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A 'new public health' perspective on building competence for end-of-life care and communication:
How death literacy can be developed and measured

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HOW DEATH LITERACY CAN BE DEVELOPED AND MEASURED

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THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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”Jag tycker ju att vi har upplevt att det är någonting som sprider sig, när man har gjort det här, så vill man prata med någon om det eller ta upp det. Så att om man gör det personalen sinsemellan så tror jag vi blir mer lyhörda och kan ställa frågorna till dom vi går till också.”

[I think we have experienced that this is something that spreads, when you have done this, you want to talk to someone about it or bring it up. So, if staff do this amongst ourselves, I think we will be more responsive and able to ask these questions to the residents we visit as well.]

(Participant, Study I)

POPULAR SCIENCE SUMMARY OF THE THESIS

Death is an unavoidable part of life that will affect everyone at some point. Advances in medical treatment and technology allow people to live longer, even with life-limiting illnesses. Dying has thus become more gradual, leading to increasing need for end-of-life care in the population. To meet these needs, a growing portion of end-of-life care is shifting from the formal health care system to elder care providers and family caregivers. To promote preparedness to engage in end-of-life care, public health initiatives have increasingly focused on building competence for end-of-life care and communication, known as *death literacy*. In this thesis, I explore how death literacy can be developed and measured.

Reflecting on and talking about what matters at the end of life has been suggested to better equip people for future end-of-life care provision. Nevertheless, research has shown that many people, also those working in health and social care, find it difficult to address death-related issues. Using tools has been found to help overcome such challenges. In this thesis, we study the use of a Swedish version of an English-language conversation tool, the DöBra cards, which has been found to support early proactive conversations about values and preferences for future end-of-life care with older community-dwelling people in Sweden. While a promising tool, the DöBra cards had not been systematically used in elder care.

Study I was conducted as a series of workshops with elder care staff in which we explored changes over time in staff's discussions about EOL conversations. Reflective exercises with the DöBra cards were used to stimulate discussion in the workshops. We found that using the DöBra cards helped participants approach thoughts and feelings related to death and dying and reflect on end-of-life care situations from different perspectives. These effects seemed to influence the changes noted in staff's reasoning and attitudes.

In Study II, we explored staff experiences of using the DöBra cards in conversations about end-of-life care with elder care residents and relatives. The DöBra cards were found to help staff lead the conversations by providing a shared structure and vocabulary. The tool encouraged sharing personal stories, thereby strengthening relationships, promoting further communication, and potentially contributing to a shared understanding of EOL care goals. The usability of the DöBra cards in elder care practice was affected by factors on the personal level, such as staff attitudes, and organizational level, such as the possibility to allocate sufficient time for conversations.

This thesis also investigates the Death Literacy Index (DLI), a questionnaire that measures six dimensions of competence related to end-of-life care. The DLI was developed in Australia but had not yet been used in other languages or countries. Therefore, the aim of Study III was to develop a Swedish-language version, the DLI-S, and use a variety of methods to assess whether it measures end-of-life competence as intended. The DLI-S was reviewed by experts and people from the general public, which identified items that were unclear or difficult to understand in Swedish. Minor changes were made to make item content better fit the Swedish context and language. The DLI-S' measurement properties demonstrated satisfactory validity, meaning that it appears to be an accurate and reliable measure of death literacy in Sweden. However, we did note some issues with the scales measuring awareness of community support for end-of-life care. These issues might be explained in part by cultural differences between Swedish and Australian health and social care systems.

In Study IV, we explored whether death literacy was linked to specific factors, such as age, education, health status, and experiences related to dying, death, and loss. Statistical analysis showed that death literacy was mainly associated with having direct experience of caring for or supporting dying or bereaved people. These factors were more influential than having care training or working as a care professional. In addition, participants who were older, widowed, and identified themselves as being religious or spiritual had higher death literacy.

Overall, this thesis shows that experiential knowledge from first-hand encounters with dying and death is central to the development of death literacy. The findings describe how reflecting on and discussing one’s own and others' end-of-life experiences can support experience-based learning and mutual exchange of knowledge. Moreover, we conclude that the DöBra cards can be a useful tool in elder care, both for developing death literacy among staff and for discussing values and preferences for end-of-life care with residents and relatives. The findings also show that the DLI-S worked well for measuring death literacy in a Swedish context.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Döden är en ofrånkomlig del av livet som berör alla förr eller senare. Framsteg i medicinska behandlingar har lett till att människor lever allt länge, även med en eller flera sjukdomar. En majoritet av västvärldens befolkning kommer därför uppleva ett långsamt döende med ökande vårdbehov när livet närmar sig slutet. Detta är ett folkhälsoproblem som inte enbart kan tillgodoses av den formella sjukvården. Istället spelar andra vårdgivare, framför allt anhöriga och personal inom äldreomsorg, en avgörande roll i att ge vård och omsorg i livets slutskede till de som behöver. Att stödja någon i livets slutskede underlättas av beredskap och relevanta kunskaper. I denna avhandling undersöker jag hur utveckling av beredskap för frågor som rör livets slutskede kan främjas och mätas.

Ett sätt att stärka människors beredskap är genom att i förväg reflektera över och prata om döden och vad som är viktigt vid vård i livets slutskede ur olika perspektiv. Forskning har dock visat att många, även personal inom vård och omsorg, upplever att det är svårt att prata om döende och död. Att använda samtalsverktyg kan ofta underlätta sådana samtal. I denna avhandling har samtalsverktyget DöBra-korten använts och studerats inom äldreomsorg. DöBra-korten har tidigare visats stödja reflektion och samtal om värderingar och prioriteringar inför framtida vård i livets slutskede med äldre hemmaboende personer i Sverige. Det saknades dock kunskap huruvida DöBra-korten skulle kunna vara användbara inom äldreomsorg, där nära 40% av Sveriges befolkning dör.

I Studie I genomfördes flera serier av workshoppar tillsammans med äldreomsorgspersonal där DöBra-korten användes som ett verktyg för reflektion och diskussion. Vi utforskade hur personalens sätt att resonera förändrades över tid, exempelvis attityder till att prata om döden eller vad som definierar kvalitet i vård i livets slut. Övningarna med DöBra-korten tycktes i hög grad bidra till att utveckla kompetens och beredskap för samtal om vård i livets slutskede, genom att deltagarna satt ord på tankar och känslor om sin egen dödlighet och reflekterade över vad som kan vara viktigt utifrån egna, boendes och anhörigas perspektiv.

Studie II syftade till att utforska äldreomsorgspersonalens erfarenheter av att använda DöBra-korten i proaktiva samtal om framtida vård i livets slutskede med boende eller anhöriga. Resultaten visade att deltagarna upplevde att DöBra-korten tillförde en struktur och ett språk som underlättade öppen kommunikation om vad som är viktigt för den boende eller anhöriga. Samtalen stärkte även den personliga kontakten mellan de som deltog. Deltagarna ansåg också att samtal med DöBra-korten skulle kunna bidra till utveckling av gemensamma mål för vården och stödja fortsatt kommunikation om livets slutskede. DöBra-kortens användbarhet i praktiken påverkades av flera faktorer, antingen på personlig nivå, exempelvis inställning till verktyget, eller organisationsnivå, så som möjlighet att avsätta tid för samtal. Reflektion och kunskapsutbyte bidrog till att utveckla personalens kompetens att leda proaktiva samtal med boende och anhöriga. Kunskapen sammanfattades i en samskapad praktisk guide.

I avhandlingen användes också frågeformuläret Death Literacy Index (DLI) som mäter olika typer av kunskaper och förmågor som kan behövas för att hantera olika vård- och stödinsatser i livets slutskede. DLI utvecklades i Australien men hade vid tidpunkten för avhandlingen inte testats i Sverige. Syftet med Studie III var därför att översätta och anpassa påståendena i DLI till svenska förhållanden för att sedan validera den svenska versionen (DLI-S). Påståendena i instrumentet granskades av en expertpanel och testades med personer ur allmänheten, vilket gjorde att påståenden som var svåra att förstå kunde förtydligas och preciseras. DLI-S uppvisade tillfredsställande validitet och tillförlitliga mätegenskaper. Dock fann vi att de skalor som mäter kunskaper om stöd i närsamhället fungerade sämre i Sverige, vilket kan förklaras av skillnader mellan svenska och australiensiska vård och omsorgssystem.

I Studie IV användes DLI-S för att undersöka vilka sociodemografiska, hälsorelaterade och erfarenhetsbaserade faktorer som var associerade med beredskap för att hantera aspekter som rör vård och omsorg i livets slutskede. Resultatet visade att beredskap främst förklarades av tidigare direkta erfarenheter av att vårda eller stödja döende eller sörjande personer. Dessa faktorer hade större påverkan än utbildning eller arbetslivserfarenheter från vård och omsorg. Beredskap påverkades även av sociodemografiska faktorer, då deltagare som var äldre, änka eller änkling, och identifierade sig som religiöst eller andligt troende hade högre beredskap att hantera olika aspekter som rör livets slutskede.

Sammanfattningsvis visar denna avhandling att beredskap för att hantera frågor som rör livets slutskede främst bygger på erfarenhetsbaserad kunskap från direkta upplevelser av döende och död. Avhandlingen beskriver också att upplevd kompetens för att samtala om vård i livets slutskede utvecklas genom att reflektera om och diskutera upplevelser och erfarenheter, och att DöBra-korten kan vara ett användbart verktyg för detta. Vi fann även att DöBra-korten underlättade för äldreomsorgspersonal att leda proaktiva samtal om värderingar och prioriteringar inför vård i livets slut, vilket kan stärka boendes och anhörigas beredskap för framtida beslutsfattande om vården. Dessutom visar avhandlingen att DLI-S är ett tillförlitligt instrument för att mäta beredskap för frågor som rör livets slutskede i Sverige, vilket är betydelsefullt för att kunna utvärdera framtida kompetenshöjande initiativ både inom och utanför vård och omsorgssystemet.

ABSTRACT

Background: Due to aging populations and prolonged dying trajectories in many high-income countries including Sweden, more people will need extended periods of care and support at the end-of-life (EOL). In light of these changes, EOL care provision is increasingly recognized as a public health issue to be addressed not only within but also beyond the health care system. However, shifting EOL care provision requires that caregivers in other settings, such as elder care and home environments, perceive themselves to be sufficiently competent and prepared to handle various aspects of EOL care. Such competence can be denoted as death literacy. Building on the field of health promotion, interventions applying new public health approaches have been prominent in efforts to strengthen capacity to engage with dying, death, and loss in wider society. However, there is limited research about feasible means for fostering EOL competence-building and evaluating it in practice.

Aim: The overall aims of this thesis are to explore how to support development of EOL competence, referred to as death literacy (Studies I, II, IV), and assess one means of conceptualizing and measuring EOL competence (Studies III-IV).

Methods: These aims were addressed in four empirical studies deriving from two large data collections. Studies I and II used a multi-case participatory action research design to explore competence for EOL communication and the feasibility of a card-based tool designed to support reflection and conversation about EOL values and preferences, the DöBra cards, in elder care settings. Study I explored changes in elder care staff's reasoning about EOL communication throughout five series of workshops (n=20) designed to promote EOL communication competence, using longitudinal qualitative analysis. Study II built on follow-up interviews (n=6) with participants from Study I and meetings (n=8) with staff from four additional services. Inductive qualitative content analysis was used to explore staff's perspective on the usability of the DöBra cards to discuss EOL care with residents and relatives in residential care homes.

Studies III and IV were based on data collected during a multistep process to translate and validate the Death Literacy Index (DLI) in a Swedish context. The DLI is a 29-item questionnaire measuring six dimensions of EOL competence developed in but not yet tested outside Australia. The aim of Study III was to develop a culturally adapted Swedish-language version of the DLI (DLI-S) and assess its validity as a measurement of EOL competence in Sweden using mixed methods. Expert review (n=10) and cognitive interviews (n=10) were used to determine content and response process validity. A psychometric evaluation of DLI-S data from a cross-sectional survey (n=503) was conducted to assess internal structure validity. The aim of Study IV was to explore factors associated with death literacy, in a nonexperimental study using data collected in the online DLI-S survey. The survey data were analyzed using linear regression models to investigate associations between death literacy and numerous sociodemographic, health-related, and experiential factors.

Findings: Reflection, involving both introspection and extrospection, about past experiences and own feelings or assumptions about the EOL was found to be a central component for supporting death literacy development (Studies I-IV). The DöBra cards showed promise as an educational tool that, promoted reflection and knowledge exchange among staff (I) and as a conversation tool that helped staff facilitate proactive conversations about EOL values and preferences with residents and relatives in elder care practice (I-II). The multidimensional conceptualization of death literacy was supported in the Swedish context (III, IV). Death literacy in the Swedish sample was found to be primarily associated with direct experiences of supporting dying and bereaved persons (IV). The overall validity of the DLI-S was supported by evidence based on content, response processes, and internal structure. However, the scale relating to community support for EOL care showed poorer performance than the other scales, indicating contextual differences between Sweden and Australia, particularly regarding the role and organization of the health and social care systems (III).

Conclusion: The thesis contributes to the understanding of how EOL-related competence can be supported and evaluated, which is of significance for competence-building initiatives in both research and practice. The findings suggest that death literacy primarily develops from experiential knowledge and can be fostered through a process of reflection, specifically introspection and extrospection of own and others' EOL experiences, and mutual knowledge exchange. The DöBra cards were found to be useful to support death literacy development and for staff to facilitate proactive EOL conversations. The thesis also contributes with new knowledge about the DLI as a viable instrument for conceptualizing and measuring EOL competence that is not context- or profession-specific in a Swedish context.

LIST OF SCIENTIFIC PAPERS

I. Johansson, T., Tishelman, C., Cohen, J., Eriksson, L.E., Goliath, I. (2021) Continuums of change in a competence-building initiative addressing end-of-life communication in Swedish elder care. *Qualitative Health Research*, 31(10), 1904-1917. https://doi.org/10.1177/10497323211012986

II. Johansson, T., Tishelman, C., Eriksson, L. E., Cohen, J., & Goliath, I. (2022). Use, usability, and impact of a card-based conversation tool to support communication about end-of-life preferences in residential elder care – a qualitative study of staff experiences. *BMC Geriatrics*, 22(1);274. https://doi.org/10.1186/s12877-022-02915-w

III. Johansson, T., Olsson, Å., Tishelman, C., Eriksson, L.E., Noonan, K., Leonard, R., Goliath, I., Cohen, J. Validation of a culturally adapted Swedish-language version of the Death Literacy Index. (*Submitted for publication*)

IV. Johansson, T., Tishelman, C., Eriksson, L.E., Cohen, J., Goliath, I. Factors associated with death literacy among Swedish adults: A cross-sectional exploratory study. (*Manuscript*)

CONTENTS

LIST OF ABBREVIATIONS

AN	Assistant nurse (in Swedish: *vårdbiträde*), also known as a care assistant or nurse’s aide
CNA	Certified nursing assistant (in Swedish: *undersköterska*), also known as a licensed practical nurse
DLI	Death Literacy Index
EOL	End-of-life
RN	Registered nurse (in Swedish: *legitimerad sjuksköterska*)
PAR	Participatory action research
PHPC	Public health palliative care
RCH	Residential care home (in Swedish: *vård-och-omsorgsboende*), here used as an umbrella term for residential elder care facilities (in Swedish: *särskilt boende*). Residential care homes can also be referred to as long-term care homes, nursing homes, or aged care homes.
SRPC	Swedish Register of Palliative Care (in Swedish: *Svenska palliativregistret*), a register containing documentation of the conditions of expected deaths in Sweden.
WHO	World Health Organization

1 INTRODUCTION

Death is an unavoidable part of life for all of us. Due to global trends of slower dying and increasing death rates, many countries, Sweden included, are experiencing growing demand for end-of-life (EOL) care. Consequently, EOL care provision has been identified as a public health challenge, extending beyond the bounds of specialized care (Cohen & Deliens, 2012). An ongoing shift towards EOL care being provided in other locations than inpatient care facilities, e.g., in elder care and people's own homes, has highlighted the need to strengthen competence for EOL care among professional and family caregivers in these settings (Bone et al., 2018; Morin et al., 2017) and the benefit of building community preparedness for EOL issues has been recognized (Collins et al., 2021). Prior studies had also noted an urgency for building competence related to communication about EOL issues. Despite the apparent need for EOL competence, however, research about feasible means for fostering and evaluating it in practice is limited. Therefore, this thesis focuses on exploring how EOL competence can be developed and measured.

This thesis is the product of a doctoral project within the DöBra research program. DöBra has the overall long-term goal of reducing avoidable suffering related to dying, death, and loss in both community and care settings. The DöBra program, including this thesis, is based on a 'new public health' perspective (Lindqvist & Tishelman, 2016), which originates from the World Health Organization's Ottawa Charter for Health Promotion (1986). One of the key characteristics of new public health is the focus on individual and community action for promoting health (Tulchinsky & Varavikova, 2014). New public health approaches concerning EOL care often involve competence-building and empowerment to better prepare individuals and communities to deal with death, dying, and loss (Kickbusch, 2003). Consequently, research conducted in the DöBra research program focuses on health-promoting aspects of EOL by studying ways to better equip people for addressing and handling EOL issues within and outside health and social care systems.

This thesis comprises four studies based on two data collection sets, using new public health perspectives on EOL care as a conceptual point of departure. I began this doctoral project with a focus on exploring competence for issues related to EOL care and communication in elder care. The idea for the first two studies of the thesis originated from an existing collaboration between the DöBra research program and strategic management at Stockholm City Elder Care Bureau, the municipal agency responsible for elder care provision in Stockholm. They saw a need to improve EOL communication as part of their ongoing effort to strengthen EOL care competence among elder care staff. My research would thereby support their work with quality improvement. Studies I and II also built further on another project in the DöBra research program in which I was involved as a research assistant, which studied advance care planning in Sweden. We had found that the DöBra cards, a tool for reflection and conversation about values and preferences for EOL care, supported discussion about future EOL care with community-dwelling older people without known care needs (Eneslätt, 2021). However, it was not known whether this would be the case in elder care, where the resident population is frailer, often with multiple health problems. Given that EOL conversations would be facilitated by elder care staff, it was crucial to first explore their views of the DöBra cards before implementing the tool in elder care practice. Studies I and II are thus based on a participatory action research (PAR) project, designed and conducted in collaboration with elder care providers in Stockholm, exploring experiences of discussing EOL care with residents and relatives[1] and the acceptability of the DöBra cards as a tool for such conversations.

Initially, I had intended to continue my doctoral project by evaluating wider implementation of EOL conversations using the DöBra cards in elder care. However, during the search for suitable outcome measures, I was faced with a challenge. As suggested in Study I and demonstrated further in Study II, working with early EOL conversations in elder care could contribute to EOL competence-building among staff. At the same time, prior DöBra research, e.g., by Eneslätt et al. (2021), had shown that engaging in proactive EOL conversations could similarly build capacity among other “end users.” Therefore, I sought means to assess EOL competence among care staff, residents, and relatives. In their literature review, Karacsony et al. (2015) noted the lack of context-specific instruments for measuring staff’s EOL competence in elder care. The availability of validated Swedish-language instruments was even more limited. While the Swedish version of the Frommelt Attitude Toward Care of the Dying Scale (Henoch et al., 2014) was relevant in scope and had been used with both professional and family caregivers, it demonstrated poor internal consistency reliability and was not suitable for use with residents.

The DöBra research group had closely followed the development of the *death literacy* concept, a comprehensive and multidimensional construct of EOL competence, for several years. Death literacy is not specific to care but targets the general public. It has been operationalized and measured using the Death Literacy Index (DLI), which was developed and tested in Australia by Leonard et al. (2022). As it became increasingly clear to me that in this thesis, I focused on ways in which death literacy can be developed and measured in a Swedish context, we established a collaboration with the Australian research group that had developed the DLI (Leonard et al., 2022). The DLI was designed for individual assessments of death literacy and group-level evaluation of educational interventions. Therefore, it was considered as potentially suitable to study the overall impact of implementing EOL conversations using the DöBra cards in residential elder care. However, as the DLI was recently developed, it only existed in English, and its validity outside the original context was unknown. Consequently, the studies in the second half of my thesis are based on an additional data collection, consisting of a multi-step process of translating and validating the DLI in a Swedish context.

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[1] The term ‘relatives’ is used in this thesis to signify all significant others (in Swedish: *närstående*)

2 BACKGROUND

This chapter provides a background for the thesis discussing EOL care provision and EOL communication, with an emphasis on new public health. The chapter thus presents the research field in which the thesis is situated and describes the rationale for the research conducted.

2.1 END-OF-LIFE CARE PROVISION AS A PUBLIC HEALTH ISSUE

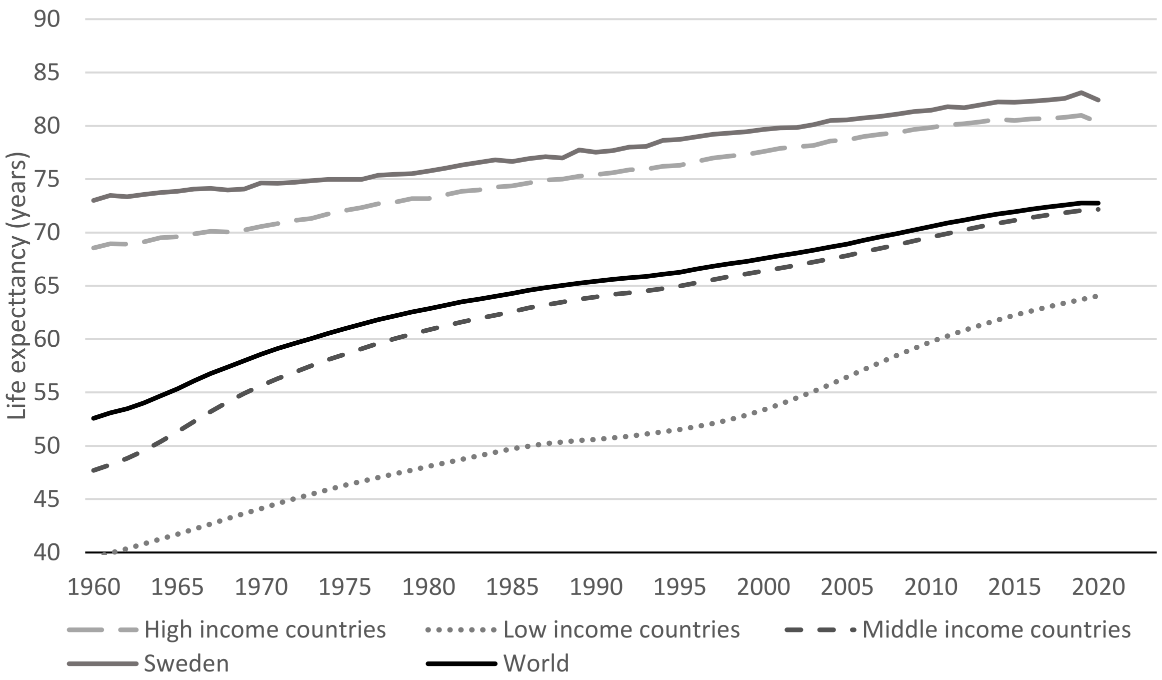
Death affects us all. Our perceptions of death are diverse and imbued with social, religious, cultural, and political meanings that evolve over time and in response to societal development (Zimmermann & Rodin, 2004). Hence, dying is closely intertwined with various norms, attitudes, and values, affecting all aspects of care provision.

How people die has changed considerably over recent generations. On a societal level, death has largely moved from the familial domain at home to the professional domain at care institutions, especially in high-income countries. In a recent Lancet commission report, it is argued that this shift, with resulting increased reliance on health care services has led to excessive focus on medical interventions while the roles and responsibilities of families and communities have been reduced, and skills and traditions for handling dying and death have diminished (Sallnow et al., 2022). In response to this development, Sallnow et al. (2022) propose a ‘rebalancing’ of death in society by establishing stronger partnerships between those who are dying, their families and communities, health and social care services, and the broader public.

The circumstances of death are also affected by demographic and epidemiological changes, such as aging populations and growing prevalence of chronic diseases, which are primary drivers of rising global death rates (Wang et al., 2016). At the same time, life expectancies are increasing (illustrated in Figure 2.1), due to improved welfare and living standards, public health measures, and advances in medical treatment (Tulchinsky & Varavikova, 2014). This means that a large part of the population, especially in high-income countries, can live for extended periods even with chronic conditions, frailty, and life-limiting illnesses and experience gradual dying rather than a sudden death (Cohen & Deliens, 2012; Walter, 2017). Consequently, demographic and epidemiological changes also affect prerequisites for EOL care provision.

