JÖNKÖPING UNIVERSITY
School of Education and
Communication

Psychosocial Support Around Death, Dying, and Grief for Children with Intellectual Disabilities in Pediatric Palliative Care

An Empirical Study

Maria Bonin

ABSTRACT

Author: Maria Bonin

Psychosocial Support Around Death, Dying, and Grief for Children with Intellectual Disabilities in Pediatric Palliative Care
An Empirical Study

Pages: 35

Many children with life-limiting health conditions in pediatric palliative care have cognitive impairments or intellectual disabilities (ID). They are confronted with their own death and need adapted psychosocial support. The assumption that children with ID might not understand death and dying can lead to limited support. Little is known about psychosocial support in pediatric palliative care around death, dying, and grief for this population. The study aimed to capture professionals' experiences in supporting children with ID in pediatric palliative care around topics of death, dying, and grief. Seven professionals who worked in pediatric palliative care in Germany were interviewed utilizing a qualitative research approach with semi-structured interviews. Inductive thematic analysis was used, and three major themes were identified: *Communication about death and dying involves both verbal and non-verbal means, Child-centered interventions are employed to enhance the child's well-being*, and *Personal factors of involved individuals influence the support provision.* The provided support was highly individualized to children's needs. Communication difficulties were identified as a challenge for professionals when providing psychosocial support for children with ID. Children's health condition and functioning, parents' beliefs, and professionals' attitudes towards ID and uncertainty about children's needs were identified as crucial factors influencing support provision for children with ID. The need for further research was highlighted.

Postal address	**Street address**	**Telephone**	**Fax**
Högskolan för lärande	Gjuterigatan 5	036–101000	036162585
och kommunikation (HLK)			
Box 1026			
551 11 JÖNKÖPING			

Table of Content

1 Introduction

Individuals with intellectual disabilities (ID) are at risk of dying at a younger age and have a shorter lifespan in comparison to the rest of the population (Heslop & Glover, 2015; Lauer & McCallion, 2015). They face various barriers to accessing and receiving palliative care. Professionals with specialized knowledge are required to satisfy the needs of this population (Adam et al., 2020; Tuffrey-Wijne et al., 2016).

It is often assumed that children with ID are not capable of comprehending death and dying, which can result in exclusions from discussions and support around death-related issues (Sormanti & Ballan, 2011). Psychosocial support for children with ID needs to be adapted to their needs to provide the best possible care for this vulnerable group in palliative care (Duc et al., 2017). Official and formal guidance regarding psychosocial support for children with ID in pediatric palliative care is limited (Adam et al., 2020; Chambers, 2018). The few available guidelines are based on case reports and recommendations, mostly focusing on adults with ID or with insufficient evidence (Tuffrey-Wijne et al., 2013; Tuffrey-Wijne et al., 2016). Little is known about psychosocial support for children with ID in pediatric palliative care settings (Lindley et al., 2017). Capturing professionals' experiences can provide insight into ways to support children with ID around death, dying, and grief in pediatric palliative care.

2 Background

2.1 Children with ID in Pediatric Palliative Care

About half of the children with life-limiting health conditions are considered to have cognitive impairments or intellectual disabilities (Feudtner et al., 2011). According to the American Psychiatric Association (2022), intellectual disability is "a disorder with onset during the developmental period that includes both intellectual and adaptive behavior deficits in conceptual, social, and practical domains". Although children with ID often face life-limiting health conditions, they are under-referred to palliative care and tend to experience limited access to it (Dunkley & Sales, 2014; Lindley et al., 2017). Little is known about appropriate and adapted end-of-life support for children with ID in pediatric palliative care. Life-limiting health conditions are illnesses for which there is no realistic chance of cure and death is inevitable (Chambers, 2018). Some life-limiting conditions lead to progressive deterioration, which makes the child increasingly more dependent on carers. Children with life-limiting and life-threatening conditions can be distinguished into four groups, with cases of severe disability in category 3 and 4, with no distinction made in the form of disability (see Figure 1).

Figure 1

Four groups of life-limiting and life-threatening conditions by Chambers (2018)

Category 1	**Life-threatening conditions for which curative treatment may be feasible but can fail**, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. *Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.*
Category 2	**Conditions where premature death is inevitable**, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health. *Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.*
Category 3	**Progressive conditions without curative treatment options**, where treatment is exclusively palliative and may commonly extend over many years. *Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.*
Category 4	**Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.** Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care. *Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.*

The combination of life-limiting conditions and disability adds complexity to the palliative care provision (Chambers, 2018). Duc et al. (2017) report that children with life-limiting conditions often have undiagnosed ID. The comorbidity between life-limiting conditions and ID makes it difficult to distinguish between officially diagnosed ID and limited cognitive functioning due to the illness. Therefore, when this study refers to children with ID, it also includes children with limited cognitive functioning due to their illness.

Palliative care is a crucial part of integrated and person-centered health care that aims to relieve serious health-related suffering in physical, psychological, social, or spiritual aspects (World Health Organization, n.d.). The suffering and health issues may have various causes, for example, cancer, organ failure, and end-stage chronic illnesses. Children in pediatric palliative care often suffer from rare diseases for which there is a lack of empirical data on the course of the disease (Kronberger-Vollnhofer & Nemeth, 2016).

2.2 Palliative Care in Germany

Palliative care is an integrated part of the healthcare system in Germany and is available to persons with serious and life-limiting illnesses, including children. People who are seriously ill and are dying have the right to receive specialized palliative care, which aims to alleviate the consequences of an illness when there is no longer any prospect of cure

(Bundesministerium für Gesundheit, 2022). Approximately 1,500 ambulant palliative care providers exist in Germany, of which 157 are pediatric palliative care services for children and young people (Deutscher Hospiz- und PalliativVerband e.V., n.d.; Deutscher Kinderhospizverein e.V., n.d.). Additionally, there are 260 hospices for adults and 19 hospices for children, adolescents, and young adults, and 4 palliative care units in hospitals for children and young people.

There is no register in Germany for children with a life-threatening disease (Zernikow et al., 2017). However, the current prevalence range of life-threatening and/or life-shortening diseases in children and young people aged 0-19 years in Germany is between 319,948 and 402,058 affected individuals (Jennessen & Burgio, 2022).

Pediatric palliative care aims to support children, adolescents, and young adults with life-limiting illnesses, their families, and relatives. The duration of care provision for a child with a life-limiting disease is significantly longer than for adults. Pediatric palliative care provision often includes several stays over a longer time to relieve the family and provide professional support (Bundesministerium für Gesundheit, 2022). It can start from the moment of diagnosis and continue over a very long period. Pediatric palliative care aims to ensure that children and their families get the needed support to deal with the psychological, physical, emotional, and spiritual impact of the illness while maintaining a high quality of life (Kronberger-Vollnhofer & Nemeth, 2016). Pediatric palliative care is highly individualized and adapted to children's and their family's individual needs (Zernikow et al., 2017).

Pediatric palliative care pursues the goal of enabling young people with life-limiting illnesses to live a dignified and self-determined life until the end. An essential aspect is enabling them to deal with the issues of illness, dying, death, and grief. That includes psychosocial support, counseling, and promotion of self-help for young people and their relatives (Deutscher Kinderhospizverein e.V., n.d.; Globisch, 2022). Psychosocial support describes different services provided to individuals in pressing need, aiming to help them cope with a serious disease or distress (American Psychological Association, n.d.). This might include support from psychologists, social workers, and counselors, in the form of education, spiritual support, and counseling, among others. Zernikow et al. (2017) highlight the communication about death and dying as the most challenging aspect of support provision for children and their families.

2.3   Children with ID and Support Around Dying, Death, and Grief

Psychosocial support for children with ID is of great importance since they might have difficulties understanding dying, death, and grief and communicating about it (Duc et al., 2017).

The assumption that children with ID are not able to comprehend the inevitability, irreversibility, and finality of death can result in exclusions from information and support around death and grief (Dodd et al., 2005; Dodd & Guerin, 2009). Although children's understanding may be influenced by the degree of their disability, they can be confronted with and affected by death, dying, and grief (McClean & Guerin, 2019).

The comprehension of death requires three components: non-functionality (all functions of the body stopped), irreversibility (finality of death), and universality (all living things will die) (Speece & Brent, 1984). Typically developing children usually understand these aspects between ages five to seven. But before the age of ten, children cannot fully comprehend the concept of death, according to Speece and Brent (1984). However, empirical evidence regarding children's comprehension of dying and death is limited (Downing et al., 2015).

Dyregrov (2008) highlights children's considerable capacity for coping with challenging circumstances if adults provide support, including insight into what is happening as well as information provision. Clear explanations and concrete discussions were found to facilitate understanding of dying and death (Ducy & Stough, 2018). In Western societies, children are increasingly isolated from death topics in their everyday life (Longbottom & Slaughter, 2018). Children learn about death through direct exposure to it, conversation about death, and the portrayal of death in media and art. Jalmsell et al. (2015) report that providing good palliative care to children requires honest and open communication about death. Communication is hereby mostly initiated by the child and narratives like stories and movies are utilized for explanation and approaching the topic. Euphemisms in media, however, can hinder children's understanding and may imply the deceased can return (Longbottom & Slaughter, 2018). Dying children might plan their funerals and graves as a preparation for death (Jalmsell et al., 2015). A common way of support is communication about dying and death, which can be challenging for children with ID who often face communication difficulties.

According to Article 13 of the Convention on the Rights of the Child, all children have the right to receive information in their chosen way of communication (United Nations, 1989). That is also highlighted in the Convention on the Rights of Persons with Disabilities with a focus on the right of individuals with disabilities to receive information equally with others (United Nations, 2006). Consequently, it is of particular relevance that professionals in palliative care find a way of informing and communicating with children with ID about issues related to death, dying, and grief.

3   Study Rationale

Research about the intersection of palliative care and children with ID is limited (Duc et al., 2017). Studies on psychosocial support for children with ID in pediatric palliative care around death, dying, and grief are not available. Existing research about psychosocial support focuses on adults with ID (Lord et al., 2017), and the issue of communicating death and dying (Foo et al., 2021; Tuffrey-Wijne et al., 2020; Tuffrey-Wijne et al., 2013; Wiese et al., 2013; Wiese et al., 2014). Limited research is available about grief support outside of palliative care for children with ID when a relative died (Ducy & Stough, 2018; Haider & Zaman, 2022; McClean & Guerin, 2019).

Children with ID in pediatric palliative care are confronted with their death and questions may arise. They have the right to receive information regarding their condition (United Nations, 1989), even though their disability might have an impact on death comprehension. To meet the needs of children with ID and provide support in an appropriate way, specific knowledge of professionals is required. More research is needed to create evidence-based guidelines for supporting children with ID in pediatric palliative care. This study can provide insight into professionals' experiences in providing psychosocial support for children with ID in palliative care around dying, death, and grief.

