



DEPARTMENT OF EDUCATION,  
COMMUNICATION & LEARNING

# THE TINY WEIGHT OF EMPTY SPACE

Multimodal literacies involved in preparing for and dealing with death and grief in digitalized work environments

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Program and/or course:	International Master's Programme in IT & Learning
Level:	Second Cycle
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Supervisor:	Ylva Hård af Segerstad
Examiner:	Sylvi Vigmo
Report no:	HT/23-2920-002-PDA699

# Abstract

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**Purpose:** The primary purpose of this study is to display the multimodal literacies embedded in how professionals deal with death and grief within two digitalized professional environments. One is a center for palliative care, in which death is at the center of professional practice. The other is a lower secondary school, in which labor is less often and less noticeably impacted by death. The focus of the investigation is on how analogue and digital intertwine and how knowledge is constructed and applied within a sphere in which being professional collides with being human.

**Theory:** This study draws on the lens of multimodality (Kress & van Leeuwen, 2001; Jewitt et al., 2001) to examine the ways in which routines and practices surrounding death and grief are distributed across modes and how they relate to spatial, temporal and technological aspects of the examined workplaces.

**Method:** Qualitative methods, framed by the principles of constructivist grounded theory (Charmaz, 2014), were employed. Data were generated through interviewing members of the staff, collecting documents and written routines, and conducting *in situ* observations within the two examined professional settings. The data was approached inductively, with emphasis on emergent discovery and considering subjectivity and my role in the construction and interpretation of the findings. I analyzed the generated data through iterative coding (line-by-line coding, followed by focused coding) and used memo writing to register and elaborate developing ideas.

**Results:** The findings indicate that professionals view death and grief differently in each of the two observed work environments and that they are required to handle these realities in different ways within the scope of their different work practices. Furthermore, the findings illustrate the intricate ways in which professional practice in this ambit is distributed across modes and involves multimodal literacies shaped by awareness, deliberation, and emotion. Finally, the results indicate that professional learning in relation to death and grief, is anchored to these multimodal literacies. Regardless of how the professional context relates to these realities, competence development in this ambit is based on doing, acting, interacting, talking, researching, and collectively preparing for handling death and grief.

# Foreword

This thesis dives into a profound topic, that touches me personally. Its waters were not always easy to navigate. I want to express my deepest appreciation to all the people that took part in my journey and helped me plot the course of this text.

I want to acknowledge my supervisor, Ylva Hård af Segerstad. I thank her for her generous support, for her time and patience. For all her feedback and valuable suggestions and for attentively and caringly having accompanied my investigation project and my writing process. Ylva's profound compassion, her curiosity, her understanding nature, and her encouraging words have played a vital role in the construction of this study.

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This project would not have been possible without the contributions of the study's participants and the other people involved in accommodating my presence in the two workplaces I examined. I thank them wholeheartedly.

Lastly, I want to thank my family and my friends who patiently supported me through this process and are an endless source of affection, strength, laughter, and lightness.

I dedicate this work to Riccardo, with all my love and gratefulness.

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# 1. Introduction

## 1.1. The tiny weight of empty space

In 1998, when I was one month away from turning 9 years old, my father suddenly died. As a child raised in an agnostic family and unaware of philosophical discussions, scientific definitions, and theological points of view, I saw his death with poignant simplicity. My father was no more. Where once there was him, there was now just empty space. And just like everyone else who has ever experienced love and loss, I had to restructure myself around that empty space.

Years later, already as an adult, I learned that, coincidentally also in 1998, a group of astrophysicists studying the supernovae found out that empty space is not, in fact, completely empty. According to their findings, each cubic centimeter of empty space contains invisible particles and waves. This very small amount of matter weights approximately  $10^{-29}$  grams and creates a tiny force.

I found reassurance in this idea as a poetical, and to some extent ironic, metaphor for loss. You see, undressed of its implications to theories on the accelerating universe, this finding was just the confirmation of something that I too had long learned: empty space can carry (tremendous) weight.

The point of departure for this thesis are my personal experiences with death and grief and a genuine curiosity in relation to how people are impacted by, make sense of and incorporate these realities into different contexts.

## 1.2. Overview of the research topic and description of the research study

Death and grief are universal human experiences, something we all share. And they leave no one untouched or indifferent. Over the last century, plentiful studies in sociology and anthropology showed that, along with the capacity to deeply disrupt individuals, families, communities and even entire nations, death and the ways in which humans collectively respond to it are one of the core engines of human societal organization (Walter, 2017). When someone dies, a hollowness is created not only within the people who loved and bonded with them, but also across the spaces and contexts that were part of that person's life. This hollowness inevitably implies a transformation and a reconfiguration of reality operated through specific individual and collective behaviors and practices.

The topic of this research is how these reconfigurations are constructed within the professional sphere. In particular, my study focuses on how professionals, working in digitalized environments, structure action, interaction and communication across a multiplicity of modes in order to integrate death and grief into their professional practice.

Digital technology has been a transforming factor both in relation to how people conduct their professional practices and in connection to how they experience death and grief. The incorporation of digital technology into work practices has led to new forms of collaboration; new space-time conceptualizations; new challenges related to surveillance and power dynamics (Aroles et al., 2019); and new trajectories in professional learning (Littlejohn & Margaryan, 2014). When it comes to death and grief, digitalization and the forms of social interaction afforded by digital technology brought significant transformations not only to how people experience illness, embody end-of-life trajectories and navigate bereavement (Hård af Segerstad et al., 2020; Hård af Segerstad et al., 2022; Refslund Christensen & Sandvik, 2014; Walter et al., 2011; Walter, 2015, 2017), but also to how people socially understand death (Hviid Jacobsen, 2016, 2021). This means that the ways in which professionals behave, communicate, learn, act, and interact in the face of death, within their professional environments, have acquired new dimensions in recent decades.

Driven by an interest in researching these dimensions and how they may be configured differently in different workplaces, I chose to observe how professionals handle death and grief within the context of

two different people-oriented workplaces pertaining to the public sector in Sweden. The two workplaces analyzed in my study diverge in their primary functions and in their essential relation to the realities of death and grief. One is a center for palliative care, an organization dedicated to providing healthcare, in which death, dying and grief are a central part of the work developed. The other is a lower secondary school, an institution dedicated to providing education and a place where death and grief are peripheral to professional activity. These professional environments, alike most contemporary professional environments, are dependent on digital tools and systems for carrying out their daily activities. This has implications for professional practice in general, but specifically, it implies that professionals distribute their knowledge and practice throughout a myriad of analogue and digital modes when dealing with the realities of death and grief.

### 1.3. Research aims and research questions

Framed by theories of multimodality (Kress & van Leeuwen, 2001; Jewitt et al., 2001) and anchored in the methodological principles of constructivist grounded theory (Charmaz, 2014), my thesis aims at enlightening the intersections between death, grief, multimodal meaning-making and learning within the professional sphere. I intend to describe the ways in which professionals view and experience death and grief within these distinct environments, gain insights into how they spread information, action and interaction across modes when dealing with these topics and form an in-depth understanding of how knowledge in relation to death and grief is constructed and applied in these two settings.

My investigation is oriented by the following research questions:

- 1) How are death and grief being integrated into professional practice in a center for palliative-care and a lower secondary school in Sweden?
- 2) Which modes, systems and sequences of communication and action are involved in dealing with death and grief in these two diverse professional contexts?
- 3) In which multimodal literacies are professionals required to engage when they address death and grief in their professional practice?

By answering the posed questions, this study contributes to an understanding of the complex and multifaceted phenomenon of how professionals construct and apply knowledge about death and grief and sheds some light on how these existential topics are being incorporated into different professional practices in distinct work environments. This may inform the design of tools and strategies for professional development and contribute to policy development. Collaterally, my study may contribute to discussions on the contemporary sociology of death, namely in connection to how organizations and individuals inserted in organizational settings envision and enact death related rituals and procedures. Finally, the findings may inspire future research on topics situated in the intersection between death studies and IT and learning.

### 1.4. Overview of the thesis

My thesis is structured in seven chapters. The first is this introduction. The second chapter is a literature review. I start with a generic overview in which I review the notion of “death taboo”; observe the intertwinements between death, grief and digitalization; and revise connections between death, grief, and learning. This converges into a revision of how death and grief have been approached in the workplace, and particularly within school and in the ambit of palliative care. In the third chapter I outline multimodality as the theoretical framework for this research. In the fourth chapter, I describe the methodological approach chosen and the methods adopted to conduct this study. The fifth chapter is dedicated to my findings. I discuss the findings in the sixth chapter in relation to aspects that emerge in the literature review and by acknowledging the study’s strengths and limitations. On the seventh chapter I present conclusions, implications, and suggestions for future research.

## 2. Literature review

This chapter reviews literature dedicated to examining death and grief from different angles, and it establishes the theoretical points of departure for my investigation. The ways in which societies relate to death and grief set the tone for how organizations, communities and individuals deal with these issues. I dedicate, therefore, the first three sections of this review to a broad, yet focused, overview of more generic social questions. First, I review the question of whether death is a taboo in post-industrial Western societies ([2.1. Death: taboo or not taboo?](#)). Then, I explore the relationship between death and technology and the impacts of digitalization on the realities of death and grief ([2.2 Death, grief and digitalization](#)). Subsequently, I outline the recognition of a learning space in regard to death and grief by reviewing literature on the cognitive processes of the grieving brain and exploring the relatively recent constructs of death literacy and grief literacy ([2.3 Death literacy](#)). Following the delineation of this generic panorama, I scaffold the core interests of my investigation in the last three sections of this review. I revise a selection of recent literature dedicated to death and grief in the workplace ([2.4 Death and grief in the workplace](#)), and then observe how these topics have been examined specifically in relation to the school environment ([2.5 Death and grief in school](#)) and the ambit of clinical palliative care ([2.6 Death and grief within palliative care](#)).

I used the *Supersearch* system provided by the Gothenburg University Library to locate and select the material reviewed in this chapter. The search followed a thematic approach and was restricted to peer-reviewed material, written in English and available (online or on-site) in the Gothenburg University Library. Aligning with the principles of grounded theory (Charmaz, 2014), in a process where neither data nor theories were discovered, but instead constructed as a result of my interactions with the participants and the generated data, the choice of themes for this review was grounded on preliminary findings and based on my initial impressions after the data generation process.

Most of the literature reviewed in this chapter was published within the last two decades to ensure the relevance and validity of the evidence and theories discussed in relation to the contemporary phenomena explored in my thesis. A small selection of older material (dating as far back as the 1950's) is included, mainly in the first section of this review ([2.1. Death: taboo or not taboo?](#)), to afford a comprehensive and nuanced picture of the discussed themes.

### 2.1. Death: taboo or not taboo?

Death is not only what it is (physically and biologically), but also what we collectively make of it. Hviid Jacobsen (2016) highlights that human understandings and responses to mortality interlace with cultural values, religious beliefs, political landscapes, socio-economic circumstances, and historical legacies. This means that death is conceived and addressed differently in different social contexts, and that, even within the same context, the social construct of death transforms across time (Hviid Jacobsen, 2016). Authors such as Ariès (1974), Hviid Jacobsen (2016), Kastenbaum (2012) and Kellehear (2007) and have engaged in retrospective reflections about how different social arrangements and life conditions influence the experience of dying and on how different eras have encompassed different social approaches to death. In this section of my literature review, I focus on a relatively recent debate when it comes to the sociology of death: the debate on whether death is or is not a taboo topic. The idea that, in Western societies, we are unable to face our own mortality and therefore avoid death related topics has been prevalent in vernacular, academic and journalistic discourses, since the mid-twentieth century (Walter, 1991) and it has been debated ever since. This discussion is addressed in this thesis for two reasons. First, I find it to be a good entry gate into the complexity of how death is constructed socially in contemporaneity. Second, it illustrates how contemporary practices surrounding death involve dealing with both opacities and transparencies.



According to the Merriam-Webster dictionary (Merriam-Webster, n.d.), the noun “taboo” means: an exclusion or avoidance imposed by social custom; a proscription against touching, saying, or doing something that is motivated by fear. The “death taboo” narrative aligns therefore, with viewing death as a topic that is avoided or hardly ever addressed by society. Interestingly, Gilmore et al. (2013) point out that the association between death and the concept of taboo goes back to the very inception of the word “taboo” into English language and is a product of colonial appropriation. The authors explain that upon the brutal violation of Māori burial sites by the British colonizers in New Zealand, the colonizers’ ignorance and social bias contributed to twist the Māori concept of *tapu* (originally associated with the idea of something sacred to be carefully kept and respected) into the concept of taboo as it came to be understood in English - connected to the idea of something dangerous and disgusting to be avoided and feared (Gilmore et al., 2013). This short etymological excursion only reinforces that the notion that there is a tacit prohibition to openly address death within Western societies (the notion commonly referred to as the “death taboo”) is inherently problematic.

Despite its elusive nature, the idea of death as a taboo has pervaded throughout the past century and arguably still exerts influence amongst scholars, in the media and within informal conversations. In the fifties of the twentieth century, British anthropologist Geoffrey Gorer (1955) refers to death as something that, in the aftermath of World War I, had become unmentionable in most social settings and compared it to pornography. According to the author, a society that refuses to publicly address death and avoids it in social settings, becomes naturally obsessed with consuming its mediated forms. Two decades later, Becker (1973) and Ariès (1974) contribute to the “death taboo” theory by defending the idea of a society that denies death and highlighting the ways in which death has become hidden and forbidden. Authors such as Gorer, Becker and Ariès convoke fear, the medicalization of death and the twentieth century crisis of the individual to justify their arguments and strengthen the idea of a society that is unable to openly face and discuss mortality. As contended by Kellehear (1984), these arguments fail, however, to set apart individual inclinations from group demeanors and tend to ignore organizational considerations when describing institutional conduct. According to Kellehear, societies do not deny death, but instead are continuously collectively organizing for it and around it. Tony Walter, who also critically revisited the “death taboo” perspective in the seminal article titled “Modern death: taboo or not taboo?” (1991), agrees with Kellehear’s perspective. In a moderate view that does not invalidate the arguments in its favor completely, Walter proposes six modifications to the “death taboo” theory. The first accepts that death came to be a taboo topic in modern industrialized societies but argues that the taboo has, in the second half of the twentieth century, begun to disintegrate and dissipate. The second alternative defends that death, although often hidden and contained within specific settings (Walter aligns with the medicalization of death argument), cannot be considered something forbidden in face of how much it is present in society and consumed in its mediated forms. The third alternative is that only certain (key) occupational groups, such as doctors and journalists, find death peculiarly problematic, and the fact that their insights have a lot of visibility contributes to the propagation of the taboo theory. The fourth is that there is a lack of consistent language to speak about death, which makes the topic extremely uncomfortable, but again, not exactly forbidden. The fifth alternative is that death can simultaneously be taboo and not taboo, which makes the discussion around this topic unsolvable and means that one can choose the side that best suits their experiences and views. Lastly, the sixth alternative is that it is the modern individual, and not modern society, that tends to deny and avoid death (Walter, 1991). In line with a critical but less polarized view over the “death taboo” theory, Mellor and Shilling (1993) examine self-identity and the sequestration (or separation from everyday life) of death in the period of ‘high modernity’ (term coined by Giddens, 1991 as cited in Mellor & Shilling, 1993). In their work, Mellor and Shilling recognize that the organization and experience of death became progressively privatized (as in increasingly handled by the death industry instead of people and families individually), but they argue that people do not lack survival or communicational strategies when dealing with death and death-related topics. The authors defend instead that dealing with death in high modernity is precarious and problematic due to the transformation of public value systems (Mellor & Shilling, 1993). Interestingly, the year of publication of Mellor and Shilling’s theory (1993) coincided with the year in which the

World Wide Web was made available to the general public. This came, as we know now, to capsize our world and it led to further (dramatic) transformations in our public value systems.

Despite how much the world has changed, in more recent times, the perception of death as a taboo still lingers in private, public, and scholarly contexts. Within the academic sphere, the narrative has become increasingly intricate and nuanced. Some authors have made instrumental use of the "death taboo" narrative to launch or support their arguments in recent decades. For example, Bowie (2000); Galende (2015); Giménez-Llort (2021); McGovern and Barry (2000); and Westerlund et al., (2018), all refer to death as a social or educational taboo in their studies. In contrast, other authors (e.g., Gilmore et al., 2013; Lee, 2008; Sayer, 2010; Stone, 2011; Tradii & Robert 2019; Wildfeuer et al., 2015; and Zimmerman & Rodin, 2004) clearly ally with a more nuanced or openly critical perspective over the "death taboo" narrative in their work. Within bereavement research and theory, the shift in paradigm that emerged in the late 1990's with Klass et al.'s continuing bonds theory (1996), can be observed as a consequence of, or a factor in, how the social construct of death has been transforming in recent decades. Very recent theories argue that after a period in which death was a forbidden topic and grief tendentially hidden, the advent of the internet and the aftermath of historical events such as 9/11 led to their resurfacing as spectacular phenomena to be shared and displayed (Hviid Jacobsen, 2021).

Despite this, in the mass media discourse, titles that bluntly associate the words "death" and "taboo" and recent journalistic articles oriented towards the idea of a death denying society are still easy to find (see, for example, Bell, 2022; Campbell, 2022; Coffee, 2023; Goddard, 2019; and Jones, 2023). This, however, goes hand in hand with the fact that death, disaster, crime, war and tragedy are explored by the media without reservations. Adding to the incongruence, we also find media titles that diffuse the ideas of growing social movements oriented towards 'normalizing' death and dying (see Leland, 2018 and Meltzer, 2018). But the very diffusion of such social movements, an example of which is the laxly defined "Death Positivity Movement"<sup>1</sup>, denotes a crucial lingering tension within the vernacular sphere: while these initiatives present themselves as defiant and liberating, they are, at their basis, legitimated by the narratives of death-denial and "death taboo" (Koksvik, 2020).

The debate surrounding the "death taboo" theory appears to be an irresolvable dilemma. Tony Walter was certainly right to declare that "people can debate endlessly and inconclusively whether death is or is not taboo" (Walter, 1991, p. 305). The present thesis is not informed by peremptory views on whether death and grief are taboo in Western societies, nor does it intend to instrumentalize one-sided perspectives in favor of constructing an argument. Instead, I invite the reader to think about this question (of whether death is or is not taboo) as a spectrum rather than the antagonism between contrasting poles. Within the framework of this thesis, the nuances and subtleties that emerge from reviewing the existing literature on this matter are embraced and death and grief are viewed as polyvalent social phenomena. In alignment with a view of death as something that is socially constructed as both normal and deviant (Hviid Jacobsen, 2022), the literature reviewed in this subsection transpires that death and grief may be very central within some contexts and quite peripheral within others. This feeds the tension between normality and deviance and implies that both opacities and transparencies are legitimately ingrained in the ways people make sense of death. Perhaps one of the aspects contributing to these contrasts is the fact that, while living, one can only experience death by proxy, through the death of others. Which means that everything we say and do surrounding death is inevitably taking place before an abyss. In this study, it is pertinent to notice how dichotomies of normalcy-deviancy and transparency-opacity are ingrained in workplace policies and the accounts of professionals about how their practices unfold in face of the abyss left by death.

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<sup>1</sup> The "Death Positivity Movement" can loosely be defined as a community of people who believe that it is not taboo to speak openly about death and dying. According to Koksvik (2020), the popularization of term, "Death Positivity Movement", can be attributed to the American funeral director, entrepreneur and YouTuber, Caitlin Doughty, but the movement's conceptual foundations date back to the roots of palliative care in 1950 and to the hospice movement in the 1970s.

A factor that adds layers of complexity to the ways in which these dichotomies play out (and one that becomes crucial in the ambit of studying professional settings that heavily rely on digital tools and systems for their daily practices) is digitalization and technological development. The continuum between analogue and digital that characterizes human practices and interactions in our contemporary societies, unsettles the ways in which death and dying are conceived and addressed, and it impacts how people grieve and support the grief of others. The following section is dedicated to reviewing recent research on these issues.

## 2.2. Death, grief and digitalization

There has never been a civilization indifferent to the posthumous manifestation of the deceased in the memory of their descendants (Bauman, 1992) and humans have always developed practices to care for and communicate with their dead (Ruin, 2018). Even if there is an intricate web of socio-cultural aspects influencing the social presence of the dead amongst the living, several authors point to communication technologies as particularly significant for these interactions (Arnold et al., 2018; Beaunoyer & Guitton, 2021; Hård af Segerstad et al., 2020; Refslund Christensen & Sandvik, 2014; Walter, 2015, 2017). Since prehistoric times, our perception of death has been intermediated by technology (understood as the use of knowledge to achieve practical goals resulting in the production and application of tangible and intangible tools). Communication media have always facilitated practices surrounding death through oral, figurative, or written representations (Beaunoyer & Guitton, 2021). Numerous examples of studies that portray how media (including online media such as social media) shape and are shaped by practices related to death, dying and grief are gathered in the collection of research papers, *Mediating and Remediating Death* (Refslund Christensen & Sandvik, 2014). This volume focuses on phenomena such as ‘mediation’, in which something is represented through media; ‘remediation’, whereby one medium is represented within another; and ‘mediatization’, referring to the process by which certain aspects of social and cultural practice assume mediated forms. By gathering studies on how these phenomena enable and transform practices related to dying and grieving and how media is appropriated and adjusted by people to fit those practices, Refslund Christensen & Sandvik are successful in illustrating that our relation to media shapes the ways in which we communicate, act and interact in relation to death. Indeed, every technological advance impacting communication media – print, telegraph, telephone, radio, photography, film, television – has been bolstering, and to an extent shifting, representations and discourses about death (Beaunoyer & Guitton, 2021). The internet and digital technologies are, in a way, just a continuation of this postulate (Arnold et al., 2018; Beaunoyer & Guitton, 2021; Walter, 2015). But they also seem to hold a special status. Indeed, digital communication tools and digital media are, according to a growing number of dedicated scholars, impactfully reshaping the boundaries of how technology influences our experiences of mortality. And the internet is considered revolutionary by many when it comes to how the interactions between the living and the dead are negotiated (Arnold et al., 2018; Basset, 2015; Beaunoyer & Guitton, 2021; Drescher, 2012; Walter, 2015; Walter et al., 2011), and how we collectively construct death and grief (Hviid Jacobsen, 2021). The internet is an embracing medium, that encompasses almost all the previous ones (writing, speech, still and moving image, etc.) (Beaunoyer & Guitton, 2021). It fosters a shift of focus in media production and distribution: from content itself to how content mediates social relationships with others. And it allows people to participate in worldwide dialogues and narratives about every possible topic, including serious illness and the experiences of dying and grieving a loss (Drescher, 2012).