Population-based estimations based on mortality data indicate a considerable increase in people with EOL care needs in the coming decades, which requires a shift in the delivery of basic care tasks from institutional care settings towards social care, primary care, and community contexts (Bone et al., 2018; Etkind et al., 2017; Morin et al., 2017; Sleeman et al., 2019). This also includes an increasing burden of responsibilities for family caregivers, defined as any relative, partner, friend, or neighbor who provides practical, social, and emotional care for people dying at home (Cohen & Deliens, 2012).

Figure 2.1. Trends in total life expectancy at birth the past 50 years*.



* The life expectancy at birth represents the number of years a newborn infant would live if prevailing patterns of mortality at the time of its birth were to remain throughout its life.
Source: The World Bank, https://data.worldbank.org/indicator/SP.DYN.LE00.IN

2.2 A QUESTION OF TERMINOLOGY: PALLIATIVE OR END-OF-LIFE CARE?

EOL care concerns any care provided in a period before death, which can be curative, rehabilitative, or palliative. Nevertheless, the term palliative care has become strongly associated and sometimes used interchangeably with EOL care. In this section, I will briefly canvass some of the issues concerning terminology and provide my reasoning for the definitions used in this thesis.

The World Health Organization (2002) defines palliative care as an approach aiming to improve quality of life and relieve suffering for people with any life-limiting illness and their relatives by considering physical, psychological, social, and spiritual needs. The underlying principles for the palliative care approach focus on enabling people to end their lives with dignity and have their autonomy respected, i.e., receive the support they wish for and require (Pastrana et al., 2008). In Sweden, these principles are set out in the *National program for palliative care* (Regionala Cancercentrum i Samverkan, 2016), but the prerequisites for achieving them vary considerably (Schelin et al., 2018). However, as the palliative care approach has become more integrated into mainstream health care services, its definition has become even more inconsistent. Pastrana et al. (2008) showed in their review a lack of consensus for the term palliative care in the literature, as it could refer to a range of care tasks, competencies, target groups, and organizational structures. Radbruch et al. (2020) reported similar discrepancies more than a decade later during the development of a proposal for a new consensus-based definition. These authors describe a division of views on palliative care primarily as alleviating suffering or mainly as care at the EOL. Attempts have been made to specify competence and organizational aspects of palliative care by differentiating *specialized* palliative care, performed in hospices or by palliative support teams in home care, from *general* (or *generalist*) palliative care, provided in various settings by several care professionals with basic training, such as general practitioners, district nurses, and other care staff (Schelin et al., 2018; Swedish Register of Palliative Care, 2020). However, this distinction has been criticized for being ambiguous, poorly understood in care practice, and muddling boundaries of roles and responsibilities for palliative care provision (National Board of Health and Welfare, 2016; Robinson et al., 2017).

Taken together, these criticisms informed my decision to use the broader term EOL care, even though this thesis focuses on what might be referred to as general palliative care. In particular, EOL care does not have specific organizational structures stipulated in the way that palliative care does, making it more applicable in both elder care and the community.

2.3 NEW PUBLIC HEALTH PERSPECTIVES OF END-OF-LIFE CARE

Following an era of public health strategies focused on preventive medicine, new public health evolved from WHO's Ottawa charter for health promotion (1986), which focuses on: "*building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services*" (Tulchinsky & Varavikova, 2014, pp. 62-63). Sallnow and Paul (2014) argue that many of the central principles in new public health are equally relevant for EOL care, such as a holistic perspective of health and an emphasis on individual and community needs.

New public health perspectives often conceptualize dying, death, and loss, as shared social processes rather than medical phenomena (Sawyer et al., 2021), as epitomized in Kellehear's (1999) assertion that promotion of health, also at the EOL, is everybody's responsibility, not only that of care professionals. Dempers and Gott (2016), however, pointed out that inconsistent use of definitions in new public health approaches has blurred the boundaries of its aim and scope. They demonstrated the use of three different paradigms in the literature: a health promotion approach emphasizing individual and community competence and empowerment, a WHO approach focusing on service provision and care systems on a national level, as well as a population-based approach applying epidemiological and policy perspectives to EOL care. This thesis is situated in the first of these paradigms, which was initially referred to as 'health promoting palliative care' (Kellehear, 1999) and, is now more commonly called 'public health palliative care' (PHPC) (Collins et al., 2021).

A key ambition in PHPC approaches is to re-balance the perceived medicalization and professionalization of EOL care by moving beyond the formal health care system to a broader context with recognition of the potential roles, abilities, and contributions of individuals, social networks, communities, and societies (Sallnow et al., 2016b). Civic engagement is, however, intended as a complement to, and not a replacement for, professional health and social care services. Instead, the emphasis in PHPC is on the value of community development. This might involve various community actors interacting and collaborating to develop knowledge and skills for providing care and support for dying people and strengthening resilience in response to dying, death, and loss (D'Eer et al., 2022; Kellehear, 2013; Sallnow & Paul, 2014). Nevertheless, Sawyer et al. (2021) recently highlighted tensions in the theoretical underpinnings of PHPC, such as how dying is conceptualized differently across stakeholders. Recently both Vijay et al. (2020) and Kleijberg et al. (2021) have argued the risks of overlooking challenges in collaborating with community partners, i.e. conflicts or unbalanced power dynamics when collaborating actors and organizations have differing privileges, motivations, or frames of reference.

2.4 THE SWEDISH CONTEXT

In this section, I describe Swedish circumstances of dying, death, and EOL care to provide a background to the empirical studies in the thesis and allow the Swedish setting to be understood in an international context.

2.4.1 Dying in Sweden

During the 21st century, Sweden has had an overall yearly mortality rate of circa 90,000 people, equivalent to approximately 1% of the population (Swedish Register of Palliative Care, 2020)[2]. Of these, about 80% die an expected death with some degree of palliative care needs. However, in the Swedish Register of Palliative Care (2020), it is reported that, in 2019, specialized palliative care reached only 11.4% of the population, though access is highly variable geographically with specialized palliative care services primarily located in urban areas. The majority of expected deaths in Sweden occur in institutional settings: the Swedish Register of Palliative Care reports that in 2017, 39% of registered deaths occurred in hospital, 36% in residential eldercare, 19% at home, and 6% at another or unknown place (SRPC, 2020). The proportion of RCH deaths is larger in Sweden than in other Nordic countries (National Board of Health and Welfare, 2022) and several European countries (Hakanson et al., 2015). In contrast, a population-based study by Pivodic et al. (2016) describing the place of death for people dying of conditions requiring palliative care showed that RCH deaths were very uncommon in South Korea (1.3%), Italy (6.1%), and Spain (7.3%), while the Netherlands (34.5%), New Zealand (33.4%), and Belgium (23.8%) had rates closer to those in Sweden. While the place of death varies according to cause of death, overall trends of decreasing hospital deaths and increasing RCH deaths have been found in many high-income countries (Bone et al., 2018; Kalseth & Theisen, 2017).

Yet, as depicted in Figure 2.1, Sweden faces similar challenges to those seen globally with aging populations, prolonged dying, and growing care needs (National Board of Health and Welfare, 2022). Almost 60% of all who died in Sweden in 2020 were 80 or older (Statistics Sweden, 2021). Projections of further increasing demand for EOL care, especially among

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[2] The Swedish Register of Palliative Care (in Swedish: *Svenska palliativregistret*) is a register in which circa 31,000 health care workers document the circumstances of **expected** deaths, such as incidence of symptoms in the last week of life or completion of EOL conversations (Swedish Register of Palliative Care, 2020).

older people, have led to proposals for reorganizing and re-allocating resources from inpatient to community-based care settings, e.g., primary care centers, social care, and home care, and improved staff training for EOL care provision (SOU, 2020).

2.4.2 Swedish elder care

Sweden has publicly funded universal health and social care, accessible based on an assessment of needs rather than financial means (Ulmanen & Szebehely, 2014). Primary and specialist health care is provided by 21 regions, whereas provision of home and social care, including elder care, is the responsibility of the 290 municipalities, as set out in the Social Services Act (2001:453) (OECD, 2019). Elder care is generally either residential or home-based[3], where staff from home-help services assist with daily chores and activities such as washing, cooking, and cleaning, in care recipients' own homes. The municipalities can provide both types, e.g., as public non-profit care, or privately run care companies (National Board of Health and Welfare, 2022). Those aged 65 and older who need assistance can apply to the municipality to receive home-based elder care or move into residential elder care. Applications are assessed, usually by social workers, with consideration to care needs (Innes et al., 2021).

There are two main forms of residential elder care facilities, residential care homes (RCHs)[4] and assisted living facilities[5]. In Swedish RCHs, residents rent and live in individual (generally studio) apartments, with 24-hour access to care staff who assist residents in their daily life, e.g., with hygiene routines, eating, cleaning, and administration of medication, and physicians usually available on-call or at certain hours (Innes et al., 2021; Nilsen et al., 2018). RCH admission requires considerable care needs: therefore, residents often have multiple health issues and can be very frail. Assisted living facilities are similar in that they offer supported accommodation with 24-hour availability to on-site care staff, but residents have fewer medical needs at admission, and there is more focus on social activities than in RCHs. As in many European countries, most Swedish residential elder care is provided in public non-profit facilities, though private for-profit and private non-profit services are considerably more common in the Stockholm region than in the rest of Sweden (National Board of Health and Welfare, 2022) or Europe (Honinx et al., 2021).

The residential elder care workforce mainly comprises certified nursing assistants[6] (CNAs, also called licensed practical nurses) and assistant nurses (ANs) as primary caregivers for residents. Swedish RCHs also have registered nurses (RNs), occupational therapists, and physiotherapists working on site. Physicians are available by phone or at set hours during the

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[3] in Swedish: *hemtjänst*

[4] in Swedish: *vård-och-omsorgsboende*

[5] in Swedish: *servicehus*

[6] A large majority of CNAs have a completed the health and social care programme in upper secondary school (in Swedish: *gymnasieprogram*) or upper secondary adult education (in Swedish: *komvuxutbildning*) that is the basis for the certification. From July 1st, 2023, the professional title CNA will become protected and will require completed education (https://legitimation.socialstyrelsen.se/underskoterska-blir-en-skyddad-yrkestitel/)

week (Nilsen et al., 2018). Characteristics of Swedish RCHs, e.g., care from on-site care staff and off-site physicians, and workforce composition correspond with other European countries (Honinx et al., 2021). Since both types of residential elder care facilities provide 24-hour access to care staff, I will use RCHs as an umbrella term for both services in the remainder of this thesis.

There have been considerable changes in Swedish RCH care during the past two decades. First, Sweden has an ‘aging in place’ policy. This means that older people are supported to live in their own homes for as long as possible, and there is a higher rate of home-based elder care in Sweden compared to other Nordic countries (National Board of Health and Welfare, 2022). In addition, RCH availability has decreased due to a 25% reduction in beds since 2001 (Schon et al., 2016). Consequently, substantial care needs are generally required for RCH admission, as reflected in the high prevalence of palliative care needs due to chronic diseases, multi-morbidity, and frailty, among residents (Cronfalk et al., 2015; Smedback et al., 2017). Moreover, Schon et al. (2016) report that lengths of stay in RCHs, i.e., time between admission and death, in Stockholm decreased from 27 months in 2006 to 19.5 months in 2012. Register data from 2015–2018 show that the median length of stay overall in Swedish RCHs was 25 months (National Board of Health and Welfare, 2022). These time intervals are comparable to those presented by Collingridge Moore et al. (2020a) in their cross-sectional study of RCH lengths of stay in Belgium, England, Finland, Italy, the Netherlands, and Poland, where the total median was approximately 17 months, ranging from 4 months in Poland to 24 months in Belgium.

Given the increase in EOL care needs, there is general agreement regarding the necessity of applying a palliative care approach in Swedish RCHs (Swedish Association of Local Authorities and Regions, 2020). In a focus-group study with RCH staff following an EOL competence-building program, Cronfalk et al. (2015) found that even if experiences of the intervention were generally positive, there was an expressed need for more long-term measures, such as mentoring or support groups. In addition, in an interview study with twenty managers, Nilsen et al. (2018) found limited readiness for implementation of a palliative care approach in RCHs, which was attributed to varying commitment to change among staff. Shortcomings in the quality of EOL care provision were further emphasized during the COVID-19 pandemic, which hit RCHs particularly hard (Martinsson et al., 2021; Swedish Government Official Reports, 2022).

2.4.3 Care provision and support for people at home

The Social Services Act also stipulates that municipalities are required to provide practical and emotional support to family caregivers who care for an older or sick person in their home. Community-dwelling older people in Sweden are increasingly receiving help from family caregivers, such as children, partners, and neighbors: almost 20% of the adult Swedish population regularly care for an older person living at home by providing practical help, coordinating contact with care services, and, less commonly, administering medications or injections or dressing wounds (National Board of Health and Welfare, 2021; Ulmanen &

Szebehely, 2014). According to findings in the Swedish National study on Aging and Care, 18.3% of people aged 80 and older rely solely on family caregivers for care and support (Wimo et al., 2020). Innes et al. (2021) suggest that the trend of family caregivers taking more responsibility for elder care provision is, at least in part, a result of the reduction in RCH availability, and it is likely that the COVID-19 pandemic has further affected this. The municipal health care provision is expanding and more Swedes, often those who are older with complex care needs, receive increasingly advanced care in their homes (National Board of Health and Welfare, 2022). Still, the epidemiological and demographic changes described above are expected to lead to a greater burden of care provision for family caregivers in Sweden (Wimo et al., 2020) as well as other European countries (Cohen & Deliens, 2012).

2.5 COMPETENCE FOR ENGAGING WITH END-OF-LIFE ISSUES

Competence is a complex concept denoting a set of attributes in relation to a specific context (Le Deist & Winterton, 2005). Regarding competence for EOL care provision, the existing literature generally agrees on a multi-dimensional conceptualization, though there is some variation in the specific components. In a white paper for the *European Association for Palliative Care*, Gamondi et al. (2013) set out that professional competence required for providing high-quality EOL care encompasses a combination of knowledge, skills, and attitudes. Desbiens and Fillion (2011) describe EOL competence similarly, also adding values as a component. Values and other personal features, such as fears and motivations, are also highlighted by Chan and Tin (2012) as influencing a facet of EOL competence they call “self-competence,” which involves use of personal resources and coping strategies in EOL situations. Expanding on the role of emotions, Gamino and Ritter (2012) propose that developing personal “death awareness,” i.e., knowing oneself well enough to perceive when and how own difficulties influence one’s care behavior, is critical for building emotional capacity needed to handle other peoples’ EOL-related difficulties and concerns.

Another central concept related to competence is self-efficacy, which derives from Bandura’s (1977; Bandura, 1982) research on social learning theory and refers to the judgement of one’s own capability to a manage a task. According to Bandura, self-efficacy appraisals, no matter if they are accurate or not, influence behavior as people with higher self-efficacy are less prone to react with fear or self-doubt in a particular situation. High self-efficacy is thus conducive to successfully managing the situation, which fosters experiential learning and further strengthens self-efficacy (Bandura, 1982). In contrast, perceptions of having insufficient capabilities are assumed to trigger fearful and avoidant responses that inhibit competence development (Bandura, 1977). While high self-efficacy seemingly promotes learning from experience, Bandura also argue that it can impede learning as people might not invest sufficient time and effort on something they consider themselves to already master. Existing research generally supports the relation between education or knowledge and higher self-efficacy for engaging in EOL care provision and communication. For example, both Ten Koppel et al. (2019) and Evenblij et al. (2019) found self-efficacy for EOL communication among care staff to be associated with higher education, formal EOL care training, and better knowledge of palliative care across several European countries. Brazil et al. (2012), on the other hand, reported that RCH staff with high self-efficacy for EOL care provision still scored low in terms of knowledge about EOL care provision. However, the authors note that the measurement for knowledge was not designed for the RCH context, meaning that context-specific and tacit knowledge might not have been captured, thereby understating competence-levels. The link between self-efficacy and actual behaviour has also been supported: Ludwick et al. (2018), for example, found that education and higher self-efficacy was associated with more engagement in EOL communication with residents in a study with American care staff.

More recently, the term death literacy has been used to denote a broader, comprehensive competence for EOL care provision. The construct death literacy is defined as a collection of knowledge and skills that enables a person to "access, understand and make informed decisions" about EOL care (Noonan et al., 2016). The term builds on health literacy, a public health concept denoting individuals' ability to "*obtain, process, and understand basic health information and services needed to make appropriate health decisions*" (Office of Disease Prevention & Health Promotion, 2010, p. 1). Specifically, death literacy encompasses knowledge and understanding about EOL care options and how to access them, capacity for care provision and communication, and emotional coping in response to EOL care. The notion of death literacy developed in Australia and derives from a study by Horsfall et al. (2014) about how caring for and supporting a dying person at home had transformative effects on awareness, knowledge, and skills in relation to dying and death, and attitudes to engaging in EOL care provision. Theoretically, then, death literacy describes the development, use, and effects of knowledge about EOL care (Leonard et al., 2022). It is assumed to be a primarily experience-based construct that captures competence gained from both formal and informal roles (Leonard et al., 2020), but had not been tested outside its original context at the time of this thesis.

2.5.1 End-of-life competence-building

As described above, PHPC approaches often aim to increase awareness, competence, and preparedness for engaging with EOL related activities, such as supporting or caring for those who are dying or bereaved (Banner et al., 2019). In a systematic review, Sallnow et al. (2016a) found that EOL competence-building based on PHPC approaches can have impact on different levels. On the individual level, interventions can contribute to learning, confidence, and attitude change, whereas at group-level, they support development of community capacity for EOL situations. There are numerous PHPC-based educational initiatives. One example is Last Aid (Mills et al., 2020), public education courses available in several European countries that teach skills for providing care and managing symptoms at the EOL using both professional and non-professional expertise. Another recent example is the End of Life Aid Skills for Everyone (EASE) course developed in Scotland, aiming to better equip people to support those dying and bereaved and build social networks among community members (Patterson et al., 2022).

Even though competence-building is commonly identified as a key prerequisite for improving EOL care provision, there is limited knowledge about effective ways of building EOL competence in practice. Gamondi et al. (2013) advise in an EAPC white paper that training in EOL care provision should involve multiple modalities, preferably integrating individual learning, classroom teaching through lectures, workshops, and seminars, and placement training that enables experience-based learning. Findings from a qualitative study by Gillett et al. (2016) exploring how nursing and medical students acquire EOL communication skills highlighted the role of reflective discussions in facilitating the strengthening of both skills and confidence. Getting people to engage with the topic on a personal level, e.g., reflecting about one's own thoughts and feelings in relation to death, has also been suggested as a means to address attitudes and values in relation to competence for providing EOL care (Chan & Tin, 2012) and addressing the EOL (Gamino & Ritter, 2012; ÖSterlind et al., 2011).

2.6 COMMUNICATING ABOUT THE END-OF-LIFE

2.6.1 Discourses about dying and death

As noted above, our views on dying and death are influenced by numerous values and attitudes. This, in turn, can manifest in contrasting discourses for how the EOL is conceptualized, also in research. Here, I will briefly describe two contrasting, yet interrelated, ideas that have affected perceptions of and discourses on EOL care in the scientific literature.

First, the notion of 'death denial' in modern society, i.e., that death is an inherently distressing phenomenon that people strive to suppress both on an individual and societal level, has been described by scholars such as Becker (1973) and Ariès (1981). Death denial is said to result from changing roles of physicians and subsequent medicalization and institutionalization of death during the mid-20th century, argued to segregate those dying and hiding death from the rest of society (Zimmermann & Rodin, 2004). Nevertheless, Kellehear (1984) has pointed out that not addressing death because it is perceived as upsetting does not equal denial, stating that such avoidance is not a new phenomenon. In addition, Walter (2017) and Zimmermann and Rodin (2004) have argued that even though medical and technological advancements have likely contributed to a perception of death as being largely preventable, this does not mean that dying is denied but merely re-interpreted with consideration to societal changes. Still, death denial, and the closely related notion of death as being silenced or taboo, have noticeably impacted the literature as examples of fundamental barriers for open communication about EOL care (Zimmermann & Rodin, 2004). Discourses also affect real-life attitudes. For example, perceiving death as taboo was identified as a hinder for public awareness about palliative care in Sweden in a study by Westerlund et al. (2018).

Second, the notion of the 'good death', emphasizing dying people's right to autonomy, dignity, and information, became a central concept for the hospice and right-to-die movements (Van Brussel & Carpentier, 2012). Even though the notion of a good death is contextual, Cottrell and Duggleby (2016) showed in their review that the contemporary understanding used in EOL care literature generally focused on accepting death and exerting individual agency to achieve a peaceful and dignified dying free from pain and distress. Furthermore, they noted a fragmented discourse: while the concept of good death promotes individual agency, empowerment, and free will, it has simultaneously become a benchmark in itself that care staff might aim to achieve ‘for’ the care recipients, even when those characteristics are not wanted or feasible (Cottrell & Duggleby, 2016).

2.6.2 The role of communication in end-of-life care

In contrast to the assumption that there is a universal view of the good death, a person-centered approach to EOL care highlights the narrative of the unique care recipient and communication about individual values and needs as necessary for high-quality care. Poor or insufficient communication has been identified as a common cause for complaints in EOL care by bereaved relatives in several different countries (Baranska et al., 2020; Cohen-Mansfield et al., 2017). Furthermore, dissatisfaction with communication has been linked to perceptions of EOL care provision as being inconsistent with a decedent’s preferences in the United States (Khandelwal et al., 2017). Communication about issues relating to dying, death, and EOL care, broadly referred to as *EOL conversations* in this thesis, is therefore a key aspect of EOL care. EOL conversations can be held with a range of stakeholders, e.g., community members, care recipients and their relatives, and care professionals. Timing varies; EOL conversations can be held proactively, i.e., performed with healthy people or as early as possible in an illness trajectory, or in reaction to a diagnosis or following deterioration in care recipients’ health (Tros et al., 2022). In this thesis, the focus is on proactive EOL conversations.

The value of EOL conversations is further emphasized as preferences for EOL care can vary considerably between individuals (Eneslatt et al., 2021; Higginson et al., 2017) and perspectives of what is important in relation to EOL care can differ considerably between care recipients, their relatives, and staff (Steinhauser et al., 2000). Awareness of individual preferences is particularly important for better equipping relatives to care or make EOL care-decisions for someone who is no longer able to speak for themselves (deLima Thomas et al., 2018; Heyland et al., 2017), although it can still be challenging to disentangle own preferences, values, and emotions from that of the care recipient (Dzeng & Morrison, 2021).

Clearly, EOL conversations should be voluntary, as not everyone wants to talk about the EOL, their prognosis, or future care. Overall, however, care recipients have been found to be generally positive towards addressing issues related to EOL care, as recently shown in a comprehensive systematic review by Bjork et al. (2021), which includes several types of patients and settings. Similarly, a systematic review on older people’s preferences for discussing the EOL by Sharp et al. (2013) found that while a minority did not wish to participate in EOL conversations at all, most were positive to being asked about their EOL preferences and have opportunity to discuss future care. A recent German interview study by Kukla et al. (2022) showed that reflection and conversations about various aspects of dying were perceived as beneficial for self-determination and wellbeing at the EOL among both older people and people with life-limiting illness.

Nevertheless, many people consider initiating conversations about the EOL to be difficult, especially when talking to someone affected by dying, death, or loss. These challenges also exist among staff in care settings: systematic reviews have indicated that main barriers for staff to engage in EOL conversations include perceived lack of communication skills, insufficient time, feeling uncomfortable with the topic, or worrying about causing distress or removing hope (Blackwood et al., 2019; Threapleton et al., 2017). Studies by Graham-Wisener et al. (2022) and Banner et al. (2019) show similar obstacles for EOL conversations in the community, i.e., perceived lack of social acceptance to address death, fear of upsetting others, and lack of experiences or skills.

Possible consequences of communication barriers were demonstrated in two studies based on interviews with staff, patients, and relatives in specialized palliative care by Clayton et al. (2005) and Almack et al. (2012). These authors pointed out how conflicting ideas about responsibility for initiating EOL conversations can turn into a waiting game, with staff awaiting patients or relatives to address the EOL when ready, while patients and relatives, in turn, assume that staff will mention the topic as needed. Moreover, observational studies have reported how RCH staff sometimes use strategies to distract or avoid direct conversations about death, such as using euphemisms, comforting, or changing the subject, both in Sweden (Alftberg et al., 2018; ÖSterlind et al., 2011) and Australia (Omori et al., 2022). Use of allusive strategies were also noted by Parry et al. (2014) in their systematic review of staff's strategies for addressing illness progression and EOL care in clinical settings.