4   Aim and Research Questions

This study aimed to examine professionals' experiences in supporting children with ID around dying, death, and grief in pediatric palliative care settings in Germany. Professionals included social workers, nurses, educators, and therapists who directly worked with a child with ID in pediatric palliative care.

The following research questions were addressed in this study:

1. How do professionals in palliative care support children with ID around dying, death, and grief?
2. How do professionals communicate with children with ID about dying, death, and grief in palliative care?
3. What are the facilitators and challenges that professionals experienced when supporting children with ID around dying, death, and grief in palliative care?

5   Theoretical Framework

The conceptual framework for complexity in palliative care by Pask et al. (2018) was used for discussing the results of this study. The complexity was identified on different ecological lev-

els, including the person with changing and dynamic conditions and needs, the person's interaction with healthcare professionals, setting, and family, as well as influences on the societal level.

The conceptual framework is based on Bronfenbrenner's ecological framework (Bronfenbrenner, 1994). The ecological levels of Bronfenbrenner's framework (*micro-, chrono-, meso-, exo-, and macrosystem*) are applied to palliative care, based on collected data from patients, families, and professionals by Pask et al. (2018) (see Figure 1):

Microsystem: The microsystem refers to the person with their characteristics and needs, including physical, psychological, social, spiritual, information, and communication needs. Individual characteristics like disability, age, resilience, or illnesses are also considered.

Chronosystem: The chronosystem refers to changes over time regarding patient needs and health. That also includes the uncertainty regarding conditions and care needs, which may change quickly for people receiving palliative care.

Mesosystem: The mesosystem describes the patient's interactions with other people and settings, including professionals, family, and the environment of care like hospice, ambulant palliative care, or hospital.

Exosystem: The exosystem comprises services and systems in which the person is not directly involved but is influenced. In this case, it describes the coordination of palliative care, the interdisciplinary approach of involved professionals, and their received education.

Macrosystem: The macrosystem represents the societal and cultural context where all the other systems are located. That context includes the organization of palliative care and the healthcare system in general, policies, cultural values, beliefs, and stigma.

This conceptual framework allowed capturing the complexity of individual needs and various factors influencing support provision in palliative care. Models of care for children in palliative care are limited (Downing et al., 2015), and frameworks focusing on the needs of children with ID in palliative care are not available. However, the complexity of palliative care is represented in the conceptual framework of Pask et al. (2018), considering the perspectives of professionals, families, and patients. That allows individual adaptation and therefore it was used in this study, although the needs of children with ID are not considered in this framework.

The presented framework by Pask et al. (2018) was utilized to map the complexity of support in palliative care, considering different factors that may influence the support, if they were mentioned by the participants of this study.

Figure 1

The framework of complexity in the palliative care context by Pask et al. (2018)
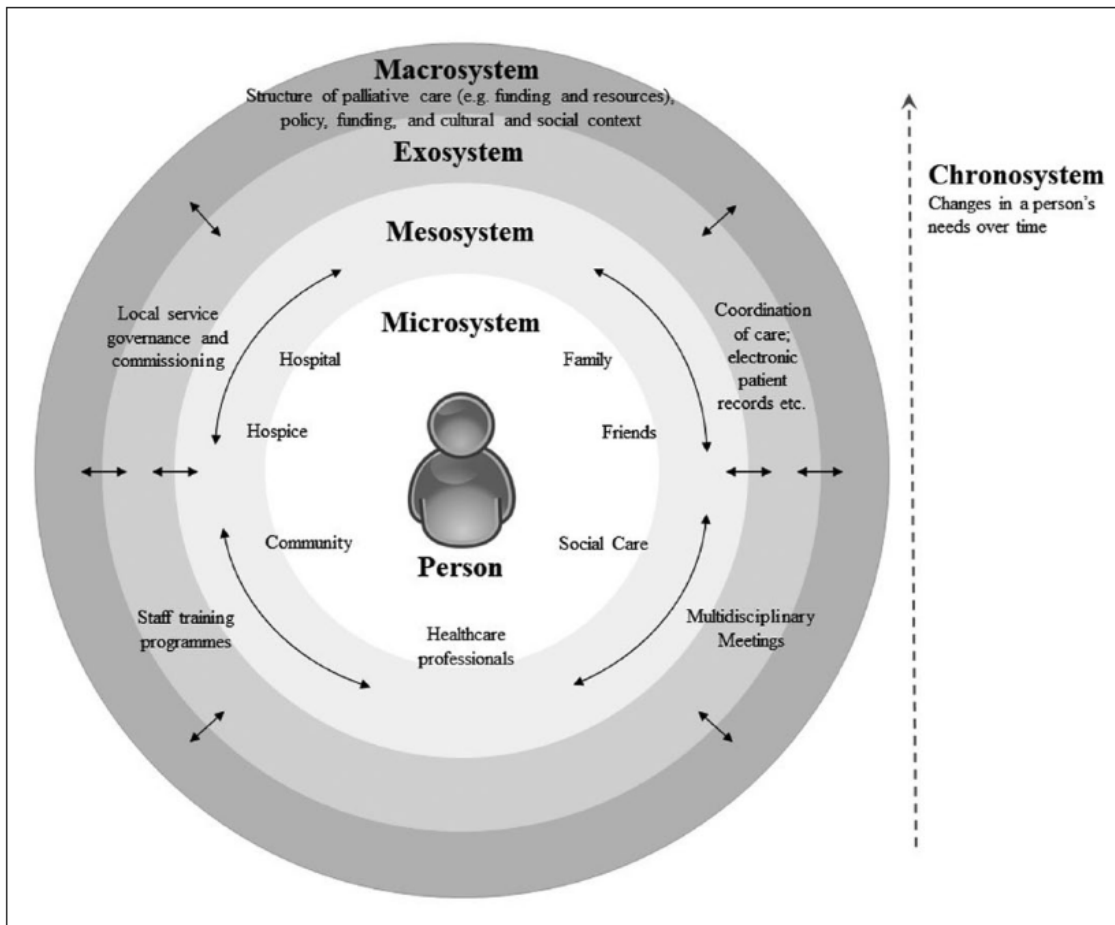
6 Method

6.1 Study Design

A qualitative study design with semi-structured interviews was applied to meet the aim of this study. Qualitative approaches can provide detailed descriptions of healthcare professionals' experiences in supporting children with ID in palliative care. Capturing participants' experiences and individual reality is a crucial aspect of qualitative research (Creswell, 2009). It may facilitate the improvement of healthcare, especially in terms of patient needs and psychosocial support (Leung, 2015).

6.2 Sample Selection

Participants were selected using a purposeful sample technique. Participants were sought who could provide the most meaningful information on the issue of interest (Lapan et al., 2012; Vanderstoep & Johnson, 2008).

Twenty-one pediatric palliative care providers were contacted via phone or e-mail to find potential participants. The person in charge of the institution was contacted and worked as a gatekeeper to recruit participants in the institution. An information letter about the study was attached to the e-mail or sent after the phone call. The contacted institutions were located in different parts of Germany.

Seven participants agreed to participate in this study and received the information letter with an attached consent form (see Appendix A). All participants were working in pediatric palliative care settings during the process of data collection. Participants met the following inclusion criteria: They had work experience in a pediatric palliative care context in Germany and supported children with ID around dying, death, and grief. The participants had experiences in psychosocial support for at least one child with ID. All participants worked in a children's hospice. Information about the participants is provided in Table 1.

Table 1

Participants

Partici-pant IN	Professional background and role	Work experience in palliative care
P1	Social worker, bereavement and end-of-life counsellor, head of the pedagogical team	10 years
P2	Music therapist, part of the pedagogical team	5 months
P3	Educator, part of the pedagogical team	5 years
P4	Educator, head of the pedagogical team	8 years
P5	Nurse, bereavement counsellor, part of the bereavement support team	5 years
P6	Nurse	4 years
P7	Pediatric nurse, family counsellor and therapist, alternative practitioner	16 years

Note: IN = identification number

6.3 Instruments

A semi-structured interview guide was developed to meet the aim of the study (see Appendix B). The interview guide aimed to capture participants' experiences in supporting children with ID, possible barriers, and facilitators. The interview questions were organized into six topics, covering the following aspects: *background* (work experience, profession), *general support* (content of support, case description), *support needs* (influence of disability on support needs and provision), *communication* (way of communication, tools, death conversation), *facilitators* (helpful in supporting children with ID), and *barriers* (challenges, problem identification). The interview guide was first developed in English and then translated into German. The German version of the interview guide was used during the data collection.

6.4   Data Collection

Data for this study was collected in semi-structured interviews on the video call platform Zoom. The participants were asked which time is convenient for them to share their experiences. The interviews were conducted in German and lasted between 30 to 50 minutes.

All interviews were audio recorded, and notes were taken during the interviews to document impressions and follow-up questions. After each interview, the researcher reflected on the interview and documented impressions and thoughts. Field notes during and after the interviews can support researcher's interpretation of the findings (Merriam, 2009).

6.5   Data Analysis

The software NVivo was used for the interview transcription and data analysis (QSR International, 2023). Emotional reactions were transcribed additionally to the semantic content of the interview to capture potential latent processes (Lapan et al., 2012). Latent themes could be underlying assumptions, ideas, and conceptualizations of the participants (Braun & Clarke, 2006). All participants were asked if they want to review the transcript and their given answers, to ensure the accuracy of the transcription. Three participants agreed and confirmed the interview transcription.

The collected interview data was analyzed by applying inductive thematic analysis, following the guideline of Braun and Clarke (2006). The focus of the analysis was on the semantic content. However, the latent content was taken into account when considering the attitudes of the participants. The transcriptions were read multiple times and analyzed continually, which included open coding, category creation, and the development of abstract themes. Codes, sub-categories, and categories were developed directly from the data to identify relevant content and evolve an appropriate interpretation of findings (Leavy, 2017). Citations from participants were used to define categories and sub-categories. The final themes, categories, sub-categories, and representative examples were translated into English. An external person who is bilingual in German and English verified the translation.

6.6   Role of the Researcher

Qualitative methods require researchers' reflection on their experiences, assumptions, values, and role in the research process to clarify biases that can influence the results (Creswell, 2009). The researcher of this study did not work in palliative care settings when the study was conducted. Palliative care providers and participants in this study were not known to the researcher before the research process. The researcher, however, worked as a volunteer in a children's hospice and a palliative care provider for adults. A certified course for counseling and support

for dying adults and their relatives was completed, which focused on bereavement counseling as part of a volunteer position. The researcher's experiences may have shaped perceptions about palliative care provision, which were critically reflected upon by the researcher throughout the research process.