In an article from 2011, Walter et al. seek to methodically list the interferences of the internet throughout what they refer to as the full arch of mortality. First, they focus on how the internet has an impact in the end-of-life stage and discuss phenomena such as online support groups (for both the terminally ill and their caregivers), blogging and online communities centered in producing, consuming and sharing personal content related to end-of-life journeys. Secondly, the authors reflect upon the ways in which the internet modifies death-related rituals. Namely, how digital technology impacts the funerary industry and is embedded into funerary practices. They report that digital

technology is commonly used to produce eulogies and media that honors the life of the deceased during the funeral and show how these materials are often created through online collaboration. Finally, the authors present a reflection on how the internet influences grieving and the archaeology of what is left behind after someone dies. They mention both intentional memorialization practices (such as different degrees of participation in cyber-cemeteries, the creation of memorial websites and the occurrence of memorializing posts on social media and on gaming platforms) and unintentional ones, connected for example to the fact that parts of our legacy remain in cyberspace and can be found and even downloaded post-mortem. Overall, the authors emphasize two main aspects. The first is that the internet has the potential to make death and grief become more communal. The second is that it allows for new possibilities in terms of continuing bonds with the deceased. The authors highlight, however, that the ways in which the internet affects death and grief are dependent on how online practices and interactions relate to offline practices and interactions (Walter et al., 2011).

Intersections between offline and online practices encompass assemblages between presence and absence, materiality and immateriality. They involve sequences of communication, action and interaction that come about through the use of objects, tools and hardware, but intersect an intangible dimension. The spatiality of such sequences is difficult to define. But it is easy to understand that a spatial dimension, characterized by dichotomies such as presence-absence and materiality-immateriality, carries philosophical and even spiritual implications to how humans make sense of their own mortality. Besides extending and blending notions related to our use of space, the intertwining of analogue and digital has enormous significance to the social construct of time.

One of the topics brought up by Walter et al. (2011) - how the internet and digital media impact the archaeology of each individual death - has aroused particular interest amongst researchers in recent years, and it even originated a new industry. In their book *Your digital afterlife: when Facebook, Flickr and Twitter are your estate, what's your legacy?*, Evan Carroll and John Romano (2011) explore the repercussions of the enormous quantities of digital information that remain after one's death. The two authors are also behind the website *The digital beyond* (<https://www.thedigitalbeyond.com/>), through which they provide guidance and services dedicated to creating, maintaining, and protecting what they define as one's digital legacy. Alongside Romano and Carroll's *The digital beyond*, there are numerous companies and a growing number of services dedicated to protecting sensitive data, affording a digital trajectory for one's heirs, or even, posthumously eliminating undesirable traces of one's private online activities and interactions. Such services attract attention and are on demand because, as pointed out by Drescher (2012, p. 205), "in the Digital Age, our identities extended from physical to digital space, from whence we can never fully retrieve or otherwise control them and where they live on long after our own departure". The realization that parts of ourselves and traces of most of our activities outlast our very existence may trick us into believing the idea of a perpetual digital body (Drescher, 2012). And, even if our digital remains are, in reality, as ephemeral as we are (Hård af Segerstad et al., 2020; Hård af Segerstad et al., 2022; Walter, 2015), the intangibility of what we construct in cyberspace certainly raises thoughts about where on the scale between ephemerality and eternity we should place ourselves.

As digital technologies and the internet increasingly interfere with our daily practices, shape our social systems, and influence the ways in which we conceive space and time; death, grief and the practices surrounding them also become increasingly digitalized. Apace with the dislocation of death-related practices, information, and services from physical space to cyberspace, Beaunoyer and Guitton (2021) highlight the need for more research within what they call "cyberthanatology", a specification of what Basset (2015) had previously defined as "thanatechnology". These terms refer broadly to how human-computer interaction influences human understandings and experiences of mortality (Basset, 2015; Beaunoyer & Guitton, 2021).

Within the professional sphere, which is the scope of this thesis, the interference between digital tools and systems and death related practices can be more or less noticeable, but it is an evidently present

phenomenon, and one worth investigating. The articulation between analogue and digital in professional practices surrounding death and grief brings consequences for how these practices unfold spatially and temporally, and implications to how knowledge and experience in this ambit is constructed by professionals. Different skills, knowledge and practices are required from professionals when death and grief intertwine with their professional practices and penetrate their work environments. Digitalization has implications to how literacies are constructed within this frame.

### 2.3. Death literacy

Despite only being addressed indirectly or in extremely context-specific ways within most contemporary educational settings (Bowie, 2000; Galende, 2015; Giménez-Llort, 2021; McGovern & Barry, 2000; Sonbul & Çelik, 2023), death is a multidisciplinary topic, and it provides an extensive and multifaceted learning space. In scholarly literature produced in the last decade, we observe the emergence of two key constructs that connect death and grief to learning - death literacy (Noonan et al., 2016) and grief literacy (Breen et al., 2022).

Death literacy has been loosely defined as the outcome of people's experiences and learnings about death and dying. It comprises practices, experiences, and knowledge about different aspects of death, and it allows for understanding and agency in relation to end-of-life and death-care options (Noonan et al., 2016). The concept of death literacy has emerged in the ambit of palliative care groundwork in Australia and has mainly been addressed by research dedicated to the public health domain. Recently, the group of researchers responsible for coining the term death literacy have been working on the development of a death literacy index (Leonard et al., 2022). The notion of grief literacy surfaced recently as an expansion of the construct of death literacy. Grief literacy is defined as the ability to gather, retrieve, process, and apply knowledge in relation to loss and bereavement resulting in compassion for self and others in the face of grief (Breen et al., 2022). The concepts of death and grief literacy are not dissonant. Death and grief go hand in hand, both from a sociological and a philosophical perspective since grieving is a natural component in the empiricism of people in relation to death. Interestingly, grief has been defined as a learning process in itself. Neuroscientist and psychologist Mary Frances O'Connor (2022), who studies the grieving brain and its cognitive processes, explains that grief is, in fact, the indispensable process of learning how to cope with loss. Our brain must come to terms with the nonexistence of someone we know and love and figure out how to navigate the present and imagine a future that incorporates their absence (O'Connor, 2022). Death originates new underlying schemes to govern people's functioning in an altered environment and within transformed circumstances. And this happens both at the individual and the collective level. In this sense, all the rituals dedicated to honoring and mourning the dead, the systems created to incorporate their absence and the operations involved in restructuring reality after their disappearance can be seen as literacy practices that are shaped by the context in which they occur as well as the views, attitudes and beliefs of the people enacting them. In my thesis, the term death literacy (DL) will be used as an encompassing concept that builds upon the ideas of both Noonan et al. (2016) and Breen et al. (2022) and refers specifically to the knowledge and perceptions of people about death and grief, developed through formal education and informal learning. As pointed out by Laranjeira et al. (2022), the promotion of DL through initiatives that involve the extended community is increasingly relevant in face of transformations in the demography of death. In Sweden, several academic initiatives contribute to the development of DL and there is an active research field in this ambit. The national research program *DöBra*<sup>2</sup> (DöBra, n.d.), which reunites researchers from Umeå University and the Karolinska Institute in Stockholm, carries out several investigation projects in this ambit. Within this frame, two iterations (2016, 2018) of an action research initiative titled *Studio DöBra* were conducted in two different cities in Sweden. Each iteration of *Studio DöBra* consisted in a set of five arts workshops about end-of-life issues involving eight children-participants and eight older-adult-

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<sup>2</sup> "Dö bra" literally translates to "die well" or "good death" but it also can mean "freaking good" since "dö" is a colloquial reinforcement word in Swedish.

participants. The realization of this project led to an understanding of certain aspects of intergenerational engagement with topics related to death, dying, loss and grief, but it also highlighted the challenge of sustainability and continuity associated to similar initiatives (Kleijberg et al., 2020). In fact, similar enterprises occur almost exclusively in connection with specific and isolated projects, and DL is most often not ingrained in elementary compulsory formal education. A very recent study done in Turkey concluded that there is not a systematic and interdisciplinary approach to the notion of death within the Turkish elementary and secondary school curriculum, and that this topic it is only explicitly addressed within Religious Culture and Ethics Education (Sonbul & Çelik, 2023). This reflects most likely what happens in many other countries. I could not find transversal research studies specifically aimed at supporting this claim, but reviewing international literature on DL and death education provides plenty of more or less explicit indications that point to a generalized gap in the curriculum when it comes to death and grief. In fact, when speaking of formal death education, Beaunoyer and Guitton (2021), define it as something that is provided “to and by health care and death professionals” (p. 4), which clearly points to a niche within tertiary and professional education in which structured formal education on the topics of death and dying is seen as relevant. But people do not need formal education to learn about death or to form thoughts, questions, and experiences around it, of course. In fact, and as pointed out by Beaunoyer and Guitton (2021), death education can be formal or informal. Informal learnings about death occur when people intentionally or incidentally come across information about death, dying and end-of-life or when people have direct or indirect contact with these issues in their lives. And even though, in post-modern societies, death is highly medicalized (Walter, 2017), that is, it occurs most frequently in hospital settings (instead of at one’s home) and is almost always handled by professionals such as doctors, nurses and mortuary workers (instead of grieving family members), the internet and the massive presence of digital platforms in our lives influence the possibilities for accessibility to these topics, facilitate the production and distribution of formal resources for death education and foster, at the same time, uncountable informal death literacy resources.

Death literacy is a multi-layered phenomenon. Learning about death may encompass direct or indirect contact with the death. It can involve personal experiences of grief or close contact with bereaved people. It might involve participating in rituals to honor or memorialize the deceased, taking part in funerals or simply engaging in conversations. It may also include formal knowledge about death across distinct domains (biological, social, cultural, judicial, philosophical, theological, etc.). And it embraces informal knowledge gained through intentional or unintentional access to information about death and grief or participation in communities related to end-of-life topics. And this implicates communication, action and interaction bound to different contexts and unfolding through multiple modes.

Regardless of the context, death and grief call for action, reconfiguration, and readjustment and this entices the development of multiple literacy practices. In this study, I am interested in the way these literacies unfold in the professional domain and specifically in professional environments that imply different levels of familiarity with the realities of death and grief. This makes it pertinent to thin out into a review of how previous literature views death and grief in the workplace.

## 2.4. Death and grief in the workplace

The separation between home and work that is inherent to metropolitan life and became the norm in industrial and post-industrial societies, has implications to how people die and dispose of death bodies (Kellehear, 2007) and impacts the ways in which people experience and manifest grief (Walter, 2009). On one hand, the cosmopolitan organization of life leads to the medicalization or industrialization of death (Walter, 2017), which means that there are professional settings that are death settings by excellence (hospitals, hospices, etc.) and professional figures that society observes as particularly equipped to handle death (doctors, nurses, priests, funerary workers, etc.). On the other hand, the separation between home and work establishes a rigorous boundary between professional and

personal, reliant on the idea that an individual's personal identity and emotional landscapes are kept strictly aside from their professional practice (Walter, 2009).

Previous literature indicates that, aspects related to human mortality tend to be absent from the majority of professional contexts (Bauer & Murray, 2018; Flux et al., 2019; Kellehear, 2007; Thompson, 2017; Walter, 2009) and argues that within environments structured to achieve specific goals as the product of organized labor, the finite nature of human existence and the impact of death on people's lives can very easily slide to the hind end of the priority list (Thompson, 2017). However, it is widely recognized that death is present in the professional sphere and that, within contemporary urban environments, it is often bound to it (in the sense that it takes place most often in clinical settings). Seminal studies within the sociology of death took place in professional settings (hospitals) and relied on the scrutiny of professionals' practices and experiences in relation to death and dying. One important example is Strauss & Glaser's *Awareness of dying* (1965), in which the authors explored patterns of death awareness amongst dying patients by observing their interactions with professionals. And another important example is David Sudnow's *Passing on* (1967), consisting of an ethnography in which the author coined the concept of social death to describe how certain patients were being treated as deceased by the hospital staff, while still living, in connection with the staff's negative assumptions in relation to these patients' social worth.

The intertwinement between death and professional practice is, however, not exclusive to hospital settings. Arguably, every professional will be required to deal with death and grief within their workplace and professional activity sometime. But this can occur in more direct or more indirect ways. In some cases, contact with the death of others is frequent, hands-on and direct. Forensic pathologists; funeral directors; cemetery workers; coroners and medical examiners; crematory operators; emergency response staff (such as paramedics, firefighters and police officers); search and rescue personnel; doctors and nurses (particularly those who work within specialties such as trauma surgery, oncology or palliative care); religious workers (such as priests); and journalists that work as war zone correspondents are examples of professionals who recurrently handle other people's deaths in a very direct manner in their professional practices. In some other contexts, the work involves instead significant risk of injury or death for the workers themselves. Military and police officers, deep-sea fisherman, miners, alpinists, and stunt performers, to name a few, frequently risk their lives at their jobs. And there are even contexts in which the risk to unwillingly provoke the death of others is an adjuvant to the work. For example, train drivers need preparation and support to deal with the occurrence of running someone over, either in accidents or in cases of suicide, since this happens fairly often (see Widell, 2019). But even professional contexts in which death is by no means considered "part of the job", are, still and all, not free from being touched by death in some manner. The death of a member of the workforce, a client, a business partner, or any of the people that closely surround them can occur and it repercussions on the functioning and structure of an organization. Regardless of how a professional activity or institutional setting relate to the realities of death and dying, whenever a member of the workforce dies or experiences a significant loss, the overall functioning of the organization as well as the functioning of its individual employees is impacted (Thompson, 2017). It is, therefore, important, and necessary to address death and grief, in their different facets, within professional settings.

Several authors have contributed to knowledge on the impact and consequences of death and grief in professional settings. Their research focuses mainly on how workplaces respond to trauma and support grieving professionals. In a literature review about employers' responses to employees' grief carried out by Flux et al. (2019) the authors concluded that workplace responses to grief are highly variable and span from openness, flexibility, and compassion to what is perceived as the utter inability to support. Neil Thompson attributes this variation to essential differences in workplace-culture and establishes that workplace-culture deeply impacts the way in which the workplace responds to trauma, death and grief (Thompson, 2017). Furthermore, and in line with what Flux et al. (2019) uncover in their findings, Thompson (2017) points out that the majority of workplaces are ill-equipped to manage

death and deal with grief. This may lead to the avoidance or oversimplification of these complex matters amongst professionals which, in its turn, brings devastating consequences in terms of human resources. The author stresses the human dimension of organizational life and emphasizes that an even bigger mistake than neglecting the importance of community aspects when dealing with death and grief, is failing to recognize the workplace as a significant part of that community context (Thompson, 2017). Alongside remarks on how the workplace is a community space where professional practice intertwines with individual human issues, an interesting point made by Thompson relates to the importance of meaning and meaning-making. The author states that meaning reconstruction (or learning) is an essential part of our natural responses to death and our process of grieving. For that reason, the issue of how professional settings shape meanings for the operational individuals within them is particularly relevant when observing how death and grief are incorporated into the workplace (Thompson, 2017). Bauer and Murray (2018), who have focused on how bereaved white-collar workers manage emotional expression in their professional environments, also highlight the importance of constructing meaning. They refer to meaning-making as context-bound and relate it to physical space by defining organizational spatial contexts such as offices, cubicles, laboratories, waiting rooms, break rooms, classrooms, etc. as platforms or artefacts and not just mere frames for professional practice. In their analysis, the authors highlight inherent flexibility of organizational spaces and encourage critical thinking about the ways in which space can act as a symbolic resource within professional contexts (Bauer & Murray, 2018). Tony Walter (2007) wrote, apropos the ways in which the separation between home and work impacts grief, that the place where the bereaved person finds themselves externally impacts what happens internally. The reviewed work of Thompson (2017) and Bauer and Murray (2018) aligns with this idea. However, while Walter observed the workplace as a place “full of what sociologists call instrumental rationality” (Walter, 2009, p. 407), Thompson (2017) and Bauer and Murray (2018) explore the possibility for embodied performances that are contrary to the original design plan or dominant spatial meanings of the work environment. The authors recognize that a legacy of thinking about home and work as separate has fostered the idea of a strict border between professional and personal, with which professionals still tacitly comply. However, they argue that in practice, and as shown by their research, this boundary is not always rigid, nor does it rule professional practice in every scenario (Bauer & Murray, 2018; Thompson, 2017).

Besides drawing an interesting and nuanced picture of how personal and professional identities might collide and sometimes merge when it comes to incorporating existential matters into the professional sphere, the reviewed literature is unanimous in emphasizing how crucial the role of support in the workplace is to the recovery process of a bereaved person. In fact, research within this topic focuses mainly on the impacts of death and bereavement on organizational life, the workforce and individual employees and seems to be aimed at informing solutions for better support. Mentions of the actual systems, sequences, and routines in place to address death and grief, and the ways in which these unfold spatially, temporally and are distributed across modes, tend to be accessory to the main research findings and conclusions. Another aspect that emerges from reviewing the literature is that the relation between death and grief and the workplace, and the experiences and strategies of professionals in relation to these topics, have been profusely scrutinized within organizations that are seen as death settings, such as hospitals and other clinical environments, and observed to some extent within corporative and business settings. But there is not an overflow of studies about professional practices surrounding death and grief in other work contexts where death is peripheral to labor. And I could not find comparative studies focused on understanding how professionals with different backgrounds and inserted into distinct professional environments, act, interact and communicate around these topics.

## 2.5. Death and grief in school

One context in which practices and systems surrounding death and grief have not attracted abundant attention from scholars, is the school context. In contrast, tragic cases in which death occurs in school, tend to rapidly be reported and explored in the media and present manifestations on various social



media platforms. Over the last few years several cases of students dying within the school premises have been reported by journalists in Sweden (see Eriksson, 2023; Hannu, 2023; Nyström, 2022; and Stigfur, 2020). Discussing death in school should, however, extend beyond the discourse of the media whenever the death of a young student occurs, in tragic circumstances, within the school environment. Death and grief can intertwine with school life at various levels, affecting students, teachers, and the broader school community. Research has shown that death literacy initiatives and efforts to integrate the topics of death and bereavement into educational settings bring significant benefits for children and young people (Talwar et al., 2011; Testoni et al., 2020), but it also highlights that conversations and activities surrounding death are not common practice and usually pose challenges for teachers, and school professionals in general, triggering uneasiness and discomfort (Dimery & Templeton, 2021; Galende, 2015; Hanon et al., 2019; Puskás et al., 2021; and Stylianou & Zembylas, 2021). This aligns with the idea that, in certain contexts, death is viewed as problematic, and therefore, tendentially avoided.

In 2002, a survey of school psychologists done in the USA suggested that death and grief were perceived by these professionals as the most important topics for the training of future school psychologists and overall members of school health teams (Allen et al., 2002). However, in 2019, almost two decades later, another study conducted in the USA and focusing on school counsellors, highlighted, amongst other things, a generalized lack of professional training when it comes to coping with death and grief in school (Hanon et al., 2019). Recent research conducted in the UK by Dimery and Templeton (2021) reinforces this idea, but with a focus on the teachers' professional role. This study focuses on the role of teachers in supporting bereaved children and on how the loss of a parent can impact the experiences of the child within the school environment. The results point to the existence of a gap in teacher education in relation to approaching death and grief and echo the idea that teachers generally experience discomfort in supporting bereaved children (Dimery & Templeton, 2021). The idea of a strong feeling of uneasiness is also corroborated by researchers studying the attitudes and experiences of teachers in relation to death, in geopolitical contexts such as Cyprus (Stylianou & Zembylas, 2021) and Sweden (Puskás et al., 2021). Despite the disquietude experienced by teachers when faced with the need to support students in coping with death and grief, Dimery and Templeton's research suggests that they have a significant role in supporting a bereaved child and their research uncovers the remarkable impact of small, dynamic forms of teacher-support in the child's experiences of grief (Dimery & Templeton, 2021). In accordance, earlier studies stress that the ability of school personnel to grant the required support can contribute significantly to the potential for healthy coping in children and adolescents following a death (Jimerson & Miller, 2008).

Despite indications about how all the adults in the school community play a relevant role in supporting children and young people in the face of death, practices addressing death and grief in school environments seem to be a tendentially compartmentalized affair. And in this matter, the school health care team is normally viewed as the competent authority. Research is, indeed, more copious in addressing these death and grief in school in connection to the work of healthcare professionals employed in schools (as happens in the studies of Allen et al., 2002; Edwards et al. 2023; Hannon et al., 2019; and Jimerson & Miller, 2008; amongst others)

I could only find one example in recent literature, in which approaching death and grief in school is observed from an encompassing organizational standpoint. This is an American quantitative study conducted in the aftermath of the Covid 19 pandemic by Khalid et al. (2022) which was set to assess the efficacy of an innovative virtual human role-play simulation in preparing educators, administrators, and overall school staff to respond to traumatic loss. The results indicate that interprofessional training directed to handling death and grief, can increase school personnel's preparedness to recognize and manage signs of trauma amongst students and school staff.

In general, what emerges from reviewing existing literature on this topic is that there seems to be a focus on the need for more and better support to bereaved students, and a hiatus in relation to when

death and grief affect the school's workforce. This is revealing of a tendentially fragmented perspective over death and grief within the school domain. Previous literature also unanimously points to lack of training, lack of confidence and unfamiliarity on behalf of the overall school personnel when it comes to dealing with these topics. Notwithstanding, schools often have crisis management plans, because they must be prepared to handle death and other crisis somehow, even though school professionals do not receive practical education when they are in training. The ways in which different school professionals prepare for, act, and interact around death and grief and the literacies required to navigate these topics in school, have only been touched upon collaterally and superficially in previous studies.

## 2.6. Death and grief within palliative care

Contrarily to what happens within the school environment and, in general, in the ambit of education, death and grief are central instances in the realm of palliative care. According to the definition proposed by the World Health Organization (WHO) and present in their website (<https://web.archive.org/web/20031004221126/http://www.who.int/cancer/palliative/definition/en/>), palliative care (derived from the Latin root *pallium*, which translates to 'cloak' in English) is an approach within healthcare that improves the quality of life of patients suffering from terminal illness as well as the quality of life of their families through the identification, assessment and treatment of pain and other physical, psychosocial, and spiritual issues. This definition aligns with a philosophy that differs from the one often adopted in other areas of medical care. Within palliative care the focus is on quality of life and on providing what is seen as a good way of dying (Kastenbaum, 2012), rather than on seeking a cure or avoiding death.

