting with the family).

However, the volunteers did not observe confidentiality obligation within the volunteer team and among related professionals, where they could discuss their experiences from the sessions and mingles with each other and an assigned supervisor. During the course, the volunteer team held two legitimate formal meetings with a supervisor, providing support and sharing reflections, emotions, and disillusioned expectations relating to the future strategies of the children, parents, and volunteers.

Children held the position of support recipients in the programme and were expected to refrain from disclosing or discussing any experiences from the programme outside it. In short, this structural premise was a requirement for participating in the programme, where children were supposed to accept the confidentiality obligation. On one hand, the programme offered the children an exclusive safe space to talk and share experiences and feelings. On the other hand, the programme restricted the children by not allowing them to share their experiences and feelings related to the programme outside its physical space. However, it was unknown to the volunteers how the children handled their imposed confidentiality. They neither accepted nor challenged this confidentiality obligation in the face-to-face meetings with the volunteers.

> Volunteer 3: '*We have some rules that everyone must follow, such as what we talk about must stay here and not be shared with anyone*

> *outside the group. We respect each other and listen to each other'.* The children sat silently during this explanation and did not ask any questions either to each other or to the group leader about the confidentiality obligation (Field observation from the first session).

The fieldwork researcher was positioned as an observer and was the only one with the opportunity to share knowledge outside the programme regarding what had happened, when, where, and in relation to whom. As a private person, the researcher could not share information outside the programme, but as a researcher, the task was to make this support programme visible outside its own framework and space by exploring it. However, the researcher adhered to research ethical laws, including the Helsinki Declaration, ensuring the research participants' integrity and confidentiality in the research process and subsequent dissemination of knowledge. In that light, the researcher could discuss and document what happened in the programme in anonymised forms, supported by permission obtained through informed consents from all the participants.

> The mother seemed positive about the study and turned to her son and said:
>
> The mother: '*Everything will be kept confidential*'.
>
> Then the mother looked at me and I confirmed that their personal data will be kept confidential, with only the research team having access to the original data (Field observation initial meeting with the family).

Overall, the volunteers held a position that allowed them to set the conditions for the children's participation without negotiation. For the children, their role in the programme depended on them accepting these conditions. However, they could follow or break the imposed confidentiality obligation without the other actors' knowledge. The children were the only actors involved who did not have a formal opportunity to express their experiences and feelings about what happened in the support programme outside of the programme itself. Conversely, the volunteers and the researcher could take their experiences and feelings outside the programme, albeit subject to different limitations and conditions.

Visible and invisible communication patterns in the classroom

Actions and interactions between children and volunteers were influenced by different organised physical contexts, such as sessions, breaks, and mingles. These different contexts created both space for interactions and clearly defined boundaries for possible interactions. The group sessions took place in a room equipped with educational facilities such as a whiteboard and pens, with a table and chairs arranged by the volunteers in advance. The lead volunteers sat at the head of the table, while the children and field researcher sat at the long sides of the table. This seating arrangement implicitly conveyed a hierarchal positioning with the volunteers symbolically assuming the power of teachers in the classroom. Furthermore, volunteers asserted their symbolic power by presenting their professional backgrounds to the children, positioning themselves as knowledgeable and mediators of information about bereavement. The children held a position as potential recipients of knowledge through the support provided by volunteers during the sessions. In addition, the two volunteers orchestrated the sessions within the hierarchal positions of their roles. The volunteer in a leading role took charge and directed all the activities, while the other volunteer had an assisting role, quietly observing the children's behaviour, always ready to support the leading volunteer if needed. The field researcher took on the position of observer, obligated to remain silent and not disturb the activities in the sessions. However, the researcher's position also held symbolic power, granting the right to determine what became research data through field notes, with none of the other actors knowing what was noted down. This symbolic power was reinforced by the presence of an additional adult in the room.