6.7 Credibility, Trustworthiness, and Transferability

Credibility and Trustworthiness describe the appropriateness of the research method, processes, and the collected data to meet the aim of the study (Leung, 2015). Including the researcher's ability to use methods that capture participants' views and reality, to enhance the trustworthiness of the findings (Denzin & Lincoln, 2017). Transparency and a systematic research process enhance the study's quality and the validity of the results (Meyrick, 2006). To ensure the authenticity and trustworthiness of the collected data, interview transcripts were sent to participants. The research process and creation of categories and themes were discussed continuously with another researcher to reduce personal bias and increase the trustworthiness of the process. The data analysis was performed with the original interview transcripts and only the results were translated into English, to avoid threats to the credibility of the process. The researcher translated all quotations which were reviewed and confirmed by an external person who is bilingual in English and German, to increase the trustworthiness of the translated examples. Thick descriptions and many examples from the data were used to enhance the trustworthiness of the findings, as well as clarification of the researcher's potential bias.

6.8 Ethical Considerations

6.8.1 Confidentiality

It is the researcher's responsibility to protect the rights, needs, and values of the participants throughout the whole research process (Creswell, 2009). The collected interview data is confidential and only accessible to researchers. Personal information, including names and contact details, was stored separately from the interview recordings and transcriptions to ensure confidentiality. The names of participants, children, and places were made unrecognizable already during the transcription. Participants' identification numbers were used from the beginning of the transcription process to not allow any conclusions to be drawn about their identity.

6.8.2 Informed Consent

Informed consent is crucial to ensure that every participant is informed about the research process, possible risks, and their rights and that they understood the provided information (Vanderstoep & Johnson, 2008). All participants received an information letter about the research and confirmed orally or in writing that they understood the information and agreed to participate

(see Appendix A). The oral consent was recorded before the interviews started. The information letter was written in German and included details about the study aim, the researcher's background and contact details, data collection, possible risks and benefits of participating, and confidentiality of the data.

6.8.3 Possible Risks

It is the researcher's responsibility to reduce participant risks and increase the benefits of participating in the study (Lapan et al., 2012). Potential harm to participants needs to be assessed by the researcher and shared with the participants (Creswell, 2009). In this study, participants were not at risk of physical or psychological harm, since they were asked to share their work experience. All participants worked in pediatric palliative care, so they were confronted with death and dying and trained in that field. However, sharing experiences connected to death, dying and grief may evoke negative memories and emotions. Participants were informed that they can decline to answer certain questions if they wish to and that they can withdraw at any time from the research.

7 Results

Following an inductive thematic analysis, three main themes were identified, which were further specified in categories and sub-categories (see Table 2). Psychosocial support around death, dying, and grief was provided to children with ID in different forms, however, the communication about death and dying was highlighted by the participants as a vital and challenging aspect of support. An overview of themes, categories, and sub-categories with examples is given in Appendix C. The first theme *Communication about death and dying involves both verbal and non-verbal means* answered the first and second research questions "How do professionals in palliative care support children with ID around dying, death, and grief?" and "How do professionals communicate with children with ID about dying, death and grief in palliative care?". It was further divided into three categories *Child-friendly media facilitate communication about death and dying*, *Incidents facilitate communication about death and dying*, and *Children's individual death perception is used for communication*. The second theme *Child-centered interventions are employed to enhance the child's well-being* answered the first research question and captured various support provided by professionals. It included the categories *Activities and trips are used to make the child have a good time*, *Being there is a key factor of support*, *Various forms of therapy are utilized for psychosocial support* and *It is important to empower parents to support their child*. The third theme *Personal factors of involved individuals influence the support provision* captured aspects that affect psychosocial

support. The three categories within that theme were *The support is dependent on the individual needs and condition of the child*, *Addressing the issue of death and dying depends on the parents' wishes* and *Support provision is influenced by professionals' attitude and approach*. Facilitators and barriers were summarized at the end to answer the third research question "What are the facilitators and challenges that professionals experienced when supporting children with ID around dying, death, and grief in palliative care?".

Table 2

Themes, Categories and Sub-Categories

Themes	Categories	Sub-categories
Communication about death and dying involves both verbal and non-verbal means	Child-friendly media facilitate communication about death and dying	
	Incidents facilitate communication about death and dying	Death communication took place when another child died
		Communication took place in form of goodbyes and preparations before the child's death
	Children's individual death perception is used for communication	
Child-centered interventions are employed to enhance the child's well-being	Activities and trips are used to make the child have a good time	
	Being there is a key factor of support	
	Various forms of therapy are utilized for psycho-social support	
	It is important to empower parents to support their child	
Personal factors of involved individuals influence the support provision	The support is dependent on the individual needs and condition of the child	
	Addressing the issue of death and dying depends on the parents' wishes	
	Support provision is influenced by professionals' attitude and approach	Professionals' fear and grief can influence the support provision
		Sensitivity of professionals is required to detect children's needs
		Professionals' attitude towards children's capacity to understand death influences the support provision

7.1 Communication About Death and Dying Involves Both Verbal and Non-Verbal Means

Communication was found to be a crucial part of psychosocial support around death, dying, and grief. Participants mentioned various approaches to death communication, the utilization of media, incidents, and children's ideas about death. The form of communication was always individually adapted to the child's perceived needs and communication abilities.

Communication with non-verbal and severely disabled children happened a lot through body language and eye contact, which was interpreted by the professionals. Professionals responded verbally or with physical contact to the perceived needs of the child. They described that it requires a lot of patience and empathy, and it was easier to respond to the needs when they knew the child. However, all participants mentioned that it can be difficult to identify the need for addressing death and dying in non-verbal children. P1 mentioned the dilemma of professionals wanting to address needs, but not being sure what the child really wants:

> I don't have to say that they are dying now, but I can only say I understand. So that's what I often say, I think I understand. I don't know a hundred percent what you want to tell me now, but I think I understand.

Children who were able to communicate verbally confronted the professionals sometimes with direct conversations about their death. Besides planning the funeral, some children asked about their illness and how it is going to end. Such conversations were often quite short, integrated into activities, and direct, like in an example given by P7: "My grandma is dead... She's gone. Will I be gone too?". Direct and verbal communication about their death and dying, however, needed to be initiated by the child to not confront them with the difficult topic when they were not ready to talk about it.

7.1.1 Child-Friendly Media Facilitate Communication About Death and Dying

Stories, books, symbols, and play were mentioned by the participants as child-friendly ways of addressing death and dying. The tools facilitated death communication and allowed the children an easier approach to the topic of death and dying, always leaving room for the child's own imagination.

> And a lot of the work happens over symbols, over stories, which, which... develop a cautious framework for this topic... And we try to build some sort of a bridge, so to speak, so that the children have the opportunity to deal with this

topic on their own, depending on what is on their mind, and find a way to deal with it (P4).

Stories and books were used by most participants to address the topic of death and dying in an easily accessible way. They often had animal analogies and were integrated into the support to provide the possibility for questions. Sometimes they were combined with subsequent creative projects to further address the subject.

Symbols from nature were used to explain and demonstrate the changing nature of living and dying. The caterpillar who becomes a butterfly, the growth and death of plants, the change of seasons, and the constant transformation in nature were given as examples by the participants. Symbols were used in grief rituals and the general thematization of death, since "in our nature there is always some sign to pick up on" (P7). In grief rituals, symbols were made or used that were associated with the deceased child. Those were sometimes placed in the coffin or kept as mementos. However, symbols or expressions that are embellishing or formulate an idea of what might be after death should be critically considered and always reflected upon, according to P4. P4 also highlighted the dilemma of child-friendly language and embellishment of death, because "symbols are also a form of embellishment, definitely, but... Well, we try to approach it in such a way that it is child-appropriate".

Play was mentioned as an important resource in capturing the emotional situation and relevance of the subject for children, especially concerning non-verbal children. They were able to express through play whether the subject of death is relevant to them at the moment, to which professionals could then respond with appropriate support. With verbal children, play was used to initiate conversations about death and dying, as described by P3:

> Sometimes there are hints in play, for example, when you realize, that one character, or that one doll, it feels like it's somehow dying every day, or the knights are all just beating each other to death… Then you can already see hints, which of course you can start with. Why is the doll dying now, or, why are the characters killing each other all the time? That is always quite useful.

7.1.2 Incidents Facilitate Communication About Death and Dying

Death communication took place when another child died

The death of a sibling or another child in the hospice led to communication about death and dying. Five participants reported a small number of cases where children with ID

experienced the death of their sibling. This mostly happened when both children had the same genetic disease. Honesty and clear language were mentioned by P2 and P4 as a crucial part of death communication. They said it is important to say that the person died, and all body functions stopped instead of using metaphoric language. Body contact and seeing the deceased sibling was mentioned by P2 as a good way of working with children with ID to help them realize that death has occurred:

> If you just say it, you don't know if they understand, but then maybe if you have the opportunity, like we do in hospice, to say, here your brother died, do you want to go into the room again and look at him?... Or simply to leave the door open and to signal to him, hey, your brother is in there, he has died, if you want, you can go see him again. And then, yes, there's a lot more to it than just saying that. Then he can look at him and can feel how he feels and then he realizes, okay, my brother is completely cold (P2)

Professionals mentioned that it happened often that another child died while children were staying in the hospice. Children with ID were also informed about the death of another child if their parents agreed. For the deceased children, a grief ceremony was usually carried out in the form of saying goodbye, singing, and escorting them out of the hospice, where other children and families were allowed to join if they wished to. Since hospice care starts with the diagnosis of a life-limiting disease, some families and children met before, knew each other, and were involved in the ceremony.

Communication took place in form of goodbyes and preparations before the child's death

Some children initiated conversations before their death in form of goodbyes or discussions regarding their funeral. Some children who were able to verbally communicate their wishes and planned their funeral with professionals or parents. P7 mentioned that some children did not pass away until the parents had spoken to them again and given permission to die when the parents had problems letting go. Most of the reported pre-death communication was non-verbal due to the child's condition. Body language and physical contact played a significant role in goodbye situations, as highlighted by P1:

> And no matter if they can speak or show it, by holding hands or holding each other, hugging and crying... […] I didn't have to say any phrases to her, and I didn't have to tell her how beautiful everything was, because we knew that. We

knew we had a good time together, but we knew that we were saying goodbye now.

7.1.3 Children's Individual Death Perception is Used for Communication About Death and Dying

Participants mentioned the need for being careful with presenting ideas of what happens after death. However, if the child had an imagination of death, they worked with that idea to facilitate the conversation. The death perception varied according to family beliefs, religion, and if a death in the family occurred. Meeting deceased grandparents again was a perception mentioned by P1 and P7.