2.6.3 Advance Care Planning

One form of proactive EOL conversations is termed advance care planning (ACP), with a large part of the international literature on proactive EOL conversations referring to ACP. It is defined by the European Association for Palliative Care as a process that "*enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate*" (Rietjens et al., 2017, p. 546). Key underlying goals include respecting autonomy, improving care quality, strengthening relationships, building preparedness, and reducing overtreatment (Fleuren et al., 2020). Systematic reviews have found ACP to be associated with reduced unwanted care procedures, higher likelihood of value-concordant EOL care, and increased satisfaction with EOL care and communication among relatives in both health care and elder care contexts (Brinkman-Stoppelenburg et al., 2014; Martin et al., 2016; McMahan et al., 2021). Still, Jimenez et al. (2018, 2019) argue that the considerable international variation in how, where, and with whom ACP, alongside lack of consistency in use of outcome measures, hinder comparison and generalization of findings about ACP impact on EOL care.

ACP is described as encompassing two main components (Prater et al., 2019). The first involves one or several conversations about EOL values, preferences, and/or priorities, facilitated by various actors including care professionals, social workers, volunteers, family members and/or friends. Increasingly, a distinction is made between "formal ACP", which refers to professional-led ACP, and "informal ACP" which involves lay-person facilitation often via community groups or educational interventions (Somes et al., 2018). A second component involves documentation of EOL preferences, often in formal legally binding documents, such as advance directives, power of attorney, or appointment of healthcare proxies to guide future care provision if decision-making capacity is lost. This kind of documentation of EOL care preferences and/or decisions is not currently legally binding in Sweden, however. Consequently, I concentrate here on the conversational ACP component, which corresponds to how the term EOL conversations is used in this thesis.

The COVID-19 pandemic updated the urgency of ACP and was also one factors leading to an intense international debate regarding its value to care practice. Much of this debate focused on articles by Morrison (Morrison et al., 2021; Sean Morrison, 2020), in which it was contended that the available evidence does not suggest that ACP improves quality of life, increases value-concordant care, or reduces overtreatment at the EOL. Similar arguments have previously been made by Johnson et al. (2017). Morrison et al.'s article also received substantial opposition. Several responses (Myers et al., 2022; Sudore et al., 2022; Tishelman et al., 2021) acknowledged the lack of support for binding and unchangeable medical decision-making in ACP documentation but maintained the value of the conversational component to improve person- or family-centric communication between stakeholders and benefit preparation for better informed in-the-moment decision-making. Overall, this debate served to highlight contrasting views of ACP, with one described as a formulaic approach of determining future care preferences and making advance decisions regarding medical treatment options in isolated discussions, and the other as a longitudinal process of conversations with stakeholders that focus on identifying what matters at the EOL to build preparedness for handling future situations. The latter model has received growing support (e.g. Auriemma et al. (2022); McMahan et al. (2021)) and aligns with the new public health approach applied here (Abel et al., 2020; Hopkins et al., 2020; Waldrop & McGinley, 2022).

Still, systematic reviews have pointed out that implementation of ACP is hindered by perceived lack of communication skills and discomfort addressing death (Flo et al., 2016; Kuusisto et al., 2020; Somes et al., 2018), and it has been pointed out that implementation strategies need to be adapted to local conditions (Collingridge Moore et al., 2020b). Thus, similar barriers are noted for ACP and more general EOL conversations.

2.6.4 Means for supporting end-of-life conversations

Conversation tools are one proposed means to overcome some barriers in discussing EOL issues and addressing the identified need for evidence-based guidance on feasible strategies for EOL conversations in care settings (Parry et al., 2014). One such tool is the *GoWish cards*, which was developed by Coda Alliance in the U.S. to help people discuss matters related to EOL care (Menkin, 2007). In care contexts, the GoWish cards have been found to support discussions about EOL preferences with patients (Delgado-Guay et al., 2016; Lankarani-Fard et al., 2010). The GoWish cards have also been used in education with medical students (Osman et al., 2018) and with older adults in the community (Banner et al., 2019). The GoWish cards have been translated and adapted to several languages, e.g., Hebrew, French, and Portuguese. Apart from the Swedish research output, which will be described below, published scientific articles about he translated versions are generally lacking. The Chinese adaptation is an exception, which has been found to encourage and support EOL conversations and increase intention to complete advance directives among Chinese Americans (Jia et al., 2021).

In this thesis, we have studied the use of the *DöBra cards*, which are the translated and adapted Swedish-language version of the GoWish cards, both as a research tool (Tishelman et al., 2022) and, later, a social innovation made available to the general public (Eneslätt et al., 2021). The DöBra cards have been found to be an easy-to-use and acceptable tool for stimulating reflection about future EOL care among community-dwelling older adults without known palliative care needs (Eneslatt et al., 2020; Tishelman et al., 2022) and with indigenous Sámi adults (Kroik et al., 2022). The DöBra cards have also been shown to help elicit information about underlying EOL values for care preferences (Eneslatt et al., 2020, 2021). The DöBra cards require no training to use and are thus an accessible tool that enables a range of actors to facilitate EOL conversations. While Eneslätt (2021) had demonstrated that the DöBra cards had generated interest for use in care settings, the tool had not been tested for this. Since the start of the DöBra research program and its work with the DöBra cards, a range of other tools have been developed to support different forms of discussions about EOL-related issues, targeting various settings and groups, described further by e.g., Eneslätt (2021); Noordman et al. (2019); van der Smissen et al. (2020).

2.6.5 End-of-life conversations in Swedish care

Even though the documentation component of ACP, e.g., binding advance directives or appointment of healthcare proxies, is not legally admissible in Sweden to date, the conversational component, i.e., discussing future EOL care with care recipients and their relatives, is used. In Sweden, discussions about upcoming EOL care, held in a transition from active to palliative treatment (‘*brytpunktssamtal*’ in Swedish)[7], were first proposed as an important means for establishing appropriate care goals for a dying person in an official report for the Swedish Ministry of Health and Social Affairs (Swedish Government Official Reports, 2001). They have since become indicators of high-quality EOL care and are recommended in national guidelines for palliative care (National Board of Health and Welfare, 2016; Regionala Cancercentrum i Samverkan, 2021).While these discussions fall under the umbrella term EOL conversations and may be seen to constitute a form of

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[7] directly translated as ‘breakpoint conversation’ in reference to the transition in care from curative to palliative

conversational ACP, I will refer to them specifically using the originally used term ‘breakpoint’ conversations in this thesis, to differentiate their stated purpose and use from that of proactive EOL conversations.

Breakpoint conversations are physician-led discussions in which care recipients and their relatives should be informed about and able to address EOL issues such as symptoms, care options and preferences, and emotional and existential matters, as the focus of care transitions from being curative to palliative, i.e., when death is inevitable and comfort care is the main goal although measures to prolong life may still be used (Udo et al., 2018). Use of breakpoint conversations have been investigated in numerous studies using data from the Swedish Register for Palliative Care. For example, Lundquist et al. (2011) reported that prevalence of breakpoint conversations were positively associated with cancer patients dying in their preferred place, relatives being offered bereavement support, and prescription of parenteral as needed drugs to control symptoms, although there were no differences in symptom-relief. More recently, Andersson et al. (2021) found use of breakpoint conversations in RCHs to be linked both with more symptoms and better symptom-relief, which they suggest might mean that conversations provide opportunity to discuss both symptoms and ways to treat them.

Other studies have highlighted uneven uptake across Swedish care settings, arguing that breakpoint conversations are insufficiently used in RCHs (Melin-Johansson et al., 2021; Smedback et al., 2017). Breakpoint conversations have also been found to occur late in the illness trajectory, sometimes only days before death, greatly limiting active participation from residents (Lundquist et al., 2011; Udo et al., 2018) Furthermore, Udo et al. (2018) noted that physicians, the intended facilitators, expressed lack of consensus and understanding regarding what a breakpoint conversation should include and how it is best conducted. Inconsistencies in what breakpoint conversations entail are also noticeable in the research, as existing studies have used varying definitions, leading to drastically different reports of prevalence in care practice. For example, Kastbom et al. (2022), noted a 97% prevalence of ACP conversations in Swedish RCHs, according to their broad definition of ACP as “*a proactive plan to handle a future deterioration of the patient, not only to handle a current, specific problem or situation.”* (p. 3). In contrast, Melin-Johansson et al. (2021) and Smedback et al. (2017) used the question about breakpoint conversations from the SRPC register, indicating use of a conversation using only a Yes/No/Don’t Know response format and with no information of discussion content.

Besides breakpoint conversations, additional initiatives concerning supporting EOL communication and improving EOL care in Swedish care have been initiated since I began the research reported in this thesis. For example, routines for implementing ACP conversations in primary care practice have been developed in a northern region of Sweden (Region Västernorrland, 2020). Moreover, other means for supporting communication between care recipients, their relatives, and staff have been investigated, such as a question prompt list to discuss the heart failure trajectory (Hjelmfors et al., 2020) and a separate card-based tool for discussing EOL care preferences in palliative care (Olsson Möller et al., 2022;

Olsson Möller et al., 2020). An additional example of proactive conversation models is the ”*Serious illness conversations – Kronobergsmodellen 2.0*”[8], developed by Sandgren and colleagues at Linnéuniversitetet, which involves structured physician or RN-led conversations about EOL needs and preferences with patients and their relatives at an early stage in the illness trajectory. The *serious illness conversations*-model is currently being implemented and evaluated in palliative care services.

2.7 SUMMARY AND RATIONALE FOR THE THESIS

Societal, demographical, and epidemiological development have had major impact on conditions for dying and introduced challenges to ensuring provision of high-quality EOL care at the population level. In addition, new public health research recognizes dying as a public health issue and calls for extending EOL care provision beyond the health care system. However, shifting the location of EOL care provision requires caregivers in other settings, such as elder care and private homes, to be prepared to engage with EOL issues.

Prior EOL care research has consistently identified a need for competence-building, for caring for dying people in general and communicating about EOL related issues in particular. There is also increasing awareness of the benefit of EOL education that is personally engaging and interactive. Still, many educational intervention studies focus on didactic teaching and theoretical knowledge, and research about ways to build more comprehensive EOL competence, such as death literacy, is limited. Furthermore, standardized measures to evaluate interventions and measure EOL competence that are not context or profession-specific are lacking. Such measures are essential to evaluate community-based efforts to build EOL competence but are also needed in settings where diverse professions work with dying people, such as elder care.

Overall, furthering the understanding for how EOL competence development can be promoted and measured is vital to advance the field of new public health approaches to EOL care and for informing the design of future educational initiatives.

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[8] in Swedish: “*Samtal vid allvarlig sjukdom*”, https://lnu.se/en/research/searchresearch/research-projects/project-serious-illness-care-program--kronobergsmodellen/

3 RESEARCH AIMS

This thesis is focused on self-perceived competence for issues related to EOL care and communication using a new public health palliative care perspective. The overall aims are to explore how to support development of EOL competence, referred to as death literacy (Studies I, II, IV), and assess one means of conceptualizing and measuring EOL competence (Studies III-IV).

In this thesis the following research questions are addressed:

1. In what ways can engagement in proactive EOL communication be promoted among elder care staff? (I)
2. How can the DöBra cards support staff competence to engage in EOL conversations in residential elder care? (I, II)
3. To what extent is the Death Literacy Index valid and reliable for measuring EOL competence use in Sweden? (III, IV) To what extent is the operationalization of death literacy supported in the Swedish context? (III, IV)

The specific research aim of each study is presented in the overview of the studies below.

4 METHODS

There is no one way of approaching science or conceptualizing truth and knowledge in research. Different scientific philosophical paradigms are characterized by distinct assumptions about ontology, the nature of reality being studied, and epistemology, the nature of knowledge and means of generating it. The choice of methodology and strategies used to answer the research aims and questions, is informed by ontological and epistemological perspectives as well as traditions of the discipline in which the study is situated (Creswell & Creswell, 2018). Research in the field of health care science can be conducted within several paradigms (Polit & Beck, 2004). In this thesis I have used both qualitative and quantitative research methods to answer exploratory research questions.

Qualitative research often involves exploring and understanding complexity in meaning(s) attributed to a phenomenon through non-numerical data from, e.g., interviews or observations. Many qualitative research approaches build on a constructivist paradigm, which posits that our understanding of the world is formed by our perception of it (Denzin & Lincoln, 2018). In contrast, Creswell and Creswell (2018) describe quantitative research as focused on testing theories through statistical analysis of relationships between variables of numerical data. Quantitative research is primarily situated in a positivist or postpositivist paradigm, in which it is assumed that objective reality does exist, and that the world is determined by causes and effects (Polit & Beck, 2004). Despite these differences, Polit and Beck (2004) point out that there is often a methodological overlap between different paradigms.

4.1 OVERVIEW OF STUDIES

The aims, methods, and materials used in the four studies are presented in Table 4.1. This thesis builds on two sets of data collection, illustrated in Figure 4.1, and the studies from each set share certain features in terms of materials and methods. The studies are presented in the chronological order in which they were conducted, as each study informed the next.

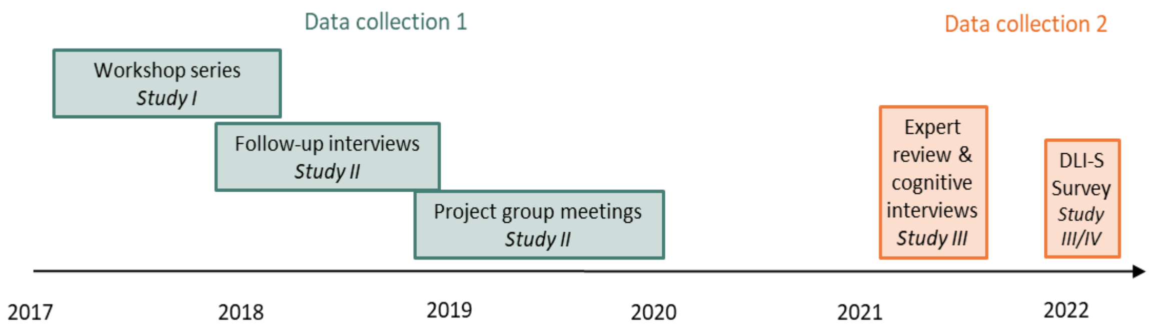
Studies I and II both explore prerequisites for EOL conversations and feasibility of the DöBra cards for this purpose, and share the same setting, elder care in Stockholm municipality in Sweden. Similarly, Studies III and IV both use data from a cross-sectional online survey. Therefore, shared methodological aspects of the studies will be presented in conjunction to the data collection they relate to.

Table 4.1. Overview of the studies included in the thesis.

	Study I	*Study II*	*Study III*	*Study IV*
Research aim	To explore change in elder care staff's discussions and reflections about EOL conversations during a series of workshops	To explore staff's experiences of use, usability, and perceived impact of using the DöBra cards in EOL conversations with RCH residents and/or their relatives	To assess the validity of a translated and culturally adapted Swedish version of the Death Literacy Index (DLI-S)	To explore demographic, health-related and experiential factors associated with death literacy in a Swedish sample
Study design	Participatory action research; qualitative	Participatory action research; qualitative	Mixed-methods validation study	Cross-sectional survey
Partici-pants & data	Staff (*n*=38) from 6 elder care services participating in focus group discussions (*n*=20)	In total, staff (*n*=13) from 7 RCHs: 5 staff from Study I participating in follow-up interviews (*n*=6), plus 8 new participants in a series of meetings (*n*=8)	*Expert review*: purposive sample of people with varied professional EOL perspectives (*n*=10) completing an online survey. *Cognitive interviews*: purposive adult sample (*n*=10) *Psychometric evaluation*: adult quota sample (*n*=503), retest of subset of quota sample (*n*=55)	Quota sample of adults in Sweden (*n*=503) completing a survey consisting of the DLI-S and sociodemographic questions
Data analysis	Longitudinal qualitative analysis	Inductive qualitative content analysis	Content analysis; content validity index; descriptive statistics; reliability analysis; confirmatory factor analysis	Bivariate and hierarchical multivariable linear regression analysis; directed acyclic graph

Notes: EOL=end-of-life; RCH=residential care homes

Figure 4.1. Timeline of data collection in the four studies in the thesis.



4.2 SHARED FEATURES OF STUDIES I AND II

This section first describes the shared features of design, context, and materials used in studies I and II. Specific aims and procedures for data collection will then be described in relation to Study I and II, respectively.

4.2.1 Study design

Both studies I and II are based on a participatory action research (PAR) approach using a multi-case design (Fletcher et al., 2015) and qualitative methods. Baum et al. (2006) maintain that PAR is not a delimited methodology with specified techniques, but can cover a range of qualitative and quantitative research approaches that emphasize participation (actively involving stakeholders in the research process to inform and adapt it to local needs, priorities, and knowledge) and action (initiating change in relation to the research topic through iterative action-reflection cycles of collaborative planning, action, and evaluation) (Kjellström & Mitchell, 2019).

The action-reflection cycle stems from Revans' theory of action learning (1982), which involves iterative learning from direct action and subsequent reflection about experiences to build or re-assess knowledge and inform further action, thus continuing the cycle. Kjellström and Mitchell (2019) argue that both reflection and reflexivity, i.e., thinking about one's own thinking, are inherent for data generation, skills development, and change in PAR. This applies equally to the researcher(s), who need to consider their own role in the data generation processes.

PAR also has an ideological basis in ambition to support social change and empowerment, often enacted by collaboratively addressing local problems through exchanges of ideas, experiences, and skills (Baum et al., 2006; Freshwater, 2005). Participation has also been proposed as a means to make research more democratic and less driven by external 'experts' (Baum et al., 2006). Nonetheless, Sallnow and Paul (2014) point out that 'participation' encompasses a spectrum of approaches, from involving stakeholders as informants or consultants, to co-production, collaboration, and finally empowerment. They also note there are varying motivations for participation, e.g., to better achieve change in relation to the research focus or perceiving it as a research outcome in itself.

Applied in health care science, Koshy et al. (2010) argue that PAR enables participants to initiate change, e.g., in care practice or in public attitudes, while simultaneously generating knowledge about the change to advance theory. For this reason, PAR has been suggested as particularly suitable for developing needs-based, relevant, and feasible interventions (Hawkins et al., 2017). Overall, the ambitions in PAR align with the new public health perspective used in this thesis and described above.

4.2.2 Partnership and participants

Our ambition was to conduct the studies as a collaboration with Stockholm City Elder Care Bureau (Studies I-II) and private care company Vardaga (Study II). Stockholm City Elder Care Bureau is a municipal agency with overarching responsibility for the regulation, development, and evaluation of elder care in Stockholm, such as residential care, home care, and day care activities, including that provided by private care companies. Vardaga is one such private for-profit care provider. Stockholm City Elder Care Bureau coordinates elder care through 13 city district departments, each representing a delimited geographical area of

Stockholm, which in turn are comprised of several municipal and/or private elder care services. Each city district department is responsible for care provision at their respective services.

The collaborative planning process for Study I also provided a basis for Study II, and is therefore presented here. Development of studies I and II began in late 2016, when we presented an initial research plan at a meeting organized by Stockholm City Elder Care Bureau for elder care managers. Managers from three city districts expressed interest in the study, leading to a second meeting to further discuss the aim and design and identify elder care services that might be research sites. One city district had no available services suitable for the study, so the recruitment process continued with two of the interested district managers who independently recruited services by distributing an information letter, formulated by the research group, to service managers. Given the exploratory design, we did not exclude any type of elder care service from participation at this stage. In total, six municipal, i.e., public non-profit, elder care services agreed to participate in Study I. At each site, the service manager appointed a contact person, often at management level. During spring 2017, these contact persons attended joint planning meetings to finalize research questions and discuss workshop content, to ensure its relevance for both services and staff. The planning meetings also served to consider local needs and prerequisites for participation as well as involve service management more actively in the study to create a shared sense of ownership and engagement, in line with the PAR approach.

Both Studies I and II used a two-phased purposive sampling strategy, where we first recruited services, and the services then appointed contact persons who, in turn, recruited individual staff members. Information about participating staff will be described in relation to Study I and II below. As we conducted Study I, described below, follow-up meetings were held with central management at the Stockholm City Elder Care Bureau and the participating services; one such follow-up meeting was also held during Study II. The purpose of these meetings was to describe what had been done and highlight particular points of discussion or challenges so that managers could continue change processes within their services if they so wished. Participating staff were informed of the planned follow-up meetings and often pointed out that management needed to be informed and involved for any further exploration or use of EOL conversations to be possible. In an effort to maintain clarity about the chronology, I describe the additional partnerships specific to Study II with presenting that study.

4.2.3 Data in the participatory action research process

In both Studies I and II, our intention was to plan the study and generate data iteratively together with participants. The format for the PAR processes in both Studies I and II were repeated focus group discussions with elder care staff. The use of focus group discussions was considered appropriate given the aim, as it is a useful method for exploring different perspectives, experiences, opinions, and beliefs, as well as enabling participants to generate their own questions and conceptualizations (Kitzinger, 2005). Furthermore, Barbour (2014) argue that focus group discussions are particularly suitable for capturing contextual aspects reflected in interactions between participants.

Specifically, Kitzinger (2005) highlight that focus group discussions enable synergies that can stimulate more emotive responses and honest criticism than individual interviews would. Given the PAR emphasis on problem-solving and initiating change, this was considered useful for both Study I and II. Focus group discussions are also well suited for PAR as they promote and capture collective problem identification and solving (Stringer, 2007) and co-production processes (Caretta & Vacchelli, 2015). Reflections and lessons learned during time intervals between focus group discussions were shared in the group to continue the action learning cycle (Freshwater, 2005). In other words, the researchers facilitated the PAR process, encouraging action and reflection among participants to support knowledge exchange in relation to EOL conversations and how these could be promoted and used in practice. All data in studies I and II were generated through the processes described here.

4.2.3.1 DöBra cards as a means for generating knowledge

The Swedish language DöBra card deck consists of 37 cards that each feature a statement that can be considered important at the EOL derived from research by Steinhauser et al. (2000). Statements cover a variety of matters of potential importance related to physical, practical, existential, and social aspects of the EOL, for example, "*To say goodbye to important people in my life*", "*To die at home*" or "*Not being short of breath*". A full list of the Swedish DöBra card statements and their English translations is provided in Appendix 1. There are also three 'wild cards' which can be used to add any individual priorities not covered by the pre-formulated cards. Instructions for using the GoWish cards and the DöBra cards follow a similar procedure. The cards are first sorted into three piles based on their perceived importance to the person using them, "very important", "somewhat important" and "not important". In a second step, the cards considered most important are ranked from 1 to 10, in order of priority. Individuals are encouraged to reflect aloud about their choices throughout the exercise to elicit information about the reasoning process for choices of card statements.

4.3 STUDY I

The specific aim of Study I was to investigate changes in staff's reasoning and discussions about EOL conversations in elder care practice throughout workshop series designed to promote EOL communication competence.

4.3.1 Participants

As a result of the recruitment process described in detail above, six services were recruited, two RCHs, two assisted living facilities, and two home-help services. Contact persons at each service invited individual staff members at their services to the workshop series. Kaasalainen et al. (2017) had previously found different professions can have varying experiences of EOL communication, and therefore, we did not impose any conditions in terms of occupation as long as participants met the inclusion criteria of having direct contact with residents and at least six months’ work experience in elder care.

4.3.2 Workshop series

The workshops consisted of focus group discussions which:

- explored prerequisites for conversations about dying, death, and EOL care;
- stimulated discussion of one’s own and others’ values for EOL care; and
- sought to build competence and preparedness among staff for engaging in EOL conversations with residents and their families.

An additional research purpose for the workshops was to explore staff acceptability of the DöBra cards in elder care. Use of activities with prompts, games, art, or photo elicitation have been recommended by both Caretta and Vacchelli (2015) and Kitzinger (2005) to trigger more in-depth discussion among participants in focus group discussions. Each workshop was guided by a theme, illustrated in Figure 4.2, using semi-structured topic guides that were iteratively revised to incorporate new perspectives and questions. In two workshops, we used the DöBra cards to stimulate reflection, critical discussion and knowledge exchange.

Five workshop series of four workshops each were conducted between May 2017 and March 2018, and are presented in Table 4.2. Workshops were planned for 2 hours each with a break in the middle and held approximately two weeks apart, to allow staff time in between to reflect on topics raised.