> Sam went in first and stood at the head of the white oval table, and then all the children entered the room. At was 17:17 and Sam introduced himself as a nurse. Karina said she also works as a nurse. Sam said that he would talk most and ask questions, and Karina would support if needed, reasoning that it is easier for the children to turn to one person when answering questions or discussing things. The children were quiet while Sam spoke, and they did not ask any questions (Field observation first session).

As a formal social context, the sessions had a fixed opening and closing ritual. The opening ritual was to light an electronic candle in memory of the deceased parent. Children followed this instruction without questioning the significance or purpose of this ritual.

> Sam moved on to the next item on the meeting's agenda, which was lighting candles and as they lit the candles, each participant had to say this line: 'I'm lighting this candle for my dad/mom and his/her name is…' (Field observation first group meeting).

The next ritual for those present was to declare their social identity through their names. Facilitated by the volunteers, everyone present in the session, including the field researcher, participated in the name game (sessions 1–3). The aim of the game was to get to know and remember each other's name. This game created a sense of community, which was an important element in group cooperation, with 'community' being a pre-defined concept supporting children in the programme.

> Sam started by saying, '*My name is Sam*'. Then Sara had to say; 'Sam, Sara', and Emma had to say; 'Sam, Sara, Emma'. Thus, everyone had to repeat the names said before theirs, followed by their own name (Field observation first session).

The closing rituals consisted of two elements: music and extinguishing the candles. The lead volunteer made a secret song list of the children's favourite songs. Only the lead volunteer knew, which song had been selected by who, and played a selected song from their smartphone at end of each session. The children's task was to guess whose song it was, which was sometimes successful, sometimes not. The music ritual was mandatory, and some children initially refused to take part in the game. The volunteer used their relational power position and persuaded those children to join in the game. Eventually, all the children had chosen a song. After the music ritual, children extinguished their electric candles before they left the room, symbolising the end of the session.

> All the children wrote their songs on a piece of paper except for two. They claimed that they didn't have a favourite song. Sam continued to ask them to think some more and that they were sure to come up with a song (Field observation first group meeting).

During the sessions, children listened to the volunteers' instructions, and engaged in individual tasks such as writing or drawing within predefined themes related to their loss, grief, and emotions. The communication had a loss-oriented focus with the objective to support children in reflecting on their emotions, thoughts, and memories of their deceased parent. In the writing tasks, children often wrote single words such as *angry*, *funny*, and *happy* on paper. In the oral explication of the written words/drawings, the volunteers often designated 'words' that could point to poor grief processing such as *anger*. In the group setting, the volunteers asked follow-up questions about the children's written words/drawings, and the children answered briefly, often by saying *yes*, *no*, or *I do not know*. Through the oral exchanges, the volunteers implicitly assessed the children's psychological condition and suggested explicit solutions for how to cope with the emotions of grief. The children did not enter dialogues with each other during these sessions or ask the volunteers questions. However, they were present, accepting, and did everything they were asked to do during the sessions.

> Axel: '*On the outside I'm happy and funny but on the inside I'm angry*'.
>
> Sam: '*What are you angry about?*'
>
> Axel: '*I don't know*'.
>
> Sam: '*Is it worse since your dad died?*'
>
> Axel: '*Yes*'.
>
> Sam: '*Are you angry at your dad?*'
>
> Axel: '*No*'.
>
> Sam: '*It's normal to feel the difficult feelings and they must come out, and you have to talk about them*'.

All the children sat quietly and listened. (Field observation fourth session).

The volunteers held high ambitions and expectations regarding the active participation and verbal expression of the children in the sessions, viewing their talking as another key element and an indicator of the programme's success.

> Sam: '*They're so difficult and don't talk much. Take Emma, for example, when I asked her who has died? She just answered 'dad' quietly and says nothing more*'.
>
> Karina: '*Axel barely says two words*'
>
> Sam: '*But he looks up more. Then he is so pale. Maybe scared?*'
>
> Karina: '*Oscar wasn't here today. He is away. He is also quiet*'.
>
> Supervisor: '*It is a difficult group regardless. Maybe help them pedagogically?*'
>
> Sam: '*Today, they drew the figure body about their feelings. They like to draw*'.
>
> Supervisor: '*Can't you talk about their idols or the Melody Festival?*'
>
> *Sam: 'No, they don't want to talk, we're struggling, but no'* (Group meeting with supervisor).