> Especially with, with children who are also disabled, then it's also little things, what they, what, when they tell you, yes, when I die or when my brother or my sister dies, then I imagine it like this and like that. And then just go into it, whether it's a rainbow bridge, at a lake somewhere, they have very special ideas and so on. And I believe that simply responding to this is already the first step towards making things better in any case. (P2)

7.2 Child-Centered Interventions are Employed to Enhance the Child's Well-Being

Psychosocial support was not limited to communication about and around the topic of death, dying, and grief, but also provided in form of activities, trips, crafts, and different therapies to make the children feel good. Spending time with the children and being with them was mentioned as a crucial factor of psychosocial support, as well as supporting and involving the parents to enable them to support their child.

7.2.1 Activities and Trips are Used to Make the Child Have a Good Time

A main aspect of support for children in palliative care was to "simply have fun with the children" (P4) and "making the kids have a good day" (P1). Activities and trips were an important part of psychosocial support and were mentioned by all participants. P2 emphasized the importance of activities for children by saying "I always notice that through activities, through trips, through creative offers, you get much further in some things than if you would talk".

7.2.2 Being There is a Key Factor of Psychosocial Support

Being there with the child and spending time together was another crucial aspect of psychosocial support. It was important to "simply signal to the child, I am here" (P2) to build a relationship and trust. Especially when children were sad, worried, or afraid,

the part of being there and not leaving the child alone with the worries became especially relevant. The presence was often combined with physical contact in the form of holding hands. P4 gave the following example:

> To accompany the child, to be there, especially when, for example, there is fear of being alone in such a situation, that we can be there, hold hands and say you can, I, I'll stay here sitting by the bed, I won't leave, I'll hold your hand, you can close your eyes, I'll be there when you open them again. When the kids need to get some rest. And I stay with you.

7.2.3   Various Forms of Therapy are Utilized for Psychosocial Support

The forms of therapy mentioned by the participants were music therapy, art therapy, aroma therapy, and animal-assisted therapy. P2 mentioned that music and art can be seen as aids so "children have the possibility to express something without language, feelings, emotions". Aroma therapy was utilized in the hospice because "you can also support the emotions with aromas. So, there are brightening aromas, or... Yes, which make everything easier or which help to process things or brighten the mood" (P5).

7.2.4   It is Important to Empower Parents to Support Their Child

Psychosocial support for the child was often connected to parent support since they were the primary contact, care, and support provider for the child. It was also important to show the child that the parents were also taken care of. The professionals' role also allowed showing parents new ways of interacting with their child, especially when the treatment was not age-appropriate due to the disability. A crucial aspect of empowering parents was to prepare them to discuss everything openly with their child, as mentioned by P3:

> And we also try to support the parents by saying, be open with your children, explain it to them. It's not easy, but […] it's not as bad as everything that children paint in their minds from what they may hear only with one ear, or from what they see on television, what death means, or from pages on the internet.

7.3   Personal Factors of Involved Individuals Influence the Support Provision

The presented forms of psychosocial support for children with ID were influenced by different factors. P4 highlighted that the support "depends not only on the disease or the intellectual disability, but also on all the other factors... Age, developmental stage, family environment…". The findings indicate that support provision was influenced by

the child's condition and functioning, parent's beliefs and needs, and professionals' attitude towards ID and their approach.

7.3.1 The Support is Dependent on the Individual Needs and Condition of the Child

The support provision was dependent on the child's health, disability, functioning, needs, and on the type of stay. In pediatric hospice, there are both respite stays when the children are not in an acute life-threatening situation and are relatively well, and final stays in crisis situations or when the state of health deteriorates rapidly. Professionals mentioned that hospice care provision starts with the diagnosis of a life-limiting disease and families might receive support over several years. Thus, the need for support around the topic of death, dying, and grief was often not there and other aspects were in the foreground.

The child's functioning and the severity of the disability were mentioned by all participants as crucial influencing factors in support provision. Participants mentioned that most children in hospice have limited cognitive functioning, except children with oncological or neuromuscular diseases. Since all children had different diseases, disabilities, or functioning, participants emphasized the need to always adapt to each child individually. The communication abilities of the child were the determining factor here, since "you get almost no response from some children" (P1). That influenced the content and approach of support and, according to P6,

> You really have to rely a lot on your instinct. On observation, of course, you have to keep a close eye on the children and observe them very well in order to see... If you don't know... we have some children who don't give you anything in response, neither a smile nor anything else.

Support provision is "depending on what the children's needs are. That varies a lot" (P4). Some children needed calm offers or discussions and others wanted activities, depending on their preferences and situation. Limited functioning in communication, however, often made it difficult to identify the child's exact needs. Professionals did not address the child's death unless the child initiated the conversation. P4 stressed that it is important to

> don't follow your own impulses or... needs, but really always look exactly what the child needs. So, it cannot be my need to talk about the death or the dying of the child, but to see if it is really the need of the child. And if it is, what is the

child's need and then respond accordingly, for example, if communication is difficult, that we look for ways to make it possible.

7.3.2 Addressing the Issue of Death and Dying Depends on the Parents' Wishes

The background, religion, and death perception of parents played a significant role in the support provision, especially regarding conversations about death and dying. Whether professionals were allowed to address the topic of death and dying was largely dependent on parents' wishes. All parents were asked how they handle this topic in the family and how they want professionals to deal with it. In rare cases, parents did not want the topic to be addressed at all, due to religious beliefs or to protect the child. Some parents, however, asked the professionals to talk to their child about death and dying when they were afraid of addressing the topic and some children preferred to talk to professionals to not burden their parents. P7 said:

> That is what you experience, every now and then, that the parents don't want to talk about it... that... because, what we just had before, speaking things into existence when I talk about that. Sometimes it's also influenced by culture, that, depending on the beliefs of the family, that you don't talk about death.... That also happens from time to time, and then you have to see how to deal with it.

7.3.3 Support Provision is Influenced by Professionals' Attitude and Approach

Professionals' fear and grief can influence the support provision

Fear among professionals of addressing death could influence the support provision, because

> if I'm afraid of it as an adult, then I ignore the sentence, grandma is dead, then you can say, ah, did you love grandma? Has she been dead for a long time? Or, what, what reminds you of your grandma? Or something. I can take that in... or I can look out and say, oh, look how nice the sun is shining (P7)

Children would recognize if professionals cannot handle the conversation and would not further address the topic. P2 also mentioned fear to address the topic directly in the beginning by saying "I was afraid at the beginning when I met him to ask him, hey, how do you deal with it, because he knew he was going to die". However, all professionals said they would not avoid the topic of death and dying, since it is part of their working life. Professionals reported that it can be challenging to provide support and keep the professional role when they were also affected by the death and experienced grief.

Sensitivity of professionals is required to detect children's needs

Supporting children with ID around death, dying, and grief required a lot of sensitivity and empathy of professionals, especially regarding non-verbal children. Since many children could not express their needs verbally, professionals needed to be sensitive and interpret the signals of the child. Many professionals said it is important to put themselves in the child's position to assess potential needs. The need for constant reflection on their approaches and if they really understood and met the child's needs was another important aspect of support. Patience was mentioned as a key factor throughout the different forms of support, since it may take time to understand the child and find ways of meeting the child's needs which also required some creativity. According to P2 "that's what's important, just this point of being patient, giving time and paying attention to small details".

Professionals' attitude towards children's capacity to understand death influences the support provision

The attitude towards the capacity of children with ID to understand death varied among professionals and influenced their support provision. Many professionals mentioned that since they did not know what the non-verbal or severely disabled children could understand, they communicated with them like with other children. Intellectual disability was more seen as a relevant aspect that need to be considered in the approach of the topic rather than the general capacity to understand. P2 mentioned the human rights aspect by saying "I think that people with intellectual disabilities have every right to know the truth and also the, the complete truth" and "I strongly believe that children can understand that, also with intellectual limitations or disabilities". It was highlighted that it is not dependent on intellectual disability if there is a need to address the topic and capacity to deal with it, but various individual factors.

On the other hand, professionals compared the ability of children with ID to understand death and dying with much younger children or babies which influenced their way of communication. P5 saw the need for support more on the physical level than on a psychological level due to limited cognitive functioning:

> I don't know why I should talk about dying with an intellectually disabled child who can't cognitively grasp it. It's more about something like body contact […] they can't process it cognitively and think about it anyway, because they often have a way of being, that is, they perceive life more as being than about the

body, how do I feel, somehow? […] even when they're in the process of dying, I think, they don't think about it, instead it is more of a... process, feeling, how am I doing, what do I need, maybe towards the outside, but not thinking, somehow.

7.4 Barriers and Facilitators in Supporting Children with ID Around Dying, Death, and Grief

Barriers and facilitators regarding psychosocial support provision for children with ID could be found across themes. Facilitators in supporting children with ID around death, dying, and grief were found in media, incidents, and imaginations of the child, which made it easier to access the topic. Physical contact was mentioned as an important facilitator in all forms of support provision for children with ID. Parents were a crucial resource in the support provision since they knew their child best and helped professionals in interpreting the signals and needs of the child. In some cases, however, parents did not want the topic to be openly communicated and professionals had to adapt to parents' wishes. Cooperation between different professionals was mostly seen as a facilitator. Professionals discussed in team meetings how children reacted to different support offers, what worked, and what could be improved. P1, however, mentioned that the opinion about children's needs sometimes differed between professionals, especially regarding a medical or psychosocial perspective. Better communication would help improve support, both in medical and psychosocial means.

The most frequently mentioned barrier in the support provision was communication, which affected all themes. It was often difficult for professionals to identify the need for addressing death and dying in non-verbal children. They were often insecure if they interpreted the child's needs correctly. It was emphasized that the topic of death, dying, and grief was only addressed directly when the child was able to communicate the wish, to not arouse fears or worries that could not be further communicated due to limited communication abilities. Children indicated discussion needs and made offers to communicate about death and dying, which was a facilitator when professionals were able to see it and react accordingly. Patience, empathy, and sensibility were key facilitators in the support provision because professionals had to sometimes guess what the child's needs were and interpret their signs. Knowing the child and their way of communicating facilitated the support provision.

The perceived capacity of children to understand death and dying was found to be both facilitator and a barrier. Professionals' attitudes worked as a facilitator for support provision when they were aware of the children's right to be informed and treated those children like every other child since they did not know what can be understood. Barriers were found when professionals compared the communication needs of children with ID with the needs of babies or much younger children. Denying any communication needs about death in children with ID was also identified as a barrier.