Figure 4.2. Overview of the workshop series and individual workshop aims

Workshop 1:
Experiences of EOL conversations in elder care

Aim:
- learn about participants’ experiences of and strategies for EOL conversations
- explore organizational features for EOL conversations, i.e. routines, role descriptions and training

Procedure: focus group discussion

Workshop 2:
What would matter to me at the EOL?

Aim:
- increase level of comfort in discussing death
- increase self-awareness of own EOL values and discuss how these may influence care provision

Procedure: focus group discussion, reflection using the DöBra cards

Workshop 3:
What matters to others at the EOL?

Aim:
- promote reflection and discussion about variation in EOL preferences
- discuss the suitability and feasibility of EOL conversations and the DöBra cards in elder care practice

Procedure: focus group discussion, reflection using the DöBra cards

Workshop 4:
Ideas for improving EOL communication

Aim:
- explore staff suggestions and prerequisites for improving EOL communication
- identify conversation barriers and facilitators and discuss how to address these
- summarize and synthesize previous workshops and explore participant experiences of the workshops

Procedure: focus group discussion

The workshops were co-facilitated by me, a PhD student with years of research experience and an educational background in psychology, and my main supervisor, Ida Goliath (IG) who is a PhD and RN with extensive experience in EOL care research and practice. None of the participants had met us before the workshops. As advised by Kitzinger's (1994), one facilitator, most often IG, acted as discussant and moderator, posing questions to participants and making sure everyone who wanted to speak got to do so. In my role as a facilitator I often, but not always, acted as observer, noting interactions and group dynamics, ensuring that important questions were covered, and making reflective notes of the discussion content. Two main approaches were used for the workshop discussions: round-the-table discussions where each participant in turn responded to the same issue or question; and open questions to the group where participants discussed freely. If needed, a speaker list was used. Each workshop ended with a closing round in which participants could share their reflections about the session, a technique proposed by Calman et al. (2013) for longitudinal qualitative studies.

Workshops 2 and 3 featured exercises using the DöBra cards to stimulate reflection among participants. In Workshop 2, they were used individually to reflect on their personal EOL values. In Workshop 3, the DöBra cards were used individually or in groups of 2-3 to reflect on what they thought a specific resident would prioritize at the EOL. In both exercises, participants followed the instructions outlined above, i.e., first sorting the cards into three piles based on their perceived importance and then ranking them from 1 to 10 according to their perceived priority. Participants were asked to present their chosen card statements and reasons for prioritizing these specific EOL values and preferences, in as much detail as they wished.

The first workshop series was held at a city district office for social care, while subsequent series were held in conference rooms at the services, so that staff would not have to travel. Attendance in the groups varied, primarily due to staffing levels and sick leave. Participant characteristics were collected in the first workshop a participant attended using paper forms. All workshops were audio-recorded and professionally transcribed verbatim. Considering the large amount of data we opted for using an experienced professional transcriber. In line with recommendations by Polit and Beck (2004), I assessed data accuracy by listening to the audio-recordings of the workshops while cross-checking transcripts. This also helped me to familiarize myself with the data as a first step in the analytic process.

Table 4.2. Overview of workshop series in study I.

Group	*Service(s)*	*Data collection period*	*Mean attendance* (total n)*	*Mean duration*
1	RCH A, Home help A	May-Jun 2017	3 (4)	105 min
2	ALF A	Oct-Nov 2017	7 (8)	96 min
3	ALF B	Oct-Nov 2017	8 (9)	104 min
4	Home help B	Nov 2017-Jan 2018	5 (6)	91 min
5	RCH B	Feb-Mar 2018	9 (10)	96 min

Notes: *RCH* = residential care home, *ALF* = assisted living facility; * = attendance over the course of the four workshops in the series.

4.3.3 Data analysis

Longitudinal qualitative analysis, an inductive method for identifying and analyzing changes in data over time (Saldaña, 2003), was used to analyze workshop transcripts. In this analysis, change was conceptualized as a gradual and dynamic process that could be detected in participants' narratives, discussions, and interactions throughout the workshops. Each of the five workshop groups was considered a case, with each workshop constituting an observation of that case. I used framing questions, e.g., "*what is different between one observation to the next?*" and "*what increases or decreases over time?*" to guide the analysis (Saldaña, 2003).

I began formal analysis by repeatedly listening to the audio recordings and reading the workshop transcripts. First, data were coded in NVivo.Pro (version 11), with data that was relevant to the study aim indexed and organized based on their content. Codes were then clustered based on commonalities, forming eight broader categories that focused primarily on facilitating or hindering factors for EOL communication in elder care. Reviewing the initial categories prompted a second coding phase in which data were reanalyzed to better recognize that observations, i.e., individual workshops in the same case, were not independent. Therefore, categories were revised to focus more on changes in how EOL values and communication were demonstrated in the workshop groups. A data matrix was constructed to determine change within and between cases over time, allowing links or interrelations between observations to be chronologically examined (Saldaña, 2003). This second coding allowed categories to be reworked into five themes that covered different processes of change at a manifest level, that is, the themes stayed close to the data and represented more surface-level content. The themes were discussed by all authors, leading to further refinement of themes on a latent level, or more interpretative level, to incorporate commonalities and differences in changes in and across cases.

4.4 STUDY II

As Study I indicated that the DöBra cards appeared acceptable both among staff and management, Study II focused on better understanding how the DöBra cards could be useful for proactive EOL conversations in RCH practice. Study I had also resulted in spin-off effects of staff-led use of the DöBra cards. The aim of Study II was thus to explore RCH staff's experiences of use, usability, and perceived impact of the DöBra cards for discussing EOL values and preferences with residents and relatives.

4.4.1 Participants

Following the workshop series described in Study I, staff in three of the services involved notified us about how they had used the DöBra cards in practice following their participation in the workshop series. For example, the DöBra cards had been used to discuss EOL care preferences with relatives to residents in a dementia ward in one service and together with residents in another. In addition, the DöBra cards had been used for staff reflection to foster awareness of and practice EOL communication.. To learn more about experiences from these staff-led initiatives of using the DöBra cards in the RCH setting, follow-up interviews were conducted with a sub-sample of the workshop participants from Study I. Thus the sample in Study II overlaps with that in Study I.

To further explore the usability of the DöBra cards, in 2019, we established a working group to test and evaluate the DöBra cards in elder care practice. The goal for this group was to co-develop practical guidance for how to conduct EOL conversations in elder care based on lessons learned. Through our existing collaborations with Stockholm City Elder Care Bureau and elder care managers in two city districts we recruited three services, of which two were new and one had previously participated in Study I. Two additional services were recruited via a new collaboration with the private care company Vardaga. The Vardaga services were located in a Stockholm city district and in a neighbouring municipality. Study II thus includes staff working in both non-profit and for-profit elder care.

As in Study I, purposive sampling was used to recruit new services in two phases: first recruiting services and then letting service management invite individual staff members to participate. The five services recruited to the study consisted of four RCHs and one assisted living facility. At each service, contact persons recruited one RN and one AN to the working group, for a total of ten group members. After participating in an initial meeting to introduce the study and the DöBra cards, one RCH withdrew, stating a lack of time needed to engage in the study. The final working group thus included eight recurring participants from four services – two public and two private – IG, and I, who participated in regular meetings.

4.4.2 Processes for data generation

As shown in Figure 4.1, data were generated through two processes, first using follow-up interviews with participants from the workshop series in study I, and second during meetings with the project group.

4.4.2.1 Follow-up interviews

Conversational follow-up interviews (*n*=6) were conducted with five participants from the workshop series in Study I, as presented in Table 4.3. Interviews were semi-structured, using a topic guide. All interviews were audio-recorded and professionally transcribed verbatim.

4.4.2.2 Project group meetings

In total, eight meetings were held (see Table 4.3). The initial meeting was held at our university department, and hosting of subsequent meetings rotated between the participating services. The individual meetings followed a focus group discussion format, useful for in-depth exploration (Kitzinger, 2005). Throughout, the meeting process was guided by the PAR cycle of collaborative planning, testing, and evaluation (Koshy et al., 2010). Topic guides for the meetings were iteratively developed by the researchers, who acted as facilitators during the meetings. The aims and procedures for the working group meetings and participant ‘assignments’ between meetings are outlined in Table 4.4. Participant assignments involved testing the tool with residents and/or relatives in their respective services, then sharing and discussing their reflections and experiences in the subsequent meeting. This process enabled joint exploration of feasible strategies for conducting EOL conversations with the DöBra cards, which were synthesized into practical guidance for staff in preparation for wider implementation in RCH practice.

Table 4.3. Overview of the data collection processes.

		Date	*Service(s)*	*n*	*Duration*	*EOL conversations (n)*
Follow-up interviews	1	Nov 2017	RCH A	2	65 min	None
	2	Apr 2018	RCH B	2	39 min	1 with resident
	3	Apr 2018	ALF A	2	58 min	3 with residents, 1 with relative
	4	Jun 2018	RCH A	2	79 min	1 with relative
	5	Nov 2018	RCH A	1	94 min	3 with relatives
	6	Dec 2018	ALF A	2	45 min	None
Project group meetings	1	Oct 2019	RCHs 1,2,3, and X[a]	8	107 min	None
	2	Oct 2019	RCHs 1,2,3, ALF 1	5	110 min	None
	3	Nov 2019	RCHs 1,2,3, ALF 1	7	112 min	10 with residents, 1 relative
	4	Dec 2019	RCHs 1,2,3, ALF 1	5	116 min	5 with residents
	5	Jan 2020	RCHs 1,2,3, ALF 1	8	106 min	2 with residents, 2 with relatives
	6	Feb 2020	RCHs 1,2,3, ALF 1	4	111 min	2 with relatives
	7	Oct 2020	RCHs 1,2, ALF 1	3	102 min	Not possible due to COVID-19
	8	Dec 2020	RCHs 1,2, ALF 1	4	86 min	Not possible due to COVID-19

Notes: *RCH* = residential care home, *ALF* = assisted living facility, [a] X=RCH that withdrew following the first meeting

Table 4.4. Overview of project group meetings outlining aims and procedures for the monthly meetings and participant assignments between meetings.

Meeting aim(s) and procedure	**Assignment(s)* and corresponding goals**
Meeting 1 - Introduce the DöBra cards, provide participants with one card deck each - Explore participants' experiences of EOL conversations - Discuss the purpose of the working group, i.e. to construct practical guidance on using the DöBra cards in elder care based on lessons learned - Set ground rules for the group **Procedure**: group discussion, self-reflection using the DöBra cards	Use the DöBra cards with a friend, colleague, family member, etc. **Goals:** practice a) introducing the DöBra cards and explain what they are used for, and b) practice facilitating use of the tool to reflect on and discuss EOL values and preferences
Meeting 2 - Discuss experiences of using the DöBra cards in EOL conversations by asking questions such as: *What happened during the conversation? What worked well and what was challenging? What did you learn about the other person?* - Identify ways to inform others at the service about the project focusing on what should be communicated, who should be informed, and how the information should be shared **Procedure**: group discussion, brainstorming using post-it notes	Invite residents/relatives to EOL conversations. Facilitate a conversation with a resident/relative using the DöBra cards (following original instructions). **Goals:** Practice informing others about EOL conversations. Test the DöBra cards' original instructions in EOL conversations with target audience.

Meeting 3 - Explore strategies for inviting residents/relatives to EOL conversations, e.g. identify ”key phrases” that can be used - Explore experiences of using the DöBra cards in EOL conversations (probing questions exemplified above) - Given the need for written information identified in the second meeting: Discuss what should be included in an information brochure about EOL conversations **Procedure**: group discussion, brainstorming using post-it notes	Facilitate EOL conversations with residents/relatives (adapting DöBra card procedure if necessary). **Goals:** Practice facilitating EOL conversations using the DöBra cards. Reflect on ways to initiate and end conversations.
Meeting 4 - Explore experiences of using the DöBra cards in EOL conversations (probing questions exemplified above) - Discuss a prototype for an information brochure about EOL conversations, aimed towards residents and/or relatives **Procedure**: group discussion	Facilitate conversation(s) with residents/relative (adapt DöBra card procedure if necessary). Document information in an existing record system. **Goals:** Practice facilitating EOL conversations. Reflect on what information should be documented and where it is most appropriate to do so.
Meeting 5 - Explore experiences of using the DöBra cards in EOL conversations (probing questions exemplified above), focusing on particular features of facilitating a joint EOL conversation - Identify what information should be documented and the documentation system alternatives available - Identify situations in which use of the DöBra cards is challenging and discuss alternative procedures to handle these **Procedure**: group discussion, brainstorming using post-it notes; paper surveys	Facilitate conversation(s) with residents/relative (adapt DöBra card procedure if necessary). Document information generated. Reflect on prerequisites for more wide-spread implementation of EOL conversations with the DöBra cards in the service. **Goals:** Practice facilitating EOL conversations. Identify organizational needs for continued uptake and implementation of EOL conversations.
Meeting 6 - Explore experiences of using the DöBra cards in EOL conversations (probing questions exemplified above) - Discuss revised prototype for an information brochure about EOL conversations, aimed towards residents and/or relatives - Reflect on one’s own role in the EOL conversation **Procedure**: group discussion, brainstorming using post-it notes; paper surveys	Facilitate conversation(s) with residents/relative (adapt DöBra card procedure if necessary). Document information generated. Teach a colleague to facilitate an EOL conversation with the DöBra cards. **Goals:** Practice facilitating EOL conversations. Identify organizational needs for continued uptake and implementation of EOL conversations.
Meeting 7 - Explore the impact of the COVID-19 pandemic in the participants’ services and how it has affected the project - Review a first draft for the practical guidance (based on group discussions, written by TJ and IG) **Procedure**: online group discussion	None given, but participants were encouraged to continue with EOL conversations if possible and to document the information generated.
Meeting 8 - Explore the continued impact of the COVID-19 pandemic in the participants’ services and how it has affected the project - Discuss a revised draft for the practical guidance **Procedure**: online group discussion	None given, but participants were encouraged to continue with EOL conversations if possible and to document the information generated.

Notes: *All assignments were voluntary and had no impact on participation in the project group

All meetings were audio-recorded and, as in Study I, data were professionally transcribed. I then cross-checked the transcripts, by listening to the audio-recording while reading. Data generated primarily comprised meeting transcripts and minutes, but also post-it notes from brainstorming exercises (see Table 4.4). In meeting 5, paper forms were introduced to maintain an overview of EOL conversations that participants held between meetings, since it became difficult to cover all during the meeting discussions. The forms covered basic information about each EOL conversation, e.g., whether the conversation was with a resident and/or relative, age and gender of the person, approximate duration, and location. Use of the paper forms worked as a compromise between the researchers' interest in collecting data to follow and report on the process and participants' preference to limit the amount of written documentation to be completed in addition to their usual professional duties.

Adaptations to the COVID-19 pandemic

The outbreak of COVID-19 in March 2020 presented challenges to concluding data collection with the project group in Study II. As frail, older people were especially vulnerable to the virus, RCHs were greatly affected by efforts to limit the spread of infection. Possibilities to conduct EOL conversations were thus limited as a result of staffing shortages due to illness, strict visitor restrictions, and new routines to minimize unnecessary close-contract interactions between residents and staff. The decision was therefore made to put data collection on hold. In early fall 2020, the group discussed on how to proceed with the study. It was decided that the last stage of the PAR process, which would have focused on organizational prerequisites for implementation of EOL conversations, was no longer feasible, but that the project group would complete the on-going work with the practical guidance. Due to the continued uncertainty in planning face-to-face meetings, the last two project meetings were held using the online video meeting platform Zoom, following the same procedure as in the physical meetings.

4.4.3 Data analysis

Kyngäs' (2020) inductive approach to qualitative content analysis was used to explore staff experiences of using the DöBra cards to discuss EOL care with RCH residents and relatives. By making reflective notes throughout the data collection process, I had already initiated an analytic process and generated preliminary ideas for data analysis, e.g., regarding potential codes. To address the study aim, I used 'meaning units', i.e., words, sentences, or statements considered relating to a central concept, as unit of analysis (Graneheim & Lundman, 2004).

I began formal data analysis by reading all transcripts while listening to the audio-recordings to familiarize myself with the data. This was followed a process of data reduction, where I used NVivo.Pro (version 11) to inductively code the raw data in according to manifest content that concerned the study aim, i.e., experiences of using the DöBra cards. These codes were then grouped based on similarity in content, a stage described by Kyngäs (2020) as data organization. These groups of codes were given names, which served as sub-categories in the coding scheme. The data organization stage was an iterative process, with both codes and sub-categories being refined and specified to better capture manifest content of data. The sub-categories were, in turn, formed into themes, i.e., main categories, in a process of data abstraction (Kyngäs, 2020).

Alternative interpretations of data were considered in two processes (Hsieh & Shannon, 2005). In line with PAR approaches, preliminary findings were presented and discussed with participants in the project group on several occasions, both as one step in the co-development of the practical guidance, and to discern potentially problematic interpretations. The coding scheme and analytical findings were also critically reviewed in discussion with the author group for the article. In one of these discussions, it was suggested that a Theory of Change framework (De Silva et al., 2014) could be useful theoretically to contextualize the themes and present the findings. The Theory of Change model describes how an intervention evolves from input to impact, using a "backwards mapping" of intermediate outcomes that act as preconditions for long-term outcomes and any influence of contextual factors on this process (Gilissen et al., 2018). It was considered useful to illustrate a chronology of the study process: from the input of researcher-led activities to the output comprising participant-led activities and then the outcomes and perceived impact of using the DöBra cards, as well as factors that influenced their usability. Applying the coding scheme to a Theory of Change model also helped visualize how the themes related to each other.

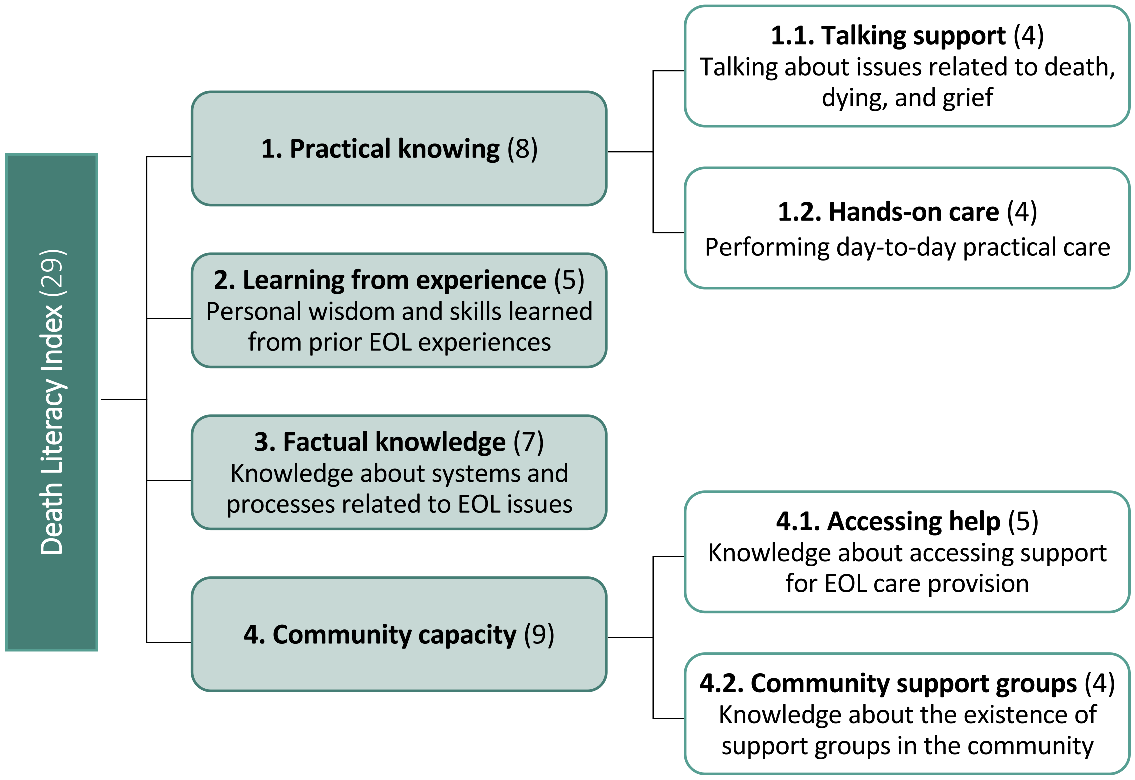
4.5 SHARED FEATURES OF STUDIES III AND IV

Following the positive findings of experiences using the DöBra cards in Studies I and II, described in the Findings section below, my focus for the thesis turned to studying wider implementation of EOL conversations with the DöBra cards in elder care practice. In the search for an instrument to evaluate a broader conceptualization of EOL competence, not specific to a particular care profession, the Death Literacy Index (DLI) was identified as potentially suitable. This instrument is the shared focus for Studies III and IV. Both studies use DLI-S data collected using an online survey, which is described in detail under Study III.

4.5.1 Death Literacy Index

The death literacy construct was recently operationalized as a new instrument, the DLI, a multidimensional measurement of a set of knowledge and skills needed for people to engage in EOL-related situations. The DLI is a self-report questionnaire containing 29 items distributed over four main scales: *Practical knowing (1)*, which consists of the sub-scales *Talking support (1.1)* and *Hands-on care (1.2); Learning from Experience (2), Factual knowledge (3),* and *Community capacity (4)*, which contains the subscales *Accessing help (4.1)* and *Community support groups (4.2)* (Leonard et al., 2022; Leonard et al., 2020). The scales and sub-scales in the DLI are illustrated in Figure 4.3. The scales represent distinct dimensions of death literacy, though some degree of correlation between them is assumed (Leonard et al., 2020). DLI items are formulated as statements to which respondents answer using ordered category responses on a 5-point Likert-type scale, often ranging from "*do not*

Figure 4.3. Overview of the dimensional scales and sub-scales of Leonard et al.'s (2020) Death Literacy Index (n of items in scale).



agree at all" and "*strongly agree*". The original DLI is provided in full in Appendix 2. Each scale and sub-scale of the instrument is scored by calculating transformed mean scores. The total DLI score is thus calculated as a higher-order composite score that represents overall death literacy (Leonard et al., 2022). Scores range from 0–10, with 0 indicating lowest possible death literacy and 10 highest possible.

The DLI was originally developed in Australia to determine population levels of death literacy and evaluate EOL-related educational initiatives (Leonard et al., 2020). Hence, it constitutes a promising measurement for generic EOL competence. However, the DLI had only been used with adults in Australia, and it was not known the extent to which it would be valid in other languages or outside the Australian context. In addition, knowledge about whether the operationalization of death literacy was comparable across countries was lacking.

4.6 STUDY III

The aim of Study III was to develop a culturally adapted Swedish-language version of the DLI (DLI-S) and assess its validity as a measurement of EOL competence in Sweden.

4.6.1 Study design

Study III was based on a mixed-methods design using a multistep iterative translation and validation process, illustrated in Figure 4.4. Geisinger (1994) advises in his influential article on cross-cultural use of instruments that validation is necessary when using an instrument with new populations or in new settings to ensure the instrument functions as intended.

Table 4.5. Sources of evidence in instrument validation.

Source of validity evidence	Description*
Content	How adequate and relevant are items for representing and measuring the construct?
Response processes	Which cognitive processes do people engage in when responding to items?
Internal structure	How do items relate to each other and to the construct?
Relation to other variables	How are instrument scores associated with external variables? E.g., convergent and discriminant evidence
Consequences	Are consequences of inferences of test scores reasonable?

Based on definitions by Zumbo & Chan (2014) and *Standards for educational and psychological testing* by the American Educational Research Association, American Psychological Association, & National Council on Measurement in Education (2014).

Instrument validity concerns the extent to which an instrument can reasonably be considered to accurately measure the intended construct, or the evidence base for inferences that can be made from scores of an instrument in relation to its intended use (Zumbo & Chan, 2014). The validation process in Study III was informed by the contemporary conceptualization of instrument validity, in which validation is described as the process of assessing sources of validity evidence that contribute to the overall validity set out in *Standards for Educational and Psychological Testing* (American Educational Research Association et al., 2014). These sources of validity evidence are based on content, response processes, internal consistency, relation to other variables, and consequences (Table 4.5).