The volunteers were focused on visible forms of communication during the sessions, such as face-to-face expressions and spoken words. However, some children communicated without using voices. For instance, some covertly used their cell phones under the table, despite an established rule requiring phones to be on silent mode and not used during sessions. Others drew shapes of hearts or stars on paper during the verbal part of the sessions while still seeming to listen. Some communicated their feelings of unease in the session room by keeping their outside clothing on. However, over time, some of those children gradually became more at ease and felt more comfortable, which led them to remove their outside clothing.

> 'Volunteer: *You must have your cell phone on silent mode*' (Field note first session).
>
> At 17:26, Alexander and Oscar were finished with their drawings. Oscar picked up his cell phone, checked it and wrote something on it under the table. Alexander waited a bit, and when he saw that no one had noticed or said anything to Oscar, he did the same, checked his cell phone and read. Then, he smiled at Oscar (Field note third session).

Free time and non-bereavement related interfaces connected people

In the spacious open lobby on the ground floor, children, parents, and volunteers gathered and mingled together before each session. The lobby functioned as a central gathering place and a waiting area for all actors before the sessions. In contrast to the structured sessions, the lobby was lively with different activities and the sounds of laughter and talking. The conversations between actors covered a range of topics, such as sports, the weather, vacations, and jobs. While mingling with each other, everyone had the opportunity to engage in free and self-selected content in the conversations. However, their positions were not equal as the children were in the company of their parents, placing parents in a higher position than children due to their custodial responsibility, including the upbringing of the children. Moreover, the volunteers had the role of 'supporters' and 'facilitators', while the others took on the role of 'potential supported'. However, the 'support' agenda was reset during these informal mingles.

> Children, parents, and volunteers were gathered in the spacious, modernly furnished lobby between 4:30 and 5.00 pm before the start of each weekly session and again at the end of each session. Eva welcomed Henrik and his mother. Then they went to get snacks and drinks. Then Emma, her mother and little brother came. Emma went straight to Henrik and started talking. They took snacks and drinks and both families sat down at a table. Sara and her father sat by themselves again as they usually do. The younger children were playing with each other. William and two other children sat on benches looking at something on their cell phones (Field observation seventh session).

During the sessions, there were breaks lasting for 10–15 min, providing opportunities for the children to socialise with whomever they wanted. Children and parents had breaks at different times. The volunteers instructed the children: '*Go down to lobby, get something to eat/drink, and come back to the session room*' (Field notes, first session). While some children followed this instruction, others chose to mingle independently in the lobby or in the corridor outside the session room. These breaks were the only 'free zone' away from adults within the programme. The children who interacted with each other had found common ground, i.e., shared interests such as the same taste in music or common affiliations, such as attending the same school.

> Alexander and Oscar remained on the ground floor having snacks and drinks and talking to each other and laughing. They didn't seem to be aware that the break was over, and everyone had gone up. Sam went down to bring them up and noticed that they enjoyed talking to each other (Field observation third meeting).

The volunteers valued the children's interactions during the breaks. According to the volunteers, '*creating communities*' was interpreted as another success factor of the programme. It also contributed to their personal satisfaction and sense of meaning relating to the effort they had put into the programme. It alleviated their concerns about the limited verbal communication and interactions between the children during the sessions. When hopeful expectations of the children interacting became a visible reality for the volunteers, they demonstrated flexibility by changing the planned time structure and content of the sessions to give children more free time to develop connections and interactions.

> Sam: '*They* [the children] *are completely engaged in talking to each other and I couldn't disturb them. That is the essence—that they should connect with each other. I don't think we'll have time for the 'iceberg' theme tonight. We'll have to take that next time. It's important to make this change*'.
>
> Karina agreed, and the break was extended (Field observation third meeting).