Kastenbaum (2012) provides a detailed historical overview of how humans have cared for the ill and the dying over time, from Ancient Greece to the modern hospice movement. The latter emerged in the late 1960s in the UK and the USA, centered on a multidisciplinary and holistic approach to people's end-of-life trajectories, and evolved into what is contemporary palliative care. In Kastenbaum's account it becomes clear that the very own foundation and philosophy of present-day palliative stems from an integrative approach and is scaffolded by research about death and bereavement coming from diverse fields (such as medicine, nursing, psychology, sociology, and anthropology amongst others). Since its re-emergence in its current configuration and with its current designation, palliative care has turned into a prolific field of research in its own right, counting with numerous engaged researchers, research groups, specialized scientific journals and dedicated academic organizations based in a number of different countries. It is important to mention, however, that there are inequalities in relation to provision and access to palliative care worldwide, related to political, juridical, cultural and socio-economic factors (see Brant & Silbermann, 2021; and Reville & Foxwell, 2014). In Sweden, where my study took place, palliative care is available within public healthcare, there are official guidelines that orient the ways in which it is provided nationally (Socialstyrelsen, 2020), and it constitutes an active and flourishing research domain. Death and grief are plainly engrained in this field of investigation since they are the central axis of all palliative care practices.

Within palliative and end-of-life care, background research has been referred to as crucial to inform best practice, support clinical decision making, and develop and test new approaches and services (Chatland et al., 2023; Higginson, 2016). The literature review for the present study has confirmed that a considerable part of the literature in this ambit is dedicated to describing practices and standards from a clinical or ethical perspective, observing existing models and suggesting improved ones. The articles written by Bilgin et al. (2022), Oosterveld-Vlug et al. (2022), Scaccabarozzi et al. (2019), and Schofield et al. (2021) are some examples of studies that have focused on best practices and ethical standards for palliative care in different geopolitical contexts.

Another aspect that literature appears to focus on is interdisciplinarity and the integration of palliative care and palliative care standards into different fields of medicine and different hospital wards, mainly those involving caring for severely ill or dying patients. Particular attention has been given, for

example, to models of integration between palliative care and oncology (see Kaasa et al. 2018; and Salek et al., 2022).

Literature in the last decades has also been reflecting the importance of involving the general public, and not just the wider medical community, in end-of-life issues. This perspective has been explored under the designation ‘compassionate communities’. According to Dumont et al. (2022, p. 1) “compassionate communities are rooted in a health promotion approach to palliative care, aiming to support solidarity among community members at the end of life”. This approach has been grounded on the pillars of “education, information and policymaking for health, dying and death” by Kellehear (2005, p. 26). The constructs of death literacy (Noonan et al., 2016) and grief literacy (Breen et al., 2022), previously mentioned in this literature review (section [2.3 Death Literacy](#)), and important for the connection between death, grief and learning, stem from research aimed at the development and implementation the compassionate communities model.

Alongside research dedicated to improving practice, incorporating palliative care into other clinical fields, and integrating it into broader contexts, less explored topics have also raised interest in recent years. Namely, the emotional landscapes and coping mechanisms of professionals working in with end-of-life trajectories or how professionals within this field make sense of their own work and frame their professional development. When it comes to emotions and coping mechanisms, studies focusing on healthcare professionals in general (and not just those working in palliative care) indicate that this is a fairly unaddressed topic (see Boerner et al., 2015; and Khalaf et al., 2018), despite the knowledge that unexamined physician emotions bring consequences to patient care (Meier et al., 2001). In their study aimed at understanding the consequences of death work to the ‘self’, which focuses specifically on the experiences of palliative care workers, Chan et al. (2016) define the ability to cope with difficult emotions as a key competence that these professionals need to acquire. When it comes to how palliative care workers make sense of their own professional practice, a study conducted in Sweden by Ågren et al. (2021) illustrates “how experts in complex ways intertwine experiences of ‘the self’ with meta-level concepts in order to make sense of the field of palliative care”. Research leaning over the notion of ‘self’ lifts interesting questions about how being a professional and being human may intertwine within this field of work.

Finally, the topics of education and professional development in end-of-life and palliative care are also active research trends. In this ambit research has focused on describing and evaluating cases of implementation of specialized advanced tertiary education programs specialized in palliative care (see, for example, Bailey et al., 2017; Berzoff et al., 2006; and Nicholl et al., 2016). Despite the existence of such programs in some countries, in the Swedish context, a very recent study pointed to a substantial need for education about palliative care in undergraduate nursing programs and additionally it highlighted a general lack of specialized palliative formal education (Hagelin et al., 2022). When it comes to professional development, there is abundant literature about professional learning solutions focused on palliative care skills. In a domain in which different professionals and disciplines intertwine, particular focus has been placed on interprofessional learning approaches (Bradway et al., 2018; McKinlay et al., 2023; Pereira et al., 2022). Within the pedagogical practices and educational solutions studied and proposed in this ambit, death and grief have a pivotal role.

Indeed, reviewing existing literature on palliative care is, to a great extent, reviewing literature on death and grief within palliative care, simply because palliative care is, contrarily to other medical specialties, structured in function of death and grief. The literature reveals that death and grief are viewed with a holistic and multidisciplinary perspective within this ambit and that efforts are being made to implement this perspective into other areas of medicine and involve wider communities in end-of-life topics. Previous research also points to gaps in formal education about end-of-life issues and end-of-life specialized care and uncovers possible tensions between professional and personal identities in this ambit.

### 3. Theoretical framework

My study is framed by multimodality theories (Bateman et al., 2017; Kress & van Leeuwen, 2001; Jewitt et al., 2001; Jewitt 2008). Multimodality stems from social semiotics, and it is grounded on Halliday's theory of communication (Halliday, 1978). It views the interplay between different representational modes as an inherent element to meaning-making (Kress & van Leeuwen 2001; Jewitt, 2006, 2008). The notion of multimodal literacy derives from this framework, and it emphasizes multimodal awareness and the purposeful use of a range of available modal resources in response to communicational and social needs (Jewitt & Kress, 2003).

Multimodality refers both to a theory and a methodology, or in the words of Kress (2010, p. 56), it "names both a field of work and a domain to be theorized". In this thesis, I draw from multimodality as a theoretical domain. My focus is on observing how professionals in two distinct digitalized work environments incorporate death and grief into their professional practice by constructing and applying knowledge that is distributed across modes. This reflects a perspective over learning and a notion of literacy that are framed by multimodal theory.

#### 3.1. Relevant perspectives over literacy: a path to multimodality

The emergent communicative repertoires of people living in an increasingly digitalized world unsettled the previously predominant view of literacy as a monolithic mental phenomenon exclusively related to the ability to read and write. Already in the 1990s, new theorizations of literacy and the notion of multiple literacies (Street, 1998; Barton et al., 2000) emerged in response to the demands of processing and producing information in a world where the overall population was increasingly schooled and where knowledge was no longer confined to the written word. When it comes to observe literacy as a pluralized and multiplied concept, Jewitt (2008) lists three seminal perspectives:

New Literacy Studies (NLS) (Gee, 1991; Street, 1993, 1997, 2003): the body of work of NLS is central in the theorization of literacies as historically, socially, and culturally situated practices. It conveys a view of literacy as something people do in the world and in society, rather than a merely mental phenomenon. The NLS perspective marks the shift from observing literacy as a neutral set of skills, to observing literacies (deliberately stated in the plural form) as situated practices. This perspective also emphasizes how formal education literacy or school literacy might not coincide with emergent literacy practices in homes and communities. By analyzing power relations, identities and forms of knowledge involved in literacy practices within schools, NLS observes literacies as social realizations.

Multiliteracies (Cazden et al., 1996): the multiliteracies model, introduced to educational researchers by the New London Group (Cazden et al., 1996), emphasizes two interconnected shifts in the communicational scene that produce an effect on what it means to be literate: the increasing significance of diversity (cultural and linguistic) and the complexity of texts with respect to non-linguistic, multimodal forms of representation and communication. This perspective places emphasis on how the learners' experiences, interests, and existing resources (technological, cultural, and linguistic) can be observed as starting points for learning.

Multimodality (Kress & van Leeuwen, 2001; Jewitt et al., 2001): stemming originally from a linguistic model, multimodality expanded its realm of reference to place emphasis on how communication and interaction convoke multiple modal resources. Building upon the notion that literacies surpass the cognitive and analytic processes of written and spoken language, the basic assumption behind this perspective is that meaning is constructed across multiple representational modes - image, gesture, gaze, body posture, sound, writing, music, speech, etc.

The above summarized theories build upon each other and form a multi-layered and plural theorization of literacy, significant to the field of educational research and in particular, to the ambit of IT and learning. Of particular interest to my thesis, as mentioned above, are the theorizations on multimodality, initially shaped in the early 2000s by Kress and van Leeuwen (2001) and Jewitt et al. (2001) and furtherly developed by these and other authors (see Bateman et al., 2017; Jewitt, 2008, 2006; Kress, 2011) in the decades following.

## 3.2. Multimodality

Carey Jewitt (2008) states that in a world characterized by multiple representations, the mode of representation should be observed as essential to meaning-making. In alignment with this thought, multimodality places emphasis on situated action and observes meaning-making as the articulation between social context, available representational resources, and people's situated choice of representations. (Jewitt, 2006). From a purely communicational and analytical perspective, multimodality has been defined as a way to characterize communicative situations that focuses on how assemblages of communicative practices work together, rather than addressing the components of communication separately (Bateman et al., 2017).

According to Jewitt, there are three underlying theoretical assumptions outlining multimodal theory. The first is that speech or writing are mere components in a wider multimodal ensemble. The second is that all representational and communicational modes have a singular meaning potential which is shaped in view of their social functions within the community using them and by their social, cultural, and historical applicability. Finally, the third assumption is that meaning is constructed by people when they select and configure different modal assemblages. This means that, when examining a representation or an interaction, the underlying modal choices available to people, their meaning potentials and the purposes for which they are chosen must be taken into consideration (Jewitt, 2013).

A central concept within multimodal theory is the concept of modal affordance (Jewitt, 2008), which relates to the idea that different modes and different combinations between modes afford different possibilities for constructing meaning. Modal affordances connect to the material, cultural, social, and historical use of a mode. According to Jewitt (2008) the physical, material, and social affordances associated with each mode create a specific logic and allow for distinct potentials of representation and communication. Observing and understanding modal affordances has been the one of the concerns of social semiotics. Studies focused on the examination of communicational resources beyond spoken language (Kenner, 2004; Kress & van Leeuwen, 1996; Martinec, 2000; van Leeuwen, 1999) have shown that people draw on their available modes to make meaning in specific contexts. Furthermore, it has been demonstrated that users continuously create new modes and transform existing ones to respond to situated social and communicational needs (Jewitt, 2008).

As pointed out by Bateman et al. (2017) situations that qualify as multimodal are everywhere. Multimodality is not something that only exists in certain contexts or an idea that only applies to specific conditions. It is rather a perspective, or a lens to observe human communication, action and interaction that focuses on how the many components involved in these processes intertwine and form a whole, instead of looking at them separately. The lens of multimodality has been widely explored in the field of education and it has implications for how learning is viewed and theorized.

### 3.2.1 Multimodal literacy

According to Jewitt and Kress (2003) the concept of multimodal literacy provides a multimodal framework and conceptual tools for a fundamental rethinking of literacy and learning.

A multimodal perspective over literacies becomes particularly relevant when it comes to the problematization of the literacy practices that stem from the digitalization of contemporary societies, since digital technologies make a wider range of modes available (Jewitt, 2013). As stated by Knobel & Lankshear (2008) the digital multimedia instruments that emerged with access to the internet, have

democratized forms of expression that are by definition hybrid and multimodal. And multimodal forms to utter and compose meaning are an underlying premise of plural literacies (O'Byrne & Murrell, 2014). In alignment with the underlying pillars of multimodal theory, multimodal literacy connects, primarily, to the ability to construct, deduct and induct meaning through combining and articulating modes. In the context of research within formal education, multimodal literacy has been characterized by Walsh (2010) as the competence to orchestrate meaning by “reading, viewing, understanding, responding to and producing and interacting with multimedia and digital texts” (p. 213). A definition that is, as stated by Crawford Camiciottoli and Campoy-Cubillo (2018), evidently drawn from the conception of *multiliteracies*, originally conveyed by New London Group in 1996 (Cazden et al., 1996). However, as pointed out by van Leeuwen (2017, p. 10) enriched and complex modal contexts, require “not only a working knowledge of multimodal ways of making meaning but also of the rules and conventions for using multimodal meaning making that have emerged, with greater or lesser prescriptiveness, in specific contexts”. The author argues that multimodal literacy needs to be critical and reflexive, particularly in what concerns how certain technological tools favor certain tendencies of discourse (van Leeuwen, 2017).

For the purposes of this thesis, and in line with a perspective that views literacy as a plural concept – literacies – the term «multimodal literacies» will be used to refer to the situated practices that individuals develop and in which they engage to construct, decode, and reflect critically upon multimodal forms of expression.

# 4. Methods

## 4.1. Overview of the research design

**Figure 1**  
*Research design*

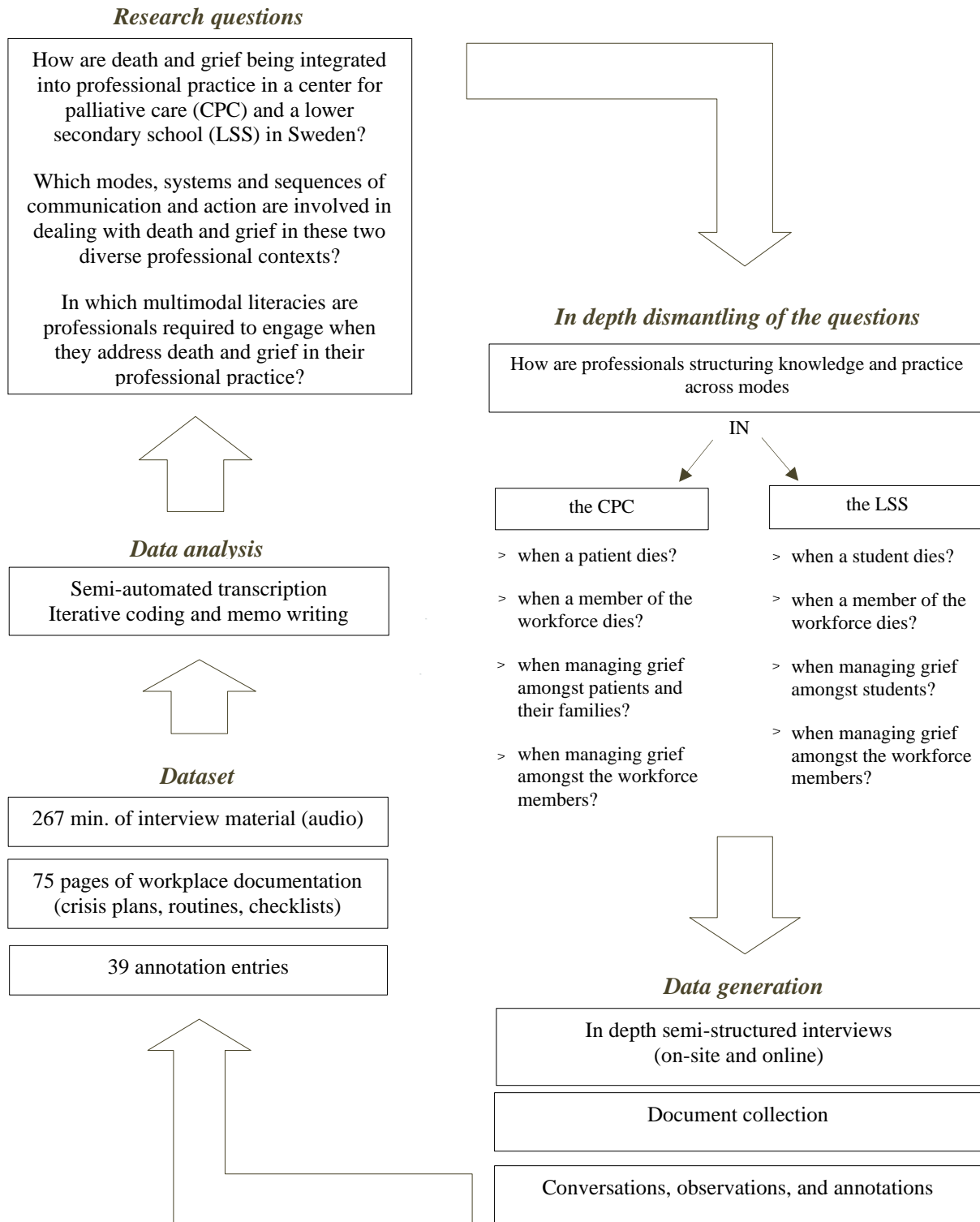


Figure 1 above outlines the design of my research. As a study aimed at finding out how a center for palliative-care and a lower secondary school in Sweden structure their responses to death and grief, this classifies as exploratory research, anchored on exploration for discovery (Stebbins, 2001). The investigation draws upon constructivist grounded theory (Charmaz, 2014) to examine the multimodal literacies required when professionals prepare for and respond to death and grief within their work environments. The object of the research is not objective data to be measured, but “meaningful relations to be interpreted” Kvale (1996, p. 11), which justifies the use of a qualitative approach throughout the investigation. To generate data, I conducted interview research, gathered documents, and made annotations during informal conversations and visits to both workplaces. This resulted in the dataset presented on figure 1, under the title *Dataset*. To answer the research questions that orient my study, I analyzed these data, in line with the principles of grounded theory, i.e., on a basis of constant comparison and iteration (Charmaz, 2014). First, the interview material was transcribed, and subsequently all the written data (interviews, documents and annotations) was subjected to iterative coding and memo writing.

Since I examine two distinct contexts, all the components in the data generation process were constructed in a double parallel design. I looked for and collected similar or comparable documents in both workplaces. I used purposive and snowball sampling (Patton, 2015), to recruit interview participants both at the CPC and LSS. I constructed distinctive, but analogous, interview guides and conducted in depth, semi-structured interviews in both contexts. And finally, my observations and annotations were intentionally oriented towards corresponding aspects within each of these two settings.

## 4.2. Constructivist grounded theory

Constructivist grounded theory methodology, defined by Kathy Charmaz (2014), builds on the fundamentals of grounded theory, first described as a methodology for qualitative research by Glaser and Strauss (1967). This methodology was forged in the aftermath of the challenges encountered by these two authors while undergoing their seminal study about death - *Awareness of dying* (1965), which is particularly interesting in the case of the present study. During their investigation, Glaser and Strauss stood up against the predominant research approach of verifying existing or hypothesized theories instead of generating the theory itself (Glaser & Strauss, 1967; Moore, 2009). As a response drawn from their disenchantment, the principals of grounded theory consist in systematic, but flexible guidelines to collect and analyze qualitative data in view of constructing theories and reflections grounded on the data themselves. Grounded theory methods are centered in an inductive approach to data. They involve iterative tactics and a continuous oscillation between the existing dataset and an emerging analytical layer (Charmaz, 2014). An important distinction between how Glaser and Strauss originally outlined grounded theory, and how Charmaz defines constructivist grounded theory relates to the acknowledgement of our bias as researchers. Charmaz’s constructivist approach breaks free from notions of an impartial observer and acknowledges how the researcher’s own subjectivity impacts interpretation.

Charmaz’s (2014) methodology suggests that if “we start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher’s position, privileges, and perspective and interactions into account as an inherent part of the research reality. It too is a construction.” (p. 13). I acknowledge that my own positioning as a researcher impacts the data generation, the analysis and how the findings are showcased. Furthermore, I embrace a view according to which the products of my investigation are a construction molded by the subjective representations and discourses contained in the data generated within the frame of this study, as well as my own subjectivity when designing, undergoing investigative practices, and writing the present thesis.

Although the dimensions and constraints of the present study do not allow for what Charmaz describes as theory construction, I view the present thesis as an analytical product, rather than a mere description



of my investigation process. In a data-driven approach, I strive for the construction of arguments that originate from my past and present interactions with the interview participants and other people involved in the investigation, my evolving perspectives and my involvement with the research contexts and my own research practices.

### 4.3. Research contexts

My research takes place in contemporary Sweden, and it focuses on two workplaces that belong to the public sector and are primary providers of people-oriented services, namely health-care and education. The two workplaces examined are a center for palliative care and a lower secondary school in a large city.

The Inglehart-Welzel cultural map (2023), that can be consulted on the World Values Survey website (<https://www.worldvaluessurvey.org/wvs.jsp>), classifies Sweden as a society belonging to Protestant Europe and shows that it scores high in secular-rational and self-expression cultural values. This map is a scatter plot based on data from the WVS wave 7 (Haerpfer et al., 2020). It classifies countries in relation to two cultural value spectrums. One spectrum stretches between survival and self-expression values, and the other between traditional values and secular-rational values. The first spectrum (traditional versus secular-rational values) observes if a given society is more dominated by superstition and religious belief or rationality and bureaucracy. Traditional values are linked to religious devotion, appreciation for traditional family structures, deference to authority and absolutist standards. Secular-rational values represent the opposite. The second spectrum (survival versus self-expression values) indicates if a society orients more towards perceived common security or subjective wellbeing. Survival values validate hard work, ethnocentric views, and align with low levels of tolerance in relation to foreign cultures. Self-expression values, contrarily, validate imagination and tolerance, favor individuality and embrace different opinions and backgrounds (Inglehart & Welzel, 2001). The Swedish culture, scoring amongst the highest in secular-rational values and self-expression values, can be characterized by its laic underlying systems, its openness to unconventional family configurations, and its detachment from patriotic standards and hierarchical systems. In fact, contemporary Swedish culture is marked by subjective notions of quality of life, activism, environmental protection, gender equality, acceptance, moderate political views and openness to foreign cultures. It is, in fact, important to consider that Sweden is very multicultural. According to the website of the government agency Sweden Statistics, in 2022 there were two million foreign-born people living in Sweden, which comprises approximately 20% of the Swedish population (Statistiska centralbyrån, 2023). The presence of many different cultures is concentrated in bigger urban centers, such as the one to which the work environments at focus in my study pertain.