8 Discussion

Duc et al. (2017) stressed the lack of studies examining the intersection of pediatric palliative care and children with ID. The present study provided insight into professionals' experiences in providing psychosocial support for children with ID around death, dying, and grief in palliative care. Participants hereby focused largely on communication about death and dying and the barriers and facilitators that are particularly relevant in supporting children with ID. As mentioned by the participants of this study, palliative care provision for children with ID is highly individualized and adapted to the child's needs and abilities. The complexity of influencing factors like age, disability, family needs, and health status of the child was highlighted. Disability was not seen as the determining factor, but as one aspect among many, which was most relevant when it came to the way of communication. Pask et al. (2018) captured the complexity of palliative care provision for adults which was adapted in this study to pediatric palliative care for children with ID. Chambers (2018) described pediatric palliative care as a dynamic and active healthcare service from diagnosis to death and bereavement. It is crucial to understand the complexity to provide effective and need-oriented care. The complexity mentioned by Pask et al. (2018) was found regarding the individual that receives palliative care (microsystem), their dynamic and changing needs and illness over time (chronosystem), the individual's interaction with professionals, family, and immediate environment (mesosystem), the palliative care service (exosystem), and societal and cultural influences (macrosystem). The discussion of the results was structured according to these aspects of the conceptual framework for complexity in palliative care (Pask et al., 2018).

According to the framework, the *microsystem* refers to the person who receives palliative care, the individual characteristics and needs which directly influence the complexity of care (Pask et al., 2018). The individual needs of each child were emphasized by

all participants in this study as a guiding factor in providing psychosocial support. Professionals mentioned that most children in pediatric palliative care have limited cognitive functioning either due to their disease or diagnosed ID. Sometimes it was difficult to say if official diagnoses of ID existed and what was caused by the illness since some conditions affected the brain functioning. This was also mentioned by Duc et al. (2017), who highlighted that many children in pediatric palliative care have an undiagnosed ID because of the comorbidity in children receiving palliative care. However, for professionals in this study, the child's communication ability was the determining factor for psychosocial support around death, dying, and grief and not the diagnosed level of ID. Other influential factors were the children's age and health condition.

Although Pask et al. (2018) did not focus on children or individuals with ID, similarities in the influence of age, health status, and communication needs were found. The insecurity regarding children's capacity to understand death and dying was mentioned as a challenge for professionals. Downing et al. (2015) emphasized the need for research about children's understanding of death and dying since it plays an important role in the care provision. Research about adults with ID suggests a part to full comprehension of death, associated with the level of ID (Chow et al., 2017; McEvoy et al., 2012). However, knowledge about death understanding in children with ID is lacking. The influence of the degree of ID was also mentioned in this study, whereby the focus here was more on communication capabilities.

Zernikow et al. (2017) reported that a child in pediatric palliative care cannot be treated separately from the family, which was confirmed in this study. Although the sick child is at the center of care and the child's needs are the determining factor, participants highlighted that pediatric palliative care always focuses on the needs of the whole family. This finding was also emphasized in the literature regarding pediatric palliative care (Kronberger-Vollnhofer & Nemeth, 2016; Zernikow et al., 2017). Chambers (2018) suggested that the child and their family need to be at the center of care planning and provision. A holistic and family-centered approach in pediatric palliative care is especially crucial for children with ID (Duc et al., 2017). Participants in this study emphasized that psychosocial support, especially regarding communication about death and dying needed to be discussed with the parents first.

The *chronosystem* captures changes in the child's needs and health (Pask et al., 2018). Since pediatric palliative care is provided from the diagnosis of the life-limiting illness

and might continue over many years (Zernikow et al., 2017), the need for death-related support might not be relevant most of the time. In this study, death communication was more important when the child's condition got worse or when another child or sibling died. However, communication about the child's own death needed to be initiated by the child and was therefore highly dependent on the child's changing needs and communication abilities, which might change in the course of the disease. There could be a risk that especially children with high support needs are less able to express it and their needs are not recognized when their functioning decreases. Participants mentioned that it is important to know the children and their communication to provide optimal support. Getting to know them requires time and continuity and can therefore be located at the chronolevel.

The *mesosystem* in the framework of Pask et al. (2018) focuses on the interaction between the individual that receives palliative care and their family or health professionals. Since the focus of this study was on the support provided by professionals for children with ID, most findings refer to the mesosystem. This was mostly between the child and the professional, although the family had to be asked before approaching the child with death-related communication. Psychosocial support was highly dependent on the communication abilities of the children, the way they could express their needs, and how the professionals interpreted the signs. Communication issues with non-verbal children with ID were a determining factor influencing psychosocial support around death, dying, and grief for children with ID. That was also reflected in professionals' insecurity about children's specific support needs and the need to address the topic of death and dying. Duc et al. (2017) stressed the importance of tailoring communication to the individual child and using unambiguous language. Participants of this study highlighted the importance of clear and honest communication about death and dying with verbal children, to facilitate children's understanding. This result is consistent with existing research literature about grief support for children with ID (Ducy & Stough, 2018; McClean & Guerin, 2019).

Communication about death and dying was often embedded in situations. The communication was mostly during and after play, affected by incidents and dependent on the empathy and awareness of the professionals and their ability to react to the situation. Using concrete incidents or symbols in nature for explaining the circle of life, including

death, is consistent with previous studies regarding death communication approaches with adults with ID (Lord et al., 2017; Wiese et al., 2014).

Participants of this study mentioned that communication with non-verbal children was characterized by physical contact, sensations, instinct, and verbal comments from professionals. Eye contact was considered important to detect changes and interpret small signs. Emotional expressions like tears or smiles were found helpful to detect children's needs and see their emotional state. Support for non-verbal children was highly dependent on professionals' interpretation of needs and signs and on parents' information provision. Children with ID have needs, preferences, and emotions similar to children without disabilities, regardless of their complex needs or communication abilities (Brown, 2014). They might express them by non-verbal or verbal means (Duc et al., 2017), which requires knowledge about the child and sensitivity of professionals. In this study, many professionals were insecure if they did the right thing or if they interpreted the child's communication correctly because they often did not get any response from non-verbal and severely disabled children.

Professionals would not start talking about heavy topics like the child's own death when not initiated by the child. A stated reason was to not awaken fears and needs for further support that cannot be provided due to communication difficulties. That the conversation needs to be initiated by the individual with ID was also highlighted in the literature about death conversations with adults with ID (Foo et al., 2021; Tuffrey-Wijne et al., 2020; Wiese et al., 2013). In the literature about children without disabilities was also highlighted that children need to initiate the conversation about distressing topics like death. However, the communication difficulties of some children with ID can make it harder to express the need for addressing the topic. The dependence on professionals' interpretation of the child's non-verbal signals makes it difficult for children with ID to gain access to this type of communication. Professionals' interpretation could be guided by fear to address the topic, which entails the risk of being unable or unwilling to notice certain cues and thus unconsciously limiting the rights of children.

Another factor influencing the support provision was professionals' attitude towards children with ID and their capacity to understand death, especially regarding non-verbal and severely disabled children. The risk that psychosocial support for individuals with ID is restricted when it comes to death-related topics was already highlighted in the

literature about adults with ID (Lord et al., 2017; Stancliffe et al., 2021). Children without disabilities also experience limited access to death-related information (Paul, 2019), which suggests an increased risk of children with ID. The attitude of professionals towards children's capacity to comprehend death has been identified as a risk factor for limited psychosocial support for those children (Sormanti & Ballan, 2011). In the present study, however, beliefs about cognitive ability and the need to address the topic of death were inconsistent. Most participants emphasized that they could never be sure what is perceived by the child, so they communicated with them like with other children. One professional specifically highlighted the right of children with ID to receive information equally with others and in their way of communication, which is in line with the Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Convention on the Rights of the Child (United Nations, 1989). Many studies, especially regarding adults with ID, found a high risk of individuals with ID not being involved in death-related discussions because of their inability to comprehend death (Brownrigg, 2018; Foo et al., 2021). In this study, however, only one participant was convinced that children with ID do not have the need to communicate about death and dying, since they would not have the capacity and would not think about it anyways. This demonstrates the high dependence of children with ID on professionals' attitudes about whether and to what extent children receive support, putting children with ID at risk of not receiving any psychosocial support.

The *exosystem* refers to systems and services that affect the support, but the child is not directly involved (Pask et al., 2018). The support provision for children with ID in pediatric palliative care was dependent on cooperation between different professionals. Team meetings and discussions of different cases were seen as facilitators in providing optimal support for children with ID. Professionals shared what worked or did not work for different children. Information provision from parents to professionals was crucial in understanding children's individual needs and communication since they could explain children's reactions and translate body language for the professionals. Connor and Corcoran (2021) stressed that parents are a crucial resource in providing effective and optimal care for children with ID. Parents should be seen as a facilitator since they know their child best and are aware of the baseline of their well-being (Duc et al., 2017). In the present study, professionals also supported parents, so they can support their children and communicate openly about death and dying.

The *macrosystem* in the framework of Pask et al. (2018) comprises the cultural and societal context of palliative care provision. This includes the structure of the health care system and cultural values like stigma and beliefs. The study's focus was on the support provided by professionals for children, limited information was given about the macrosystem. However, various factors on the macrolevel influenced the support provision, like the religious beliefs of the families and societal taboos.

Longbottom and Slaughter (2018) expounded on the problem that in Western societies children's exposure to death is increasingly limited. The socio-cultural tendency of removing death from everyday life may result in seeing death as a taboo subject. Walter (1991) suggests a theory of limited taboo, arguing that death is a taboo for certain groups in society, including children. The death taboo for this group due to their status as children and their developing intellect was also highlighted by Paul (2019). In the present study, one participant saw the presentation of death in in the media as an issue, because it might confuse children and awaken fears if things are not well explained to them. This issue is also reflected in adults' tendency to use euphemisms in death communication, avoid the topic and underestimate children's capacity to understand death (Longbottom & Slaughter, 2018). The argument of limited death comprehension in children could be seen as even more relevant in children with ID, reinforcing the taboo for this target group. In the present study, the limited understanding was used as an argument for denying children's needs for death-related communication. Paul (2019) highlights that experiencing and understanding death are contradictory, because even without fully understanding the concept children are responding to and experiencing death. This highlights the importance of support around death, dying, and grief regardless of the full comprehension of the subject. Moreover, if professionals and parents are reluctant in addressing the topic of death and dying, children have limited possibilities for learning about it and coping with it. This problem is even more prevalent in children with ID, who additionally face the societal stigma of limited understanding which might increase adults' unwillingness to address the topic.

Furthermore, the crucial role of parents and their beliefs in the support provision was highlighted in the present study. Matalon (1998) found that parents with increased death anxiety were also more avoidant when it came to death communication. The death-taboo, religious beliefs, and societal concerns about children's capability to cope with death-related information may limit the support provision for children with ID.