Extended breaks made more children-led (inter)actions possible, and the volunteers paid attention to children who were not engaging with others. In contrast to the sessions, children actively talked with the volunteers about things other than their feelings and emotions. Communication centred around common interests, such as sports and pets. Both the children and volunteers smiled, laughed, and seemed to enjoy the conversations and each other's company. The ways in which volunteers and children communicated and the topics they discussed changed when the context shifted from the formal sessions to informal breaks, and the formal bereavement agenda was temporarily set aside. The formal sessions on loss, bereavement, and emotions were put on hold, and conversations were based on mutual interests. Over time, informal parts of the programme saw interactions between children and volunteers blossom and friendships develop between the children.

> Sam sat down next to Axel who was sitting on a sofa in the hall outside the session room. Sam started talking to Axel about football. Like Axel, Sam likes football, and then I heard Axel talking quite a lot despite usually being quiet during the sessions. Karina and Sara talked about their dogs, and Sara looked happy while Emma was drawing (Field observation third meeting).

In the last session, a balloon ceremony was conducted as a formal conclusion of the programme. This involved the release of balloons with letters to the deceased parent. This could be seen as a rite of passage, symbolising the transition back to their everyday lives after completing the support programme, and implicitly that they should be able to navigate their parental bereavement in new and better ways. A strong connection developed between some of the children during this ceremony when one of the children accidently let go of their balloon before they reached the hill where the balloons were to be released. The child without a balloon was supported by another child who they had developed a friendship with during the programme. The friend assisted the child without a balloon and encouraged them to write a new letter. Afterwards, this smaller group went to the hill where they released their balloons together with the rest of the group.

> Alexander accidentally let go of his balloon and it quickly flew up into the sky as it was quite windy. Everyone just said 'what, oh no', and he looked so surprised, and the balloon disappeared quickly. Alexander stood by the roadside and wrote another letter against a wall. Oscar waited with him while he wrote it. After the balloon ceremony we came back, and Oscar and Alexander were sitting together at a table talking to each other (Field note seventh and the last session).

Symbolically, children engaged in individual communication with their deceased parent while simultaneously visualising a sense of joint action within the shared community. However, after the last session, all actors separated from each other, marking the formal dissolution of the programme.

Discussion

The discussion highlights three main findings from the current study. Firstly, the significance of confidentiality obligation emerged as an essential element in the programme's structure with variations in premises depending on the actors' positions, symbolic power, and cultural capital. Secondly, the impact of different physical settings, coupled with their related content, influenced, and shaped the conditions of possibility of actors' (inter)actions. Finally, the third main finding to be discussed was that shared interests, hobbies, or daily encounters, such as attending the same school or living in the same residential area, connected the actors more than the fact that the children had all lost a parent.

The main finding showed the importance of confidentiality obligation in the structure of the programme, functioning on different premises for children, volunteers, and the researcher. Confidentiality obligation is a cornerstone of medical ethics and a fundamental aspect of healthcare services, and it is obligatory for all healthcare professionals to protect the privacy of individuals (51, 52). In the current study, volunteers and the researcher adhered to their formal professional confidentiality obligations to build trust and protect the privacy of participating children and their parents. This aligns with the principles of medical ethics (53). Furthermore, the results showed that the volunteers imposed confidentiality obligation on children, which can be seen as a further way to protect their privacy in a group context. However, this can also be interpreted as an embedded risk of conflicting with the principle of non-maleficence and potentially causing harm (53). Contrary to the programme's intentions, the imposed confidentially obligation restricted the children from sharing their programme-related experiences and feelings outside of the physical space of the programme. This limitation may add a layer of potential suffering, as studies show that many children have difficulties in finding ways to share and cope with their bereavement (20, 54). Moreover, the confidentiality obligation for children can also be regarded as a challenge in relation to the principles outlined in the United Nations Convention on the Rights of Child (UNCRC) (55) regarding children's right to freedom of speech, which is applicable in Sweden (56). The UNCRC and Swedish law declare that decisions made by adults must reflect on how their impact will affect children to avoid causing harm (55, 56). Other studies also highlight this problem, showing that professionals often lack the expertise to meet children's needs and live up to their rights in healthcare, including the context of paediatric care (57, 58). The results also showed that volunteers had the possibility to share information about the content and activities within the formal physical setting of the programme, where the researcher could share this information outside this formal setting. However, children did not have the same opportunity. These hierarchal and positional differences in conditions of possibility can be reflected in the light of Bourdieu and Passeron's work (59), showing that such inequalities exist in the education system. The studied support programme was designed as a school-like set-up, allowing for reflections on the continuation of the educational system and the mirroring of positional inequalities, particularly regarding the conditions of handling confidentiality obligation.