Taking this wider picture into consideration and bearing in mind that the ways in which people experience death and grief are highly influenced by cultural values and social structures, let me now zoom in and observe the main characteristics of each one of the two workplaces that are at the center of my research.

Table 1 below, describes the two workplaces examined in this study. I specify the sector to which these workplaces belong to, the orientation guiding their labor and the main focus of the work activities taking place in each work environment. Furthermore, the overall characteristics of each workplace are listed, I describe their facilities and the way in which work is distributed spatially in each one and I label the larger structures that administer and host each professional environment (without giving away sensitive data such as name or location). Finally, I describe the human resources available within each professional environment and mention the number of people that each one attends to or works with yearly, in approximation. All the elements that would facilitate the identification of the examined contexts are purposefully not represented in the table, in order to protect the integrity of the examined organizations and, more importantly, ensure the anonymity of the people that participated in the research.

**Table 1***Research contexts – the two examined workplaces*

Workplace description	Workplace	
	Center for palliative care (CPC)	Lower secondary school (LSS)
Sector	Public	Public
Orientation	People-oriented	People-oriented
Focus	Healthcare with a focus on end-of-life care; research and professional education on end-of-life care	Elementary education (7th-9th grade)
Characteristics	Professionals with different competences collaborate to provide qualified and specialized end-of-life care to patients at home, in the hospice or at the hospital, support the patients' loved ones and educate health-care professionals and the overall community about end-of-life issues.	Professionals with different skills collaborate to provide 7th-9th grade education to students in accordance with the programs and structures stipulated by the Swedish National Agency for Education (Skolverket). Basic first-aid care, nutrition and psychological support are also offered by the school.
Facilities and spatial distribution of the work	Professional practices unfold across different spatial contexts. Professionals have their own individual or shared offices on the first floor of a three-story building that belongs to the hospital and that hosts a hospice in the upper floors. They travel to patients' homes and different hospices to provide care, and often allocate in different hospital wards for consulting and formative purposes.	Professional practices are, under normal circumstances, circumscribed to the school facilities. These consist of one two-story building and the adjacent land. The school has approximately 20 classrooms, a canteen, a library and spacious indoor halls. The school yard has a basketball hoop and a volleyball court, as well as other large outdoor courts for ball games.
Context	The CPC is a section of a very large hospital in Sweden. Overall, it follows the hospital's policy. There is a certain degree of autonomy, but ultimately the CPC's management and all of its activities are regulated by the hospital administration.	The LSS belongs to a municipality in Sweden, and follows the orientations and rules stipulated by the municipal administration of elementary school. There is a degree of autonomy in the school's management, but the school principal is headed by the municipality.
Human resources	The CPC has 56 employees including managers, doctors, nurses, counsellors, nursing assistants, secretaries, and other administrative and technical personnel.	The LSS has 42 employees including the principal, teachers, special needs teachers, teaching assistants, the school nurse, the school psychologist, the school counsellor, technicians, and administrative personnel.
Number of patients/students over the last year (approx.)	650	430

In addition to the contextual information depicted in the table above, it is important to reiterate that both professional contexts described, similarly to what happens in most workplaces today, are extensively relying on digital tools and systems in their everyday practice. The employees at the CPC use a range of different information technology systems in their daily professional activities. These

systems span from tools to report and manage working hours, absences, and displacements to platforms for activity planning and communication and even include fully digital, centralized, patient clinical records as well as other systems connected to managing patient care. The same situation occurs in the LSS. Professionals working at the LSS are also dependent on various information systems and services for their daily activities. The school employees rely on the use of management systems, reporting systems, digital tools for teaching, accessibility tools, digital tools for communication, learning management systems, digital calendars and a variety of content creating and activity planning tools.

## 4.4. Course of action

In this section, the work conducted to originate data for this study and the process of analyzing these data is described in detail. I begin by explaining the steps that preceded the data generation. I proceed with a detailed description of the methods employed to collect and generate data. And I conclude by describing the methods used to analyze the dataset pertaining to this study.

### 4.4.1. Establishing connections and creating research spaces

Gaining access to the two workplaces examined in my study required preparation and involved contacting several people and visiting different places. In this section I describe the process of establishing these connections and creating the conditions to conduct the investigation. My goal is to render visible the unseen actions and interactions that lay behind the data generation stage, in recognition of how they may have influenced my reasoning even without having produced most of the palpable/analyzable data.

The beginning of my thesis work was marked by a two-hour conversation with my supervisor about my motivations and initial expectations and ideas. This was the first time that I could anticipate that the aspirations I had for my study could turn into tangible research. Not only did I receive validation and suggestions to focus and resize my project into a viable master thesis, but I received suggestions of people to contact both within the Swedish school system and within a Swedish organization dedicated to palliative care. These initial contact persons were the departing point for my research.

Gaining access to the CPC was easier than I initially expected. After sending out a very short presentation of my project via e-mail, one employee at the CPC reached out and made themselves available to be a bridge between me and the organization throughout my research. I subsequently organized a first meeting, on-site, with this person to discuss how our collaboration could be configured and get to know the main facilities of the CPC. This meeting took place in the beginning of February 2023, and it was not recorded. It allowed me to get a first image of the workplace and some detailed information about its functioning. I made notes about what I observed and the discussed topics, and these initial notes and thoughts had an impact on how the subsequent research was designed. In the sequence of this meeting, I contacted the judicial department of the large hospital to which the CPC pertains in order to be granted access to official statistics and documentation. It was also with the support of my contact person at the CPC that I recruited participants for the interview research and got in touch with administrative personnel in order to look through and collect workplace documents.

Obtaining access to the LSS was a longer and more tortuous ordeal. Things unraveled in a non-linear top-down succession of contacts. First, I reached out to one employee at the municipal center for school development and presented my project to them via e-mail. This person then referred me to a contact inside the municipal administration for elementary school, who works specifically with crisis planning and school safety at municipal level. I started by presenting my project to this person by e-mail. This led to the organization of an on-site meeting to discuss how the municipal school administration views death and grief, get insights on how higher policy around these issues is constructed, and request assistance and advice in relation to how to approach schools and find one organization willing to participate in my study. This meeting, which befell in the beginning of March

2023 and was not recorded, allowed me to form an overview of how schools within the municipality are instructed to act in the face of death, grief and traumatic events and gain access to municipal level policy. I collected documentation and made extensive notes during this encounter, and it is undeniable that this contributed to shape the course of my investigation. After our conversation, the person I was meeting kindly offered to contact several school principals in my name and help me find a school willing to take part in my research. It was through this chain of events that I finally came to be in touch with the principal of the LSS that is the object of this study. Within the LSS, the principal functioned as a bridge between me and the organization throughout my research. They supported me in recruiting members of the staff to be interviewed and they cooperated in the organization of the interviews which took place at the premises of the LSS.

The networking process inherent to gaining access to the organizations observed in my study translated into an accumulation of email chains, phone calls and personal meetings. Part of my data (higher level policy documents and annotations) was generated in this explorative stage. And far from being insignificant in relation to the subsequent stages of interview research, the process of carving out research spaces remarkably shaped the course of my investigation. In the process of creating the conditions for my investigation, I sharpened the research design, revisited the research questions and reflected upon my envisioned methods and their ethical implications.

#### **4.4.2. Data generation**

In accordance with the ideas portrayed by Charmaz (2014) the quality of a research study, starts with the data. This means that the scope and depth of what is gathered and generated makes a difference when it comes to the validity and quality of the investigation. In my research, I strived for data that, within the time and size constraints of my project, would be sustainable, representative and sufficient. As mentioned in the beginning of this chapter, the methods used to generate these data combined document gathering, interview research and observations and annotations conducted in both the examined work environments, the CPC and the LSS. The choice to have varied sources of data aligns with the principles of constructivist grounded theory and is guided by the intention of obtaining rich and multidimensional data that illuminates the research questions guiding my study.

The on-site component of the data generation stage (including the realization of in loco interviews, meetings, and observations) befell between February and March 2023 at the center for palliative care; and between March and April 2023 at the lower secondary school.

##### **4.4.2.1. Document collection**

When contacting judicial and administrative personnel within the examined workplaces with the intent of requesting documents, protocols, and written routines, I prioritized the establishment of a relation with these people which I viewed as collaborators within my investigation.

I strived for clarity and transparency in defining what I was looking for and the reasoning behind my research. Besides presenting the research project and summarizing my overall intentions and goals, I explained that I was specifically interested in collecting documents related to handling death and grief within the work environment (both when it impacts the workforce and when it happens at patient/student level). Moreover, I specified that I was interested in studying the use of multiple modes and in understanding both the analogue and the digital dimensions involved in envisioning and documenting practices surrounding death and grief. Or, in simpler terms, that I was interested in accessing written documentation related both to practical, physical, workplace routines and the management and updating of IT systems.

My interactions with administrative and juridical personnel in both examined workplaces resulted in the collection of a total of 75 pages of workplace documentation, comprising local and internal crisis plans, checklists, written instructions and routines. These documents are categorized and inventoried on table 2 below.

**Table 2**  
*Inventory and categorization of the documents collected*

Organization	Document(s)	Created by	Contents
CPC	Checklist in the event of an employee's death	Human resources strategic department of the Hospital to which the CPC belongs	13 steps to follow upon the death of a member of the workforce, divided in 8 mandatory and 5 facultative steps
CPC	Instructions to update IT systems	Administrative and management staff at the CPC	Detailed instructions on how to remove a patient from different internal IT systems
LSS	Generic local school crisis management plan and overall information	Crisis management group within the municipal school administration	Municipal/local-level crisis plan for schools, including guidelines for cases of death or serious injury
LSS	LSS internal crisis plan	Internal crisis management group at the LSS	Internal crisis plan of the LSS, including guidelines for cases of death or serious injury

#### **4.4.2.2. In-depth, semi-structured interviews**

Interviewing is viewed by grounded theorists as a way to gain access to the views and experiences that can illuminate the phenomena that are the object of study (Charmaz, 2014), therefore, it makes sense to adopt an intensive, or in-depth, approach to interviewing. Within the frame of my study, this translated into semi-structured, in-depth interviews. An in-depth approach implies a one-sided, mildly guided, conversation in which the inquirer focuses in creating the conditions for the informant to talk freely and on their own terms about different topics (Charmaz, 2014). With this in mind, I decided to conduct the interviews for my study in Swedish, since I interviewed Swedish informants. I did this to create comfort and easiness and remove possible language barriers that could limit the informants' accounts. The preparation of the interview guides involved preliminary knowledge about the examined work environments. This knowledge was acquired in my interactions with my contact persons within each organization and it involved getting familiar with the workplace's regular activities and prominent technical questions.

I used this knowledge to prepare two interview guides, one for the interviews at the CPC ([appendix 3](#)) and one for the interviews at the LSS ([appendix 4](#)). The guides were designed in a specular manner, to ensure comparability and rigor in the generated data, but each one was carefully adjusted to the context in which it was to be used in. I constructed the interview guides in a model that includes a section dedicated to initial questions, a section of intermediate questions (divided in themes that are relevant for the research) and a final section of ending questions. For each section, I created suggested wide interrogations, more detailed follow-up questions and prompts to help the conversation flow. The interview guide was piloted and iterated twice before the interviews were conducted. Once I reached a final version of the guide, I used it as a tool during the process of interviewing. Focus was placed on creating space for personal testimonies within the investigated topics and being open to the emergence of unforeseen insights (Cohen et al., 2002), rather than on following the interview guide strictly.

I gave the participants the choice between participating on an interview in person or online. In accordance with the participants' preferences, 5 interviews were conducted in person, at the participants' respective workplaces, and 2 interviews were conducted online on Zoom videoconferencing. Regardless of the format, I dedicated the initial part of the interview to presenting myself and establishing a rapport with the interviewee. In both cases (in-person interviews and online

interviews), audio was recorded. The interviews were transcribed using a semi-automated, *non-verbatim* intelligent transcription.

#### 4.4.2.3. Sampling

The participants in the interview research were recruited through a combination of non-probability sampling techniques, namely purposive and snowball sampling (Patton, 2015). The recruitment criteria were flexible and drawn from the knowledge and ideas that arose from my initial contacts with the examined workplaces. The focus was on representativeness of different professional categories. Which means that I was interested in gathering testimonies from different professional figures within each organization. With that in mind, and with the assistance of my contact persons within each context, I distributed participation requests and obtained contact with interested participants through an online form.

#### 4.4.2.4. Research participants

Below (table 3), I present a list of the participants who took part in the interview component of this study. The list includes a pseudonym, the professional role, and the years of professional experience of each participant. The age and gender of the informants are not relevant in the ambit of my analysis and are therefore not specified in the table below (table 3). When reporting the findings, the informants hereby addressed with the pseudonyms Anna, Sara, Pia, Lisa, Vera and Britta will be referred to by using feminine personal pronouns (she, her) and the participant hereby addressed with the pseudonym Lars will be referred to by using masculine personal pronouns (he, him). The participant's names were changed into pseudonyms, and the years of professional experience of each participant are given in approximation for confidentiality purposes. It was determined that indicating the professional roles of the participants was of significance for my study and would not compromise participant anonymity since the CPC and the LSS names and location in Sweden are never revealed.

**Table 3**

*Research participants – informants interviewed for this study*

Pseudonym	Institution/Workplace	Professional role	Professional experience
Anna	LSS	Teacher	< 10 years
Sara	LSS	School nurse	< 10 years
Pia	LSS	Principal	≈ 20 years
Lisa	CPC	Nurse	> 30 years
Vera	CPC	Doctor	> 20 years
Lars	CPC	Counsellor	< 10 years
Britta	CPC	Counsellor	> 40 years

#### 4.4.2.5. Observations and annotations

As pointed out by Cohen et al. (2002), the distinctive feature of observation as a research method is that it gives an investigator the opportunity to make sense of “live” data from spontaneous social situations. In my study, observations and annotations were present in all the stages of the investigative process. I relied on observation techniques and made annotations during my visits to the observed work environments, during the interview research and in conversations with people involved in my investigation. With an approach aligned with the principles of constructivist grounded theory, I undertook to register details that I viewed as independent of my presence as an observer as well as details that might have been a consequence of my presence within the studied contexts.

I made notes on spatial disposition, contextual information, body language of the participants, artefacts and tools, and aspects that were mentioned during informal dialogues. My annotations complement the data generated by the document collection and the interview research.

#### **4.4.3. Data analysis**

In my analysis, the generated data were approached as representations of subjective discourses and accounts. The documents embody what their authors have presumed as objective facts, but in themselves are not representative of objective facts (Coffey, 2014; Charmaz, 2014), the interview testimonies represent what the informants view as relevant in their subjective experiences and my own annotations depict my account of what may be of interest to the investigation I am conducting.

As for the methods used to analyze these data, they consisted in a conjoint combination between coding and memo writing. Charmaz (2014) defines the process of analysis not only as iterative, but also as interactive. In particular in what concerns coding since the words that constitute the researcher's codes are a choice of the researcher and not the product of an existing theory waited to be confirmed (Charmaz, 2014). In my coding practices, the collected documents, the interview transcripts, and my own annotations were approached as a vast unit of textual data. This means that I applied the same analytical strategies and techniques, true to constructivist grounded theory methodology, to all my study's data. These strategies involved three essential elements:

- 1) Initial line-by-line coding to ensure that implicit ideas were brought to the surface and highlighted throughout the dataset.
- 2) A second stage of focused coding (Charmaz, 2014, p. 140), which provided a terser profile of codes and allowed me to start comparing emergent ideas across the data.
- 3) Finally, memo-writing which allowed me to start the process of theorizing from the data and provided the grounds for the findings section of the present thesis. Charmaz (2014) advises in favor of memo-writing so that "by examining the specifics, you understand the whole of your studied phenomenon, often in new ways" (p. 164).

I have generated my analysis based on constructivist grounded theory methods and alongside the theoretical framework of multimodality to elicit grounded reflections and observations from the data.

#### **4.5. Ethical considerations**

A focus on integrity and sound ethical standards was present in all the different phases of this study. My research was structured in alignment with the ethical guidelines published by the Association of Internet Researchers (Franzke et al., 2020). These form an experientially grounded ethical approach that is reflective and dialogical instead of prescriptive. I view this approach as adequate in the ambit of an exploratory empirical project such as this thesis. I affiliate with the idea that setting about diligence to the ethical dimensions ingrained in the research questions, the methods adopted, and the overall research design contributes to upholding reciprocity and cohesive development between these elements throughout the materialization of the investigative process.

A basic principle when conducting research is avoiding harm both to research participants and to researchers (Franzke et al., 2020). Assuming that being mindful of what can cause harm is often not possible before certain actions take place, or until after certain facts, I adopted an iterative approach and continuously questioned the steps taken and the decisions made, both beforehand and in hindsight.

My investigation was conducted in Sweden and the research participants were adults older than 18 years old, capable of independently decide whether to participate in the study and able to understand the study's characteristics and goals, when provided with legitimate information. The topic of my research touches upon questions that may be considered sensitive and emotionally charged, but the focus on the professional sphere and the perspective adopted (namely the choice to focus on literacy practices and the use of analogue and digital modes), may place these questions in a more objective

plan and render them less sensitive to the participants. It was determined that the possibility of causing harm, in this case, was predominantly connected to questions such as anonymity, confidentiality, integrity and bias.

My striving to avoid harm was, therefore, oriented by four primary intentions:

- 1) ensuring secrecy and protecting all the organizations involved, while portraying the differentiated characteristics of the research contexts in a factual manner.
- 2) protecting the identity and integrity of the research participants, while showcasing excerpts of their testimonies to back up the report of the findings.
- 3) protecting the identity and integrity of third parties mentioned in the interview research when reporting on recounts of action involving people other than the interviewee.
- 4) being aware of my role as a researcher and my position as a human in relation to the participants in my research.

Complying with the above specified goals involved a range of considerations. Importance was placed on providing information, asking for permission, and ensuring anonymization. The juridical and administrative entities competent within each or the observed professional environments were contacted in order to obtain access and permission to workplace documents. In the ambit of interview research, informed consent forms ([appendix 2](#)) were signed by participants who agreed to be interviewed for the study, and these included a request for permission to record audio during the interview. In alignment with principals connected to competence, voluntarism, and full information (Cohen et al., 2002), participants were notified about the context and purpose of my investigation and what their participation would implicate through an information letter ([appendix 1](#)). To ensure confidentiality, the institutions that were examined are never named and their location in Sweden is not revealed. Additionally, the names used in this thesis, when referring the interview participants, are pseudonyms. Finally, any personal details that may be used to identify a person were purposefully removed from the quotes and excerpts used in this report.

I also considered the implications of conducting in-depth interviews aimed at exploring themes that encompass suffering for individuals and their families. With this in mind, the principle of data minimization (Ess & Hård af Segerstad, 2019) was applied, and the interview guides ([appendix 3](#), [appendix 4](#)) were built to focus mainly on action, procedure and personal experience. Moreover, while conducting the interviews attention was put into maintaining a balance between allowing the informant to explore what they deemed relevant and refraining the scrutiny of unnecessary or accessory aspects. Another element that was taken into consideration was that while conducting my research I penetrated spaces (the workplaces examined) that besides the study's target population (adult professionals) also host sensitive groups, namely people that are terminally ill, their family members, and underage school students. This was taken into consideration, and I tried to be the less invasive and the most respectful I could be throughout my incursions to the studied workplaces. Finally, my role as a researcher was also taken into consideration from the standpoint of cultural awareness and biased interpretation. I undertook all the components of the research with an awareness of my positioning as a white cisgender woman who is a Portuguese emigrant in Sweden. I am cognizant of how my cultural and linguistic background and other factors may influence my interpretations. I was thorough with linguistic questions when transcribing, analyzing, translating, and describing the data and paid attention to the socio-cultural dimension in which my identity is inserted throughout the investigation process.



## 5. Findings

This chapter presents the findings that emerged from analyzing the data generated within the two professional environments that are the object of my study – the CPC and the LSS. The research questions that guide this research provide the underlying structure for this chapter and are addressed in the following order and manner:

*RQ1 - How are death and grief being integrated into professional practice in a center for palliative care (CPC) and a lower secondary school (LSS) in Sweden?*

In the first section of this chapter ([5.1. Integration of death and grief into professional practice](#)), I explore five categories, drawn from the data, to illustrate how professionals integrate death and grief into their practices, within each of the two analyzed professional contexts. Besides substantiating that death is a crucial part of the job at the CPC and a tragic rare occurrence at the LSS, the results portray: 1) how policy and routines related to death and grief are constructed within the CPC and the LSS and how professionals within these contexts relate differently to written documentation; 2) how professionals view and experience death in different ways in each observed context and how this may impact their practice; 3) how tasks and sequences of action and interaction differ in the CPC and LSS when it comes to the aftermath of a death; 4) how each organization is prepared to handle grief and provides bereavement support to different extents and how this reflects on the individual experiences of professionals; and 5) how professionals within the CPC and the LSS experience learning and competence development in relation to death and grief.

*RQ2 - Which modes, systems and sequences of communication and action are involved in dealing with death and grief in these two diverse professional contexts?*

In the second section of this chapter ([5.2. Modes, systems and sequences of communication and action involved in dealing with death and grief in the two examined professional contexts](#)), I present two visualizations that lay out the modes, systems and sequences of communication and action involved in dealing with death and grief within the CPC and the LSS. The visualizations draw on what was uncovered when analyzing the data and show that death-related practices, within both contexts, are characterized by an articulation between analogue and digital and encompass multimodal communication, action and interaction.

*RQ3 - In which multimodal literacies are professionals required to engage when they address death and grief in their professional practice?*

In the third and last section of this chapter ([5.3. Multimodal literacies required when addressing death and grief in professional practice](#)), I use the visualizations presented in the previous section and the results of my analysis to describe the multimodal literacy practices required when professionals deal with death and grief in their digitalized professional contexts. The findings show that, when it comes to dealing with death and grief at work, professionals rely on the available modal resources to construct meaning and organize their practices. Furthermore, the findings display that users select modes in alignment with what they perceive to be social and communicational needs within this ambit, and that they create new modes and alter existing ones to respond to those perceived needs.

In all the sections of this chapter, I use quotes from interviews and excerpts from written documents to illustrate and support the information that is being described. All the quotes and excerpts included have been translated from the original Swedish to English, for the purpose of this thesis.