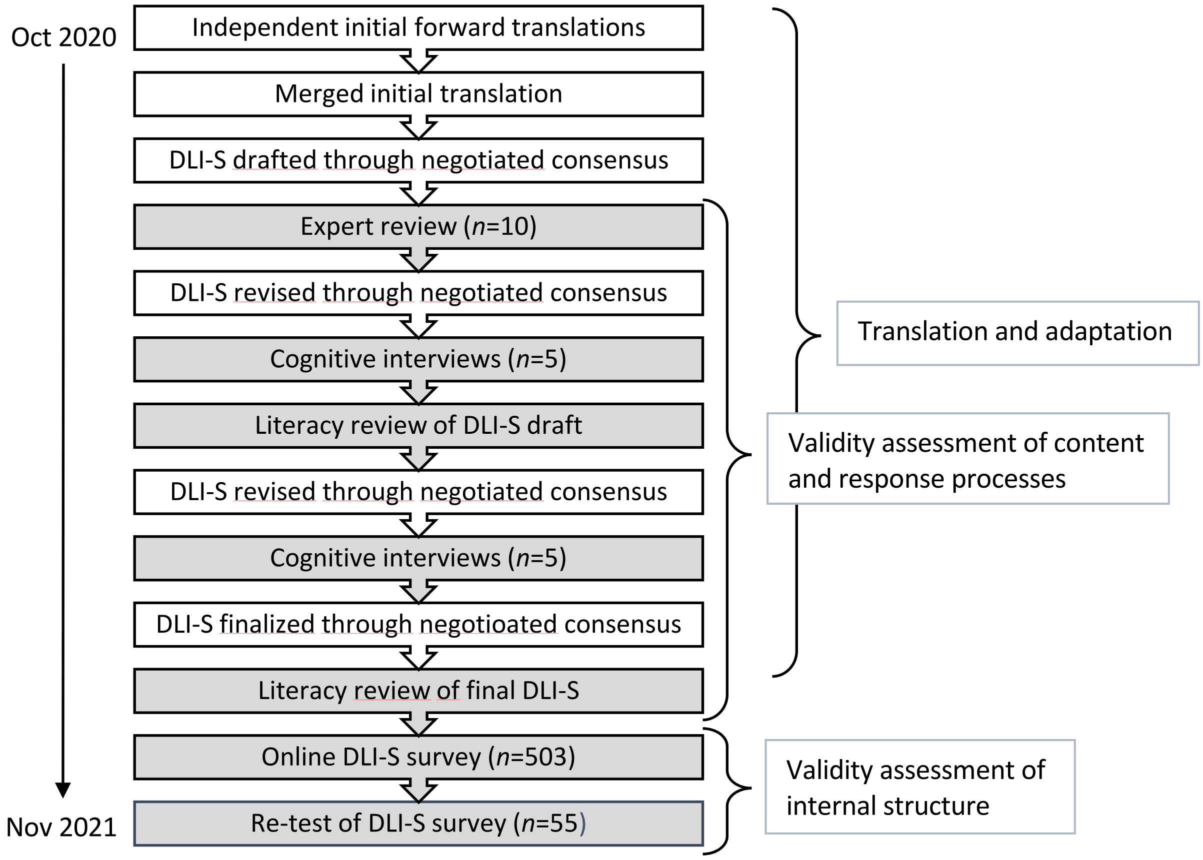
4.6.2 Participants

Data were collected at three steps of the iterative multistep process: expert review, pilot testing through cognitive interviews, and an online survey (see Figure 4.4). Descriptions of inclusion criteria, selection of participants, and procedure of data collection are presented in relation to each step in the validation process below.

4.6.3 Procedure for translation and adaptation

Both Beaton et al. (2000) and Beck et al. (2003) recommend that instrument translation processes should involve cultural adaptation of items to the new context. In other words, semantic equivalence of items is not sufficient for a cross-culturally viable instrument, but there should also be equivalence in connotative meaning between original and translated items. In Study III, the translation process was informed by McGreevy et al.'s (2014) iterative procedure consisting of forward translation; negotiated consensus for translation; expert review of translation and content validity; and pre-testing through cognitive interviews (Figure 4.4). To make the DLI-S as comprehensible as possible, and thereby limit bias or systematic discrimination based on literacy (AERA et al. 2014), an external literacy review was included in this process.

Figure 4.4. Schematic of the DLI-S translation, adaptation, and validation process.



Notes: White boxes in the procedure indicate steps performed by members in the research group, whereas grey boxes indicate data collection with external participants.

Overall, the translation process followed the gold-standard protocol set out by Beaton et al. (2000), though we excluded back translation to assess content equivalence between original and translated items. While back translation is recommended for detecting “inconsistencies or conceptual errors” in a translation (Beaton et al., 2000), it has been criticized for overlooking variation in idioms and cultural nuances (Behr, 2016; Geisinger, 1994). For example, Behr (2016) pointed out that discrepancies between the original and back translation might be due to errors in the back translation just as well as to errors in the forward translation. Furthermore, Behr highlights that the desired close agreement between back translation and the original is problematic in situations where cultural adaptation is necessary, which was expected for the DLI-S as it concerns care systems and cultural and societal norms.

After obtaining permission to translate the DLI from the original developers (Leonard et al., 2022), all items, instructions and response categories were independently translated from English to Swedish by both fellow doctoral student Åsa Olsson (ÅO, co-author of the article about study III) and me. The two translations were compared and discussed to identify discrepancies and ambiguous wordings, resulting in a joint draft translation. The draft was sent for individual review to four members of the multidisciplinary research group, comprising native English and Swedish speakers. Items were revised and refined through a process of negotiated consensus in a series of meetings (*n*=3).

4.6.4 Procedure for validation of content and response processes

Three sources of validity evidence were assessed in Study III: *content*, *response processes,* and *internal structure* (see Table 4.5 for definitions). Validity evidence based on content was assessed using expert review and cognitive interviews, in line with recommendations in *Standards for Educational and Psychological Testing* (AERA et al. 2014). Response process validity was assessed using cognitive interviews. In addition, internal structure validity was assessed through a psychometric evaluation of DLI-S data collected in an online survey. Each step is described in detail below.

4.6.4.1 Expert review

To assess translation quality and content validity of the DLI-S items compared to the original items, an expert review was performed, i.e., an external examination of the items' relevance to measure the intended construct by experts in related topics (Grant & Davis, 1997). Since DLI targets the general population, there is no delimited area of relevant expertise. Purposive sampling was used to recruit reviewers with varying ages, backgrounds, and personal and professional perspectives in relation to the EOL, e.g., palliative care, gerontology, ethnology, professional translation, clinical nursing, and from patient interest organizations. Inclusion criteria were proficiency in Swedish and English. Ten potential reviewers were contacted via email, with information about study purpose and methods. All ten agreed to participate. Each expert reviewed the DLI-S independently through an online survey administered using SurveyMonkey. Since death literacy is a new construct, the expert reviewers received written information about the conceptual model and intended use of the DLI-S. Providing information about the construct measures has been suggested by Grant and Davis (1997) as a way to reduce incongruity in conceptualizations or understandings, which might then invalidate the ratings. The review consisted of two main sections.

- **Review of item translation:** experts assessed the semantic and cultural equivalence of each DLI-S item in comparison to the original English-language item. Ratings were made on a four-point scale indicating whether an item needed further revision or not (from 1=*not an equivalent translation* to 4=*a semantically and culturally equivalent translation*). For each item, there was an opportunity to provide written comments and suggestions for improvement.
- **Assessment of content validity:** experts rated each item's 1) perceived relevance for the construct, and 2) clarity of content in the Swedish context. The two ratings were each made on a four-point scale (from 1=*not relevant to the measured domain/not clear in the Swedish context* to 4=*highly relevant to the measured domain/clear in the Swedish context*).

4.6.4.2 Cognitive interviews

The DLI-S was pre-tested in cognitive interviews to investigate its acceptability and comprehensibility, i.e., how items, instructions, and response options are interpreted, providing data to assess both content and response process validity. The cognitive interviews were conducted using a combination of think-aloud and verbal probing. Think-aloud is a technique where the respondent is encouraged to describe their reasoning as they read and respond to each item (Fonteyn et al., 2016). Verbal probing, in contrast, is when the interviewer asks the respondent probing questions to clarify and explore any issues (Willis et al., 2011).

Ten participants were recruited using convenience sampling through the researchers' networks, making efforts to reach a heterogenous sample in terms of gender, age, professional care background, and language proficiency (Willis et al., 2011). Between May–July 2021, cognitive interviews (*n*=10) were conducted by me and ÅO. The interviews were held online, using Zoom, as the Covid-19 pandemic made physical interviews inappropriate. Written information about study aim and method were sent in advance via e-mail and repeated before the interview. All participants orally consented to participate in audio-recorded interviews. Data were obtained from the interviewers' field notes, as the audio-recordings were not transcribed and only used by interviewers to clarify their notes, if needed.

4.6.4.3 Literacy review

As one additional means of assessing content validity of the DLI-S, an external consultant conducted literacy reviews to assess its vocabulary level and linguistic complexity. Including this step was motivated by our ambition to make the DLI-S as accessible as possible in terms of language. Since the target population is the general adult population, it was necessary to consider the diversity in language proficiency in the Swedish population (Bussi & Pareliussen, 2017) to avoid bias or systematic discrimination on the basis of literacy (American Educational Research Association et al., 2014; Beaton et al., 2000).

4.6.5 Procedure for validation of internal structure

4.6.5.1 Cross-sectional survey

Data was collected from September–November 2021 using an online survey, administered by a commercial data collection agency with a pre-existing panel of Swedish adults who opt in for answering surveys on various topics. The data collection procedure is reported in line with the Survey Disclosure Checklist (American Association for Public Opinion Research, 2021). Panel members are compensated for their participation in surveys, usually at the rate of 1 SEK/minute. Panel members can choose to convert accumulated compensation to gift vouchers at numerous stores and companies or donations to charity.

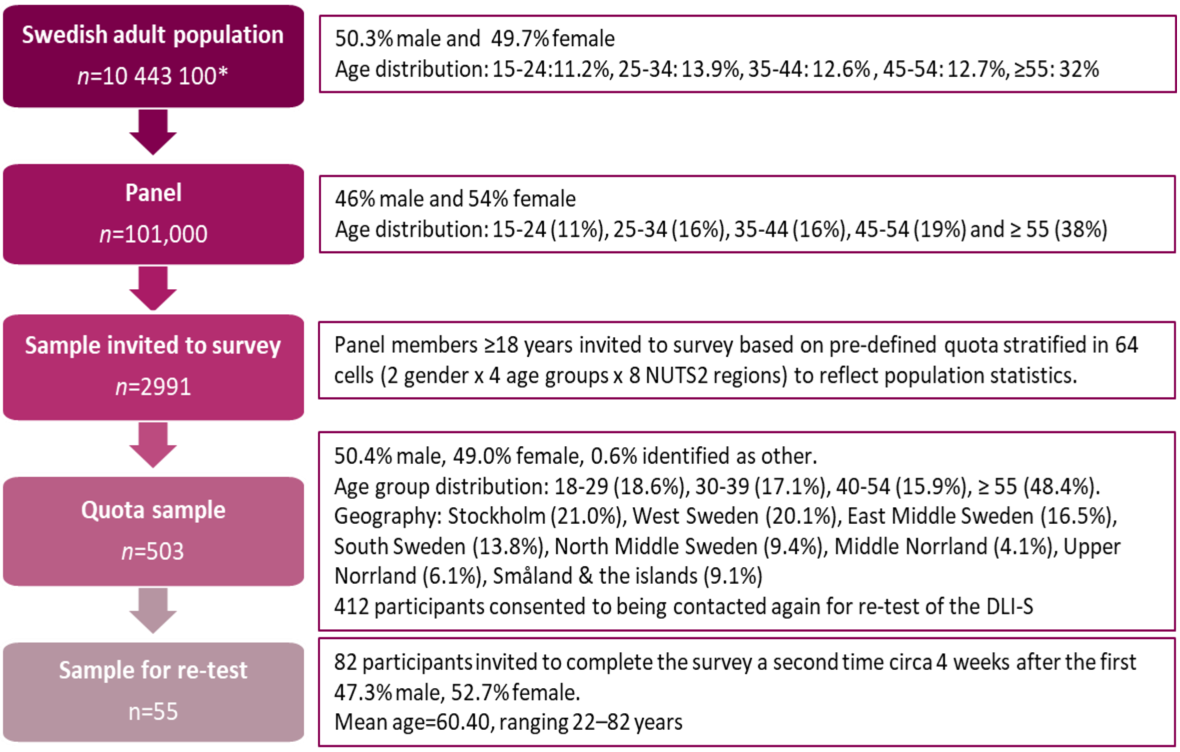
The survey comprised the DLI-S items (see Appendix 3) and questions about sociodemographic variables and EOL experiences. Only those consenting to participate could access the survey. Participants were informed they could withdraw from the survey at any time and were provided with the researchers' contact information in case they needed support or had questions or comments following participation.

Sampling plan

Internet-based panels are generally considered to not be readily generalizable to the general population (Fricker, 2017). For example, to be able to join the panel, participants need to have a mobile phone or other electronic device with internet connection, requiring a certain level of digital proficiency. Nevertheless, a randomized sample was not considered necessary here as the aim was exploratory, striving for theoretical generalization rather than generalization based on statistical population inferences (Pasek, 2016). Still, to thoroughly explore the distribution of death literacy we opted for quota sampling stratified to reflect the heterogeneity within the Swedish population. The sampling plan is presented in Figure 4.5.

The minimum sample size was set to 500 to have sufficient data and power for confirmatory factor analysis (CFA) (Mundfrom et al., 2005). As shown in Figure 4.5, panel members were sampled from the existing national panel (*n*=2991) using pre-defined quota stratified by gender, age, and geography. In total, 503 people completed the survey, giving a response rate of 17%. To assess test-retest reliability, a sample of minimum 50 participants was needed to generate sufficient data for calculating intra-class correlation coefficients (Shoukri et al., 2016). When completing the survey for the first time, participants were asked if they were willing to complete it a second time, to which 412 answered yes. A time interval of 4 weeks was chosen to allow enough time to avoid rehearsal effects but short enough to minimize the risk of participants experiencing real change that might alter their responses (Polit, 2014). A sample of 55 participants was selected to complete the survey a second time.

Figure 4.5. Sampling plan for the online survey data collection.



50.3% male and 49.7% female
Age distribution: 15-24: 11.2%, 25-34: 13.9%, 35-44: 12.6%, 45-54: 12.7%, ≥55: 32%

46% male and 54% female
Age distribution: 15-24 (11%), 25-34 (16%), 35-44 (16%), 45-54 (19%) and ≥ 55 (38%)

Panel members ≥18 years invited to survey based on pre-defined quota stratified in 64 cells (2 gender x 4 age groups x 8 NUTS2 regions) to reflect population statistics.

50.4% male, 49.0% female, 0.6% identified as other.
Age group distribution: 18-29 (18.6%), 30-39 (17.1%), 40-54 (15.9%), ≥ 55 (48.4%).
Geography: Stockholm (21.0%), West Sweden (20.1%), East Middle Sweden (16.5%), South Sweden (13.8%), North Middle Sweden (9.4%), Middle Norrland (4.1%), Upper Norrland (6.1%), Småland & the islands (9.1%)
412 participants consented to being contacted again for re-test of the DLI-S

82 participants invited to complete the survey a second time circa 4 weeks after the first
47.3% male, 52.7% female.
Mean age=60.40, ranging 22–82 years

Notes: *Nov 2021; NUTS=Nomenclature of Territorial Units for Statistics.
Population statistics from Statistics Sweden.

4.6.6 Data analysis

A variety of analyses were used to examine the diverse data generated in this study.

4.6.6.1 Expert review

The review generated both qualitative data to further refine item translations, and quantitative data, i.e., numerical ratings of translation equivalence and content validity, to calculate content validity index (CVI) at both item-level (I-CVI) and scale-level (S-CVI) (Polit & Beck, 2006). Qualitative and quantitative data were collated in two separate data matrices.

Reviewers' comments about translation and content were summarized and indexed in relation to the scale or item to which it referred. This qualitative data matrix highlighted comments about item comprehensibility, relevance, and acceptability, as well as suggestions for change. This matrix was reviewed during consensus meetings with the research group to identify and address problematic items, thus informing the continued translation and adaptation process.

I-CVI is calculated as the number of experts rating an item positively (a 3 or 4) divided by the number of experts rating negatively (a 1 or 2). Polit et al. (2007) recommend that I-CVI should be at least 0.78 when using a panel of 8–12 experts, with lower values indicating poor operationalizations of the measured construct, or that the review was poorly conducted, with unclear instructions or experts that were biased or not adequately knowledgeable. For the S-CVI, the average proportion method was used, where ratings are first summed up and then averaged across reviewers, as this is the recommended method for panels of $\geq$8 experts (Polit & Beck, 2006).

4.6.6.2 Cognitive interviews

Participants' comments and suggestions from the field notes were compiled in a summary matrix in relation to the item, scale, instruction, or response categories they referred to (Miller et al., 2014). This provided data overview on both a general and detailed level, allowing easier comparison between participants and, thus, identification of recurring issues. As recommended by Willis et al. (2011), the matrix informed decisions regarding further item revision in three negotiated consensus meetings with research group members.

4.6.6.3 Literacy review

The DLI-S was reviewed externally using the software tool *AntWordProfiler* (Anthony, 2022) to produce the linguistic coverage rate of the instrument, i.e., how many words that are represented by the 5000 most common words in the Swedish language. A text with coverage rate of 95% is considered accessible and easy-to-read, though this may not be a feasible goal, depending on the intended use. The external consultant provided suggestions for alternatives to difficult or less common words which were used to adapt the DLI-S linguistically.

4.6.6.4 Psychometric evaluation

The psychometric evaluation of the DLI-S was performed using statistical analyses conducted in SPSS (IBM, version 28) and R (version 4.1.1), using the *lavaan* package

(Rosseel, 2012). Statistical significance was accepted if $p \leq 0.05$. Descriptive statistics were used to analyze central tendencies and dispersion on item- and scale-level. Floor or ceiling effects of scales, i.e., whether more than 15% of responses are in the maximum and/or minimum category, were calculated to examine whether scales measured the full range of intended construct (McHorney & Tarlov, 1995).

Reliability analysis

Internal consistency reliability, i.e., the degree to which items are intercorrelated, was assessed by calculating Cronbach's α coefficients and confidence intervals of items, scales, and the full DLI-S, with values ≥0.8 indicating good reliability (Clark & Watson, 2019). Cronbach's α is, however, is only accurate when assumptions of unidimensionality (all items in a scale belong to a single dimension) and tau equivalence (the true scores of items in a scale are equal) are met (Sijtsma, 2009). We therefore calculated an additional, more robust measure of internal consistency, average inter-item correlation (AIC), for which values should ideally range between 0.15–0.5 (Clark & Watson, 2019). To assess scale test-retest reliability, i.e., whether DLI-S scores are stable over time, intra-class correlations (ICC) were calculated using the two-way mixed effects, single measure model (ICC type 3,1). ICC >0.9 indicates excellent reliability, whereas ICC >0.75 is considered good, >0.5 is moderate and <0.5 suggests poor reliability (Koo & Li, 2016).

Confirmatory factor analysis

To assess the fitness of the factor structure of the proposed death literacy model, we conducted Confirmatory Factor Analyses (CFA). Three different factor models were tested: with death literacy treated as one universal factor; as four factors (corresponding to the main scales); and as six factors (corresponding to all DL dimensions, e.g., two main scales (*2* and *3*) and four sub-scales (*1.1, 1.2, 4.1, 4.2*). First, the CFAs were performed using robust maximum likelihood estimation, which is suitable for continuous data (Li, 2016). However, since the 5-point response range used in the DLI was relatively short, data were modelled as ordinal rather than continuous and CFAs were tested again using diagonally weighted least squares as model estimator, as this has been found to perform well with ordinal data (Li, 2016). We followed Hu and Bentler's (1999) indices of model fit: Tucker-Lewis index (TLI) and Comparative Fit Index (CFI) >0.95, root mean square error of approximation (RMSEA) >0.06, Standardized Root Mean Square Residual (SRMR) >.08. We also report *p* value for χ^2, which should not be significant, although it is known that larger sample sizes, e.g., >200, cause *p* to decrease (Alavi et al., 2020).

4.7 STUDY IV

While Study III generated knowledge about the DLI's validity for use in Sweden, determining which factors are linked with death literacy is helpful to better understand the construct and how it develops. The aim of Study IV was, therefore, to explore sociodemographic, health-related, and experiential factors associated with death literacy, so a nonexperimental study was conducted using data collected in the online DLI-S survey described above.

4.7.1 Participants

The survey was completed by 503 participants. Data collection is described in Section 4.6.5.

4.7.2 Data analysis

Statistical analyses were performed in SPSS (IBM, version 28). Statistical significance was accepted if $p \leq 0.05$. Descriptive statistics were used to investigate participant characteristics and examine central tendencies and distribution for each variable and DLI-S total score. As the dependent variable found to function well also as a continuous variable in Study III, linear regression was considered appropriate for the purposes of the study. Bivariate and hierarchical linear regression analyses were used to investigate individual, relative, and collective influence of explanatory (independent) variables on the outcome (dependent) variable, death literacy (total DLI-S score).

4.7.2.1 Bivariate regression analysis

First, the direction and strength of the relationship between each explanatory variable and death literacy was tested using bivariate regression analysis. Polychotomous variables were dummy coded or combined to create mutually exclusive variables. Given the large amount of explanatory variables in this study, only those with statistically significant regression coefficients were retained for continued analysis.

4.7.2.2 Directed acyclic graph

To postulate direct and indirect pathways between explanatory variables and death literacy, a directed acyclic graph (DAG, also known as causal diagram) was created using the online tool DAGitty (Textor et al., 2016). Construction of the DAG helped identify potential confounding variables to control for and guided the structure of the regression model (Williamson et al., 2014). A DAG illustrates uni or bi-directional relationships between explanatory and outcome variables, which are represented as nodes. Assumed relationships, “directed edges”, are depicted as arrows between nodes. Absence of arrows suggests there is no assumed relationship. The construction of the DAG was informed by Ferguson et al.’s (2020) protocol.

Retained variables from the bivariate regression analysis were entered as exposure nodes in a DAG template, with death literacy as the outcome node. Arrows indicating assumed relationships were drawn between nodes. The assumed relationships were then assessed based on three criteria: *Temporality*, whether exposure can be assumed to precede outcome; *Face validity*, whether the assumed relationship is plausible at face value; and *Theory*, whether the assumed relationship is supported by prior findings or relevant theory (Ferguson et al., 2020). These criteria are in line with general recommendations for selecting explanatory variables in multiple regression analysis (Field, 2018). The subsequent integrated DAG thus depicts retained assumed relationships between exposure node(s) and outcome.

To increase the readability of the DAG, the following variables were combined, as they were considered to represent similar components or facets of EOL experiences:

- Professional experience working in healthcare and working in social care were combined as node *Care background*
- Professional and personal EOL care experiences were combined as node *EOL care*
- Paid work and volunteering with dying and/or grieving people were combined as node *EOL work/volunteering*

The DAG depicted in Figure 4.6 illustrates the posited direct and indirect paths for the associations between explanatory variables and death literacy that provided a basis for the multivariable hierarchical regression analysis.