Furthermore, the main findings showed that (inter)actions of actors were influenced by the different organised physical settings and their related content. The sessions and mingles/breaks had different set-ups that shaped the conditions for the actors' position-related (inter)actions. Studies show that school breaks, as opposed to classes, are often unstructured, allowing children to make free choices regarding activities and interactions, while adults mainly regard their roles as safety monitors (60, 61). Bourdieu (46) also shows that actors behave differently in social contexts based on their position and access to valuable capital and symbolic power. The current study suggests that physical settings hold significance for patterns of (inter)actions, and one may ponder on the implications this has for the success of the programme. Future studies may explore the significance of sessions, breaks, and mingles in support programmes to understand their implications for success. According to Moos (62), any social context is a powerful setting, and individuals mutually influence each other for better or worse. Therefore, interventions involving people should highlight contextual aspects in the measurements of its impact (63).

The present study also showed that volunteers held expectations that children should express themselves during the sessions, with the children taking on the role as well-behaved pupils who do what they were asked but provided verbal responses that were short and concise. According to Højlund (64), children's experiences and behaviours are closely tied to the concrete social context or institution they are in. Winter et al. (65) shows that professionals, like the volunteers in the current study, often have an unrealistic perception of and personal preference towards children who strike up meaningful communicative encounters with them. According to Chater et al. (29), support programmes employing talk therapies, both at individual and group levels, are not always welcomed by all children as they can feel discomfort in talking about their feelings. Other studies show that children may prefer structured talk therapy based on verbal communication between the actors (36, 66).

In addition, the main findings show that children had other communication strategies than the adult-led's strategies such as communication without using their voices, for example through their cell phones or by drawing. According to Højlund (64), children actively contribute to the construction of a social context as they adapt to the social expectations and categorisations imposed upon them, both visibly and invisibly for the adults. In line with the current results, Adebäck (67) shows that bereaved children often hide and do not outwardly express their feelings in their appearance or behaviour in their day-to-day lives. However, the current study highlights that children developed their own strategies within the adult-led programme, both during the sessions and the mingles/breaks. Further research on children's independent, purposeful, and beneficial(in) visible strategies is needed to more fully understand the complexity of children's bereavement strategies. Venkatesan (68) argues that there is often a misconception among adults that children lack the ability to handle their emotions regarding grief and bereavement, and they need adults to guide them (68). However, adults need to take into consideration not only what children need to know and understand, but also what and how children want to learn about topics related to death and grief (69). Researchers argue that death, grief, and bereavement should be regarded as natural life events, and suffering should be acknowledged as a part of living life without pathologising it, as individuals often possess the capacity needed to be able to handle their suffering (23, 70, 71).