### 5.1. Integration of death and grief into professional practice

My choice of observing two professional environments that differ in their essential relation to the realities of death and grief, rested on the intention of gaining nuanced insights about how professionals

in different settings may have different perspectives on these topics and, consequently, rely on different strategies to address them in their professional practice. The interview research confirmed that death assumes a central role within the CPC and a peripheral one within the LSS and that, as a consequence, professionals pertaining to each setting view it differently. All the interviewed professionals working at the CPC asserted that death and grief are at the very core of their professional practice and an essential part of their daily work in direct and indirect ways. The comments below illustrate this idea:

[In the context of the informant's professional practice] "death is there as an undertone the whole time. It is part of everything." (Lars, counsellor)

"We work in close contact with death the entire time, death is a constant presence. Patients, families and professionals alike know that a palliative healthcare trajectory will end with death." (Vera, doctor)

In contrast, the professionals working at the LSS either refused the idea of death and grief as a part of school life or reluctantly admitted that death and grief can be a part of the school environment but judged this as an unfortunate or negative fact. The following comments surfaced, when members of the school workforce were interrogated on whether death is a part of life in school:

"No, not really. It is quite disconnected from what we do here. It might come up indirectly, for example in History class, when we speak about certain historical events, but other than that it is not something we speak about very much really. It is not a part of our job." (Anna, teacher)

"I would like to say no, to protect everyone. But that is not possible, because death becomes a part of life in school when it happens, and it does happen occasionally. Students, parents and school staff sometimes die. So, it exists, and one might be confronted with it in school. Unfortunately, that is the reality." (Sara, school nurse)

The testimonies of all the other interview participants reinforce the distinction expressed above and allow me to infer that death is experienced as an underlying absoluteness at the CPC and as an unpleasant and unfamiliar truth at the LSS. In the following sections, I describe how death and grief are integrated into professional practice in the observed workplaces by focusing on five categories that seek to cover how professionals relate to written documentation, how they view and confront death, how they reorganize different dimensions in the aftermath of a death, how they view and deal with grief and how they develop competences in this ambit.

### **5.1.1. Policy surrounding death: knowledge in the head and knowledge in the world**

In collaboration with administrative personnel at the CPC and the LSS, policy documents and written routines related to death and grief were gathered within each of these professional settings. The analysis of the collected material led to the findings that I describe in the next paragraphs.

Both the CPC and the LSS possess written documents provided by the bigger organization that steers their work (the hospital and the municipal school administration, respectively), as well as internal written documents specifically created within the workplace for specific purposes or consisting of an adjustment of the generic guidelines to the workplace functioning and requirements.

The CPC appears to not strongly rely on written norms and routines when it comes to structuring action and communication in relation to death and grief. When it comes to the death of a patient, and despite the fact that there are very specific routines and sequences of action that follow such an event (for example, the death must be established and confirmed by a doctor or nurse, a death cause certificate and a death certificate must be written, the body must be handled by the staff and prepared for transportation, etc.), there is almost no written documentation that supports, regulates or details these practices. Interestingly, the only written routines related to patients' deaths that were found, regard the use of digital systems and tools. There is, in fact, detailed documentation, directed at the

administrative staff of the CPC, that provides clear instructions on how to handle and update different internal informatic upon a patient's death. In these instructions, actions such as "terminating the patient" in various systems, filling in death certificates within those systems and using the systems for booking and documenting meetings with the deceased's relatives in the aftermath of their death, are described in detail. When it comes to the death of a member of the workforce, the CPC relies on the hospital's guidelines in the form of a 13-step checklist created and distributed by the hospital's human resources strategic department. This checklist is transversal to all the hospital's departments and dependencies, and it has not been modified or adjusted by the management team of the CPC. It contains eight steps that must take place in the event of a staff-member's death, and five steps or actions that optionally may be arranged. The necessary steps comprise informing the deceased's co-workers; naming a contact person to handle the situation; contacting different internal services (communication department, human resources) in order to organize how communication and information about the event are to be handled; contacting the deceased's family and the external parties responsible for the funerary services; organizing the deceased's physical belongings and arranging their devolution to the next of kin; and terminating the deceased's presence within workplace systems, digital documentation and devices. The facultative steps relate to rituals and memorialization practices and include the suggestion of providing time and space for internal dialogue about the event. When it comes to handling grief at different levels (amongst a deceased patient's loved ones, within the workforce), no formalized routines or written documents were found. Nonetheless, numerous brochures produced and distributed by the regional healthcare administration were found at the CPC and these are resources that the CPC's professionals use to educate and support patients and the patients' next of kin in handling illness, death and grief.

In relation to policy and documented or instructed action within the CPC, two important aspects emerge from the interview research: 1) amongst CPC professionals, all the hands-on, patient-related work is performed without relying on written guides or checklists and this includes the tasks and operations surrounding the death of a patient; 2) when death occurs outside the scope of the palliative care being provided (for example when a member of the workforce dies or is impacted by the loss of a close relative), the organization strongly relies on the management team to steer action and interaction and this may be supported by existing written guidelines. Professionals that do not hold managing positions are most likely not familiar with these guidelines, and they rely on their managers for instructions and support.

The excerpts below are illustrative of how knowledge is not anchored in written documentation when it comes to the professionals at the CPC handling patients' deaths, but rather based on practice and of a tacit nature:

"When a patient dies, there are some things that must be done, such as filling in the death cause certificate and the death certificate or arranging the body (...) but we don't really have any checklists or written instructions that we follow when we do this." (Britta, counsellor)

"The routine depends on the context, if it happens at the hospital, in the hospice or at the patient's home (...) [the informant proceeds to describe in detail numerous configurations]. Some things need to be a part of the routine, regardless of the context; other things are more flexible (...), but there is no manual that tells you exactly how to structure your work." (Lisa, nurse)

The quotes below, in their turn, reveal that the CPC's professionals rely mainly on their immediate managers to handle death and grief within the workforce and that they are often unfamiliar with existing written routines in this ambit:

"Many years ago, when I was in a managing position, there was a situation in which a colleague died suddenly and, at that time, I was confronted with the fact that there was almost no written plans or guidelines available to help us deal with the situation. (...) I don't know how it is now, and I don't know if some clear written rules exist for when a member of the workforce dies. But we rely on our immediate superiors to gather the team and tell us how to proceed." (Vera, doctor)

“I can’t really say [if there are written routines for when a member of the workforce dies]. I believe that there are some rules or checklists written by the HR department, but I don’t know them. In such cases, all is mediated by our manager.” (Britta, counsellor)

“The first thing that comes to mind, as a spontaneous answer [to whether there are guidelines orienting what one should do when a member of the workforce dies], is my manager.” (Lars, counsellor)

The findings depict that the professionals pertaining to the CPC and working directly with patient care generally do not rely on written information to act, interact, and communicate in relation to death and grief. Indeed, when these occur in what is perceived as the daily job sphere (at patient level), professionals appear to be reliant on practice-based, tacit knowledge to incorporate death and grief into their practice. Written guidelines seem to become pertinent for professionals holding managing or administrative positions, i.e., who have a less hands-on contact with death in their work. And these texts contain instructions to facilitate human-computer interaction and manage systems in the face of a patient's death, or directives to proceed in the face of a death that occurs outside the daily job sphere (specifically the death of a member of the staff).

Dissimilarly from what happens at the CPC, extensive general (municipal/local-level) and specific (internal-level) written policy - aimed not only at supporting professionals in handling death at different levels but also at preventing and containing other eventual emergency scenarios - is found within the LSS. In this professional setting, there are detailed documents, written routines and specific artefacts available and ready to be used upon what are perceived as acute situations. A document titled *Local crisis management plan* - created and distributed by the municipal school administration - regulates and informs, in generic terms, how schools within the municipality should handle crisis. This document includes guidelines for a variety of emergency situations that may or may not include the occurrence of death. The sections of this document that specifically contemplate death are detailed and seek to cover a range of situations. They contain detailed instructions for the eventuality of a student, a member of the staff or a close relative to one of the above becoming severely hurt or dying. There is differential information for when such an event happens in the school premises or during school hours, and when it happens outside school and outside school hours. The instructions guide action, interaction and communication and include check-lists and suggestions of how to act, who to contact and how to organize work and distribute responsibilities. Materials such as pre-written letter examples that may be used to inform the students’ guardians about a death or notify them about the realization of funerary ceremonies are also included in this document. There are guidelines to approach possible contacts with the mass media, directives for putting together a “crisis box” containing artefacts (such as candles, a white tablecloth, and a picture frame) and resources (such as books and brochures) that may be used to create the conditions for memorialization practices within the school premises and facilitate onsite support in the immediate aftermath of a death.

Drawing from this generic document, the LSS administration, namely the internal crisis management group (formed by the principal of the school area, the school principal, the school psychologist, the school nurse, the school counsellor, the special education teacher and three teachers in representation of the LSS’s teaching teams) created the LSS’s own internal crisis plan. This document is designed to provide information beforehand, but also to be used as a resource during a crisis. It contains an index that allows the user to easily access any given section and it is divided in sixteen sections. The first fourteen sections contain introductory and generic information. Two short introductory sections are followed by a definition of what a crisis within the school environment might look like. Interestingly, death is used in this document as the first example of a crisis in school as shown in the excerpt below:

“3. Example of what a crisis is:

A crisis in a school can arise for many different reasons. A student, a member of the school staff, or a student's relative may unexpectedly pass away”.

(Excerpt from the internal crisis management plan created by the administration of the LSS)

The remaining sections, within the fourteen-sectioned introductory part of this document, contain instructions on how to prevent and prepare for crisis; references to literature on the topic; a basic check-list aimed at establishing priorities in the event of a crisis; a list of internal contacts; a list of external contacts (such as emergency services, the police force, the local hospital and the local church); generic information about how children and young people cope with acute situations; and basic knowledge about how adults can support children and young children through crises and emergencies, including few remarks on how to address children's grief. The fifteenth section, divided in seven subsections, is dedicated to routines. It includes routines for sharing information and notifying staff members, students and students' guardians about unpredicted tragic events (including death); routines in case a student dies, in school or outside school; routines in case a staff member dies, in school or outside school; routines in case a student suffers the loss of a close relative; routines for when serious accidents occur, in school or in the school's surroundings; and finally, information about where to find the school's crisis box and as well as an inventory of its contents. The sixteenth and last section of this document is a four-question guide aimed at evaluating the LSS's response to a crisis retrospectively.

When it comes to how professionals relate to written documentation and policy at the LSS, when dealing with death and grief, the analysis of the interview data reveals a strong reliance on stipulated written routines, and a focus on frequently and consistently improving and updating these routines.

The following testimonies illustrate this:

[Referring to the written crisis plan] "It is here in case something happens, not to remind us, or scare us, but just because death is a part of everything. And that is why the crisis plan exists, so that we all know who we need to call, who we must contact, in what order, who is responsible for what (...) so that all is clear, and all have directions to guide us and feel prepared in case something happens." (Pia, school principal)

"I would say that before I had no idea how we as a school are supposed to do things. And then when it happened [referring to the unpredicted death of a student], I got a more concrete picture. There are written routines, and we used those, but until we had to follow them and experience all the steps it was harder to form a concrete understanding of how things can be handled." (Anna, teacher)

"In our action plan there are different steps (...) the instructions depend on if it happens in school or outside school, if it is something we are prepared for or if it is something unpredicted. (...) I am a part of the action plan as an adult who can provide support and guidance." (Sara, school nurse)

The interviewed professionals at the LSS mentioned the written crisis plan not only when interrogated both about dealing with the death of a student but also when questioned about dealing with the death a member of the workforce. Contrarily to what happens at the CPC, the findings indicate that professionals at the LSS rely strongly on written information in order to act, interact and communicate in relation to death and grief.

### **5.1.2. Death itself: when the (un)expected happens**

The data generated by interview component of my research allowed me to gain insights into how professionals within the CPC and the LSS view death and grief differently. The adjectives and nouns used by professionals when they refer to death and describe their experiences are indicative of these differences.

The death of a patient at the CPC occurs frequently and is expected. It signals the end of an often hard and painful illness trajectory and is therefore viewed by professionals as something that provides relief and closure to both the patient, their relatives and the staff. Additionally, at the CPC there is space for light-hearted and uplifting conversations about death amongst professionals, perhaps because this very profound topic acquires familiar and routine traits in this setting. The comments below depict this sense of lightness:

“There may be difficult situations to handle, but we talk about it a lot. And we joke with each other sometimes. It's quite common that people say, ‘if I die in this way’ and ‘if I die in this other way’ and so. It's a bit like this, we laugh sometimes. There is definitely room for a little laughter.” (Lisa, nurse)

[Referring to the emotions and feelings that follow the death of a patient] “It can be a sense of loss mixed with a sense of relief that someone's suffering is ending. Relief that a problematic situation is resolved or gets closure.” (Lars, counsellor)

“Often death is a relief to us. That's when we end our problems. And for patients who have had a hard time, when they die, that hard time is over.” (Vera, doctor)

Death at the LSS is, on the other hand, rather uncommon, often unexpected, and professionals in this setting generally perceive it as tragic, shocking and unfortunate. The interview excerpts below portray a sense of unfamiliarity and show how emotions like sadness, surprise and grief are convoked:

[Speaking about encountering death in the school environment] “If you have thought about it enough times, you become more capable to handle it. Obviously, you will be sad and surprised, but you can still remember the things you thought previously and that might make it easier for you to act and react.” (Pia, school principal)

[Speaking about death] “It is unfortunate and painful. It is not something I go around talking about, in case it doesn't happen, I will tell you that.” (Sara, school nurse)

Practicalities connected to encountering death differ greatly between the CPC and the LSS. While the deaths of patients at the CPC are frequent occurrences and imply a sequence of practical tasks that relate directly to death itself, death at the LSS is not only infrequent (in all of its manifestations), but it is also something that professionals handle and experience only in mediated or indirect ways. In the context of the CPC, tasks such as confirming, documenting and certifying a patient's death, supporting the loved ones of the deceased person, preparing the body for transportation and reorganizing physical space once the body is removed are all a part of the job. The remark presented below illustrates this very direct contact with death.

“It's like this: the staff, doctors and nurses must establish that the patient is dead. They must prepare the patient's deceased body and take care of it so that it will be presentable, regardless of whether you are at the patient's home, at the hospice or in the hospital ward. You must also take care of the patient's next of kin so that they have all the information they need about the moment of death and have the opportunity to say goodbye in the place where you are. Sometimes, as a counsellor, I have been involved in the death. I sometimes get a lot of questions in those moments. ‘What should I do? Should I contact a funeral home? What happens now?’ And some people don't really have questions. But have instead fears and intense emotions, this psychosocial thing. And those fears can exist physically as well, so to speak, so we must face them and provide support.” (Britta, counsellor)

At the CPC, hands-on work with death and dying is inherent to the professional practice. Death can, of course, acquire different contours when it happens to a staff member, but that does not invalidate that the CPC's professionals are used to deal with it in a direct way in their daily practices. At the LSS, in contrast, any encounter with death is, most often, indirect. The deaths of students, staff members or the loved ones of these two groups commonly occur outside of the school premises. In the rare event of someone dying in school, during school hours, external medical, police and religious personnel is called to the scene and takes responsibility for dealing with death-related documentation, caring for the dead body, evaluating the need for a criminal investigation, and communicating the death to the next of kin of the deceased. In relation to this last aspect, connected to communication practices when death occurs in the school premises, the crisis plan provided by the municipality to all the municipal schools clearly stipulates that:

“A death notice must always be given to the next of kin by the police, doctor or priest.” (Excerpt from the local crisis management plan created and distributed by the municipal school administration)

In fact, what is expected from the LSS professionals is not to handle death directly, but to accommodate death, in the extent to which it may impact their work, as well as to have the necessary information and tools to contact external specialized professionals, whenever direct contact with death is required. In the comment included below one member of the LSS personnel confirms that practices surrounding death in this setting focus on obtaining information, passing that information on to different people and convoking internal and external resources.

[Recounting one situation in which a student died during a holiday period] “It was mostly that we needed to get confirmation from the deceased’s family and keep in touch with them in order to structure our organizational response according to their wishes. In this case the principal received information directly from the family. Otherwise, whoever obtains the information needs to contact the principal and the student-health team [referring to a team of professionals within the school, led by the school principal and composed by the special education teacher, the school nurse, the school psychologist and the school counsellor]. Then one needs to inform the class’s teacher and every other teacher as well. We also need to inform the students in the affected class and other classes, and the students’ guardians. In this occasion we decided that it was best that the guardians took responsibility for informing their children. (...) We also contacted the local church and received the support of a priest that was present in school for two days when the classes restarted after the holidays.” (Anna, teacher)

The way professionals within the CPC and the LSS refer to the occurrence of death is indicative of predominantly different views of death within each one of these contexts. These views intrinsically connected to how labor intertwines with death differently within each professional environment. A direct, hands-on contact with often difficult end-of-life trajectories leads to the expected deaths of patients at CPC. Moreover, the CPC’s professionals are equipped for and expected to not only be present in the very moment of death, but also relate to death closely through a set of actions and practical routines that involve, amongst other things, direct contact with the dead body and the newly bereaved loved ones of the deceased. At the LSS the contact professionals have with death is most often indirect or mediated. And what they are expected to do in the face of a death connects mainly to handling information and communication surrounding the event in a manner that preserves the underlying organizational structures of the LSS and is adequate within its functioning.

Despite these differences, both workplaces are prone to reconfiguration and readjustment, in smaller or larger degrees, in the aftermath of a death.

### **5.1.3. The aftermath: rituals, conversation and reorganization**

What happens beyond the moment in which professionals encounter death in their work, and extends for weeks or months after these encounters, is also a part of how death and grief are integrated into professional practice. The generated data points to three main things occurring in the aftermath of a death within the examined workplaces: rituals, conversation, and reorganization. The extent to which each one of these components is present and how they manifest is different in the CPC and the LSS.

The collected data indicates that memorialization practices and rituals are not common practice in connection to the deaths of patients at the CPC. Nevertheless, some professionals spoke of spontaneous, discrete gestures that may be considered of ritualistic character and can sometimes happen in connection to a patient’s death. Such gestures can be picking wildflowers outside and using them in a decorative manner when preparing the dead body to be viewed by the deceased’s loved ones or lighting a candle in a meeting about the deceased patient. The occurrence of these informal rituals seems to depend on the team who is responsible for the patient’s care and other contextual factors. The comments below illustrate this:

[Speaking about the death of patients] “It has happened that people light a candle or meet and speak a little about the deceased person and their surviving family members, but it depends on the context. There are usually no rituals.” (Britta, counsellor)

[Speaking about the death of patients] “There was a time some years ago, when every time a patient died during the weekend or overnight, we used to mark that by lighting a candle on the table where we

reunited before starting our morning round. And that way we would always exchange some words on the person had died and inform each other about how it went.” (Vera, doctor)

“Sometimes we see rituals when we work with other hospital wards also. The other day I was in another of hospital ward where one of our patients died, and we decided to run down to the garden and come back with a flower to place on the body before bringing in the family members. (...) It depends on the context, on time also. In the emergencies ward, there is no time to think about small details. But otherwise [in other wards or at the hospice], a deceased body normally stays where it is for circa 2 hours after death, so there is time for small gestures amongst formalities and routines. (...) When the patient [registered to receive domiciliary palliative care] dies at home, there is normally the possibility to do everything in a more personal and intimate manner since there are fewer external pressures with time and other constraints.” (Lisa, nurse)

The sporadic occurrence of informal and spontaneous rituals in connection to a patient’s death is, however, not what professionals recount as the most important thing occurring on such occasions. In the context of the CPC, what seems to be of the utmost importance in the aftermath of a patient’s death is conversation and dialogue. These take both informal and formalized forms. Conversations between colleagues happen informally as a means to make sense of certain (sometimes complex) situations, exchange opinions and share experiences. While formalized debriefing sessions, follow-up meetings and reflection group sessions usually take place at the end of a patient’s trajectory with the goal of evaluating the work done, reflect upon the methods and practices adopted in hindsight and debate how to approach other patients in similar situations. Formalized debriefing sessions include mainly the professionals directly involved in caring for the patient, while informal conversations potentially encompass every member of the workforce and enhance interprofessional and cross-team collaboration.

[Referring to the death of a patient] “In one way or another, we speak about it, every single time. (...) Regardless of the context, the group that worked specifically with that patient meets and reviews the patient’s trajectory and plans the encounters and follow-up meetings with the patient’s surviving loved ones.” (Lisa, nurse)

“In our daily communication, across the hall, during work breaks, in formal meetings or by leaving messages on the tools we use to plan the work, we speak and make sense of the situation when a patient dies. Death is a part of our work, and it is mostly present in our conversations. It becomes concrete through dialogue.” (Lars, counsellor)

“We speak a lot about it [the death of each patient]. After a patient dies, we always discuss how it was in hindsight. If the situation was complicated, we can create a group that reflects on the process and discusses how to improve it.” (Britta, counsellor)

Conversation and dialogue are also used as a meaning-making tool and a means of support when a member of the workforce dies, within the CPC, but in these cases formalized memorialization practices are more likely to occur. It is common to create the conditions for memorializing ceremonies (including music, readings, objects, and artefacts that represent the deceased) and the workplace usually organizes direct or indirect ways of participating in the funeral and send collective condolences to the family of the deceased. The configuration of these practices seems to be dependent on managerial decisions and also on how the workplace community relates to the deceased. The checklist provided by the hospital administration includes suggestions related to rituals and memorialization, namely the examples quoted below:

“If there are requests, a room or a place arranged for a few days with a single bouquet of flowers and possibly a photo can be provided.”

“A book can also be prepared, where colleagues can write greetings or short stories. This book is then handed over, sometime after the funeral, to the next of kin.”



(Excerpts from the checklist for when an employee passes away created and distributed by the hospital's human resources strategic department)

Recounts of action from the CPC's employees reinforce that, although dialogue is often used as a meaning-making and supporting tool when a staff member dies, formal rituals are viewed as valuable and are present as a part of the workplace response to this kind of event.