In summary, many of the findings were consistent with research findings on psychosocial support around death, dying, and grief for adults with ID. Especially ways of approaching the topic of death and dying, communication difficulties, and professionals' attitudes toward death comprehension in individuals with ID. This indicates similarities in the support provision, needs of individuals with ID, and challenges faced by professionals. However, the family-centered and holistic approach in pediatric palliative care adds complexity to this subject and was found to be especially crucial for children with ID since parents know the child best and can provide important information. Chambers (2018) emphasized the increased complexity of palliative care provision when it comes to the combination of disability and life-limiting conditions. This is reinforced when it comes to non-verbal children with ID and their increased dependence on adults' interpretations, attitudes, and needs. Furthermore, professionals might face the dilemma of meeting both parents' needs and children's rights. If the needs are not compatible with children's rights, rights and practices cannot always be easily combined. The wishes of parents who can express themselves verbally and know their rights as guardians are therefore more likely to be taken into account and children bear the consequences if parents are afraid of the death issue and do not want it to be discussed.

Due to the comorbidity in children receiving palliative care, there are many children with some degree of ID (Duc et al., 2017). This demonstrates the relevance of this issue for professionals in pediatric palliative care, who are likely to work with children with ID. Interestingly, not the level of ID was an important factor for professionals' support provision but the communication abilities of the child. Although the cognitive and communication difficulties were highlighted by all professionals as challenging, professionals' attitude towards children's capacity to understand death was identified as a risk factor for limited psychosocial support. Denying their needs for psychosocial care and comparing them to toddlers or babies is incompatible with children's rights to information and equality with children without disabilities (United Nations, 1989, 2006).

9 Limitations

Several limitations need to be acknowledged when interpreting the findings of this study. The research was conducted by only one researcher, which increases the risk of personal bias and reduces the credibility of the findings. The translation of participants' quotations is a limitation of the study because underlying meanings and nuances in the

expression might not be translated correctly. However, the translation was confirmed by a person who is bilingual in English and German.

Only seven professionals were interviewed, and all participants worked in pediatric palliative care settings in Germany, which limits the transferability of the findings. The interviews were conducted via Zoom and small disturbances in the internet connection interrupted the data collection in one interview. The interviewee changed the location and the interview continued without problems.

The utilized conceptual framework of Pask et al. (2018) was only partly suitable for the complexity of pediatric palliative care for children with ID since it did not include their specific needs. A framework focusing on the needs of children with ID in pediatric palliative care was not found and needs to be developed, with specific consideration of communication issues. The high dependence of children with ID on professionals' interpretation of children's needs must be taken into account in theoretical considerations. Also, the child should be with the family at the microlevel and center of care planning and provision.

Furthermore, only the perspective of professionals was captured in this study, which might differ from parents' and children's experiences.

10 Future Research and Practical Implications

The findings of this study provided insight into the experiences of professionals in dealing with children with ID on the topic of death, dying, and grief about which little research currently exists. More evidence is needed about psychosocial support for children with ID, especially regarding non-verbal or severely disabled children. Children's understanding of death and dying is another important research area that needs to be explored, including children with ID. Little is known about death perception in children with ID and their need for support around death, dying, and grief. Moreover, it is important to also capture the perspective of parents and children about psychosocial support provision in pediatric palliative care.

Furthermore, it is crucial to develop a theoretical framework that captures the specific needs of children with ID in pediatric palliative care with specific consideration of communication abilities. In this regard, it also needs the development of evidence-based guidelines for professionals to ensure high-quality support for this vulnerable group in pediatric palliative care.

11 Conclusion

This was the first study that gave insight into healthcare professionals' experiences in providing psychosocial support for children with ID around death, dying, and grief in pediatric palliative care. Stories, symbols, incidents, and children's death perceptions were used for approaching the subject. Support in the form of activities, therapies, and family support was also mentioned by participants. The support was found to be highly individualized to the children's needs and communication abilities. The children's communication was the determining factor for psychosocial support around death, dying, and grief and not the diagnosed level of ID. The issue of verbal and non-verbal communication and professionals' uncertainty about the children's needs permeated the findings and was the biggest factor influencing psychosocial support around death, dying, and grief for children with ID. All forms of support were dependent on communication, the ways children could express their needs, and how professionals interpreted the signs. The level of communication abilities also influenced professionals' attitudes towards ID and death comprehension. Cognitive and communication difficulties in children with ID were identified as a challenge for professionals when providing psychosocial support. Knowing the child and their way of communicating, however, was found to be a key factor.

Many of the findings were consistent with research on psychosocial support for adults with ID. However, children's age and the family-centered approach of pediatric palliative care added complexity to psychosocial support for children with ID. A conceptual framework that captures the needs of children with ID in palliative care, with the family at the center of support planning and provision needs to be developed. More research is required to capture children's and parents' perspectives on support provision around death, dying, and grief. Evidence-based guidelines should be developed to ensure optimal support for children with ID in pediatric palliative care.

References

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders: DSM-5-TR* (5th ed.). American Psychiatric Association Publishing.

American Psychological Association. (n.d.). Psychosocial support. In *APA Dictionary of Psychology*. https://dictionary.apa.org/psychosocial-support

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Bronfenbrenner, U. (1994). Ecological models of human development. *International encyclopedia of education, 3*(2), 37-43.

Brown, E. (2014). Supporting children and young people with an intellectual disability and life-limiting conditions. In S. Read (Ed.), *Supporting people with intellectual disabilities experiencing loss and bereavement* (pp. 184-195). Jessica Kingsley Publishers.

Brownrigg, S. (2018). Breaking bad news to people with learning disabilities: A literature review. *British Journal of Learning Disabilities, 46*(4), 225-232. https://doi.org/https://doi.org/10.1111/bld.12232

Bundesministerium für Gesundheit. (2022). *Versorgung von schwerstkranken Menschen und Sterbenden (Palliativversorgung)*. https://www.bundesgesundheitsministerium.de/palliativversorgung.html

Chambers, L. (2018). *A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families* (4th ed.). Together for Short Lives.

Chow, A. Y. M., McEvoy, J., Chan, I. K. N., Borschel, M., Yuen, J. H. L., & Lo, J. Y. M. (2017). Do men and women with intellectual disabilities understand death? *Journal of intellectual disability research, 61*(12), 1130-1139. https://doi.org/https://doi.org/10.1111/jir.12431

Connor, E. O., & Corcoran, Y. (2021). Caring for a child with a life limiting condition: The experiences of nurses in an intellectual disability service provider. *Journal of Intellectual Disabilities, 26*(4), 938–953. https://doi.org/10.1177/17446295211018588

Creswell, J. (2009). *Research Design Qualitative, Quantitative and Mixed Methods Approaches* (3rd ed.). SAGE.

Denzin, N. K., & Lincoln, Y. S. (2017). *The SAGE Handbook of Qualitative Research*. SAGE Publications.

Deutscher Hospiz- und PalliativVerband e.V. (n.d.). *Zahlen zur Hospiz- und Palliativarbeit*. Retrieved May 15, 2023 from https://www.dhpv.de/zahlen_daten_fakten.html

Deutscher Kinderhospizverein e.V. (n.d.). *Fachinformationen*. Retrieved May 15, 2023 from https://www.deutscher-kinderhospizverein.de/wie-wir-unterstuetzen/fachorganisation/fachinformationen/

Dodd, P., Dowling, S., & Hollins, S. (2005). A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of intellectual disability research, 49*(7), 537-543. https://doi.org/10.1111/j.1365-2788.2005.00702.x

Dodd, P. C., & Guerin, S. (2009). Grief and bereavement in people with intellectual disabilities. *Current Opinion in Psychiatry, 22*(5), 442-446. https://doi.org/https://doi.org/10.1097/YCO.0b013e32832e2a08

Downing, J., Knapp, C., Muckaden, M. A., Fowler-Kerry, S., & Marston, J. (2015). Priorities for global research into children's palliative care: results of an International Delphi Study. *BMC palliative care, 14*(1), 36-36. https://doi.org/10.1186/s12904-015-0031-1

Duc, J. K., Herbert, A. R., & Heussler, H. S. (2017). Paediatric palliative care and intellectual disability-A unique context. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 1111-1124. https://doi.org/https://doi.org/10.1111/jar.12389

Ducy, E. M., & Stough, L. M. (2018). Teacher Perspectives on Grief Among Children with Intellectual Disabilities. *Journal of Loss and Trauma, 23*(2), 159-175. https://doi.org/10.1080/15325024.2018.1434859

Dunkley, S., & Sales, R. (2014). The challenges of providing palliative care for people with intellectual disabilities: a literature review. *International journal of palliative nursing, 20*(6), 279-284. https://doi.org/10.12968/ijpn.2014.20.6.279

Dyregrov, A. (2008). *Grief in children a handbook for adults* (2nd ed.). Jessica Kingsley Publishers.

Feudtner, C., Kang, T. I., Hexem, K. R., Friedrichsdorf, S. J., Osenga, K., Siden, H., Friebert, S. E., Hays, R. M., Dussel, V., & Wolfe, J. (2011). Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study. *Pediatrics, 127*(6), 1094-1101. https://doi.org/10.1542/peds.2010-3225

Foo, B., Wiese, M., Curryer, B., Stancliffe, R. J., Wilson, N. J., & Clayton, J. M. (2021). Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews. *Palliative Medicine, 35*(4), 738-749. https://doi.org/10.1177/0269216321998207

Globisch, M. (2022). Definition und Grundsätze der Kinder- und Jugendhospizarbeit. In M. Globisch & T. Hillmann (Eds.), *Handbuch der Kinder- und Jugendhospizarbeit*. der hospiz verlag.

Haider, N.-u.-a., & Zaman, N. I. (2022). Bereavement among Adolescents with Intellectual Disability: A Qualitative Study. *OMEGA - Journal of Death and Dying, 0*(0), 1-15. https://doi.org/10.1177/00302228211065275

Jalmsell, L., Kontio, T., Stein, M., Henter, J.-I., & Kreicbergs, U. (2015). On the Child's Own Initiative: Parents Communicate with Their Dying Child About Death. *Death Studies, 39*(2), 111-117. https://doi.org/10.1080/07481187.2014.913086

Jennessen, S., & Burgio, N. M. (2022). *PraeKids: Erhebung der Prävalenz von Kindern und Jugendlichen mit lebensbedrohlichen und lebensverkürzenden Erkrankungen in Deutschland*.

Kronberger-Vollnhofer, M., & Nemeth, C. (2016). Hospiz- und Palliative-Care bei Kindern, Jugendlichen und jungen Erwachsenen. *Pädiatrie & Pädologie, 51*(6), 249-252. https://doi.org/10.1007/s00608-016-0424-2

Lapan, S., Quartaroli, M. T., & Riemer, F. J. (2012). *Qualitative research an introduction to methods and designs*. Jossey-Bass.