The main findings also showed that the connections among the actors were forged based on shared interests, hobbies, or regular encounters at shared physical locations such as school or residential areas, rather than solely on the children's common experience of parental loss. This aligns with LaFreniere and Cain's (72) study, showing that bereaved children do not want to be marked as different due to their bereavement. Instead, they want to be perceived as 'normal' and not distinguished from their peers (72). Bourdieu (73) shows how individuals with similar ways of living, tastes, and preferences tend to connect with each other, and these similarities also function as a means of distinction from those with different tastes, preferences, and ways of living and thinking. The current findings suggest that children find their own ways and strategies within the organised support programme that focuses on bereavement and related contents. In a systematic literature review on children's everyday lives when a parent is seriously ill with the prospect of imminent death, Author et al. (10, 23) [Blinded for reviewers] also highlight that children in vulnerable situations are still capable of adapting and finding strategies in their daily living. It was obvious that bereavement experiences alone were not enough to connect the children in the studied support programme. This calls for the need to explore how to engage and involve children in future programmes that aim to meet their needs and interests by embracing democratic processes and fostering collaboration with researchers, professionals, and children. Recognising children as proactive collaborators in the creation, development, and execution of different support programmes is crucial (39, 74). It seems important that professionals, researchers, politicians, and decision makers recognise the significance of essential and natural activities such as leisure activities in everyday life, providing coping strategies, and connecting people. This has the potential to improve children's health and quality of life (75), even in bereavement situations.

Finally, the current study has both strengths and limitations. The ethnographic methodology employed in the research made it possible to gain knowledge through direct encounters in the studied programme, allowing the researcher to observe actions and interactions between the actors in 'real life' situations. This multifaceted approach to data collection enhanced the trustworthiness of the results (76). In the observational part of the study, it was only possible to observe the actors' bodily communication and expressions, while the spontaneous interviews during the field study provided additional insights into the actors' inner thoughts and emotions, contributing to data triangulation, and strengthening the study's credibility (76). The study's transparency in outlining the design process, which entails providing a clear description of the support programme's context, content, and demographic information of the actors including age and profession, contributes to the transferability and thereby the trustworthiness of the results (77). Moreover, the field researcher's lack of prior familiarity with the programme and the participants (volunteers, parents, and children) adds to the empirical and analytical distance, enhancing the credibility of the study. The field researcher did have experience in caring for bereaved children, which called for an ongoing awareness and reflection of possible medical/psychological preunderstanding regarding children's loss and grief. A diary was used for such reflection throughout the research process and functioned as a valuable tool for breaking with the researcher's preunderstanding. According to Bourdieu and Wacquant (48), a critical reflective approach is essential throughout the research process, involving a double break. The double break means the researchers must break with both the spontaneous experiences of the studied participants and the spontaneous theorising of the researchers. The research team continuously reminded each other about the need for critical self-reflection during the analysis of the empirical material regarding medical pre-understanding and theoretical perspectives.

Conclusion

Participants in the programme were significantly influenced by the structural framework of the programme, including the rule of confidentiality obligation and different organised physical settings such as sessions, breaks, and mingles. The positions of the actors within the programme provided them with different conditions of possibility of how to ensure the demand of confidentiality obligation. The adults had both formal and informal settings to share their experiences of the programme and what happened, while children were expected not to share their experiences outside the programme. The physical settings and their related content defined the roles and positions of the actors, which influenced and shaped the conditions for their (inter) actions. During the sessions, communication between volunteers and children resembled a teacher-student dynamic, where children followed verbal instructions and briefly answered the teacher. At the same time, the children developed strategies for additional non-verbal communication without adult instruction, which also included interactions with the other children. During breaks and mingles, (inter)actions occurred between some children, leading to the development of friendships based on shared interests or common meeting places such as school or residential area. Other children did not form connections with each other, despite all the children having the shared experiences of a parental death and participating in the support programme. The current results highlight the importance of children's daily activities and interests as both ways to cope with parental bereavement and connect them to other people. Future research focusing on children's strategies in their daily lives for coping with the loss of a parent and related adult support strategies is needed. Additionally, exploring the development of support programmes using democratic processes that involve children in designing the concepts and implementation of such programmes would be valuable.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the Swedish Regional Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

HK: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Writing – original draft, Writing – review & editing. PL: Formal analysis, Supervision, Writing – original draft, Writing – review & editing. SG: Conceptualization, Formal analysis, Methodology, Supervision, Investigation, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix I-VIII

Intervjuguide: Studie: Sjuksköterskors erfarenheter av att möta barn som närstående vid onkologisk palliativ vård

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanter

Bakgrundsfakta
Erfarenhet inom palliativ vård?
Utbildning och examensår
Ålder
Kön

Inledande frågor
Kan du berätta om hur en arbetsdag kan se ut?
Vilka patienter träffar du i din dagliga verksamhet?
Kan du berätta för oss om dina erfarenheter av att möta barn som närstående?
Kan du beskriva hur du upplever dessa möten?
Vilka möjligheter eller svårigheter ser du i mötet med barn som närstående?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?