[Speaking about when a member of the workforce dies] "Speaking and supporting each other through conversation is the most immediate thing that we do. Then, most often the managers organize an official memorial. We read some poetry or sing something; someone will sing something or say some words. (...) On one occasion, a janitor that almost the entire hospital knew died, and that time we were invited to participate in a memorial that took place in a large auditorium, we were many people, from many different wards and departments. (...) we could say some words, sing or just speak to each other about our memories of that person and how we felt in that moment." (Britta, counsellor)

[Speaking about when a member of the workforce dies] "It is important to have such rituals. It is important that everyone in that person's life can participate. We normally send flowers to the family and take part in the funeral. Memorial rituals are also organized at work. And we remember the person and speak about who they were. We offer support to each other that way." (Vera, doctor)

In the CPC, characterized by familiarity, experience and openness in relation to death and dying, rituals and symbolic gestures in connection to death are sometimes present and are viewed as valuable, but professionals refer to conversation as their most powerful meaning-making tool and it emerges as the predominant aspect in the aftermath of a death in this environment.

In contrast, memorialization practices and ritualized action in connection with death seem to be the dominant aspect within the LSS, regardless of the plan in which death occurs. In connection to the death of a student or the death of a member of the workforce, death-related rituals and the creation of what are viewed as mourning spaces seem to be the most important aspects in how professionals accommodate death into their labor at the LSS. The excerpts below, taken from the LSS's internal crisis management plan, illustrate how rituals are described when policy is constructed and how rituals are a part of pre-established written guidelines:

"Flagging: when all classes have been informed, the flag is raised at half-mast. Flowers to the family."

"Memorial ceremonies should take place ideally one day after the death has been announced. The memorials may include: using the crisis box; some words from the school principal; the presence of a priest; words from the doctor; poetry readings; singing; music."

"The crisis box is located [indication of the box's placement within the LSS]. It contains the following items: 1) notebooks with empty pages. The name of the deceased should be written on the first page. After the notebook is filled, it is delivered to the deceased's family in an appropriate manner. 2) a vase. 3) tablecloths. 4) matches."

(Excerpts from the internal crisis management plan created by the administration of the LSS)

The recounts of professionals at the LSS confirm the importance of memorialization rituals in past occasions. The quotes below are examples:

[Speaking about the death of a student] "We had several memorials. We had a room that functioned as a memorial room for a week, where everyone could go and spend time. On the first day of school after the death occurred, we had a minute of silence in honor of the deceased's memory. And we ended that first week with an official memorial service at the school that lasted one and half hours."

[Speaking about the same occasion] "We prepared the memorial room with a table dressed in a white tablecloth, candles that burned every day, a picture frame containing a picture of the student that the mother sent to us. We wanted that the friends and classmates had the opportunity to grieve." (Pia, school principal)

The interview data revealed that, in the occasion recounted above, the memorial room that was opened for one week was not only a place where students and members of the staff could honor the memory of the deceased, but also a space for dialogue. Informants reported that during that week, the memorial room counted with the continuous presence of internal (school nurse, school psychologist, school counsellor) and external resources (a priest was present in the first two days) and explained that these professionals were there to provide support to the student body in making sense of the event. At the LSS, the creation of these mourning spaces appears to coincide with the creation of conversation opportunities. The findings indicate that particular attention is given to supporting the students by providing these compartmentalized safe spaces and ensuring the presence of adult figures that are available to answer questions and comfort.

Amongst professionals, in the context of the LSS, and similarly to what happens in the CPC, conversation has also been pointed out as an important meaning-making tool. This is evident in the following comment:

[Referring to ways to proceed professionally in the face of death] “I don't think there is any solution sheet or that anyone can teach us anything about it, you have to talk about it, put it on the table, have an agenda, a concrete plan, compare - 'how did you do?', give tips to each other.” (Pia, school principal)

Besides generating rituals and conversation, to smaller or greater extents, any death that affects one of the observed professional environments implies some degree of reorganization. The findings show that in the aftermath of a death, professionals, both within the CPC and the LSS, are required to collaborate in reorganizing both a physical and a digital dimension. This involves reassigning and emptying physical spaces, managing objects and personal belongings, rectifying written documents (in digital and paper formats) and updating different digital systems. The conformation of these practices appears to depend on factors such as workplace policy, workplace culture, spatial and temporal constraints and the underlying structure of the software and systems used by the organization. Such practices do not follow strict formulas.

Practicalities connected to the reorganization of physical space are contextually bound and obviously different within the CPC and the LSS. But these aspects vary even within the same work environment from one occasion to the next. The death of one of the CPC patients might imply emptying and cleaning the room where the patient was staying, discarding disposable equipment, and giving back personal objects to the patient's next of kin. While the death of an employee might require a desk to be emptied and reassigned, a locker to be opened and different work gadgets and equipment to be gathered and delivered to the next of kin of the deceased. The objects and spaces to be managed will be different in connection to each individual death and the fine-grained details of these practices are unique and personal every single time. The excerpt below is a testimony from one of the CPC's employees referring to one past situation in which a member of the workforce died:

“There was a lot in motion. There were formalities that had to do with the HR department and the salary administration, the person's work-computer needed to be cleaned and reset. There is no panic nor rush in these situations, but all of these things must be considered. After a while, the mother of the employee came to the workplace. She had managed to find the key to the deceased employee's locker. I opened it up for her and she collected all their personal belongings. I separated the hospital equipment and the employee's name plaque. I had a conversation with the mom and gave her the notebook that we had filled with sentences and drawings during our memorial practice in the workplace, earlier that month. This was maybe a month after the burial.” (Lisa, nurse)

When it comes to updating systems, and managing hardware and software after a death, interestingly, the findings reveal an important difference between the CPC and the LSS. Namely the fact that most of the internal systems used in the context of the LSS are directly connected to the databases of the official population registration, while this is not the case with the systems used by the CPC. This aspect brings practical implications in terms of human-computer interaction when it comes to the aftermath of a death. At the CPC, the work of removing a person's name and data from a system or

registering the death status of a person in a system must be done by an employee, instructed and equipped to perform such administrative tasks. On the other hand, at the LSS a person (student or employee) is automatically no longer represented in the majority of the workplace's internal IT systems after their death has been registered by the official population registration services.

In both cases, discrepancies can arise. Both at the CPC and the LSS, energy and time are put into making sure that printed documents match the information on different systems. When someone dies, their absence needs to be consistent across modes.

While at the CPC conversation and dialogue seem to be the prevalent residues and meaning-making tools after someone's death; at the LSS there seems to be more focus on creating space for rituals and memorialization practices, and, in this setting, dialogue tends to happen in a more compartmentalized configuration. In both professional settings, different dimensions (analogue and digital) must be reorganized, and the deceased's absence must be made consistent across different modes. Something professionals within both settings were unanimous about is the idea that life must go on.

#### **5.1.4. When work is stained by grief: having what it takes**

After a death, life goes on. The clock moves forward and the days on the calendar go by. But the death of someone who meant something to us does not leave us untouched.

Grief, our natural human response to the death of someone we bonded with, presents itself in different ways at the CPC and the LSS. At the CPC, grief is a part of the job, as much as death is. At the LSS, it is peripheral to the work, appearing sometimes as an unexpected visitor that requires attention.

In the ambit of the CPC, professionals are used to work with and around grief and bereavement. While caring for a patient in a terminal stage, professionals encounter the patient's and their family's anticipatory grief and once the patient dies, they support the next of kin with their post loss grief trajectories. In addition to regularly dealing with the grief of others, the CPC's professionals are not immune to experiencing grief themselves, triggered by their work with patients, or in response to the personal loss of a loved one, a friend or a colleague. It is, therefore, adequate to say that grief exists in two different planes, in the context of the CPC. There is grief at patient level, i.e., the grief experienced by patients and their families (which is viewed as part of labor). And there is grief at personnel level, i.e., the grief that professionals themselves embody grief triggered by what they experience as losses (which is viewed as external to labor).

My analysis points to two relevant aspects in connection to grief, within the CPC. The first is that grief is not contemplated in workplace policy. This means that the ways in which grief at patient level is encountered are based on tacitly constructed routines and methods and that the ways in which the organization attends to bereaved staff members are dependent on managerial decisions and on peer-support. The comments below relate to this aspect:

“Through the manager and the Human Resources department one can have access to psychological support in case that becomes relevant or is desired. (...) Part of it can involve that the work team reunites with the manager and organizes adjustments and methods that can help support that person. (...) It is individual depends on the situation.” (Britta, counsellor)

“We can be offered psychotherapy and support by being directed to a division called ‘health and work life’ and we also offer collegial support to each other, basically by being open to listen and talk and being aware of each other's needs.” (Lars, counsellor)

The second aspect identified in the analysis is that the CPC's professionals show developed strategies to handle grief at patient level but reveal some reluctance and concerns when it comes to their experience of grief in their professional roles, i.e., in connection to the deaths of patients. The following testimonies depict how professionals express themselves in this regard:

[Referring to the deaths of patients] “We can feel sad, but not really grieve. (...) We can feel sympathy for the surviving family members, support their grief, but we don’t participate in it. (...) When a colleague dies or loses someone very close, then the professional shield we otherwise wear falls apart.” (Vera, doctor)

“There is something that people don’t speak very much about, but that I think is not uncommon within palliative care and that is the fact that we experience grief in connection to the fact that all our patients die, and that death is the way our contact with them comes to an end, invariably. It’s a losing streak even for us as professionals, and it is not often talked about. It is not a taboo, far from it. But still, we don’t speak much about the grief that we feel in connection to our professional activity.” (Lars, counsellor)

“If there are difficult situations or strong emotions in relation to a patient’s death, we have a more structured opportunity to create a space for reflection together, we debrief, revisit technical and human aspects, talk to each other and that helps us to cope.” (Lisa, nurse)

At the LSS, professionals are not used to work with grief, as much as they are not used to work with death. Nevertheless, in the LSS, both professionals and students can experience grief related to personal losses or triggered by the loss of someone within the school community. This means that grief, in this context can also be classified as existing on two levels: student level or personnel level. In this setting, grief is always viewed as external to labor, regardless of the level in which it presents itself. However, when grief is present, professionals may need to adjust their practice in smaller or greater ways. I identified two pertinent aspects when it comes to the integration of grief into the LSS’s practices.

The first is that grief is, in the context of the LSS, mentioned in policy documents. The analysis of the data retrieved from the LSS reveals, however, that written information about grief is scarce, misleading and focused exclusively on grief impacting students. In fact, the information (which is uncritically presented and does not refer to any sources) is, in actuality, based on an outdated or misunderstood conception of grief theories. The two instances of grief-related information found in policy documents are: 1) vague instructions about how different professionals may approach a bereaved student and instruct other students about thoughtful and supportive behavior around a bereaved classmate (found in the internal crisis management plan, LSS); and 2) general information about how children and adolescents experience grief (found in the local crisis management plan, municipal school administration). The instructions about approaching bereaved students (internal crisis management plan, LSS) focus on respecting the bereaved student’s wishes and needs, offering them the opportunity to receive support from the LSS’s health team and preparing the other students in the class to the fact that the bereaved student might be more sensitive than before. The general information about how young people experience grief (local crisis management plan, municipal school administration) consists of a list of what is labelled as the four stages of grief. These stages are identified as the shock phase, the reaction phase, the processing phase, and the reorientation phase. Information about how long each stage is expected to last is provided. And that is all. The fact that this four-stage model is presented as a fact and no further information is offered to the reader shows how deeply embedded such an obsolete understanding of grief is in contemporary society and calls for further education. When it comes to handling grief within the workforce, no information or formalized routines/instructions were found, but the results of the interview component of my research revealed that the LSS relies on external entities and on informal peer-support, as depicted in the following comment, here used as an example for something other professionals also have confirmed with their testimonials:

“There is an external unit that we, school employees, can contact to get psychological support. (...) And then we have a very nice work team, and we speak a lot with each other. So, we also help each other. If someone is having a crisis in their lives, we show our support. But formally, we must contact someone external.” (Anna, teacher)

The second interesting aspect, in relation to how grief is integrated in the LSS, is that not all professionals in this setting feel equipped to deal with grief. Indeed, the findings indicate that there is a tendency to rely on professional figures who are viewed as more competent, when it comes to handling grief. The interview excerpts below are revealing in this regard:

“I think it is very important to have good communication with the school health team, the school nurse, the school counsellor, the school psychologist. Because it [referring to working with grief] is more their profession that it is our profession as teachers. I can obviously have a dialogue with a student in an attempt to support them, but I always wonder if I am saying the right thing or if my words might have an undesired harmful effect.” (Anna, teacher)

[Recounting the resources used to provide support to bereaved students after the death of a classmate] The school counsellor and the school psychologist were available for the students in the memorial room. And if one student wanted to speak privately, or the professionals noticed that one student was extremely distraught, they pulled them aside to another space in order to have a private dialogue. (...) The priest from the local church was also present, not for religious purposes, but as a safe figure, to provide extra support.” (Pia, school principal)

These cases disclose that the agency of the individual to support and react as a fellow human-being is, in this context, removed, out of fear of causing harm. In instances above, both Anna and Pia report rather relying on figures who supposedly have adequate professional competences to deal with something that belongs to the everyday sphere of compassion between people.

My findings in relation to how grief is understood and processed within these two distinct environments point to significant differences in envisioned and enacted practices between the CPC and the LSS. Moreover, the results highlight that in both contexts, underlying tensions surrounding professional identities are present. These display differently in the CPC and the LSS. At the CPC, they relate mainly to difficulties and silences in the mingling between professional and personal. At the LSS, they manifest in the assumption that some professionals are more competent in being human than other professionals.

#### **5.1.5. Death literacy: in work as in everyday life**

Professionals at the CPC and the LSS learn and develop competencies through their professional and personal experiences in connection death and grief. Their learnings and the ways in which they construct and apply knowledge in this ambit are revealing relation to how death and grief are integrated into their practices.

Despite the previously listed evident differences between the CPC and the LSS, when it comes to death literacy amongst professionals working in these two professional settings, the data points to two interesting outlooks, that are common to both workplaces. The first is a possible gap when it comes to the presence of these topics in schooling and formal higher education. The second is a porosity between being professional and being human when it comes to forming and applying knowledge about death and grief. Both these aspects were present in each of the examined professional settings.

In both professional settings (the CPC and the LSS), informants with different backgrounds and different professions, revealed that the subjects of death, dying and grief were either totally absent or only cursorily touched upon during their formal education. Including the official higher education path required to specialize and legitimate them in their professions. An exception were the two interviewed nurses, who have recounted that in their formal education there was some theory and some practice in connection to these topics. When asked if they have had contact with the topics of death and grief during their formal education, here is what the informants said, in their own words:

“No, not really. We spoke very little about that.” (Vera, doctor, CPC)

“Not one single time. I can’t recall one single time in the 8,5 years I have studied, first to become a teacher, and then later to become a principal. No.” (Pia, principal, LSS)

“We spoke very little about it. I remember that we spoke about death in one single lecture, and that was it.” (Lars, counsellor, CPC)

“The answer is no. Not that I remember in any case during my four-and-a-half-year education.” (Anna, teacher, LSS)

“It started much before my education. (...) And although we spoke about certain aspects during my education, I would say that these themes were developed through my work, more than they were understood during in my education.” (Lisa, nurse, CPC)

“In my education as a sociologist, we spoke and read a lot about the psychosocial dimension with which I later came to work with, but not specifically in relation to illness, death and end-of-life, no.” (Britta, counsellor, CPC)

“Yes, we spoke about it. I think we had opportunities to explore such topics. I wrote my thesis about a topic that was directly connected to handling death within healthcare.” (Sara, school nurse, LSS)

As shown in the comments above, there is possibly a gap in schooling and formal higher education, observable even in the formal preparation of medical professionals, when it comes to approaching topics related to death. Additionally, the previously mentioned aspect of an apparent porosity between humanity and professionalism inherent to death literacy amongst professionals is discernible in the testimony of Lisa, nurse at the CPC. When she states that her contact with the topics of death and grief started long before she was formally trained to be a nurse, Lisa discretely points to a blur in the line between life and work experience, in terms of learning and developing competencies to handle death and grief. Indications of an intersection between being a human and being a professional surfaced also in the testimonies of other interviewees, pertaining both to the CPC and to the LSS, when they described their knowledge and learnings in relation to death and grief. The following interview excerpts illustrate this:

“The ability to cope and even think about death and dying can, most definitely, have to do with one’s own personal life, as much as it can be impacted by one’s professional experiences.” (Sara, school nurse, LSS)

“In my job I could learn and confirm my knowledge about what it means to be human.” (Lars, counsellor, CPC)

“My father’s death has impacted me as a professional. I was a recently graduated doctor and was in the first years of my career. Being in a position in which I was simultaneously a doctor, working in a hospital, and a family member to a patient, dying in a hospital setting, has influenced me deeply.” (Vera, doctor, CPC)

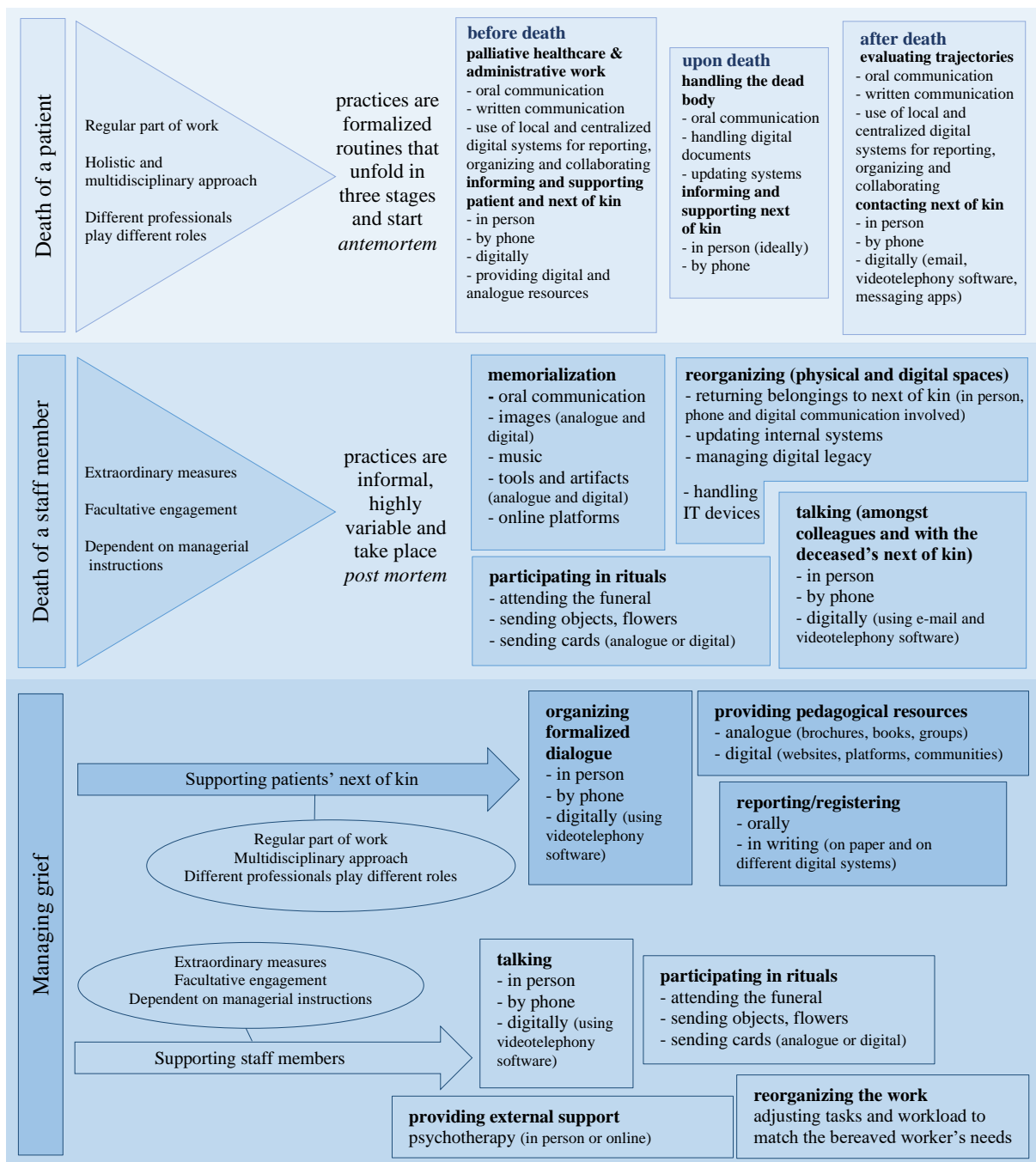
Interestingly, the data reveals that when it comes to sheer knowledge and learning experiences in the ambit of death and grief, the tension between professional and personal seems to uniformly dissipate. While in aspects connected to the exercise of professional practice, the articulation between professional and personal identity around death and grief may present as problematic (as shown in the previous section), when it comes to how knowledge about these topics is constructed, all the interviewed informants spontaneously mixed personal and professional experiences in their recounts.

The data shows that, notwithstanding how the professional context relates to death and grief, professional learning, and competence development in this ambit, are anchored in doing, acting, interacting, talking, researching, and collectively preparing for and handling death and grief. These actions unfold across modes and imply multimodal literacies.