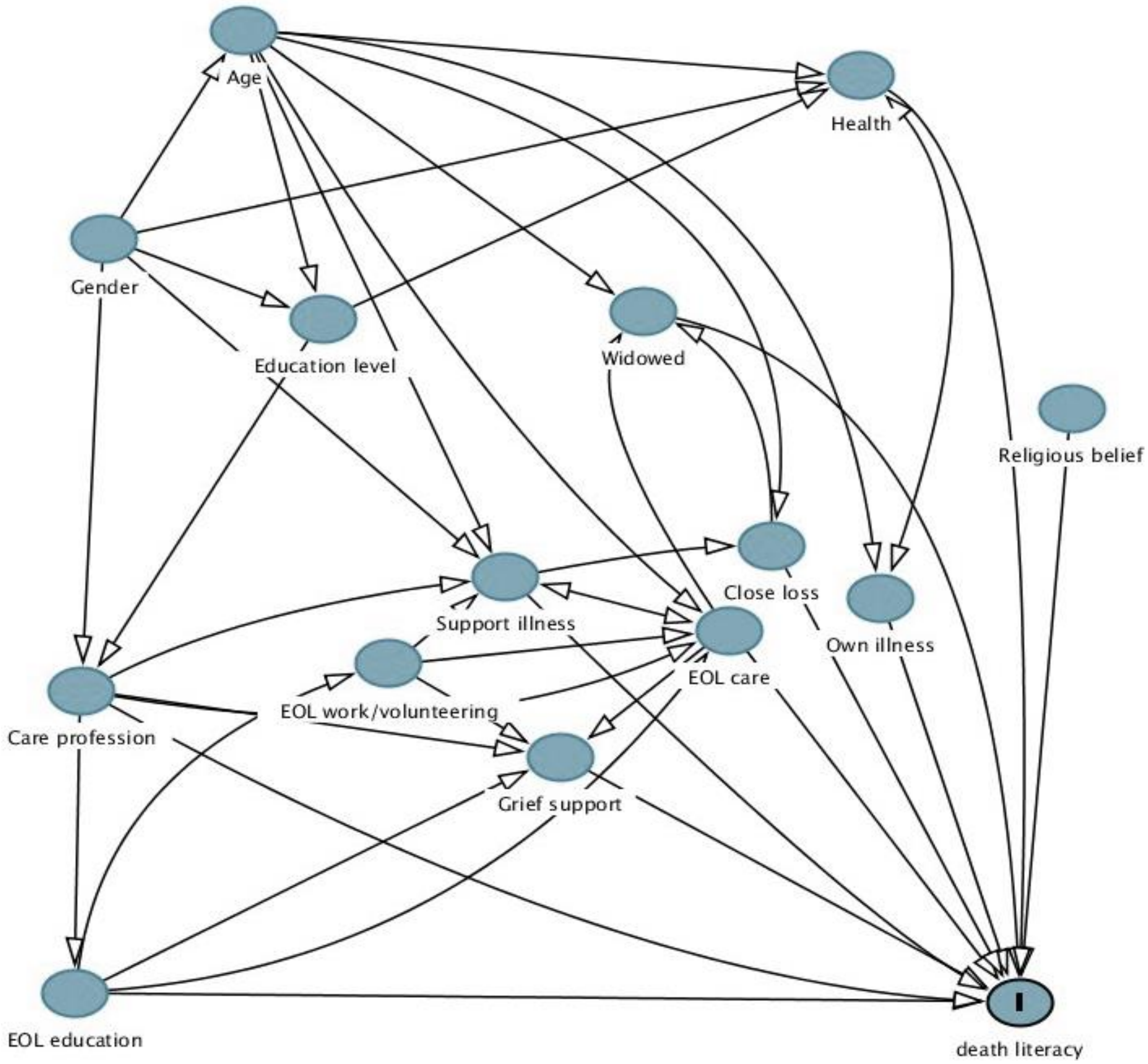
4.7.2.3 Multivariable hierarchical regression analysis

Collective and relative relationships between retained explanatory variables and death literacy were tested using hierarchical regression analysis, a form of multiple linear regression in which explanatory variables are added in separate blocks to examine changes in explanatory power of the model. The primary motivation for using hierarchical regression analysis in this study was its theory-driven approach and ability to statistically control for covariates, which is useful when constructing exploratory models with multiple, potentially correlated, explanatory variables (Field, 2018).

Before constructing the hierarchical model, key assumptions of multiple linear regression analysis were checked (Field, 2018). The assumption of normally distributed variables was maintained by visually examining histograms. The assumption of homoscedasticity, i.e., whether residuals of explanatory variables are equally distributed, was supported through visual inspection of P-P plots. The assumption of no multicollinearity, i.e., that variables should not correlate with each other, was upheld by conducting paired Spearman's ρ correlations, as most of the variables in the regression model were categorical.

The DAG suggested a chronology to the explanatory variables that was taken into consideration when determining the blocks, in line with the recommended principle of causal priority (Petrocelli, 2003). Thus, the first block included variables that had been found to correlate with death literacy during the development of the original DLI, such as age, being widowed, and religious belief. Additional sociodemographic variables that were considered to temporally precede other variables were also entered here, for example, gender, education level, and health. The second block included variables concerning professional care experience, which are considered theoretically important and assumed to generally, but not necessarily, precede remaining variables. The third and final block included experiential variables, which were considered chronologically successive, i.e., causally posterior, to prior variables.

Figure 4.6. Directed acyclic graph of posited causal paths between explanatory variables and death literacy.



5 ETHICAL CONSIDERATIONS

The studies in this thesis were conducted in accordance with the ethical standards set out in the Declaration of Helsinki and its amendments, which state that in medical research with human participants, the potential benefits should outweigh the risks or burdens (World Medical Association, 2013). Studies I and II received ethical approval from the Regional Ethical Review Board in Stockholm (2017/488-31/4 and amendment 2018/105-32) and studies III and IV from the Swedish Ethics Review Authority (2021-00915). This thesis also adheres to the ethical principles regarding individuals who partake in biomedical research: respecting participants' autonomy and right to confidentiality, providing benefits (beneficence), avoiding harm (non-maleficence), and acting just, i.e., fair and appropriate distribution of benefits of research and protecting participants from unnecessary burdens that might arise from the study (Childress & Beauchamp, 2001). The ethical considerations pertaining to the studies are discussed below.

5.1 AUTONOMY AND VOLUNTARINESS

All presumptive participants received written information about the aim, scope, and methods of the specific study, as well as about potential risks and benefits. Participants were also informed participation is voluntary and they could withdraw at any time, without consequences or the need to explain themselves. Written informed consent was obtained from each participant in each study. One participant withdrew from the workshop series in Study I, as personal circumstances were said to make continued participation too emotional. During a follow-up conversation, this participant expressed appreciation for attending the workshops and declared there was no need for any further support. It is not known whether any participants withdrew from the DLI-S survey, and if so how many.

In the qualitative data collection of Studies I-III, participants also had opportunity to ask questions before giving consent. For practical reasons, this procedure was not feasible with participants of the online survey. Participants in Studies I and II were also informed that the reflective exercises with the DöBra cards were voluntary. All participants present during these sessions chose to complete the exercises, though some opted to only disclose limited information about the reasoning for their chosen card statements.

It should be noted that in Study I and II, participants were recruited by people at management level in their services. It cannot be excluded that the power relation between individual staff members and managers might have led to a perceived pressure to participate. At the initial workshop of each series, we therefore explicitly stated that no one should feel forced to participate due to being asked by a superior, and that we would not inform managers about attendance in the workshops.

5.2 RISKS AND BENEFITS OF PARTICIPATION

Overall, the risk of harm to participants in the project was considered low. Still, a general ethical consideration for the research in this thesis is that, for some, the EOL is a sensitive topic and participation could risk bringing up difficult experiences. For this reason, we clearly described the research topic and purpose in the study information provided to all presumptive participants, enabling those who were not comfortable to decline. Participants also obtained contact information to the researchers, who could refer participants to external providers of further support, if needed. The existing literature, however, shows that asking research participants about dying or death is unlikely to cause harm, though it may have an effect on immediate mood (Labott et al., 2013; Pessin et al., 2008).

In fact, participation in research about sensitive topics can involve benefits. Dying and death is often not talked about. A systematic review by Alexander et al. (2018) showed that the majority of studies included found participants willing to discuss sensitive topics that are otherwise often avoided. Alexander et al. demonstrate several reported benefits from participating in research about sensitive topics, such as catharsis, generating a new perspective of experience, building new knowledge, and a sense of contribution to the research field. Therefore, being asked to consider EOL-related experiences and reflections may provide opportunity for participants to consider issues, values, or attitudes not previously acknowledged and learn about oneself, whether through participating in the workshop series in study I, the interviews or working group meetings in Study II, or the online DLI survey in Studies III and IV. Such opportunity for reflection may in turn lead to increased EOL preparedness or identification of gaps in one’s knowledge. It is therefore possible that study involvement in and of itself contributed to death literacy development among participants.

In Studies I and II, it is also possible that participation had a beneficial effect for the services, as participating staff identified areas of improvement in EOL care provision and had opportunity to build capacity for EOL conversations. Skill development and empowerment are explicit goals in PAR and relate to the ethical principles of beneficence as well as justice (Baum et al., 2006; Koshy et al., 2010). Consequently, participating services might benefit as PAR also can serve as a form of, or initial steps of, practice development.

The online survey in Studies III and IV provide participants with a direct benefit, as panel members at the commercial panel agency we used are compensated for their time. While the compensation rate is low, approximately 1 SEK/per minute that the survey is expected to take to complete, it does provide incentive to participate. At the same time, it should be noted that panel members are compensated for each survey they complete, and thus, there was no additional motivation to partake in the DLI-S survey as compared to the other survey available to panel members.

5.3 PRIVACY AND CONFIDENTIALITY

Another important ethical consideration is confidentiality and participants’ right to privacy. Data collected in this project were only accessible to the research group and pseudonymized prior to analysis. Physical raw data, such as consent forms and paper surveys, were stored in a locked, fire-proof cabinet. Digital raw data were encrypted, and the encryption key was only known to core members of the research team. Data collected from the online survey in Studies III and IV were received in pseudonymized format from the panel agency, meaning that the responses could not be connected to a specific respondent and there was no code key accessible. Collection and processing of personal data, i.e. any data that can be linked to a living person, for the research purposes of this thesis complied with the EU General Data Protection Regulation (GDPR) and had a lawful basis in consent from the data subjects (the participants). The informed consent forms included information about GDPR, data storage, and how to contact the controller (Karolinska Institutet). All participants thus consented to having personal data collected, processed, and stored.

All participants also consented to having de-identified personal data published. In the articles reporting Studies I and II, direct quotes were linked to professional role and data collection stage to provide a contextual and chronological perspective, but not to any individual person or participant number to protect the participants’ anonymity. At the same time, the expectation of participant anonymity is questioned in PAR as it is noted that participants might wish to be named and credited for their contributions (Wilson et al., 2018). In discussions with management at the two organizational partners in studies I and II similar attitudes were expressed, and they are therefore named both in the articles and in this thesis. In the articles covering Studies III and IV, results were only reported at group level.

In addition, the use of group discussions for data collection highlights certain challenges for participant confidentiality, as the participants disclose information to the researchers as well as to each other (Sim & Waterfield, 2019). We made efforts to reinforce discretion by establishing clear ground rules for the sessions at the beginning of the workshop series and emphasizing that participants should not share stories from the discussions outside the group. Still, some participants might have been affected by the presence of colleagues and thus chose not to share certain experiences or reflections. It is also possible that the group setting could have influenced participants to refrain from the studies altogether.

6 FINDINGS

6.1 STUDY I

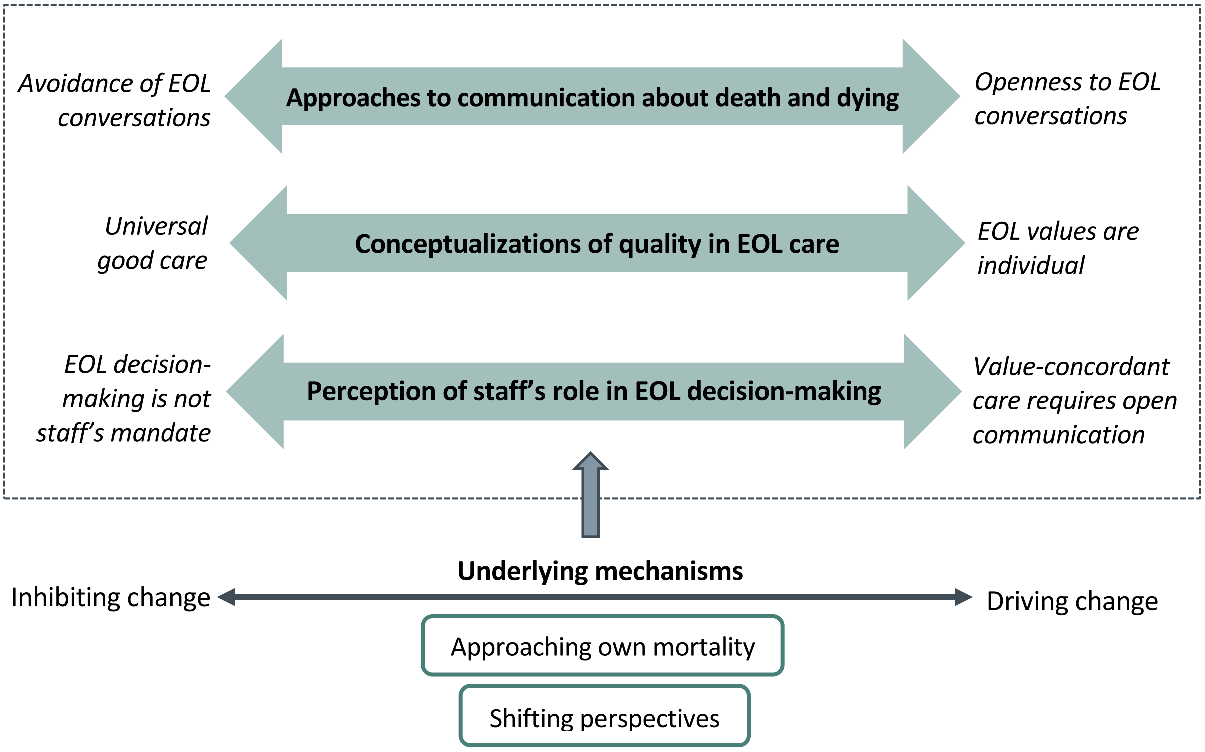
In Study I, changes in elder care staff's reasoning about EOL communication during the workshop series were analyzed using longitudinal qualitative analysis. In total, five series of four consecutive workshops (n=20) were held with staff (n=38) of varying professions. Participant characteristics are presented in Table 6.1. Participants in the follow-up interviews are only presented in the column for Study I, thus, only newly recruited participants for the project group are presented in the Study II column.

Three themes and two underlying mechanisms of change were identified, illustrating change both within and between workshop groups, as depicted in Figure 6.1. The themes were conceptualized as continuums of change along which participants would fluctuate, rather than unidirectional progression. The mechanisms, in contrast, related to procedures that seemed to affect change by enabling participants to reconsider and reevaluate their assumptions, attitudes, and behavior.

Table 6.1. Sociodemographic characteristics of participants in study I and II.

	Study I *n=38*	*Study II* *n=8*
Total number of facilities	6	4
Participant characteristics		
Women/Men	32/6	6/2
Profession		
Certified nurse assistant nurse (CNA)	26	4
Registered nurse (RN)	3	4
Nursing aide	2	-
Activity coordinator	3	-
Other	4	-
Education (completed)		
Primary (9 years)	1	-
Upper secondary education	19	-
Higher vocational education diploma	4	4
University qualification (<3 years)	5	-
University diploma (>3 years)	9	4
Country of birth		
Sweden	19	3
Europe excl. Sweden	4	2
Africa	5	1
Asia	6	1
North America	2	-
South America	2	1
	Study I	***Study II***
Median age (are range)	52 (23–65)	47 (32–56)
Median elder care work experience in years (range)	17 (0.5–41)	17 (0.5–30)

Figure 6.1. Illustration of change continuums within three themes and the underlying mechanisms influencing change.



Themes representing continuums of change in staff reasoning

The first continuum, *Approaches to communication about death and dying*, concerned reasoning about staff engaging in conversations about the EOL in the RCH context and ranged from avoidance to openness. Overall, the participants' own attitudes towards death appeared to influence their approaches to EOL communication, i.e., whether they tended to respond to or avoid the topic in conversations. The findings show how talking about dying and death generally came to be seen by participants as more feasible and valuable over time. Initially, many participants argued that the topic of death was sensitive and potentially upsetting, especially with frail residents who were considered particularly vulnerable. It was generally acknowledged that most residents are likely aware that they will die soon. Still, it was common to want to protect residents from distress by avoiding death, which could become entrenched in the work culture: "*my experience is that you should avoid* [mentioning death]. *You sweep it under the carpet.*" (Group 3, Workshop 1). Following the reflective exercises with the DöBra cards, discussions became more centered around potential benefits of EOL conversations: "*it's essentially about some kind of comfort, both for the person who is dying and for those who are left*" (Group 4, Workshop 2). Participants also came to scrutinize their own behaviors, e.g., deliberately diverting conversations about the EOL. There was increasing nuances in how participants discussed the tendency to protect residents from the EOL: "*it can be very healthy* [...] *to feel worried and sad and to let that out*" (Group 2, Workshop 4). Throughout the progression of the workshops, reflecting on and discussing EOL values and professional as well as personal experiences served as learning opportunities that increased participants' preparedness for, and feeling at ease with, engaging in EOL conversations at work.

The second continuum, *Conceptualizations of quality in EOL care*, covered the varied views of what quality entails in relation to EOL care provision. The theme ranged from assumptions that what constitutes quality in EOL care is broadly generalizable or even universal, to conceptualizations highlighting individual variation in EOL values. Initially, "high-quality EOL care" was generally discussed in relation to a set of universal human needs and values, in particular "not dying alone" and "not dying in pain.". Individual preferences were said to become discernible over time by providing bodily care for a resident through making inferences from wordless communication, such as body language and facial expressions, rather than from explicit conversation. During the reflective exercises in Workshop 3, when the DöBra cards were used to reflect on a specific resident's EOL values, attention was brought to this fact, as most participants acknowledged basing their decisions on guesses: "*I actually have no idea, I've only seen the facade, the outside.*" (Group 5, Workshop 3). Over time, discussions increasingly highlighted how varied EOL preferences can be and that values can be incorrectly assumed. Nevertheless, there was clear disagreement in some groups whether values can be inferred from professional experience or not, which often related to whether EOL conversations were described as necessary or not. Still, many participants emphasized that even if many EOL care values might be universal, there are exceptions that can be missed if residents are not asked. The notion of quality at the EOL also affected participants' wellbeing at work, as the sense of having been able to care for a resident according to their wishes was held as important for staff to feel content following the death of a resident. In contrast, awareness of EOL care provision that was contrary to a resident's preferences could be a source of stress.

The third continuum, *Perception of staff's role in EOL decision-making*, concerned staff's capacity and responsibility for promoting EOL conversations to ensure that care is provided in accordance with residents' values. It ranged from focusing on how decision-making and EOL conversations were considered to be outside the mandate of care staff to how open communication about death is a prerequisite for value-concordant EOL care. While residents' wishes were said to determine care provision, residents were rarely mentioned as actively involved in decision-making processes. Instead, relatives were described as influential in making EOL care decisions, and hurried discussions about EOL care marked by decision uncertainty or conflict among relatives were said to be common. While many participants expressed initial concern about causing long-term harm to their relationships with residents and relatives if they were to bring up EOL care, this apprehension appeared to dissipate over the course of the workshops. Instead, there was more emphasis on the potential value of EOL conversations for preparing for future decision-making by clarifying care preferences:

> *In some way* [EOL care preference] *must come up, so that you don't do things that are totally wrong* [...] *These are things that you otherwise don't know* [...] *that relatives don't talk about amongst themselves either.* (Group 5, Workshop 3)

Nevertheless, there was persisting disagreement regarding when and how to address EOL care without being confrontational:

> *CNA1: I'm thinking about the end, how they want it to be. Asking* [residents]*"do you want to talk about* [future EOL care]*? Do you want us to talk to your family members?" earlier.*
> *CNA2: Are residents ready for that when they move here? It's a huge step to arrive here* [...] *it's asking too much.*
> (Group 2, Workshop 3)

In addition to a perceived lack of experience, skills, and time for initiating EOL conversations among participants, the question whether this was, or even should, be the responsibility of care staff was mentioned in several groups.

Mechanisms influencing change processes

The underlying mechanisms seemed able to both drive and inhibit change processes by prompting participants to *approach their own mortality* cognitively and emotionally, and *shift perspectives of EOL care*, i.e. imagining different viewpoints, questioning assumptions, and analyzing one's own behavior. These mechanisms became most noticeable during the reflective exercises with the DöBra cards, which appeared to constitute a cognitive aid for reflecting about the EOL that provided a language and structure said to help make future EOL care more concrete, and therefore easier to approach and verbalize preferences for. This, in turn, allowed deeper introspection. The emotional component was demonstrated in participants descriptions of reflecting on their own EOL values as a moving experience that allowed examination of thoughts and feelings that might otherwise be avoided. Even though some participants expressed not wanting to delve into their future EOL, the exercise was described by many as meaningful, insightful, and empowering. Participants with a strong emotional response to the exercise were often more vocal about the EOL being an important matter to address with residents and relatives. In contrast, in later workshops, it was more often those participants who had been uncomfortable reflecting and talking about death themselves, who maintained that the EOL was not suitable to discuss in elder care.

In addition, the reflective exercises with the DöBra cards were said to help participants imagine EOL care values from different viewpoints, e.g. as a resident or a relative. Shifting perspectives in this way provided opportunity for extrospection, i.e. enabled participants to review their own and others' behavior in EOL situations and question previously taken-for-granted assumptions. For example, while describing their own EOL preferences, some participants expressed concerns about being able to maintain their future autonomy and dignity if they were to be institutionalized, which sparked discussions about how staff would sometimes inadvertently disregard wishes, coax, or make decisions for residents in everyday care. The exercises thus appeared to help participants extend their frames of reference, illuminate ways in which staff influence care provision, and generate ideas for how to promote EOL care in line with residents' and relatives' preferences.

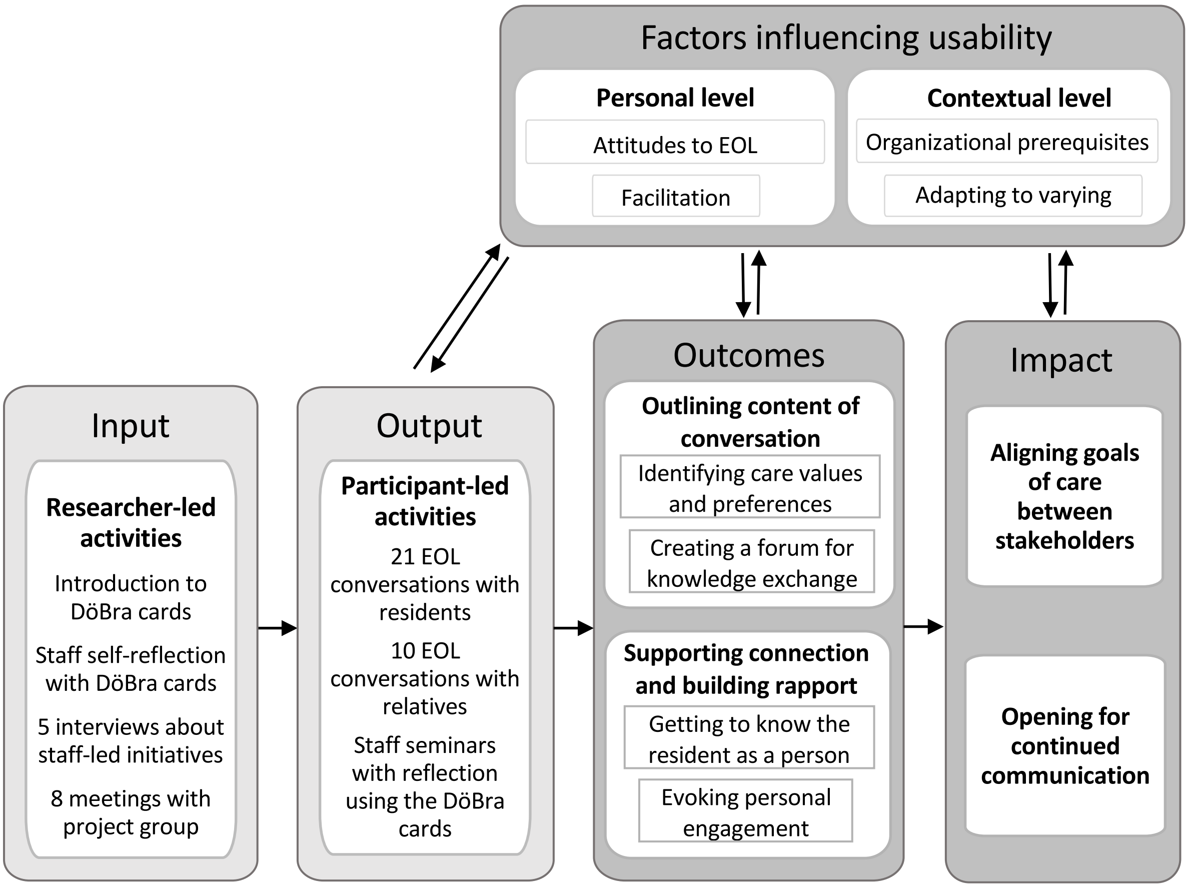
6.2 STUDY II

In study II, RCH staff's experiences of using the DöBra cards to support EOL conversations with residents and/or relatives were explored using qualitative content analysis. Participant characteristics are presented in Table 6.1. Three main themes were identified, concerning direct outcomes, perceived impact, and use and usability, which are summarized below. These themes were inserted into a Theory of Change model to contextualize the findings in relation to the overarching study procedure, as illustrated in Figure 6.2.