Leavy, P. (2017). *Research design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches*. Guilford Publications.

Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *J Family Med Prim Care, 4*(3), 324-327. https://doi.org/10.4103/2249-4863.161306

Lindley, L. C., Colman, M. B., & Meadows, J. T., Jr. (2017). Children with intellectual disability and hospice utilization. *J Hosp Palliat Nurs, 19*(1), 28-33. https://doi.org/10.1097/njh.0000000000000301

Longbottom, S., & Slaughter, V. (2018). Sources of children's knowledge about death and dying. *Philosophical Transactions of the Royal Society B: Biological Sciences, 373*(1754). https://doi.org/10.1098/rstb.2017.0267

Lord, A. J., Field, S., & Smith, I. C. (2017). The experiences of staff who support people with intellectual disability on issues about death, dying and bereavement: A metasynthesis. *Journal of Applied Research in Intellectual Disabilities, 30*(6), 1007-1021. https://doi.org/https://doi.org/10.1111/jar.12376

Matalon, T. H. (1998). *The relationship among children's conceptualization of death, parental communication about death, and parental death anxiety*. Fordham University.

McClean, K., & Guerin, S. (2019). A qualitative analysis of psychologists' views of bereavement among children with intellectual disability in Ireland. *British Journal of Learning Disabilities, 47*(4), 247-254. https://doi.org/https://doi.org/10.1111/bld.12284

McEvoy, J., MacHale, R., & Tierney, E. (2012). Concept of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of intellectual disability research, 56*(2), 191-203. https://doi.org/https://doi.org/10.1111/j.1365-2788.2011.01456.x

Merriam, S. B. (2009). *Qualitative research: a guide to design and implementation* (2 ed.). Jossey-Bass.

Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *J Health Psychol, 11*(5), 799-808. https://doi.org/10.1177/1359105306066643

Pask, S., Pinto, C., Bristowe, K., van Vliet, L., Nicholson, C., Evans, C. J., George, R., Bailey, K., Davies, J. M., Guo, P., Daveson, B. A., Higginson, I. J., & Murtagh, F. E. M. (2018). A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals. *Palliative Medicine, 32*(6), 1078-1090. https://doi.org/https://doi.org/10.1177/0269216318757622

Paul, S. (2019). Is death taboo for children? Developing death ambivalence as a theoretical framework to understand children's relationship with death, dying and bereavement. *Children & Society, 33*(6), 556-571.

QSR International. (2023). *NVivo*. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Sormanti, M., & Ballan, M. S. (2011). Strengthening grief support for children with developmental disabilities. *School Psychology International, 32*(2), 179-193. https://doi.org/10.1177/0143034311400831

Speece, M. W., & Brent, S. B. (1984). Children's Understanding of Death: A Review of Three Components of a Death Concept. *Child development, 55*(5), 1671-1686. https://doi.org/10.2307/1129915

Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltes, G., Barton, R., & Clayton, J. M. (2021). Does talking about end of life with adults with intellectual disability cause emotional discomfort or psychological harm? *Journal of Applied Research in Intellectual Disabilities, 34*(2), 659-669. https://doi.org/https://doi.org/10.1111/jar.12835

Tuffrey-Wijne, I., Finlayson, J., Bernal, J., Taggart, L., Lam, C. K. K., & Todd, S. (2020). Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff. *J Appl Res Intellect Disabil, 33*(5), 927-938. https://doi.org/10.1111/jar.12714

Tuffrey-Wijne, I., Giatras, N., Butler, G., Cresswell, A., Manners, P., & Bernal, J. (2013). Developing Guidelines for Disclosure or Non-Disclosure of Bad News Around Life-Limiting Illness and Death to People With Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 26*(3), 231-242. https://doi.org/https://doi.org/10.1111/jar.12026

United Nations. (1989). *Convention on the Rights of the Child*.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*.

Vanderstoep, S. W., & Johnson, D. D. (2008). *Research methods for everyday life: Blending qualitative and quantitative approaches*. John Wiley & Sons.

Walter, T. (1991). Modern death: taboo or not taboo? *Sociology, 25*(2), 293-310.

Wiese, M., Dew, A., Stancliffe, R. J., Howarth, G., & Balandin, S. (2013). 'If and when?': the beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. *Journal of intellectual disability research, 57*(10), 980-992. https://doi.org/https://doi.org/10.1111/j.1365-2788.2012.01593.x

Wiese, M., Stancliffe, R. J., Dew, A., Balandin, S., & Howarth, G. (2014). What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death. *Journal of intellectual disability research, 58*(7), 679-690. https://doi.org/https://doi.org/10.1111/jir.12065

World Health Organization. (n.d.). *Palliative care.* https://www.who.int/health-topics/palliative-care

Zernikow, B., Gertz, B., & Hasan, C. (2017). Pädiatrische Palliativversorgung – herausfordernd anders. *Bundesgesundheitsblatt - Gesundheitsforschung - Gesundheitsschutz, 60*(1), 76-81. https://doi.org/10.1007/s00103-016-2479-4

12 Appendices

Appendix A: Information Letter and Consent Form

<div align="center">

Information letter

Empirical study about psychosocial support for children with intellectual disabilities around death, dying, and grief in palliative care

</div>

My name is Maria Bonin and I hereby invite you to participate in my study about **psychosocial support for children with intellectual disabilities around death, dying and grief in palliative care**. As part of my Master thesis, I would like to conduct interviews with professionals in palliative care who have experiences in supporting at least one child with intellectual disabilities around death, dying and grief.

What is this study about?

This study investigates professionals' experiences in supporting children with intellectual disabilities in palliative care around death, dying and grief. Of particular interest is how to deal with topics such as death, dying and grief in interaction with children with intellectual disabilities. This includes children being confronted with their own death or experiencing the death of a relative who received palliative care. I would like to capture ways of engaging about this topic, facilitators, and challenges you experienced.

Who am I?

My name is Maria Bonin, and I am studying in the Master program "Interventions in Childhood" at Jönköping University in Sweden. I am from Germany and have a background in special education. I have experiences in working as a volunteer in a children's hospice and a hospice for adults, mostly in supporting everyday activities and visiting patients who wanted some company. Those experiences shaped my interest for this research area.

What will you be asked to do?

If you are willing to give me an interview, I would like you to share your stories and experiences of working with children with intellectual disabilities in palliative care. The interview will last approximately 30-45 minutes and can be conducted online via zoom or on the phone, according to your preferences. The participation is voluntary, you can withdraw at any time during the process (before, during or after the interviews) without any consequences. You can decide not to answer questions if you wish.

What are the benefits of participating?

You will have the opportunity to share and reflect on your experiences and perspective on supporting children with intellectual disabilities around death, dying, and grief. Little research is available about how to support those children. Your experiences can give an inside about professionals' experiences, faced challenges and facilitators in working with children with intellectual disabilities in palliative care. After participating you will get access to the final thesis to see the results of the study and read about other professionals' experiences.

What are potential risks?

You are not at risk of experiencing physical or psychological harm from participating in the study, as you are asked to share your experiences and perspective on supporting children with intellectual disabilities. However, the topic of this study is sensitive and could be emotional. Telling prior experiences could lead to negative feelings like grief and sadness. For that reason, you can decline to answer questions if you wish to and withdraw whenever you want.

Confidentiality

The collected data will be confidential and only accessible to researchers. The interviews will be audio recorded and transcribed using pseudonyms for names, places, and institutions. During the research process, no names or other personal information will be stored together with the interview data to ensure confidentiality of the participants. At the end of the research process, all audio recordings will be deleted. Before the analysis of the interview, you will have the possibility to receive the transcribed interview to review and confirm the accuracy of the transcription.

Consent

Before participating in the study, the attached consent form needs to be signed. With your signature you confirm that you understood the information and that you are willing to voluntarily participate.

If you have any questions or comments, please do not hesitate to contact me.

I am looking forward hearing from you

Maria Bonin

Contact information

Mail: boma21kd@student.ju.se

Phone: +46736704754

Jönköping University

Gjuterigatan 5

Box 1026

55111 Jönköping, Schweden

Consent Form

I hereby confirm that I received and read the information letter about the empirical study about **psychosocial support for children with intellectual disabilities around death, dying and grief in palliative care.** I understand that I can withdraw from participation at any time and without justification. By signing this form, I confirm that I have understood all the information and that I am participating voluntarily in this study.

Date and Signature

Full name

Appendix B: Interview Guide

- Thanks for participating.

- Inform about right to withdraw and possibility to not answer certain questions.

- Audio recording

- Do you have any questions before start?

Topic	Possible Questions
Background	• Could you please say some words about your profession and your work environment/responsibilities? • How many years of work experience do you have?
General support	• Could you please describe your experiences in working with children with ID in palliative care? • Could you describe one or more cases where you supported a child with ID in palliative care? • What are aspects of the provided support? How does the support looks like? • What do you consider most important in supporting children with ID?
Support needs	• Do the support needs of children with ID differ to typically developing children? If yes, in what way? • To what extend did the disability influence the support provision? • Why do you think children with ID need more/less support?
Communication	• Could you describe if and how you communicated with the child about death and dying? And how about grief? • Did you inform children with ID about their condition? / Their relatives condition? • Did you use any tools for communicating about death, dying or grief?
Facilitators	• What did you consider helpful in supporting a child with ID? • When you look back on your experiences, what worked well? And why?
Barriers	• What challenges did you experience in supporting a child with ID? • When you look back on your experiences, what did not work well or what would you do differently?

End:

- Is there something else you would like to add that we did not discuss?

- Want to receive the transcription and thesis?