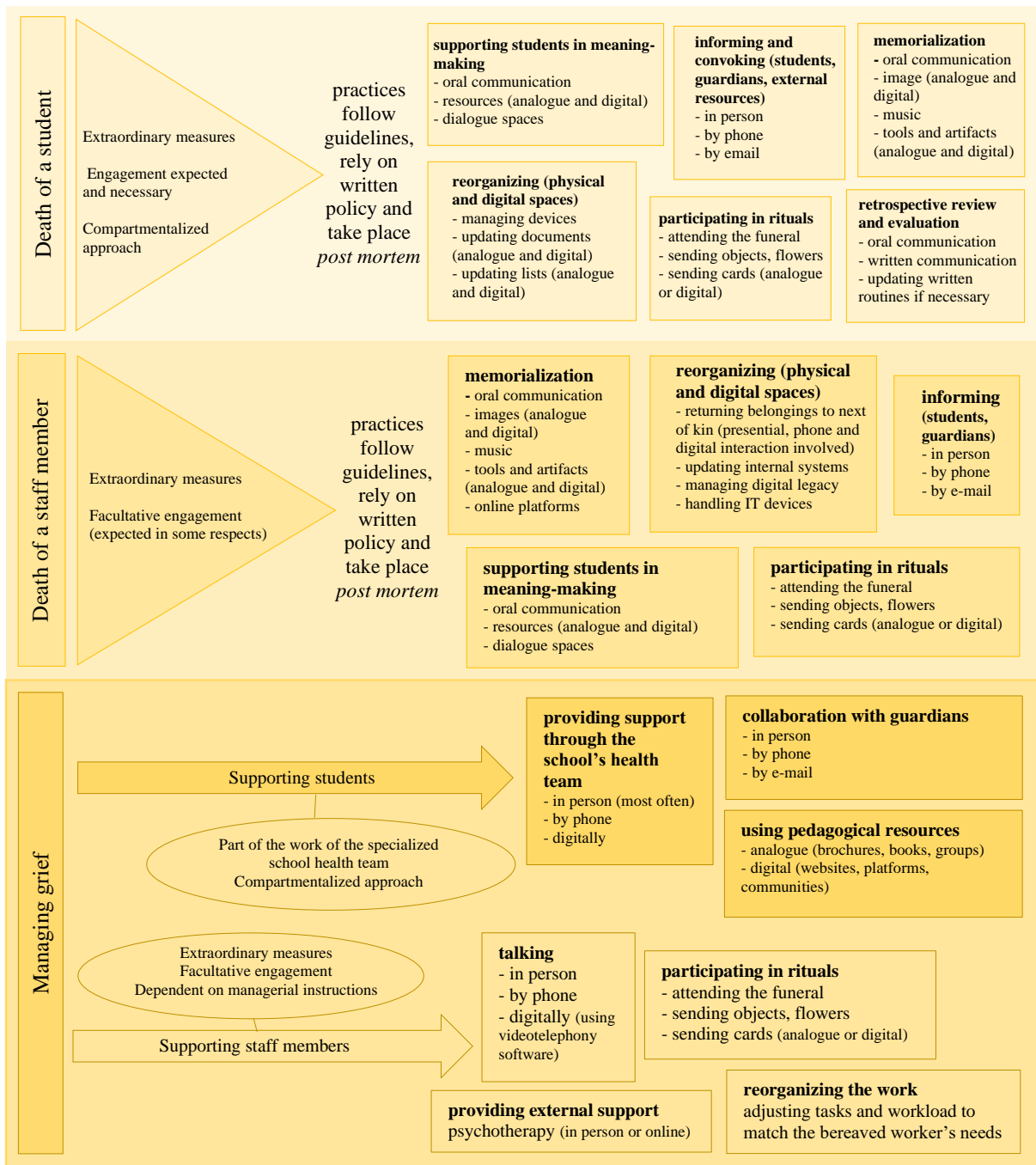
## 5.2. Modes, systems and sequences of communication and action involved in dealing with death and grief in the two examined professional contexts

Comparatively examining the modes and sequences involved in communicating, acting, and interacting around death and grief in two contexts that are so inherently different as the CPC and the LSS becomes more tangible through the observation of the visualizations below (figure 2 and figure 3). The visualizations draw on the data analysis to display an overview of practices related to death and grief at the CPC (figure 2) and the LSS (figure 3). The figures were constructed through the lens of multimodality.

**Figure 2**  
*Dealing with death and grief at the CPC*



**Figure 3**  
*Dealing with death and grief at the LSS*



The schemata represented in figure 2 and figure 3 above uncover the multiplicity of modes involved in handling death and grief at the CPC and the LSS. As shown in the figures, despite essential differences in approach and perspective, there is an assortment of different representational and communicational channels being convoked when professionals encounter death and grief in both professional environments. Practical and social instances, temporal and spatial constraints and different modal affordances shape the ways in which different channels are selected and assembled into sequences of action, interaction, and communication, by professionals.



### 5.3. Multimodal literacies present when addressing death and grief in professional practice

Despite evident differences in how death and grief are viewed and approached in each of the examined settings, professionals pertaining to each setting envision, enact, and evaluate a unique and complex set of specific routines and procedures every time they are faced with death in their work. And they do this with an approach that is resistant to formulas and constraints set on stone. In fact, the ways in which practices are structured in connection to death and grief tend to be unique and adjusted to the situation every single time, both at the CPC and the LSS. The comments below are enlightening in this regard:

“What fits and what will be good? What is the best way, and who is the best person to do what? You must follow your instincts and adjust to the circumstances.” (Sara, school nurse, LSS)

“We are all so different, it can look so different for different people. (...) One needs to take into consideration personal characteristics and individual wishes to make sure practices and rituals align with that person.” (Britta, counsellor, CPC)

“There is no right or wrong. It is very much adapted to the specific situation we have at hand.” (Anna, teacher, LSS)

In their uniquely structured responses, professionals convene an array of communicational and representational modes; they construct and decode meaning in a continuum between analogue and digital media; and they engage in numerous instances of human-computer interaction.

My findings point to three essential aspects characterizing the multimodal literacies of these professionals. These aspects are present in both the examined work environments.

The first aspect relates to awareness. The data reveals that professionals within the two observed settings are, in general, aware of the effects and consequences of digitalization in their practices but have not dedicated much thought to specific or highly nuanced aspects. Indeed, the results show that intertwinements between analogue and digital occur most often so seamlessly that professionals overlook the way in which they might influence meaning-making. When interrogated about how digitalization influences their work, all the informants demonstrated to be very aware of the extensive interaction with different systems that occurs in their daily professional practice. They were able to provide detailed descriptions of different tools and platforms and recount how these are used in different ways by different people with different purposes. In contrast, all the informants appeared to feel puzzled and intrigued when interrogated about the impacts of hybrid and multimodal forms of interaction in the way they make sense of death and grief in their practices. When prompt to elaborate on their situated multimodal constructions in this ambit, the multitude of different representations involved in their procedures seemed to go unnoticed in favor of focusing on the result of their actions. Most of the informants are hence not consciously aware of the ways in which their practices and knowledge, in the ambit of reacting to death and grief, may be impacted by affordances and constraints of available modal resources.

The second aspect in relation to the multimodal literacies developed by professionals at the CPC and the LSS in connection to death and grief is deliberation. Parallely to the above-mentioned sense of perplexity and lack of awareness, the observed practices and the recounts of practice provided by the interviewed professionals, reveal deliberate choice in relation to the modes and modal configurations used. When describing their practices, the informants revealed that there are certain modal configurations that are preferred and others that are avoided based on contextual conditions, social assumptions, and communicational needs. This aspect is illustrated by the comments below.

[Speaking about communicating someone’s death to their relatives] “Well, it is most often in person. Preferably one does not want to notify someone about the death of their loved-one via telephone... Or

worst in writing. Sometimes it is the only option, and one is forced to do it. Sometimes it is not even that controversial. But I would go quite extensive lengths to avoid delivering the news about an unexpected death by telephone.” (Lisa, nurse, CPC)

[Speaking about informing different people about a death] “It is preferably in person. But it depends on the recipient and the situation. With colleagues it is in person, with the student health team it is in person, but with the student’s guardians it is most often via email or via message sent through the school system, because it is not possible to ring every single family.” (Anna, teacher, LSS)

“During the pandemic, all these video-calls made things harder. (...) It works sometimes, but it always works only partially in my opinion. One can’t have the same type of dialogue that one is able to conduct in person.” (Britta, counsellor, CPC)

Finally, the third aspect characterizing the multimodal literacies of professionals in relation to death and grief, at the CPC and the LSS, connects to emotion. The results reveal that the affordances and constraints associated to certain modes or modal configurations have the potential to trigger emotional responses and value judgements. The excerpts included below depict this aspect.

[Referring to how digital technology may impact grief] “Social media are devastating. False rumors circulate and get out of hand. It can hurt you more than do you any good.”

[Speaking about removing someone from an IT system due to their death] “That is the worst one can do... Just removing someone from a system like that.”

(Sara, school nurse, LSS)

“Our secretaries sit down and update digital clinical files for all our patients, from A to Ö. And some of them think it is very hard to read and write about so many people in difficult end-of-life situations, whose health is progressively deteriorating until they die. I am quite unsure about how they process those feelings, and I don’t think they get support in doing that.” (Lisa, nurse, CPC)

“I think that digital technology is good, because at the same moment the death is registered by Skatteverket [the Swedish Tax Agency], the deceased person disappears automatically from our systems. And there is no risk that the family of a student that passed away receives, by accident, an e-mail welcoming the student to the new semester, for example. (...) We live here and now. If a person no longer exists, they also don’t exist in our IT systems. But it can happen that it causes pain also. For example, one of the teachers felt very upset when she saw that the student’s name [referring to a student who died] had disappeared from the list. They know it happens automatically... but at the same time, the fact that the name was gone made the student’s absence concrete.”

“It feels safe to have the crisis plan and follow instructions when something unexpected and scary happens. It feels good and safe to have it in print and flip through the pages.”

(Pia, school principal, LSS)

The findings indicate a generalized lack of conscious knowledge in relation to how the communicational and representational resources in use may influence meaning construction. This is consistent with an instrumental use of these resources to achieve determined goals. However, the results also reveal a great level of deliberation and tacit cognizance in the selection and articulation of different modes for different purposes, consistent with an intuitive and instinctive sort of modal awareness. Finally, the findings point to the fact that modes and modal assemblages trigger emotional responses that are subjective. Overall, what my findings show is that even without necessarily being able to explain why, people seem to know or feel that certain modes and combinations of modes are more appropriate than others for certain purposes.

## 6. Discussion

The digital age has indisputably brought transformations to all spheres of human activity and nowadays the use of digital technologies and online systems is embedded in the ways in which individuals, organizations and societies deal with death and grief. Within the professional domain, it is evident that professionals envision, enact, and evaluate their practices in relation to death and grief across an assemblage of analogue and digital representational modes. My study allowed me to gain insights into the death-related multimodal practices and literacies of professionals pertaining to two distinct professional environments. Namely, a palliative care center (referred to in this study as the CPC) and a lower secondary school (referred to in this study as the LSS). In this chapter, I critically revisit some key findings of this study to reflect about broader aspects that were identified as relevant when reviewing previous literature and within the theoretical frame of multimodal theory. In addition, I outline the study's strengths and limitations, critically discussing them.

### 6.1. Reflections on opacity and transparency

In the first section of this thesis' literature review ([2.1 Death: taboo or not taboo](#)) I brought up and critically reviewed the dilemma of whether death is socially constructed as a taboo in post-industrial western societies. Based on that review, I affirm that the tension between normalcy and deviancy (Hviid Jacobsen, 2022) which characterizes the way societies construct death is fed by the fact that the realities of death and grief are very central in some contexts and situations while they are peripheral and overlooked in others. Furthermore, I argue that this tension means that both opacities and transparencies are naturally ingrained in the ways people make sense of and relate to the realities of death and dying.

Through the data analysis, I inferred that death is, in fact, observed as central and present in the work practice at the CPC and as peripheral or mostly absent from the work practices at the LSS. What initially was a generic assumption, shaped by what has been reported in previous literature and my own superficial knowledge of professional settings similar to the ones observed in this study, became tangible as an accurate way to describe the examined environments, on the grounds of the generated data.

At the CPC death is everybody's business, in a very literal sense, for as long as it sticks to patient-level. Circumscribed to that level, it is a significant part of people's daily professional practices, and it is viewed with familiarity in a practical, well-versed, and professional manner. Death at patient-level implies hands-on, direct contact with facets of death that are not embraced in many other contexts. For example, seeing and handling the deceased body. And, in this professional context, death remains unproblematic until it somehow penetrates the personal sphere. This happens when a member of the workforce dies or when professionals experience grief related to their work or to personal losses. In those instances, death becomes a more challenging presence that needs to be addressed, often by setting into motion extraordinary measures, that are viewed as external to labor.

At the LSS, in contrast, death is nobody's business most of the time. It is seen as "a part of life" that is not in evidence, and that does not need to be evidenced, within that particular setting. And it remains extrinsic and unproblematic until it somehow penetrates the school environment. This happens when a student dies, when a staff member dies or when someone closely related to a person belonging to either of these groups dies. When this happens, death becomes a problematic presence that needs to be dealt with by engaging in extraordinary practices and procedures that are observed as marginal to labor. These practices do not involve direct, hands-on contact with death. Instead, they depict a mediated and indirect contact with this reality.

In both the examined professional contexts, there are instances in which death and grief acquire problematic and unfamiliar contours.

The results have shown that opacities and omissions, to an extent collusive with the “death taboo” or “death denial” narratives, surface when death is seen as problematic and unfamiliar, regardless of the social and professional context framing it. Contrastingly, a greater level of transparency (both when it comes to practice and discourse) is associated with situations in which death acquires familiar contours and represents something known and understood to the parties involved.

## 6.2. Reflections on materiality and immateriality

In the second section of this thesis’ literature review ([2.2 Death, grief and digitalization](#)) I reviewed literature about the connections between death, grief and digitalized practices. I used the examined literature to discuss how dichotomies connected to the spatial and temporal dimensions of such practices may influence our conceptions of death and experiences of grief. To describe the spatial features of practices that occur in a continuum between analogue and digital, and grounded on the ideas developed by Walter et al., 2011, I convoked the dichotomic relation between materiality and immateriality and presence and absence. In the settings observed in my study (the CPC and the LSS), the articulation between materiality and immateriality was one of the elements observed when examining the activities undertaken by professionals in response to death and grief.

At the CPC (where contact with death is direct and involves hands-on work with dead bodies and bereaved families), professionals use physical documents, medical devices, and digital systems only in an instrumental manner, and generally do not rely on written information to act, interact, and communicate in relation to death and grief. In contrast, at the LSS (where contact with death is indirect), professionals strongly depend on written information and printed documentation in order to proceed in the face of death and grief and they rely on a fixed set of artefacts (crisis box) to perform ritualized action. This points to an inverse relation between the nature of contact and the materiality of knowledge: when contact with death is more direct, professionals mainly construct knowledge in the head, and when contact with death is indirect, professionals tend to rely on knowledge in the world. Given the essential differences in how death is inserted into the two observed professional contexts and the different perspectives that professionals have over these topics in each of these contexts, the results also point to a relation between familiarity with death and grief and how material and immaterial resources are constructed, used, and combined.

A noteworthy aspect in relation to materiality and immateriality and use of spatial and physical resources is the way in which rituals seem to be anchored to physical objects, in both the observed workplaces. The results have shown that, in both environments, ritualized actions seem to have physical presence and the use of symbolic physical objects and artefacts as a common denominator. At the CPC ritualized action occurs in a spontaneous, flexible, and unplanned manner and it involves, therefore, the use and modification of existing resources not originally meant for ritualistic purposes. At the LSS, contrarily, ritual it is envisioned as a fundamental part of the response to a death, so much so that there are written guidelines created to orient certain rituals and there are certain artefacts (gathered in the crisis box) that are available at the workplace exclusively for ritualistic purposes. In both settings, rituals surrounding death seem to involve the same symbolic resources (flowers, candles, half-mast flags, memorial notebooks, silence, music and written and spoken texts). This speaks to wider social constructs about death and attests to the dominant socio-cultural traits of contemporary Sweden.

Finally, and still in relation to the dichotomic relation between materiality and immateriality, it becomes clear that, both in the CPC and the LSS, when someone dies, their absence needs to be concretized across material and immaterial resources and professionals strive to achieve coherence and consistency across modes. Understanding the ways in which these professionals operate to avoid discrepancies related to absence/presence across physical and digital dimensions and understanding that these discrepancies often originate from the cleavage between automated and human-operated systems opens paths for future studies and may inform the design of tools and tool features.

### 6.3. Reflections on eternity and ephemerality

The quest to achieve consistency amongst the various planes in which someone's presence or absence is represented also has implications connected to temporality and touches the ethical sphere. Still within the scope of [2.2 Death, grief and digitalization](#), I argued that the dichotomy between eternity and ephemerality provides a frame to how we conceive the temporal features of practices that encompass both an analogue and a digital dimension. Our posthumous presence in online platforms and digital systems, has led research to focus on aspects such as digital legacies and digital traces (Drescher, 2012; Hård af Segerstad et al., 2020; Hård af Segerstad et al., 2022; Romano & Carrol, 2011; Walter, 2011; Walter, 2015).

Drescher (2012) argues that our identities are prolonged in digital spaces, from where it is difficult to fully recover them and where they linger after we no longer exist in the physical world. This is accurate when speaking about interactive technologies of which a person makes private use, such as social media. However, in an inverse dynamic, the results of my study have shown that when a person dies within a professional setting, their presence is extinguished in the digital systems related to that professional setting. When a patient dies at the CPC, their clinical information, and the traces of their presence within the systems that steer clinical work are eliminated manually by dedicated administrative personnel. When a member of the CPC's staff dies, the digital devices connected to their work are reset and the traces of the work they developed previously are eliminated. The same happens at the LSS. When a student's death is registered by the Swedish population registry, they are automatically removed from the school's learning management system. The same applies if one of the teachers dies. The devices and systems that were used in school by a member of the school community (student or staff member) who dies are cleaned, reset, and prepared to be assigned to a new user. The quantity of work, writing material, authorial material and personal information about one's school performance or health status that is eliminated after a death is considerable, and none of the policy documents examined in my study considered the ethical implications of this or the possibility that a surviving family member may wish to have access or hold on to some of these digital materials. This represents an aspect worthy of consideration and further investigation by policy makers working at local, national, and even international level with policies for digital transformation.

### 6.4. Reflections on learning and knowing as a professional and a human

In the third section of the literature review of this thesis ([2.3 Death literacy](#)), I mobilized the constructs of death literacy (Noonan et al., 2016) and grief literacy (Breen et al., 2022). I defined that, within the scope of my study, the term death literacy (DL) would be used as an embracing concept, referring to people's experiences and learnings about death and dying and consequently about loss and grief. Indeed, I defined DL as the outcome of people's learnings in relation to their own mortality and the death of others and their direct or indirect, individual and collective experiences of grief. As previously mentioned, both formal education and informal learning can contribute to DL (Beaunoyer & Guitton, 2021).

My findings have shown that almost none of the study informants developed DL as a product of their formal education, regardless of their background. This confirms that the topics of death and grief are only approached indirectly or in very circumscribed ways in most educational settings as pointed out in numerous studies, such as those of Bowie (2000); Galende (2015); Giménez-Llort (2021); McGovern and Barry (2000); or Sonbul and Çelik (2023). Furthermore, this is conniving with the idea that people's knowledge about death results from people's direct or indirect contact with death, dying and end-of-life issues in their lives, and stems from situations in which people intentionally or unintentionally come across information about such topics.

All the participants in this study have referred to their knowledge about death and grief as originating from an amalgamation of personal and professional learnings and the result of experiences, readings, conversations, and participation in social practices. This calls for expertise in connection to the

articulation between the personal/human sphere and the professional domain and requires the development of critical literacies.

At CPC, in which death is a regular part of professional practice, there is an underlying structure of research, construction of pedagogical materials, clinical practice, administrative practice, informal conversation and formalized debriefing centered on death and grief. This means that professionals develop their competencies about these topics in their everyday work practices and have the opportunity to develop critical and reflexive literacies about their professional approach to these topics. However, aspects connected to the negotiation between personal and professional identities, and modal awareness are being overlooked and addressing them would most likely benefit professional practice. This appeals to further investigation and reveals an interesting space for the creation of professional learning materials and designs.

At the LSS, in which death is infrequent and experienced indirectly, there is a general lack of underlying structures allowing professionals to develop competences in relation to death and grief. The materials and guidelines used by the LSS to orient practice in this ambit contain oversimplified and outdated information that is uncritically delivered as factual. In this context, both written documentation and the recounts of professionals have revealed a generalized prevalence of old models (for grief, for example) and popular assumptions (about death and dying) that still linger within vernacular understanding. The fact that dialogue and conversation about death only takes place when death penetrates the LSS environment, and that it is held in a compartmentalized manner, is also revealing in this regard. Finally, the fact that certain professionals (teachers, for example) view themselves as incompetent or incapable of managing such topics in this ambit and that, consequently, these topics are delegated to what is seen as “capable” professional figures, is indicative in relation to the overpowering medicalization of death (Walter, 2017) that characterizes our social organization. I argue that the fact that people do not feel competent in what are basic human emotions (such as empathy and compassion) is telling in relation to how society views death and grief. Furthermore, another facet of the tension between personal and professional identity is highlighted when the agency of the individual to provide support as a fellow human-being is, in the professional context, sequestered, due to fear of provoking damage.

Overall, and across both the observed professional environments, what the findings have depicted is tensions of a different nature between professional and human identities (or between being human and being professional); the lack of modal awareness; and, within the LSS, the absence of critical literacies. Multimodal literacies require critical reflection, as brought up by van Leeuwen (2017). The fact that people, in both the analyzed settings, seem to know that certain modal resources and modal compositions are preferable to others for certain purposes, without being able to explain why is interesting but also potentially problematic, since certain modal resources may favor certain types of discourse and annihilate others. This aspect can be addressed by future learning solutions and must be taken into consideration when reflecting about professional learning and competence development in digitalized environments.

## 6.5. Strengths and limitations of the study

My study provides insights how professional practices connected to death and grief unfold across modes and involve multimodal literacies. The primary strength of this study is the identification and delimitation of an underexplored research field in which theoretical understandings of fundamental human questions are being torn between professional practice, social norms, personal reactions, and modal affordances and constraints. I also view this study’s contribution to discussions on how digitalization impacts learning and practice in connection to profound existential issues as a strength. Finally, I consider this study’s multidisciplinary approach to its multifaceted research topic as an asset.

The limitations of this study connect primarily to the choice of a research project designed as a comparative case-study (Cohen et al., 2002). The findings, although lifting relevant and multi-layered

questions that can have implications in other contexts, are profoundly bound to the examined professional settings and I see them as the product of how contextual characteristics were intersected by my investigation practices. This means that extrapolation and generalization of the results is not possible. This limitation is, however, aligned with my project's goals and aims. I intended to focus on the in-depth investigation of specific and delimited realities and on the suggestions and indications that arise from comparing them, without pretensions to decipher wider phenomena.

A limitation of the chosen methods of document analysis, interview research and direct observation, connects with possible bias on the behalf of the researcher, and the risk of “projection of researcher’s own values and judgements onto the situation” which is being observed or analyzed (Cohen et al., 2002, p. 240). This was addressed in my research by using inductive and iterative coding methods and paying particular attention to contextual nuances and the emergence of outlying cases. It is important to clarify, however, that, in alignment with the methodological framework of constructivist grounded theory (Charmaz, 2014), I view my subjectivity as a researcher as a natural component of the research process. One that needs to be recognized and taken into consideration, instead of being disguised or muffled. I acknowledge that the mere presence of a researcher in the examined environments, may have had an influence on the research participants and on the encountered situations and my analysis and reflections, I have taken this aspect into account.