Sonderande frågor
Har du fler exempel om den situationen?
Är det så du upplever det?
Känns det så?

Specificerande frågor
Vad tänkte du då?
Vad gjorde du då?
Vad kändes obehagligt?

Strukturerade frågor
Jag tänkte fråga om ett annat ämne

Tystnad
Tystnad ska utnyttjas

Tolkande frågor
Du menar att
Så du känner att

Appendix II

Intervjuguide för läkare och kurator

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanter

Bakgrundsfakta
Erfarenhet inom palliativ vård?
Utbildning och examensår
Ålder
Kön
Civilstånd
Barn

Vanlig arbetsdag
Kan du beskriva hur en arbetsdag kan se ut? Vad gör du när ditt arbetspass börjar tills du går hem?
Kan du berätta om dina erfarenheter av att möta cancerpatienter med underåriga barn?
Kan du beskriva hur dessa möten sker?
Vilka rutiner har ni på er arbetsplats som måste följas i mötet med barn som anhöriga?

Utmaningar och möjligheter
Med vilka i familjen integrerar du och vad gör du i dessa möten?
Kan du beskriva ett lyckat möte/situation med barn som anhöriga?
Kan du beskriva ett mindre lyckat eller problematiskt möte/situation med barn som anhöriga?

Intervjuguide för efterlevande förälder innan start av interventionsprogrammet

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanten

***Bakgrundsfakta*:**
Ålder
Utbildning och yrke
Antal barn
Partners diagnos

Huvudtema:
Berätta om ditt liv innan din partner blev sjuk och fick sin diagnos?
Kan du berätta om ditt liv under din partners sjukdom och behandling?
Berätta om din erfarenhet kring professionell hjälp?
Berätta om din erfarenhet kring stöd från familj och vänner?
Berätta om ditt liv efter din partners död?
Kan du berätta hur det kommer sig att du vill delta i interventionsprogrammet?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?

Sonderande frågor:
Har du fler exempel om den situationen?
Är det så du upplever det?
Känns det så?

Specificerande frågor:
Vad tänkte du då?
Vad gjorde du då?
Vad kändes obehagligt?

Strukturerade frågor:
Jag tänkte fråga om ett annat ämne

Tystnad:
Tystnad ska utnyttjas
Tolkande frågor:
Du menar att
Så du känner att

Intervjuguide för barn/ungdomar innan start av interventionsprogrammet

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanten

Bakgrundsfakta
Ålder
Fritidsintresse
Vilken årskurs i skolan
Vänner

Huvudtema:

Kan du berätta om ditt liv innan din förälders sjukdom och död?
Berätta om din vardag, hur du hanterade skolan, vänner, fritid och förälderns sjukdom?
Kan du berätta om din vardag nu efter din förälders död?
Kan du berätta hur det kommer sig att du vill delta i interventionsprogrammet?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?

Sonderande frågor:
Har du fler exempel om den situationen?
Är det så du upplever det?
Känns det så?

Specificerande frågor:
Vad tänkte du då?
Vad gjorde du då?
Vad kändes obehagligt?

Strukturerade frågor:
Jag tänkte fråga om ett annat ämne
Tystnad:
Tystnad ska utnyttjas

Tolkande frågor:
Du menar att
Så du känner att

Intervjuguide för efterlevande förälder efter deltagande i interventionsprogrammet

Information om inspelning av intervju
Eventuella frågor från informanten

Huvudtema:
Berätta om din erfarenhet av interventionsprogrammet?
Berätta något positivt som ni har upplevt under interventionen?
Berätta om något negativ ni har upplevt under interventionsprogram?
Saknade du något i interventionsprogrammet och i så fall vad? Ge exempel.
Hur ser ditt liv ut idag efter deltagande i interventionen? Din sorg bearbetning? Din relation med ditt barn etc?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?