Outcomes of using the DöBra cards to discuss EOL values and preferences

Participants' experiences of using the DöBra cards to discuss EOL care highlighted two main direct outcomes of the tool on the conversations. First, the DöBra cards *outlined the content of the EOL conversations*. Instructions for using the DöBra cards were said to provide a framework for the discussion and the card statements were described as helpful to identify and explore EOL care preferences in more detail, by both stimulating reflection and providing a shared vocabulary for exploring EOL values and preferences. In addition, using the DöBra cards appeared to create forums for mutual knowledge exchange about how RCHs and staff can work to provide EOL care in line with individual values. Thus, the EOL

Figure 6.2. Schematic of findings in study II integrated with a Theory of Change model.



Note: Findings are integrated with a Theory of Change model (De Silva et al., 2014) and outlined in relation to input and output. Arrows illustrate the directional influence of personal and contextual factors on output, outcomes, and perceived impact of using the DöBra cards to discuss EOL values in RCH practice.

conversations enabled staff to learn more about the resident, as the concreteness of the card statements prompted sharing of prior experiences that often served as underlying reasoning for EOL care preferences. Conversely, card statements could trigger questions from residents and relatives that staff could answer to, e.g., informing about EOL care in general and local care routines in particular.

Second, the tool *supported personal connection and development of rapport* by expediting open and intimate conversations where EOL-related values were often shared in relation to firsthand experiences, which highlighted the resident as a whole person. Sharing of these stories, in turn, was described as conducive to building closer personal connections between staff and the resident and/or relative(s): "*I almost got the feeling that it became... something magical that you cannot put your finger on when you sit there. That you get very close to each other"* (RN, project group meeting 3). This perceived closeness and connection were discussed as the foundation for establishing trusting relationships with residents and/or relatives. It was also said to evoke an engagement among staff to provide value-concordant EOL care. However, it was noted that the procedure of sorting and ranking of the DöBra cards could lead to an excessive focus on the tool, which limited dynamic conversation and connection.

Perceived impact of card use in EOL conversations

In addition to the outcomes of using the DöBra cards that affected the EOL conversation process, participants noted more lasting impact on the individuals involved in the conversations and the communication between them. Such perceived impact related long-term contributions to residents' and relatives' preparedness to discuss EOL care in the future. In particular, participants perceived two potential long-term benefits of introducing EOL conversations with the DöBra cards. It was suggested that residents, relatives, and staff might experience more and easier *Openings for continued communication* about the EOL that could make the topic of death more normalized, or at least less intimidating. Participants generally acknowledged that EOL conversations were not one-off events but a starting point for continued reflection and discussion, which should be revisited and developed further, as suggested by this CNA: *I think this isn't just one meeting,* [rather] *a process that must be complemented mutually. Sometimes … you have to end the conversation ... and say "Okay, now we have started talking about it and I will return."* (Project group meeting 2). Similarly, it was noted that EOL values might change over time.

In addition, participants argued that EOL conversations using the DöBra cards could be a means to clarify and *Align future EOL care goals among residents, relatives, and staff*, thereby reducing the risk for later decision conflicts. The procedure of the DöBra cards was described as a means to help find common ground and agreement between relatives and staff in terms of a resident's EOL care, particularly in scenarios when residents can no longer make decisions for themselves. The ultimate goal of facilitating EOL conversations related to improved likelihood of staff being able to provide person-centered EOL care.

Factors that influence use and usability of the DöBra cards

Personal factors

Use of the DöBra cards, i.e., uptake, and apparent usability of implementing the tool in RCH practice were influenced by several factors on the personal and contextual level. One primary personal factor concerned *Attitudes to engaging in EOL conversations*. From the outset, participants' attitudes towards EOL conversations influenced their motivation to use the DöBra cards: those who spoke of the importance of discussing EOL care in RCHs were more positive to the tool, whereas participants who expressed more doubt, or disliked the name of the DöBra cards, were more hesitant about using them in practice. In Swedish, "DöBra" is a pun that means both "*dying well*" and *"awesome"*. Common initial concerns related to the tool name as being potentially provocative, and that card statements addressed the EOL too directly. Moreover, the Swedish word for a deck of cards ('*kortlek'*) literally means *"card game"*, which was said to imply that EOL conversations involved playing, which some participants argued might confuse residents or relatives. Though participants mentioned how some residents and relatives commented on the name, participants' concerns appeared to diminish over time, as noted by an RN in the project group: "*almost all of us were also rather skeptical before, if you think about the first meeting, and now we are sitting here and are quite positive*" (Project group meeting 5). Prior experience of discussing the EOL and their self-perceived competence appeared to influence uptake and use of the tool. Participants who were less confident or comfortable with talking about the EOL more often described the DöBra cards as a catalyst, whereas those more experienced had often developed their own ways of addressing the EOL and occasionally perceived the imposed structure of the tools to be constraining.

A second personal factors concerned *Facilitation style*, as participants varied in how they led the EOL conversations. This in turn affected the usability of the DöBra cards, in terms of direction and depth of the discussions. Being curious about the resident or relative and being comfortable with emotional reactions were key features, while apprehension about triggering negative emotional reactions and thereby damaging trust were the main barrier for asking follow-up questions or engaging in EOL conversations at all. Since residents/relatives decide which card statements to discuss and how much they wish to share in relation to them, staff cannot rely on the tool to advance the conversation but need to actively engage in facilitating discussions. Thus, the usability of the DöBra cards depends on staff having sufficient communication and interpersonal skills to be flexible and adaptable in how to incorporate them in EOL conversations. This finding also suggests that conversations can have other end-results in addition to a ranking of prioritized EOL care preferences.

Contextual factors

In addition, there were contextual factors, beyond individual staff member's control, which influenced prerequisites for conducting EOL conversations in practice and their perceptions of usability of the DöBra cards. One contextual factor related to *Organizational prerequisites for EOL conversations*. It was emphasized that facilitating conversations with the DöBra cards cannot be done on autopilot or when pressed for time. Participants strongly expressed needing to be able to allot sufficient uninterrupted time, at least an hour, to be fully present and attentive: "*you can't do anything besides be involved in the conversation ... you absolutely don't want to be interrupted … so one needs to be completely spared* [from other duties]" (RN, project group meeting 6). Moreover, due to the private and often emotional nature of the EOL conversations, participants underscored the need for having calm and secluded environments available in the RCH. The disparate documentation systems used across services and professions constituted an additional barrier for the usability of the DöBra cards, as documentation about EOL conversations and any identified EOL care preferences could not be shared effectively in the services.

Another main contextual factor concerned *adapting DöBra card use to residents' varying needs*. Given the variation in cognitive and physical status among RCH residents, the default instructions were not always feasible. Sorting 37 card statements and then ranking them was considered both time-consuming and demanding, especially for residents with cognitive decline, limited ability to concentrate, fatigue, impaired sight, or loss of motor skills. Sometimes only minor alterations were required when participants noticed that a resident was becoming tired or appeared to be struggling with choosing cards, for example, skipping the ranking component or letting the resident/relative choose important cards without sorting them. Suitability of using the DöBra cards with residents with dementia was more perceived convoluted, as there was a perceived greater risk of harm and lower potential gain. Instead, it was suggested that the DöBra cards could be used with relatives of such residents.

6.3 STUDY III

Overall, the Swedish-language culturally adapted version of the DLI, the DLI-S, was found to demonstrate satisfactory validity to measure death literacy in the Swedish context in terms of content, response processes, and internal structure. The findings supported the six-factor death literacy model. During initial translation and adaptation, several changes were made to adjust item content to the Swedish context, for example, to fit the organization of the Swedish health care system. Additional adjustments were made following the expert review and cognitive interviews, primarily to address ambiguity or difficult terminology in items and unclear instructions. The psychometric evaluation showed adequate internal consistency reliability for the full scale and each sub-scale. Test-retest reliability was acceptable. However, the sub-scales measuring *Community capacity* (4.1, 4.2) were found to perform worse than the other scales in the DLI-S, which suggests that these scales might function differently in the Swedish than in the original Australian context. Detailed findings for each step are presented below.

6.3.1 Translation and adaptation of the DLI-S

Throughout the translation process, minor changes to content were made for the Swedish items so that they would convey a similar conceptual meaning as intended in the original DLI (Beck et al., 2003). The negotiated consensus meetings with the research group (*n*=3) allowed translated items to be further revised and refined. Two of the original developers attended one of these meetings to discuss the intended meanings of items that proved difficult as they contained terms that had no direct Swedish translation, like ‘community’, or words which could be translated in several ways with slightly different meanings, such as ‘compassionate’ or ‘cemetery staff’. For these translations, the intention of the original DLI item was used as reference to ensure conceptual equivalence.

Given the iterative process of translation, adaptation, and validation, changes to items, instructions, and response categories were made throughout, according to findings from the expert review, cognitive interviews, and literacy review. In the expert review, the free-text comments helped to identify words and terms that were awkward or unclear in terms of language, or unsuitable in terms of relevance in the Swedish context. Minor changes to content were made for several items to address such issues. Table 6.2 provides detailed examples of revision throughout the process, using two items as examples (presented in Swedish). The cognitive interviews provided further insight into problematic terms (Table 6.4), which are described further in the section below. The final version of the DLI-S was translated from Swedish back to English to demonstrate changes made compared to the original to allow for nuance, idioms, cultural meaning, and differences in health care systems. The English translation is provided in Appendix 3.

6.3.2 Validity based on content and response processes

6.3.2.1 Expert review

Ten people reviewed the DLI-S. Seven of the expert reviewers were women, reflecting the health care science field in general (Adams, 2010). As shown in Table 6.3, CVI for all items exceeded the minimum threshold for item retention set out by Polit et al. (2007), indicating that the reviewers considered each item relevant for the death literacy construct. Overall, content validity for the DLI-S was high, Scale-CVI_{Ave}=0.94.

6.3.2.2 Cognitive interviews

No sociodemographic information was collected from the ten participants, but we had made efforts to recruit a heterogenous sample in terms of gender, age, professional care background. Overall, findings from the cognitive interviews (*n*=10) suggested that while some items could raise emotional memories of past experiences, the DLI-S content was acceptable, i.e. interesting and not considered distressing. Six types of issues requiring minor changes to the DLI-S items and/or scales were identified based on observations of participants’ response processes, comments about the instrument, and suggestions for improvement. Table 6.4 presents an overview of the types of issues, affected items or scales, as well as the changes that were made by the research group to address the issue (for detailed examples, see Table 6.2). For example, for sub-scale 1.1 (*Talking support*), it was noted that some participants differentiated their willingness to talk from their perceived difficulty of a conversation about the EOL. Consequently, the question was reformulated to “*how prepared* *would you be to talk about the following?*", to better guide respondents to consider their readiness to engage in conversations when answering these items.

Table 6.2. Examples of DLI-S item* revision at different steps of the translation and validation process.

Step	Item 4	Item 19
Initial translation	*Prata med vårdpersonal om stöd i hemmet eller på annan plats där en döende person vårdas* **Original item**: *Talk to a GP* (general practitioner) *about support at home or in their place of care for a dying person.* *Reasoning:* While there is a Swedish equivalent term for GP ("husläkare"), they are rarely involved in palliative care. Instead, 'care staff' was chosen as it is a common term with a broader conceptual meaning.	*Jag har tillräcklig förståelse kring olika sjukdomars förlopp för att kunna ta informerade beslut om medicinska behandlingar och hur de kan påverka livskvaliteten i livets slutskede* **Original item**: *I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life* *Reasoning:* It was decided to translate illness trajectories using more common and concrete words for the Swedish item to avoid using medical jargon.
Expert review	***Att*** *prata med vårdpersonal om* ***stöd till en döende person i hemmet*** *eller den plats där* ***denne*** *vårdas* *Reasoning:* Experts point out that care staff is not semantically equivalent to GP but that it is a term more suitable to the Swedish care system. It is also suggested that the Swedish wording sounded artificial.	*Jag* ***förstår*** *tillräckligt om olika sjukdomars förlopp för att kunna ta informerade beslut om* ***tillgängliga*** *medicinska behandlingar och förstå hur de kan påverka livskvaliteten i livets slutskede* *Reasoning:* Experts point out that the Swedish item does not clarify that it concerns medical treatments available, the same way the original item does, making it possible to interpret as any type of medical treatment (e.g. experimental ones). Item statement is made specific to available care.
Cognitive interviews	*Att* ***samtala*** *med vårdpersonal om stöd till en döende person i hemmet eller den plats där denne vårdas* *Reasoning:* Participants consider "prata" ("talk") too generic, i.e. it could imply small talk or just a quick exchange. Instead, "samtala" ("converse") was suggested to imply a more in-depth conversation	*Jag förstår tillräckligt om olika sjukdomars förlopp för att kunna ta informerade beslut om tillgängliga medicinska behandlingar och förstå hur de kan påverka livskvaliteten i livets slutskede* *Reasoning:* The item is said to be hard to understand as it is long and contains several logical steps. It is also found difficult to rate, since it's unclear to participants whether they should rate their knowledge, decision-making capacity, or both. Furthermore, the term "informed decision" seems ambiguous, particularly for people without professional care backgrounds.
Literacy review	*Att prata med vårdpersonal om* ***stöd till en person som kommer att dö*** *i hemmet eller på den plats där* ***hen får vård*** *Reasoning:* The literacy consultant states that "prata" ("talk") is a much more common that would make the item statement more accessible to people with lower literacy levels.	*Jag* ***vet*** *tillräckligt för att kunna* ***ta beslut*** *om medicinska behandlingar och förstå hur de kan påverka livskvaliteten* ***i livets slut*** *Reasoning:* The item was made shorter and more concise. Suggestions from the literacy consultant led to additional changes to make the language easier to understand.

Notes: DLI-S items 4 and 19 are used as examples here as they were found to be problematic in terms of clarity, relevance, and/or language. * Item statements are presented in Swedish, with item revisions marked in bold, with reasoning provided in English.

Table 6.3. Ratings of relevance and content validity index (CVI) at item- and scale-level.

Item	Relevance *(positive rating*)*	Relevance total score *(max=40)*	Item-CVI
1	10/10	38	1.00
2	10/10	36	1.00
3	10/10	38	1.00
4	9/10	36	0.90
5	9/10	37	0.90
6	9/10	36	0.90
7	10/10	38	1.00
8	10/10	38	1.00
9	10/10	39	1.00
10	10/10	39	1.00
11	10/10	39	1.00
12	8/10	36	0.80
13	9/10	38	0.90
14	9/10	36	0.90
15	9/10	35	0.90
16	9/10	37	0.90
17	10/10	39	1.00
18	10/10	39	1.00
19	9/10	38	0.90
20	8/10	32	0.80
21	9/10	38	0.90
22	8/10	36	0.80
23	9/10	37	0.90
24	10/10	38	1.00
25	10/10	38	1.00
26	10/10	40	1.00
27	9/10	37	0.90
28	10/10	39	1.00
29	10/10	40	1.00
		$\text{S-CVI}_{\text{Ave}}$	0.94

Notes: $\text{S-CVI}_{\text{Ave}}$ = Scale-level CVI *Positive rating=number of experts rating the item 3 or 4 on a 4-point scale. I-CVI was calculated as (*n* of raters rating 3 or 4/total *n* of raters). S-CVI was calculated using average proportion of I-CVI values.

6.3.2.3 Literacy review

The DLI-S was reviewed at two occasions. The first literacy review was performed after five cognitive interviews had been held and generated a linguistic coverage of 84.7%. The consultant provided suggestions for more common or easy-to-read alternatives to uncommon or difficult words, which resulted in further revision to item content during consensus meetings. The consultant's suggestions were followed as far as they were not considered to alter the conceptual meaning of the item. This revised DLI-S version was then assessed in another five cognitive interviews. After the DLI-S translation was finalized, a second literacy review was conducted on the final version. The coverage rate had increased to 93.3%, which was deemed sufficient for the purposes of the instrument.

Table 6.4. Types of issues identified in the cognitive interviews and how they were addressed.

Issue	Affected items/scales	Revisions to address issue
Vague or ambiguous item statement	4, 13, 14, 16,19, 24	Items clarified to better reflect conceptual meaning and/or semantic precision
Double-barrelled item (item statement contains more than one behaviour/trait)	19	First section removed to make item statement more concise and focused on the trait in question
Item relevance or fit to Swedish context	14, 15, 20, Scale 4.1	Examples provided clarify content (21); item wordings revised and refined (14, 15, 21). Question in scale 4.1 rephrased to better suit the Swedish context with universal health care
Overlapping items (item content perceived as repeating)	Scale 2	No change at this stage, all items retained as they are considered to contribute with distinct aspects on a theoretical level
Unclear question format	Sub-scales 1.1 and 4.1	Questions specified to better reflect intended use of the instrument; clarifying instructions added for the instrument to highlight that questions relate to individual perceptions and that there are no right or wrong answers
Unsuitable or unclear response categories	Sub-scales 1.1 and 1.2	Response categories changed to better suit the scale question (from *very difficult/very easy* to *not prepared at all/very prepared*)

6.3.3 Validity based on internal structure

The mean age in the survey sample (*n*=503) was 49.95 (SD=17.92), ranging from 18–86 years. Additional sociodemographic characteristics are presented in Table 6.5. The sub-sample (n=55) participating in the retest were slightly older than the full sample (mean age=60.40, SD=18.43), but similar in gender distribution (47.3% male, 52.7% female), education level (9.1% lower secondary, 41.8% upper secondary education, 49% tertiary education), and country of origin (94.5% were born in Sweden).

Scale descriptives are presented in Table 6.6. All response alternatives were used for all items. Total DLI scores and scale scores were normally distributed, with the exception of the sub-scale 4.1 (*Accessing help)*, which demonstrated a floor effect, i.e., a negatively skewed distribution. Inter-item correlations within sub-scales were generally high, i.e., >0.5.

Table 6.5. Characteristics of survey participants in studies III and IV (*n*=503).

Participant characteristics	*n*	%
Gender*		
Male	253	50.4
Female	246	49.0
Highest level of completed education (ISCED)		
Lower secondary education or less	42	8.4
Upper secondary education	231	45.9
Tertiary education, diploma or higher	230	45.7
Household composition		
Single, children living at home	19	3.8
Single, no children at home	104	20.9
Partner, children living at home	124	24.9
Partner, no children at home	240	48.2
Widowed, with or without children	11	2.2
Country of origin		
Sweden	467	92.8
Nordic countries, excl. Sweden	14	2.8
Europe, excl. Nordic countries	12	2.4
Outside Europe	10	2.0
Mother's/Father's origin		
Sweden	428 / 429	85.2 / 85.3
Nordic countries	39 / 32	7.8 / 6.3
Europe, excl. Nordic countries	18 / 20	3.6 / 4.0
Outside Europe	17 / 22	3.4 / 4.4
Health status*		
Excellent	50	9.9
Very good	176	35.0
Good	169	33.6
Fair	79	15.7
Poor	26	5.2
Religious belief		
I believe there is a God	71	14.1
I believe there is a spiritual life force	128	25.4
I don't know what to believe	148	29.4
I don't believe there is a God or life force	156	31.0
Work or volunteer experience**		
Worked with people at the EOL	73	14.5
Volunteered with people at the EOL	29	5.8
Worked with supporting people in grief	50	9.9
Volunteered with supporting people in grief	30	6.0
Current or prior work in the care sector**		
Healthcare	72	14.3
Social care	51	10.1
EOL experiences**		
Close personal loss (family member, close relative, or friend)	413	82.1
Loss of a relative or acquaintance	287	57.1
Own life-threatening illness	46	9.1
Support someone with a life-threatening illness	116	23.1
Support a bereaved person	177	35.2
Provide care for a relative at the EOL	67	13.3
Professional EOL care provision	57	11.3
Attending EOL-related event	155	30.8
EOL-related education or training	70	13.9
No experience	28	5.6

Notes: EOL=end-of-life; ISCED=International Standard Classification of Education
*Missing values=3;**Multiple-choice question, sum≠503

6.3.3.1 Reliability estimates

As seen in Table 6.6, the DLI-S demonstrates high internal consistency reliability for the full scale, α=0.94 and AIC=0.36. The main scales and sub-scales performed slightly worse, but still adequately, α 0.81–0.93, AIC 0.52–0.74. Test-retest reliability was good for the full DLI-S, ICC=0.85, and acceptable at scale-level, ICC 0.66–0.84.

6.3.3.2 Confirmatory factor analysis

To assess the assumption of unidimensionality, the one-factor model was tested first, demonstrating adequate fit but not meeting all recommended fit indicator thresholds. The four-factor model generated a better fit, though still not meeting all thresholds. The six-factor model showed good fit, performing best of the models tested, providing support for the multi-dimensional death literacy model hypothesized by the original developers. CFA results for each model are shown in Table 6.7. As illustrated in Figure 6.3, the factor loadings for the six-factor model were generally high, ranging 0.57–0.95 and correlations between factors in the model were moderate to strong, ranging 0.43–0.86.

Table 6.6. Descriptive and reliability statistics for the full DLI-S and each sub-scale.

	Mean score (SD)[a]	**Floor/ ceiling effect (%)**	**Cronbach's α (95% CI)[b]**	**AIC[b]**	**Intra-class correlation (95% CI)[c]**
DLI-S (full instrument)	5.15 (1.86)	0.2/0.6	0.94 (0.94-0.95)	0.36	0.85 (0.76-0.91)
1.1 Talking support[d]	6.28 (2.28)	0.8/8.9	0.82 (0.78-0.84)	0.52	0.68 (0.50-0.80)
1.2 Hands-on care[d]	5.63 (2.69)	1.6/10.3	0.81 (0.78-0.84)	0.53	0.81 (0.69-0.88)
2 Learning from experience	6.59 (2.05)	0.2/8.7	0.83 (0.84-0.88)	0.56	0.66 (0.49-0.79)
3 Factual knowledge	4.13 (2.49)	3.2/2.0	0.89 (0.87-0.90)	0.53	0.84 (0.73-0.90)
4.1 Accessing help[e]	3.34 (2.71)	18.5/2.0	0.92 (0.91-0.93)	0.69	0.72 (0.57-0.83)
4.1 Community support groups[e]	4.21 (2.89)	13.1/6.2	0.92 (0.91-0.93)	0.74	0.67 (0.50-0.79)

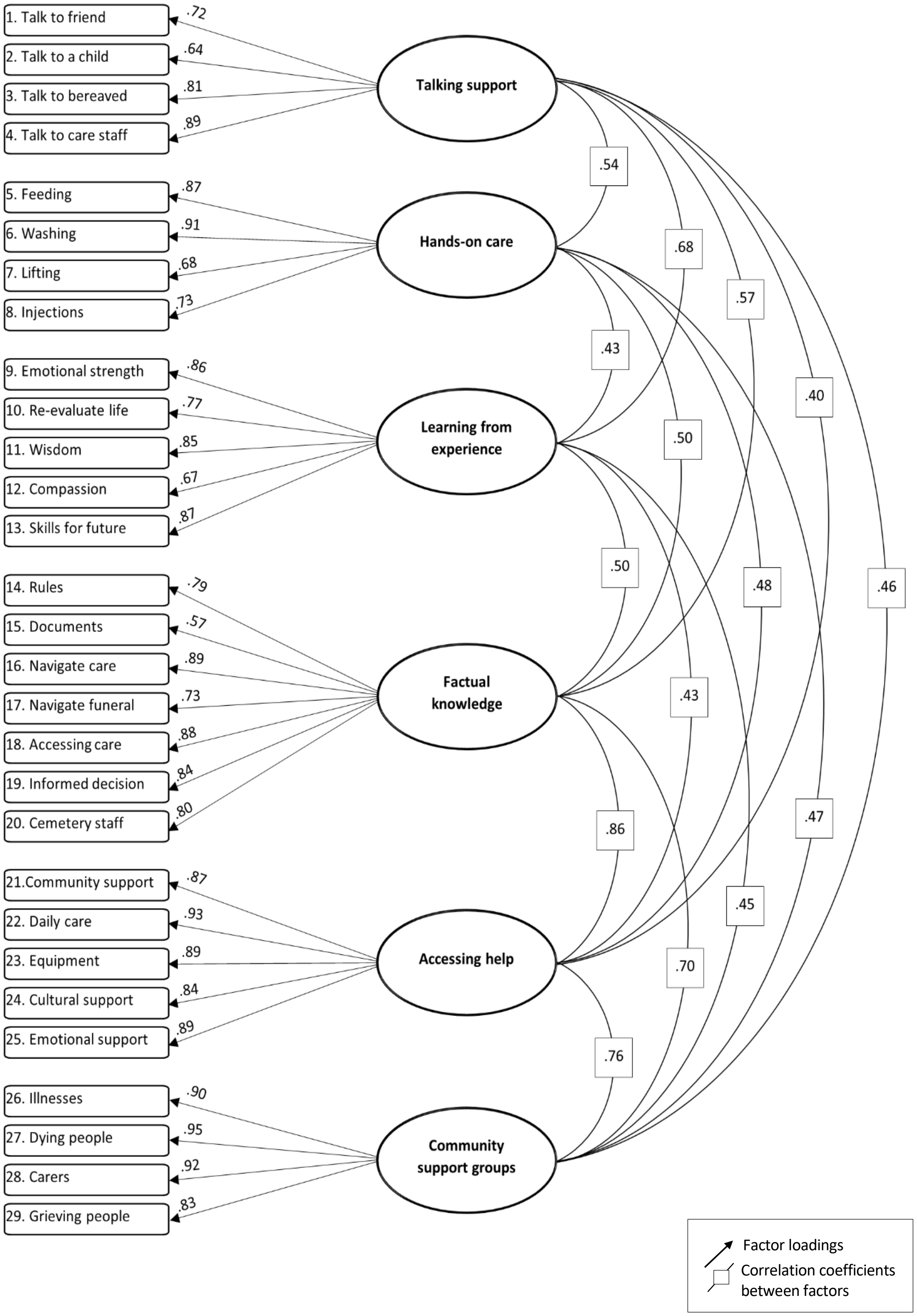
Notes: [a] Transformed mean scores ranging 0–10; [b] *n*=503; AIC=Average inter-item correlation; [c] *n*=55; [d] Sub-scales of scale *Practical knowledge*; [e] Sub-scales of scale *Community capacity*

Table 6.7. Fit indicators of tested factor models of death literacy (*n*=503).