Lastly, a constraint of this study, intrinsic to the approached topics, and perhaps exacerbated by my positioning as a foreign researcher (for whom neither Swedish nor English are native languages) was language. Throughout my research, I was faced with situations in which, regardless of the language in use, words seemed insufficient or inadequate to reflect upon the examined topics. I felt this in my interactions with the study participants, when analyzing the interview transcripts and the collected documents and in my own writing process. I consider this specific difficulty worthy of attention and reflection on behalf of whoever decides to undertake an investigation about death, since it is telling in relation to how individuals and societies feel intrinsically ill-equipped to address such profound and abysmal topics. Let us be reminded that one of the alternatives to the “death-taboo” theory presented by Walter (1991) - as mentioned previously, in the literature review section of this thesis - is that language is scant to express ideas about death. And that the fact that death is scarcely discussed in most social settings does not testify to it being a social taboo, but only to how exiguous human language is to define and describe such a comprehensive and unfathomable topic.

## 7. Conclusion

I began this thesis with four paragraphs about the tiny weight of empty space. The tiny weight of empty space is an important finding in the field of astrophysics that I view as a poetic and in part ironic metaphor for loss. Throughout the research process, I examined how people in different professional contexts engage in intricate operations and develop manifold sequences of action, interaction, and communication to deal with the empty space left by someone's death. After examining the complexity of the practices that occupy a very small fraction of the hollowness created by one singular death, I conclude this thesis by affirming that empty space represents a promise to be filled. An interval that can hold a multitude of gestures, sounds, words, steps, movement, images, texts, music, emotions, decisions, and other human constructions, distributed across a multiplicity of representational modes.

### 7.1. Implications

This study sheds light on how professionals construct and apply knowledge about death and grief in two distinct digitalized professional environments in Sweden, one in which death is a central part of work and one in which death is peripheral to labor. By focusing on a topic that is relatively unexplored, my research has uncovered significant gaps. Namely, in what concerns policy construction, critical reflection about practice and opportunities for professional learning in environments where death assumes a peripheral role. The implications of this study are, therefore, both of practical and theoretical nature. My findings may have implications to practice by highlighting the need for educational solutions and pedagogical materials that are grounded on a critical understanding of current theories on death and grief and take into consideration the multimodal nature of knowledge and professional practice in relation to these topics. Furthermore, the findings of this study may contribute to inform policy making, at local and perhaps higher level, in connection with digital transformation. Lastly, this study may have implications to the ongoing theoretical development of new understandings of literacy in connection to practices situated in digitalized environments. Finally, this thesis can afford hints to how knowledge on existential topics is structured within professional practice, and in that way be significant to less explored facets of professional learning theory.

### 7.2. Future research

With governmental entities, health care systems, funeral industries and overall societies being swayed by the use of digital systems, there is a strong need for empirical studies that illuminate how social norms surrounding death, grief, and dying are being shaped by the integration of digital technology into everyday life (Beaunoyer & Guitton, 2021).

When it comes specifically to how professionals structure their knowledge and professional practice in connection to death and grief, numerous questions remain unanswered. My study uncovered gaps in relation to policy, professional development, and critical multimodal practice in connection to death and grief. This creates valuable spaces for further investigation within the disciplinary frame of IT and learning. Future investigation can take the form of design-based projects, additional empirical research, or theoretical investigation.

Investigative paths to follow may include expanding the empirical research I have conducted and make it wider and deeper. One way to make it wider is to investigate and compare a larger number of professional contexts (and chose contexts pertaining to varied sectors), maintaining the focus on the multimodal literacies involved in how death and grief are incorporated into professional practice. A way to make it deeper is to conduct a similarly designed study (in which only two distinct professional



settings are compared) but including more interviews with different categories of staff and dedicating more time to ethnographic observations.

Conducting future design-based participative research, in which interviews and observations can be combined with participative workshops with professionals, can positively inform the delineation of tools and platforms to improve professional competence and support professional learning in relation to death and grief.

Theoretical studies focused on the intersection between death, grief and professional practice can dig deeper into the detected tension between professional and personal or further explore the role and characteristics of ritualized action within the professional sphere. Theoretical research within cognitive science and learning theory, may, on its turn, aim to expand on the nuances of how knowledge about essential existential topics is situated and shaped by social, cultural and fine-grained contextual affordances and constraints.

Finally, within the field of educational sciences, research dedicated to examining and informing policy and curriculum construction, may address the generalized absence of a multidisciplinary educational approach to the topics of death and grief that seems to prevail within formal education, at all levels and across geopolitical contexts.

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# Appendices

## Appendix 1 – Information letter

### INFORMATIONSBREV

Hej [deltagarens namn] och tack så mycket för ditt intresse!

Du är inbjuden att delta i en forskningsstudie om hur kunskap, förståelse och praktiker som har med döendet, döden och sorg att göra utformas på arbetsplatsen. Studien genomförs inom ramen för det internationella mastersprogrammet i IT och Lärande vid Göteborgs Universitet. Deltagandet i studien består av en intervju som tar cirka 45 minuter. Under intervjun kommer du att bli ombedd att beskriva uppdrag, upplevelser och rutiner i ditt dagliga arbete samt att dela med dig av dina synpunkter och tankar kring hanteringen av döende, död och sorg på olika nivåer på din arbetsplats. Det är din erfarenhet och kunskap som medarbetare och dina individuella och spontana tankar om hantering av döende, död och sorg på din arbetsplats som jag skulle önska att du delade med dig av, så inga förberedelser behövs från din sida.

Varför bedrivs denna studie?

Det finns ett stort utrymme för lärande kring ämnen som död och förlust men samtal om döende, död och sorg är fortfarande långt borta i de flesta sammanhang. Ämnet har refererats av experter som både ett socialt och ett pedagogiskt tabu. Om å ena sidan forskning visar att ett pedagogiskt förhållningssätt till sådana teman kan ha betydande fördelar för individer och samhällen, har det också visat sig att engagemang i samtal och aktiviteter som rör döden ofta upplevs som svårt för de flesta människor.

På arbetsplatsen finns det ett behov av att vara beredd att hantera och omfatta död och förlust på olika nivåer och det finns oftast rutiner och system på plats för detta ändamål. I hopp om att bidra till en diskussion om hur död och sorg bemöts och hanteras i den professionella sfären, är det övergripande målet med denna studie att utforska hur yrkesverksamma hanterar död och sorg i två olika arbetsmiljöer (på palliativt centrum och inom grundskolan). Genom att studera hur information, kommunikation och praktiska handlingar som rör döendet, död och sorg är strukturerade på olika sätt inom två olika arbetsmiljöer, syftar studien specifikt till att: a) reflektera över hur yrkesverksamma utformar praxis kring döende, död och sorg inom sina olika yrkesutövningar; b) förstå artikulationen mellan analogt och digitalt i utvecklingen av system och implementering av rutiner för att hantera död och sorg i arbetsmiljön; och c) ta reda på hur yrkesverksamma lär och utvecklar sig i teman döende, död och sorg.

Vad handlar studien om?

Studien handlar om att göra en jämförande analys av två arbetsmiljöer som skiljer sig i sin grundläggande relation till död och sorg: ett palliativt centrum (där döden är förväntad och som ingår i det dagliga arbetet) och en offentlig grundskola (där döden ses som oväntad och ovanlig). Studien kommer att genomföras genom intervjuer med personal i de båda arbetsmiljöerna, observationer på plats och analys av styrdokument och skriftliga rutiner på dessa två arbetsplatser.

Hur kommer ditt deltagande att fungera?

Du deltar i studien genom att bli intervjuad om rutiner och praktiker kring döende, död och sorg på din arbetsplats. Att delta är frivilligt. Under intervjun kan du hoppa över frågor som du inte vill svara på. Dina åsikter är viktiga, därför kommer jag att be om ditt tillstånd att spela in vårt samtal i syfte att använda som underlag för studien. Inspelningen görs dock enbart om du godkänner detta. Dina svar under intervjun kommer att anonymiseras så att ingen information som kan identifiera dig kan urskiljas. Dina svar kommer att behandlas så att inte obehöriga kan ta del av dem. Detaljerad information om hur data kommer att hanteras finns i dokumentet *Informerat samtycke till deltagande i studien* som bifogas till detta brev.

Kontakta mig gärna via mejl om du vill veta mer eller har några frågor [mejladress].

Jag ser fram emot att träffas vid intervjun och jag passar redan nu på att helhjärtat tacka för din tid, tillgänglighet och bidrag till studien.

Med vänliga hälsningar,

*Maria do Carmo Salgueiro*

## Appendix 2 – Informed consent form

### INFORMERAT SAMTYCKE FÖR DELTAGANDE I STUDIEN

Forskningsstudie: *The tiny weight of empty space: Multimodal literacies involved in preparing for and dealing with death and grief in digitalized work environments*

Forskare: Maria do Carmo Salgueiro Pinto Antunes

Internationellt mastersprogram i informationsteknologi och lärande | Göteborgs universitet | [Mejladress] | [Telefon]

Handledare: Ylva Hård af Segerstad

Docent i Tillämpad IT | Institutionen för Tillämpad IT, Göteborgs universitet | [Mejladress] | [Telefon]

Samtycke till att delta i studien

Jag har läst och förstått informationen i det bifogade informationsbrevet angående studien och jag har haft möjlighet att ställa frågor och få all ytterligare information om denna forskning. Jag ger härmed mitt informerade samtycke till att delta i denna studie under följande villkor:

• Jag ger mitt tillstånd att intervjun spelas in och transkriberas (vänligen välj ett av följande svar):

- Ja  
 Nej

• Deltagande innebär att tala om mina erfarenheter på min arbetsplats och beskriva min yrkesverksamhet i detalj samt reflektera över teman som kan anses vara känsliga såsom döden och sorg.

• Under intervjun kan jag tacka nej till att svara på någon av frågorna som ställs utan att behöva motivera mitt val.

• Innehållet av intervjun kommer endast att användas inom ramen för denna studie och kommer inte att delas med någon tredje part.

• Sekretess garanteras och det jag delar med mig av under intervjun kommer att behandlas som konfidentiellt.

• Alla digitala filer, avskrifter (om tillämpligt) och sammanfattningar kommer att ges koder och lagras separat från eventuella namn eller personliga uppgifter.

• I alla rapporter om resultaten av denna studie kommer min identitet att förbli anonym genom att mina personliga uppgifter samt att alla detaljer i min intervju som kan avslöja min identitet eller identiteten på personer jag pratar om ska döljas.

• Undertecknade samtyckesformulär, originaljudinspelningar och eventuella transkriptioner av intervjuerna kommer att lagras på en säker lagringsyta som Göteborgs universitet tillhandahåller. Lagringsytan är kopplad till Maria do Carmo Salgueiro Pinto Antunes studentkonto på Göteborgs universitet. All forskningsdata kommer att bevaras tills forskningsstudiens avslutas och kommer därefter att raderas.

• Jag har rätt att få tillgång till informationen jag har tillhandahållit när som helst medan den lagras enligt ovan.

• Jag är fri att när som helst kontakta Maria do Carmo Salgueiro Pinto Antunes för att söka ytterligare förtydliganden och information.

• Jag kan när som helst dra mig ur hela eller delar av denna studie utan att behöva motivera mitt beslut.

Deltagarens namn och telefonnummer: \_\_\_\_\_

Deltagarens underskrift: \_\_\_\_\_

Datum: \_\_\_\_\_

## Appendix 3 – Interview guide CPC

1. Inledning			
Ämne	Huvudfråga	Följdfrågor	Fördjupning
Deltagarens bakgrund och jobb beskrivning	Vad har du har för yrke och vilken arbetsroll har du på palliativt centrum?		
	Hur länge har du arbetat inom palliativ vård?		
	Kan du beskriva ditt dagliga arbete och ditt uppdrag?		
	Hur påverkas ditt arbete av digitalisering?	Hur använder du digital teknik i ditt arbete? Kan du beskriva verktyg, enheter och system som du använder i ditt dagliga arbete och hur du använder dem?	Det kan sträcka sig från att svara på e-mejl, till att använda specifika arbetsledningssystem och även hantering av elektronisk utrustning relaterade till patientvård
2. Rutiner och system kring död och sorg på deltagarens arbetsplats			
Ämne	Huvudfråga	Följdfrågor	Fördjupning
Död på arbetsplatsen	Vilka aspekter av döden möter du i ditt arbete?	Hur artikuleras mänskliga aspekter med vetenskaplig kunskap och praktiska aspekter?	Finns det en del som är viktigare än de andra i just ditt arbete? Vilken?
	Vad händer vid dödsfall av en patient?	Skulle du kunna beskriva arbetsrutinerna som gäller vid dödsfall av en patient?	Vad har du för ansvar och uppdrag då?
		Vilka aspekter måste du ta hänsyn till i ögonblicket före döden, när den inträffar och efter den?	Finns det aspekter som ingår i rutinen med alla patienter och aspekter som varierar efter situationen? Till exempel?
		Vem blir inblandad i dödsfalls hantering?	Hur fördelas arbetet och vem svarar för vilka uppgifter?
Vad händer vid dödsfall av en patient?	Hur kommunicerar ni medarbetare för att ordna och bedriva arbetet då?	Finns det olika kommunikationsmedel som används för att dela information vid en patients död? Kan du ge exempel på vilka?	
	Kan du berätta lite om kommunikationen mellan er som jobbar här och externa personer och enheter vid ett dödsfall?	Vem behöver ni kontakta? Vem ansvarar för det? Hur blir dödsfallet meddelat till befolkningsregister? Hur kommunicerar ni med anhöriga och enheter som ansvarar för begravningen?	
	Utöver de praktiska aspekter, finns det några ritualer som följs för att hedra personens minne?	Kan du ge exempel av sådana ritualer?	
Vad händer vid dödsfall av en medarbetare?	Är du medveten om rutiner och handlingsplaner som aktiveras vid dödsfall av en medarbetare?	Kan du berätta lite om det?	
	Vad är de praktiska aspekter som är viktiga?	Beroende på situationen, vad behöver ni tänka på?	
	Utöver det praktiskt, finns det ritualer för att hedra personens minne?	Kan du ge exempel av sådana ritualer?	

Sorg på arbetsplatsen	Hur hanterar ni förlusten och sorgen på din arbetsplats?	Finns det några rutiner och handlingsplaner som tillägnas att stödja medarbetarna i att hantera svåra känslor relaterade till förlusten av en patient?	Kan du beskriva dessa rutiner?
		Finns det ett stödsystem för medarbetarna i hanteringen av sorg orsakad av personliga förluster?	Kan du berätta hur det fungerar?
		Finns det resurser som används i din arbetsplats för att främja lärande och dialoger om död, vård i livets slutskede, sorg och förlust?	Vilka? Kan du beskriva dem?

### 3. Personliga erfarenheter och lärande

Ämne	Huvudfråga	Följdfrågor	Fördjupning
Personliga erfarenheter	Skulle du vilja dela med dig av några upplevelser och erfarenheter som du tycker utformade dina kunskaper och tankar om död och sorg?	Har du upplevt förlusten av en arbetskamrat i ditt arbetsliv?  Har du varit/är du inblandad i sorg hantering på din arbetsplats?	Skulle du vilja berätta om hur du upplevde det och vad du lärt dig av denna erfarenhet?  På vilka sätt?
Kunskaper och lärande om död och sorg	Utöver dina egna erfarenheter, varifrån kommer dina kunskaper om döende, död, förlust och sorg?	Har du haft kontakt med teman döende, död och sorg under din formella utbildning?  Finns det några aspekter som du har lärt dig om död, förlust och sorg under ditt arbetsliv och genom din professionella utveckling?  Känner du till online och offline utrymmen, resurser och plattformar för lärande och samtal om teman död och sorg?  Engagerar du dig i sådana teman utanför ditt professionella liv?	På vilka sätt? Vad lärde du dig då?  Vilka? Hur enligt dig  Kan du berätta för mig vilka du känner till? Använder du dem?  På vilka sätt?

### 4. Avslutning

Ämne	Huvudfråga	Följdfrågor	Fördjupning
-----	Vill du lägga till något?	Känner du att du vill gå tillbaka och fördjupa någon av punkterna som diskuterats idag?	Vilken?
-----	Känner du att något lämnats osagt?	Fanns det aspekter som inte nämndes och du tycker är viktiga?	Vilka?

## Appendix 4 – Interview guide LSS

1. Inledning					
Ämne	Huvudfråga	Följdfrågor	Fördjupning		
Deltagarens bakgrund och jobb beskrivning	Vad har du har för yrke och vilken arbetsroll har du på skolan?	-----	-----		
	Hur länge har du arbetat inom skolmiljön?	-----	-----		
	Kan du beskriva ditt dagliga arbete och ditt uppdrag?	-----	-----		
	Hur påverkas ditt arbete av digitalisering?	Hur använder du digital teknik i ditt arbete?  Kan du beskriva verktyg, enheter och system som du använder i ditt dagliga arbete och hur du använder dem?	Det kan sträcka sig från att svara på e-mejl, till att använda specifika arbetsledningssystem, och administrationssystem (med HR rapportering och sådant). Det kan även innebära användning av digital utrustning eller online verktyg och resurser i ditt arbete.		
2. Rutiner och system kring död och sorg på deltagarens arbetsplats					
Ämne	Huvudfråga	Följdfrågor	Fördjupning		
Död på arbetsplatsen	Döden är en del av livet. Är döden en del av livet i skolan?	På vilka sätt blir teman som död och sorg inkluderade i skolas dagliga arbete?	När pratar man om sådana teman i skolan? Vilka möjlighet finns det för lärande och utveckling kring dessa?		
	Vad händer vid dödsfall av en elev? Vilka handlingar och system blir inblandade i att hantera det?	Skulle du säga att döds- och sorg hantering är en del av ditt arbete i skolan?	Om ja, på vilka olika sätt?  Om nej, varför det?	Kan du berätta mer?	
		Skulle du kunna beskriva handlingarna, samtalen och arbetsrutinerna som gäller vid dödsfall av en skolelev?	Vem i skolan blir inblandad i dödsfalls hantering?	Vad har du för ansvar och uppdrag då?  Hur fördelas arbetet och vem svarar för vilka uppgifter?	
		Hur kommunicerar ni medarbetare för att ordna och bedriva arbetet då?	Hur sker kommunikationen mellan er, medarbetare, och eleverna kring dödsfallet?	Vilka kommunikationsmedel används för att dela information vid döden av en elev?  Vem ansvarar för samtal med och stöd till eleverna? Är det allas ansvar eller delar ni ut detta arbete?	
		Hur sker kommunikationen mellan er som jobbar i skolan och externa personer och enheter vid ett elevs dödsfall?	Utöver de praktiska aspekter, finns det några ritualer som följs för att hedra elevens minne?	Vem brukar ni kontakta? Vem ansvarar för det? Hur kommunicerar ni med vem som inblandas i så fall?  Kan du ge exempel av sådana ritualer?	
		Vad händer vid dödsfall av en kollega?	Är du medveten om rutiner och handlingsplaner som aktiveras vid dödsfall av en av skolans medarbetare?	Vad är de praktiska aspekterna som är viktiga enligt dig?  Hur berättar ni för eleverna att någon som jobbar i skolan dog?	Kan du berätta lite om det?  Beroende på situationen, vad behöver ni tänka på?  Vem ansvarar för samtalet med och stödet till eleverna?



		Utöver det praktiskt, finns det ritualer för att hedra personens minne?	Kan du ge exempel av sådana ritualer?
	Hur påverkas dödshantering i skolan av digitalisering?	Använder man digitala verktyg för att kommunicera, agera eller interagera vid ett dödsfall som påverkar skolan?	Vilka? Kan du ge exempel?
Sorg på arbetsplatsen	Hur hanterar ni förlusten och sorgen på din arbetsplats?	<p>Finns det några rutiner och handlingsplaner som tillägnas att stödja medarbetarna i att hantera förlusten av en skolelev eller en kollega?</p> <p>Vilken typ stöd erbjuds till eleverna när en elev eller en av skolpersonal dör?</p> <p>Finns det ett stödsystem för medarbetarna i hanteringen av sorg orsakad av personliga förluster?</p> <p>Finns det ett stödsystem för eleverna i hanteringen av sorg orsakad av personliga förluster?</p> <p>Finns det resurser som används i skolan för att främja lärande och dialoger om dessa teman både mellan medarbetarna och eleverna?</p> <p>Engagerar du dig i sådana teman utanför ditt professionella liv?</p>	<p>Kan du beskriva dessa rutiner?</p> <p>Kan du berätta hur det fungerar? Kan du ge exempel?</p> <p>Vilka? Kan du beskriva hur det fungerar?</p> <p>Vilka? Kan du beskriva hur det fungerar?</p> <p>Vilka? Skulle du kunna visa/ge exempel på sådana?</p> <p>På vilka sätt?</p>

### 3. Personliga erfarenheter och lärande

Ämne	Huvudfråga	Följdfrågor	Fördjupning
Personliga erfarenheter	Skulle du vilja dela med dig av några upplevelser och erfarenheter som du tycker utformade dina kunskaper och tankar om död och sorg?	<p>Har du upplevt förlusten av en elev eller en arbetskamrat under tiden du har arbetat i skolan?</p> <p>Har du varit/är du inblandad i sorg hantering på din arbetsplats?</p>	<p>Skulle du vilja berätta om hur du upplevde det och vad du lärt dig av denna erfarenhet?</p> <p>På vilka sätt?</p>
Kunskaper och lärande om död och sorg	Utöver dina egna erfarenheter, varifrån kommer dina kunskaper om döende, död, förlust och sorg?	<p>Har du haft kontakt med teman död och sorg under din formella utbildning?</p> <p>Finns det några aspekter som du har lärt dig om död, förlust och sorg under ditt arbetsliv och genom din professionella utveckling?</p> <p>Känner du till online och offline utrymmen, resurser och plattformar för lärande och samtal om teman död och sorg?</p>	<p>På vilka sätt? Vad lärde du dig då?</p> <p>Vilka? Hur enligt dig har du utvecklat dina kompetenser genom sådana erfarenheter?</p> <p>Kan du berätta för mig vilka du känner till? Använder du dem?</p>

### 4. Avslutning

Ämne	Huvudfråga	Följdfrågor	Fördjupning
-----	Vill du lägga till något?	Känner du att du vill gå tillbaka och fördjupa någon av punkterna som diskuterats idag?	Vilken?
-----	Känner du att något lämnats osagt?	Fanns det aspekter som inte nämndes och du tycker är viktiga?	Vilka?