- Feel free to contact me if you would like to add something or questions arise

Appendix C: Themes, Categories, and Sub-Categories with Examples

Themes	Categories	Sub-categories	Examples
Communication about death and dying involves both verbal and non-verbal means	Child-friendly media facilitate communication about death and dying		*"There are many animal analogies, we have quite a few and they are nice, the stories. You can also use one and read it out loud and wait to see if it raises any questions"* (P3) *"We also have various books as tools, where dying, death and grief is addressed in a child-friendly way, which you can then integrate thematically"* (P4) *"What is somehow upcoming right now, in our nature is always some sign to pick up on"* (P7) *"What is often used as a symbol is the caterpillar, which becomes a butterfly, is a common symbol, which can be used well... With flowers, with rainbow"* (P4) *"Sometimes there are hints in play, for example, when you realize, that one character, or that one doll, it feels like it's somehow dying every day, or the knights are all just beating each other to death... Then you can already see hints, which of course you can start with. Why is the doll dying now, or, why are the characters killing each other all the time? That is always quite useful"* (P3)
	Incidents facilitate communication about death and dying	Death communication took place when another child died	*"if you just say it, you don't know if they understand, but then maybe if you have the opportunity, like we do in hospice, to say, here your brother died, do you want to go into the room again and look at him?... Or simply to leave the door open and to signal to him, hey, your brother is in there, he has died, if you want, you can go see him again. And then, yes, there's a lot more to it than just saying that. Then he can look at him and can feel how he feels and then he realizes, okay, my brother is completely cold"* (P2) *"So we had two children who were sitting over there and you didn't really know, okay, did they understand that now or do they think he's asleep, and then all of a sudden they look at you and say, well, it's boring here, now I want to go outside again or play or... paint. [...] you have children who sit there for an hour and try out everything, and pick up the arm and shake it again and give him kisses and whatever. And there are children who go out and say, no, that's too boring for me, I'd rather play"* (P2) *"Well, here it happens that one of the children dies while the other children are there... And in that case we have to ask the parents first if we can inform the child about it. And yes.... we have talked to the child. But I don't really know how much has reached the child. How, how they realized that the other child is no longer there... I don't know, but we do talk about it with the children, if we are allowed to, from the parents"* (P6)

		Communication took place in form of goodbyes and preparations before the child's death	*"We wrote down and planned his entire funeral" (P2)* *"And no matter if they can speak or show it, by holding hands or holding each other, hugging and crying... of course that goes deep, deep, deep into the heart and bones, but is so important and so you just said to yourself, right? that you say goodbye. I didn't have to say any phrases to her, and I didn't have to tell her how beautiful everything was, because we knew that. We knew we had a good time together, but we knew that we were saying goodbye now and that at least she would no longer see me alive, that I would no longer see her alive..." (P1)*
	Children's individual death perception is used for communication		*"Especially with, with children who are also disabled, then it's also little things, what they, what, when they tell you, yes, when I die or when my brother or my sister dies, then I imagine it like this and like that. And then just go into it, whether it's a rainbow bridge, at a lake somewhere, they have very special ideas and so on. And I believe that simply responding to this is already the first step towards making things better in any case. And that's actually a small thing, isn't it? So I think anyone can do that" (P2)*
Child-centered interventions are employed to enhance the child's well-being	Activities and trips are used to make the child have a good time		*"It's all about making the kids have a good day" (P1)* *"I always notice that through activities, through trips, through creative offers, you get much further in some things than if you would talk" (P2)* *"So that we simply have fun with the children" (P4)* *"yes, to get her out of her, how should I put it, out of her grief situation a bit, to cheer her up a bit. We did things like taking her to a bar, she was already seventeen (laughs), and later she was eighteen, and then she was allowed to have a tattoo, and things like that somehow. And that also gave her a lot of joy and she also thought that was great... and she lived out her youth a little bit, with us, a little bit" (P5)*
	Being there is a key factor of support		*"simply signal to the child, I am here" (P2)* *"To accompany the child, to be there, especially when, for example, there is fear of being alone in such a situation, that we can be there, hold hands and say you can, I, I'll stay here sitting by the bed, I won't leave, I'll hold your hand, you can close your eyes, I'll be there when you open them again. When the kids need to get some rest. And I stay with you" (P4)*

	Various forms of therapy are utilized for psychosocial support		*"as a music therapist, so what I simply took from the training or also from later experiences […] to take music as an aid, to take musical instruments as an aid […] that the children have the possibility to express something without language, feelings, emotions..." (P2)* *"we do a lot with aromatherapy, […] you can also support the emotions with aromas. So, there are brightening aromas, or... Yes, which make everything easier or which help to process things or brighten the mood" (P5)*
	It is important to empower parents to support their child		*"but our task is actually to prepare the parents that well so that they can discuss this with their child because of course it should stay in the family. That is the best. Because it is much better for the salvation of the soul and also for dying itself and also for coping with grief afterwards, right? So when parents know I have discussed everything with my child and we have expressed what was on our minds from both sides, that helps, even if it is incredibly painful at the moment, but it is much better for healing, because you haven't missed anything" (P1)* *"And we also try to support the parents by saying, be open with your children, explain it to them. It's not easy, but […] it's not as bad as everything that children paint in their minds from what they may hear only with one ear, or from what they see on television, what death means, or from pages on the internet" (P3)*

Personal factors of involved individuals influence the support provision	The support is dependent on the individual needs and condition of the child		*"It starts with why is the child with us? Is it a respite stay... where other issues are often actually in the foreground for the child, or does the child come to us in a crisis, in a crisis situation...?" (P4)* *"You really have to rely a lot on your instinct. On observation, of course, you have to keep a close eye on the children and observe them very well in order to see... If you don't know... we have some children who don't give you anything in response, neither a smile nor anything else" (P6)* *"Some children, you get almost no response from some children" (P1)* *"Then, of course, it depends enormously on the age, the impairments that the child has... Exactly. Many of the children are also developmentally delayed" (P4)* *"But that depends, as I said, on the degree of disability" (P5)* *"But then there are children with us who are so severely disabled that I don't need to do it, somehow, because I'm sure that not much will reach them" (P5)* *"Depending on what the children's needs are. That varies a lot" (P4)* *"What does the child like, what does the child need in particular? To what does he react?" (P6)* *"But in any case, I think what always has to be taken into account is really to always pay attention and also to reflect on yourself that you don't follow your own impulses or... needs, but really always look exactly what the child needs. So, it cannot be my need to talk about the death or the dying of the child, but to see if it is really the need of the child. And if it is, what is the child's need and then respond accordingly, for example, if communication is difficult, that we look for ways to make it possible." (P4)*

| | Addressing the issue of death and dying depends on the parents' wishes | | *"Unless the parents, the family, are not able to talk about it because they don't want to, and can, and push it aside, and then, of course, the children and young people are looking for the people who.... give them answers" (P1)*

"Then it depends enormously on the family background of the children, what the family or the parents say in particular, to what extent this is addressed or what is also addressed at home. Perhaps religious backgrounds play a role. There are also very different perceptions of dying, death and grief possible" (P4)

"Are the parents willing to talk about it? That is the next point. Because I can't talk to a child just like that... just as I would like to, somehow, if the parents can't do that, well, then it becomes difficult, because... you can't ignore the sensitivities of the parents" (P5)

"That is what you experience, every now and then, that the parents don't want to talk about it... that... because, what we just had before, speaking things into existence when I talk about that. Sometimes it's also influenced by culture, that, depending on the beliefs of the family, that you don't talk about death.... That also happens from time to time, and then you have to see how you can deal with it" (P7) |
| | Support provision is influenced by professionals' attitude and approach | Professionals' fear and grief can influence the support provision | *"So especially when you yourself are so affected by the death or the dying, because maybe he's been coming here for years, you've spent super intense time with him, you're also grieving somehow, right? And still keep a clear head in those moments" (P2)*

"I was afraid at the beginning when I met him to ask him, hey, how do you deal with it, because he knew he was going to die" (P2)

"And... if I'm afraid of it as an adult, then I ignore the sentence, grandma's dead, then you can say, ah, did you love grandma? Has she been dead for a long time? Or, what, what reminds you of your grandma? Or something. I can take that in... or I can look out and say, oh, look how nice the sun is shining..." (P7) |

			Sensitivity of professionals is required to detect children's needs	*"Pause, take time to see if the child, adolescent or young adult wants to tell me something right now"* (P1) *"And yes, I think that's what's important, just this point of being patient, giving time and paying attention to small details"* (P2) *"So I think you can't always do everything one hundred percent right and interpret and understand correctly, but, you try, with a lot of patience"* (P2) *"Which is really important, just, it comes together a bit with patience, simply empathy, if you can put it that way. Just... Trying to put yourself in the child's place"* (P3) *"Yes, I think you really have to approach this subject very carefully and very sensitively and... yes, to approach this topic empathetically"* (P4)
			Professionals' attitude towards children's capacity to understand death influences the support provision	*"Because I don't know what may be received. And that's why we should always work as if the children had no impairment for us"* (P1) *"he simply broke the silence and said to himself again, Yes, it sucks that he had to die now, he used his words without thinking about it. And I found that very impressive and super beautiful, and I thought, yes, we are actually the ones who are disabled and not the disabled, because they can often deal with it much better and don't have these social barriers inside them"* (P1) *"But I strongly believe that children can understand that, also with intellectual limitations or disabilities"* (P2) *"But I think you have to be careful that you don't try to somehow trivialize everything, to simplify... even if the communication cannot take place just like with healthy people. And I think that people with intellectual disabilities have every right to know the truth and also the, the complete truth"* (P2) *"I think for both intellectually impaired children and children without intellectual impairment, that can be a topic. Even with children without intellectual impairment, I think there are children and adolescents for whom it is more of an issue than for others, for example. Yes... and I think you really have to look at the individual person, regardless of his or her condition, so that shouldn't be the primary focus.... to judge whether there is a need or not, but that it is only relevant for how do I approach this topic, in what way, how do I work with this topic, then with the child together.... How is that communicated?... Exactly. And that there are other factors that make the bigger difference"* (P4)

				"So I don't know why I should talk about dying with an intellectually disabled child who can't cognitively grasp it. It's more about something like body contact [...] And not, we are now talking about death. I think that doesn't help the child much in that moment, because they can't process it cognitively and think about it anyway, because they often have a way of being, that is, they perceive life more as being than about the body, how do I feel, somehow? I think they... I don't know. Even when they're dying, well, that's just my theory now, even when they're in the process of dying, I think, they don't think about it, instead it is more of a... process, feeling, how am I doing, what do I need, maybe towards the outside, but not thinking, somehow." (P5) *"But, of course, if the child is fit enough to talk about something like that, even if he has a little intellectual disability, then I would.... talk to him in a similar way to how I might talk to a three year old" (P5)* *"There are always various, different diseases. If, for example, the child has had a serious accident, where it is said that they used to be quite normal and now has a severe craniocerebral trauma or something like that, where the brain is now impaired, then I would still talk to them, and they may no longer be able to express themself verbally, then I would still talk to them quite normally, because you really don't know to what extent the brain still hears, sees, perceives everything, but can no longer express it to the outside world. That is sometimes a difference... But then there are children with us who are so severely disabled that I don't need it, somehow, because I'm sure that not much reaches them. It's just, a little bit based on the feeling, you know? And from the previous illness" (P5)* *"Intellectually disabled and intellectually disabled, that's such a spectrum, isn't it? And it really depends... If the children are intellectually disabled and are now, let's say, twelve years old and are at the level of a four-year-old, they are intellectually disabled, but a four-year-old also asks questions. More childish, but he asks questions and he also wants answers, right? And there it is again, I have to look... where does the child stand? What does he want from me? And it needs an age-appropriate or... stage appropriate, so if i'm twelve years old, but in intellectual development i'm four, then i'll just have to go with a four-year answer" (P7)*