Sonderande frågor:
Har du fler exempel om den situationen?
Är det så du upplever det?
Känns det så?

Specificerande frågor:
Vad tänkte du då?
Vad gjorde du då?
Vad kändes obehagligt?

Strukturerade frågor:
Jag tänkte fråga om ett annat ämne

Tystnad:
Tystnad ska utnyttjas

Tolkande frågor:
Du menar att
Så du känner att

Intervjuguide för barn/ungdomar efter deltagande i interventionsprogrammet

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanten

Huvudtema:
Berätta hur ditt liv ser ut idag efter deltagande i interventionen?
Berätta något positivt som du har upplevt under interventionen?
Berätta om något negativ som du har upplevt under interventionen?
Berätta ett exempel på vilket sätt interventionen har hjälpt dig att hantera din sorg?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?

Sonderande frågor:
Har du fler exempel om den situationen?
Är det så du upplever det?
Känns det så?

Specificerande frågor:
Vad tänkte du då?
Vad gjorde du då?
Vad kändes obehagligt?

Strukturerade frågor:
Jag tänkte fråga om ett annat ämne

Tolkande frågor:
Du menar att
Så du känner at

Intervjuguide för gruppledarna: Fokusgruppsintervju

Introduktion om studiens syfte och bakgrund
Information om inspelning av intervju
Eventuella frågor från informanter

Huvudtema:
Berätta era tankar kring interventionsprogrammets upplägg?
Berätta en positiv erfarenhet som ni har upplevt under interventionen i relation till barn och föräldrarna?
Berätta en negativ erfarenhet som ni har upplevt under interventionen i relation till barn och föräldrarna?
Berätta om utmaningar som uppstår i mötet med deltagarna, hur löser ni sådana situationer?
Skulle ni vilja ändra på något i interventionsprogrammet?

Följdfrågor:
Kan du utveckla detta lite mer?
På vilket sätt?
Hur kände du då?
Vad menar du?
Har någon annan liknande erfarenhet?

Avslutande frågor:
Finns det något mer som ni skulle vilja ta upp?
Har vi missat fråga något viktigt angående interventioprogram?

Appendix VI

Observation guide study III

Date:

Time of observation:

Length of sessions:

Length of break and mingle:

Description of the physical place:

Description of participants role, how they acted and interaction:

When, where and how participants interacted:

What material and technique were used in the programme:

(Fangen, 2004)

Appendix VII

Matrix for field note

First meeting between group leaders and the family	**Participants position in interventions context [social space]**	**Intervention context [place, environment, atmosphere]**	**Participants disposition and lifestyle**	**Cod/intuitive though and meta-understanding**
Selection of participant				
How/why participant as parent joined the group intervention				
How/why participant as children joined the group intervention				
How/why participant as group leaders joined the group intervention				
Interaction/relation between group leader and children				
Interaction/relation between children as participants				
Interaction/relation between parents and group leaders				
How parents interact with each other and how they build relations				
Parents interaction/relation with their children and their relationship				
How group leader interacts with each other and what kind of relation they had				

Intervju kurator/läkare	**Fakta/Data**	**Synpunkter (positionering eller position till fakta?)**	**Konkreta handlingar** **Livsstil/sättet att leva**	**Tankar/kommentarer**
Vem är den professionella **(Habitus** **Dispositioner** **Position i fältet** **Härkomst** **Symboliskt kapital** **Socialt kapital** **Ekonomiskt kapital** **Kulturellt kapital** **Utbildningskapital)**				
Vad gör kurator på en arbetsdag				
Med vem arbetar kuratorn tillsammans med, var, när och hur professionella relationer				
Kurators möte med patienten **När** **Med vem** **Hur**				
Kurators möte med vuxna anhöriga **När** **Med vem** **Hur**				
Kurators möte med barn som anhöriga **När** **Med vem** **Hur**				