Tested model (DWLS)	**CFI**	**TLI**	**RMSEA (CI)**	**SRMR**	**χ^2/df**
One factor	0.933	0.928	0.200 (0.196-0.204)	0.139	7966.767/377***
Four factors	0.980	0.978	0.110 (0.106-0.114)	0.081	2629.432/371***
Six factors	0.993	0.993	0.064 (0.060-0.068)	0.054	1107.631/362***

Notes: DLWS=Diagonal weighted least squares; TLI=Tucker-Lewis Index, CFI=Comparative Fit Index
***p <0.001

Figure 6.3. Path diagram of the six-factor model, showing standardized factor loadings for items and correlation coefficients between factors.



6.4 STUDY IV

Characteristics of the survey participants (*n*=503) are presented above in Table 6.5. There were no missing values in the data set, as a mandatory response procedure was used for the survey, which required all questions to be answered for participants to continue. The mean total Death Literacy Index score in the sample was 5.15 (*SD*=1.86, range=0.61–10).

Table 6.8. Results of bivariate linear regression analysis between explanatory variables and death literacy (total DLI score[1]).

Explanatory variable		Unstandardized β (95% CI)	SE	*p*
Gender	Female vs male	0.66 (0.33-0.98)	0.16	**<0.001**
Age	Age (in years)	0.02 (0.01-0.03)	0.01	**<0.001**
Education level	Upper secondary vs lower secondary	0.29 (-0.31-0.90)	0.31	0.341
	Tertiary vs lower secondary	0.70 (-0.09-1.31)	0.31	**0.025**
Health status	Fair vs poor	-0.99 (-1.78- -0.21)	0.40	**0.013**
	Good vs poor	-0.93 (-1.65- -0.20)	0.37	**0.013**
	Very good vs poor	-1.03 (-1.75- -0.30)	0.37	**0.006**
	Excellent vs poor	-1.47 (-1.84- -0.41)	0.43	**<0.001**
Household composition	Single with children vs single, no children	0.69 (-0.21-1.59)	0.46	0.133
	Partner, no children vs single, no children	0.30 (-0.13-0.71)	0.21	0.169
	Partner with children vs single, no children	0.02 (-0.45-0.50)	0.24	0.931
	Widowed vs single, no children	1.95 (0.81-3.10)	0.58	**<0.001**
Religious belief	Agnostic vs atheist	0.04 (-0.37-0.45)	0.21	0.836
	Religious/spiritual belief vs atheist	0.77 (0.56-1.58)	0.20	**<0.001**
Healthcare profession	Yes (current or prior) vs no	2.07 (1.64-2.50)	0.22	**<0.001**
Social care profession	Yes (current or prior) vs no	0.79 (0.25-1.32)	0.27	**0.004**
EOL education	Yes (any length) vs no	2.12 (1.69-2.55)	0.22	**<0.001**
Paid work with dying and/or grieving people	Yes vs no	2.05(1.67-2.44)	0.20	**<0.001**
Volunteer work with dying and/or grieving people	Yes vs no	1.34 (0.79-1.90)	0.28	**<0.001**
Distant personal loss	Yes vs no	0.17 (-0.15-0.51)	0.17	0.293
Close personal loss	Yes vs no	0.71 (0.29-1.14)	0.21	**<0.001**
Support bereaved person	Yes vs no	1.23 (0.91-1.55)	0.17	**<0.001**
Own life-threatening illness	Yes vs no	0.58 (0.02-1.15)	0.29	**0.042**
Supporting someone with life-threatening illness	Yes vs no	1.45 (1.08-1.82)	0.19	**<0.001**
Caring at the EOL	Yes vs no	1.90 (1.45-2.35)	0.23	**<0.001**
Professional EOL care	Yes vs no	2.61 (2.15-3.07)	0.23	**<0.001**
Attending EOL-related event	Yes vs no	-0.15 (-0.50-0.20)	0.18	0.404

Notes: [1] Ranging 0–10, with higher scores indicating greater death literacy; EOL=end-of-life

6.4.1.1 Associations between individual explanatory variables and death literacy

The bivariate linear regression analyses demonstrated significant associations between most explanatory variables and death literacy, presented in Table 6.8. Specifically, variables relating to professional care background and prior EOL experiences were found to have stronger correlations with death literacy than did socio-demographic and health variables. Two variables, *Distant personal loss* and *Attending EOL event*, were excluded from the regression model since they were not statistically significantly associated with death literacy. In the variable *Household composition*, only one category, *Being widowed*, was significant and was therefore recoded as a separate dichotomized variable in the regression model.

6.4.1.2 Hierarchical regression model

Associations between sixteen explanatory variables and death literacy were statistically tested in three multivariable hierarchical regression models. The model statistics results are presented in Table 6.9. The final model accounted for 40.5% of the variance in death literacy, F(22, 477)=14.75, *p*<0.001. In the first model, the sociodemographic factors age, gender, education, health status, and religious belief were entered, together accounting for 13.7% of variance in death literacy. In the second model, professional care background and EOL education or training were added, contributing with an additional 15.8% of variance. In the third model, experiential factors were included, accounting for another 11.0% of variance.

Table 6.9. Model statistics of the hierarchical regression analysis.

	R^2	R^2 change	P value	Adjusted R^2
Model 1	0.137	0.137	p<0.001	0.117
Model 2	0.294	0.158	p<0.001	0.274
Model 3	0.405	0.110	p<0.001	0.377

Notes: EOL=end-of-life

As shown in Table 6.10, the final regression model comprised eight variables that were significantly associated with death literacy. Among the sociodemographic factors, being widowed (b=1.55, p<0.001), being older (b=0.01, p=0.001), and having a religious or spiritual belief (b=0.25, p=0.002) were positively correlated with death literacy. In addition, having worked in healthcare was shown to have a positive association with death literacy (b=0.61, p=0.017). Both professional (b=1.06, p<0.001) and personal (b=0.94, p<0.001) experience of providing EOL care, having supported a bereaved person (b=0.54, p=0.001), and having done paid or volunteer work with dying and/or grieving people (b=0.51, p=0.048), were experiential factors significantly associated with higher death literacy.

Table 6.10. Results of the hierarchical regression model of relationships between explanatory variables and death literacy (total Death Literacy Index score[1]).¨

Variables		*Block 1: Sociodemographic factors*			*Block 2: Professional background*			*Block 3: EOL experiences*		
		B (95% CI)	**SE B**	***p***	**B (95% CI)**	**SE B**	***p***	**B (95% CI)**	**SE B**	***p***
Age	Age (in years)	0.02 (0.01–0.02)	0.01	0.002	0.02 (0.01–0.03)	0.00	<0.001	0.01 (0.01–0.02)	0.00	**<0.001**
Gender	Female vs male	0.46 (0.15–0.78)	0.16	0.004	0.14 (-0.16–0.44)	0.15	0.350	-0.04 (-0.32–0.24)	0.14	0.771
Widowed	Yes vs no	1.58 (0.52–2.65)	0.54	0.004	1.75 (0.78–2.72)	0.49	<0.001	1.55 (0.64–2.45)	0.46	**<0.001**
Health status	Fair vs poor	-1.05 (-1.81– -0.29)	0.39	0.004	-0.54 (-1.23–0.16)	0.35	0.128	-0.16 (-0.81–0.49)	0.33	0.625
	Good vs poor	-0.80 (-1.49– -0.11)	0.35	0.024	-0.26 (-0.90–0.37)	0.33	0.416	0.01 (-0.58–0.61)	0.30	0.962
	Very good vs poor	-0.96 (-1.65– -0.26)	0.35	0.007	-0.44 (-1.07–0.20)	0.32	0.178	0.01 (-0.59–0.62)	0.31	0.963
	Excellent vs poor	-1.20 (-2.01– -0.39)	0.41	0.004	-0.60 (-1.34–0.15)	0.38	0.116	-0.10 (-0.80–0.61)	0.36	0.788
Education level	Upper secondary vs lower secondary	0.56 (-0.03–1.14)	0.30	0.061	0.32 (-0.22–0.85)	0.27	0.248	0.35 (-0.15–0.85)	0.25	0.169
	Tertiary vs lower secondary	0.96 (0.37–1.55)	0.30	0.001	0.58 (0.04–1.12)	0.27	0.034	0.44 (-0.07–0.94)	0.26	0.090
Religious belief	Agnostic vs atheist	-0.25 (-0.59–0.10)	0.18	0.158	-0.29 (-0.61–0.20)	0.16	0.066	-0.29 (-0.58–0.01)	0.15	0.054
	Religious/spiritual vs atheist	0.34 (0.15–0.53)	0.10	<0.001	0.26 (0.09–0.44)	0.09	0.003	0.25 (0.09–0.41)	0.08	**0.002**
Healthcare profession	Yes (current or prior) vs No				1.14 (0.65–1.63)	0.25	<0.001	0.61 (0.11–1.11)	0.25	**0.017**
Social care profession	Yes (current or prior) vs No				0.30 (-0.19–0.79)	0.25	0.231	-0.02 (-0.50–0.45)	0.24	0.919
EOL education or training	Yes vs no				1.33 (0.82–1.85)	0.26	<0.001	0.38 (-0.17–0.92)	0.28	0.173
Paid work with dying and/or grieving people	Yes vs no							0.51 (0.01–1.02)	0.26	**0.048**
Volunteer work with dying and/or grieving people	Yes vs no							0.05 (-0.46–0.56)	0.26	0.847
Close personal loss	Yes vs no							0.26 (-0.10–0.62)	0.18	0.158
Support bereaved person	Yes vs no							0.54 (0.22–0.86)	0.16	**0.001**
Own life-threatening illness	Yes vs no							-0.05 (-0.53–0.42)	0.24	0.828
Supporting someone with life-threatening illness	Yes vs no							0.27 (-0.10–0.64)	0.19	0.146
Caring at the EOL	Yes vs no							0.94 (0.50–1.37)	0.22	**<0.001**
Professional EOL care	Yes vs no							1.06 (0.57–1.66)	0.30	**<0.001**

Notes: EOL=end-of-life; [1] Ranging 0–10, with higher scores indicating greater death literacy.

7 DISCUSSION

In this thesis, I have explored competence for engaging in end-of-life (EOL) care provision and communication, i.e., death literacy, in elder care and community settings, focusing specifically on how such competence can be developed, conceptualized, and measured.

The main findings will be discussed first in this chapter and will also refer to prior research and the existing literature. This is followed by a discussion of methodological considerations, highlighting the strengths and limitations of the studies.

7.1 DEVELOPMENT OF DEATH LITERACY (STUDIES I-IV)

As described earlier, EOL competence is defined as multifaceted, often encompassing knowledge, skills, attitudes, and values. In this thesis, death literacy is explored as a possible framework for conceptualizing aspects of EOL competence and the Death Literacy Index (DLI) is examined as a potential measure of this competence. Leonard et al. (2022) argue that death literacy concerns the relationship between having knowledge about, and being prepared to engage in, EOL care-related situations. This perspective was supported in Study III, where it was found that items in the DLI could be understood as measuring the extent to which a person perceives having sufficient knowledge to act in a particular situation, their preparedness to do so, and their beliefs in or attitudes concerning their ability to gain knowledge from prior EOL experiences.

Overall, the findings in this thesis indicate that numerous types of knowledge contribute to death literacy, including theoretical, practical, and communicative knowledge, as well as tacit knowledge based on intuition and lived experience, and emotional competence. This is in line with seminal theories describing the competence required for working in care professions and which integrate theoretical and empirical knowledge with explicit and implicit elements of practical skills and personal knowledge (Carper, 1999; Kennedy, 1998).

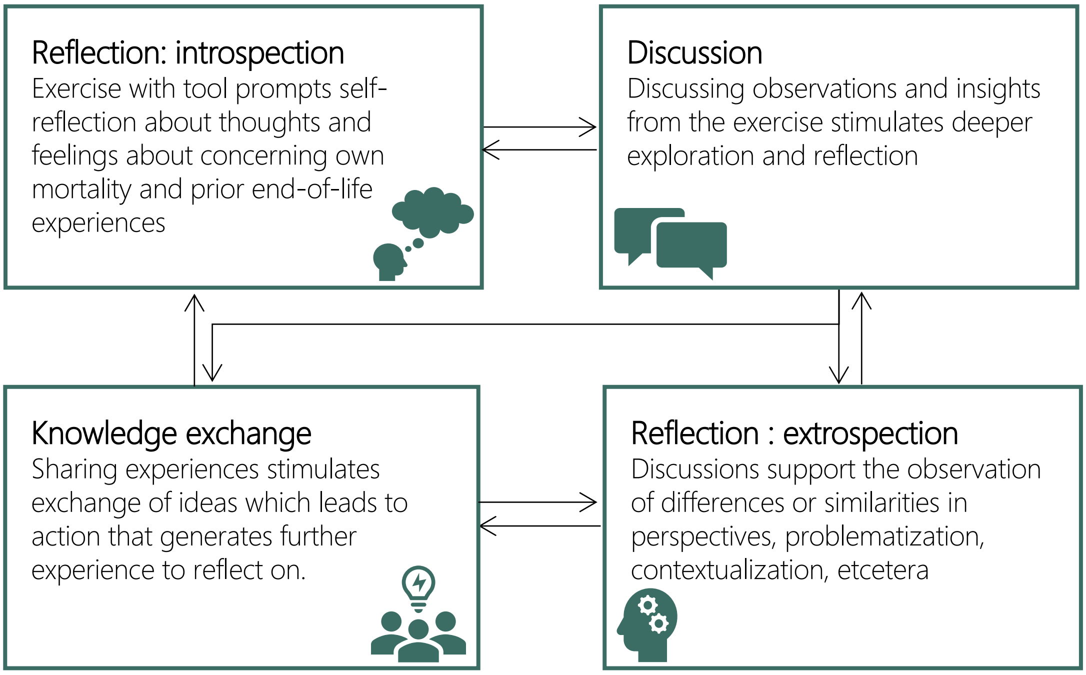
7.1.1.1 Experience-based learning

Results from Studies I, II, and IV, as well as the cognitive interviews in Study III, all showed that prior experiences of situations related to the EOL, especially first-hand encounters with dying, death, and loss, play a significant role in the development of death literacy. Moreover, results from Study IV showed that direct EOL experiences could function as independent precursors and mediators in the associations between other explanatory variables and death literacy. These results support the idea of death literacy being competence primarily derived from experience-based learning, as suggested by Leonard et al. (2022) and Noonan et al. (2016). Prior work experience, particularly having directly cared for dying people, has previously been shown to significantly influence self-perceived competence among care staff in palliative care (Chan et al., 2015), primary care (Haavisto et al., 2021) and home-based elder care (Craftman et al., 2022). In Study I, we found that personal experiences could also trigger learning and were particularly useful for highlighting how prior situations can be re-evaluated from new perspectives. This is in line with the idea that experience-based learning is a biographical process that interlinks education, work, and personal development, building on direct encounters rather than hypothetical scenarios (Kolb, 2015).

In general, the factors found to be associated with death literacy in Study IV correspond to the primary source of self-efficacy: experience of mastery, also referred to as performance outcomes (Bandura, 1977). In line with Ten Koppel et al. (2019), we found in Study IV that factors providing the opportunity for mastery experiences, such as being older, widowed, or having worked in a care profession were strongly associated with death literacy. As stated in Bandura's theory, this could be because older people and people working in care settings are more likely to be confronted with EOL situations and therefore have had more opportunities to practice and build mastery. On the other hand, Evenblij et al. (2019) demonstrated that RCH staff, who care for dying residents in their everyday work, could still have low self-efficacy with regard to EOL communication. Similarly, our findings in Studies I and II demonstrate that few participants had engaged in EOL communication despite describing dying and death as being part of daily life in RCHs. It should be noted, however, that prior research findings about the relationship between knowledge, self-efficacy, and actual behavior in EOL communication are contradictory. For example, Gilissen et al. (2020) showed that self-efficacy, not knowledge, was a primary predictor of staff's participation in EOL conversations. Nevertheless, a more recent study (Gilissen et al., 2021) found that while RNs had more knowledge about, and were more actively involved in, ACP than other care professions, this was not reflected in higher self-efficacy rates. In sum, the existing evidence indicate that having first-hand experience of being actively involved in caring for dying people or communicating about EOL issues is necessary, but not sufficient, for both self-efficacy and death literacy to develop.

In Studies I and II, we focused on the death literacy dimension that relates to communicative skills and the findings provide a more detailed understanding of how competence for EOL communication can be fostered. In these studies, EOL competence and preparedness were found to develop from an iterative process of experience-based learning, depicted in Figure 7.1, including components of reflection, discussion, and knowledge exchange using prior experiences as reference points. In Studies I and II, this process was initiated through reflective exercises using the DöBra cards, although the components represent a series of generalizable steps in a learning cycle of experience, reflection, abstraction and action (Kolb, 2015; Revans, 1982) that might be incorporated into competence-building initiatives in various settings. The process corresponds to the constructivist learning theory described by Biggs and Tang (2011), which states that learners construct knowledge through their activities and make interpretations based on their existing mental models or 'schemata'. From this perspective, effective learning is about actively engaging people into building knowledge based on their existing understandings and through reflection. This, in turn, can enable change in perspectives and attitudes.

Figure 7.1. Schematic of central components in the experience-based learning process that supports death literacy development.



Reflection: introspection
Exercise with tool prompts self-reflection about thoughts and feelings about concerning own mortality and prior end-of-life experiences

Discussion
Discussing observations and insights from the exercise stimulates deeper exploration and reflection

Knowledge exchange
Sharing experiences stimulates exchange of ideas which leads to action that generates further experience to reflect on.

Reflection : extrospection
Discussions support the observation of differences or similarities in perspectives, problematization, contextualization, etcetera

7.1.1.2 Reflection

In experience-based and action learning, reflection has been highlighted as a useful means of uncovering and learning about both explicit and tacit knowledge (Kennedy, 1998; Revans, 1982). By reflecting on action, Kennedy (1998) describes how a person can revisit past experiences, both professional and personal, and analyze their outcomes to achieve a new or deeper understanding; this is essential for care practitioners being able to generate and develop knowledge in practice.

Findings in Studies I and II indicate that staff reflection is valuable in supporting EOL competence-building processes. Identifying and challenging personal values in relation to EOL care and workplace norms was a way to cultivate awareness, interest, and a sense of responsibility for EOL communication. This constituted an important step in death literacy development. The qualitative data presented in Studies I and II further demonstrate how different experiences not only served as a basis for gaining knowledge and skills (e.g., "*experiencing X taught me that…*") but also as a mechanism for reflection to enable a person to understand their own competence (e.g., "*when thinking about my experience of X, I realize that I learned about…*") and areas they might need to improve. Thus, reflection was found to facilitate discussion and deeper exploration, raising other aspects of EOL care and communication which allowed continued reflection and exploration, thereby stimulating the experience-based learning process. This is in line with Schön's view of reflective practice (1983).

Studies I and II indicate that opportunity for reflection and sharing of experiences about EOL issues with colleagues could be beneficial in elder care as a means for competence-building, changing work norms and attitudes, and social support. Similar proposals have been presented by Hockley (2014) and Gilissen et al. (2018), who argue that providing reflection groups for RCH staff is valuable for supporting continuous learning about EOL care provision and communication. Nevertheless, our results show that staff in elder care currently lack such opportunities.

7.1.1.3 The DöBra cards as a tool for introspection and extrospection

The analyses indicated that the exercises with DöBra cards had two main uses for reflection, both of which stimulated learning: building engagement and identifying personal prerequisites (through introspection, i.e., observation of one's own thoughts and feelings) and acquiring and generating knowledge by sharing prior experiences with others (through extrospection, i.e., observing and perceiving things external to one's own mind). The reflective exercises using the DöBra cards in Studies I and II demonstrated the individual variation in EOL care preferences, leading to discussions about the importance of creating an opportunity for making such preferences known to others. In addition, using the DöBra cards to reflect on and discuss one's own and others' EOL values and experiences provided an opportunity for participants to re-examine their prior experiences and learn from them, facilitating recognition of personal assumptions and behavioral patterns and stimulating spontaneous knowledge exchange. This process was found to be useful for identifying barriers for EOL communication and finding potential solutions, both in terms of specific conversation strategies and workplace attitudes, norms, and routines. Thus, the cards provided an efficient means of promoting individual and joint critical reflection about assumptions related to EOL care and communication that might otherwise remain tacit. In addition, the reflective exercises helped provide a safe space for sharing experiences, concerns, and ideas, and receiving collegial support and input regarding improvement.

The combination of introspective and extrospective reflection also served an important function in the PAR process. Increasing the awareness of individual staff members about how their own behavior might affect care provision triggered discussions about the possibilities for change at both the individual and organizational levels, generating several of the ideas that were later carried out in the staff-led initiatives. These outcomes are in line with Schön's (1983) description of how the opportunity for joint reflection on, and discussion of, prior experiences— particularly focusing on situations that worked well—can help construct a point of reference for making sense of other encounters and identify what could have been done differently. More recently, Croker et al. (2022) found that a similar process of repeated joint reflection and discussion helped staff consider the human aspects of EOL care.

The stepwise experiential learning process (Figure 7.1) described is not reliant on using the DöBra cards, but rather describes components that are important to include in competence-building initiatives, not necessarily using any specific tool. Our findings in Studies I and II suggest, however, that having a trigger for reflection significantly helped participants to reflect more deeply than they had done before. Nevertheless, reflection can be stimulated in several ways, such as using reflective models, creative visualization, mind maps, or vignettes. The process for EOL competence-building presented here could help the recognition and use of existing tacit knowledge, identify the potential impact of norms and attitudes on staff behavior, and generate a basis for continued experiential learning.

7.1.1.4 Knowledge exchange

The final central component in the learning process in Figure 7.1 relates to knowledge exchange, which was found to be useful for recognizing and problematizing diverse prerequisites for proactive EOL conversations across participants, professions, and services. These interactions appeared to be stimulated by using the DöBra cards as the exercises created opportunities for joint inquiry and analysis of problems, and potential solutions based on existing knowledge and earlier experiences. In other words, knowledge exchange involved the generalization of experiences and the development of ideas into suggestions that could be tested in practice. A similar process of abstracting experiences has been previously described by Sand et al. (2018) as especially beneficial for complex situations that cannot be managed with standardized ‘cookbook’ instructions. Overall, these findings are supported by Biggs and Tang’s (2011) conceptualization of learning, which suggests that dialogue can elicit activities, such as knowledge exchange, that stimulate, develop, and deepen understanding and learning. In addition, mutual knowledge exchange has been previously identified as important for staff competence-building in care settings, since it is argued that different professions or services can gain new insights and understanding from each other (Frey et al., 2019).

7.2 PREREQUISITES FOR PROACTIVE EOL COMMUNICATION BY ELDER CARE STAFF (I-II)

Findings in Studies I and II elucidated certain aspects concerning the facilitation of proactive EOL conversations in elder care, which will be further discussed here. Engagement in EOL conversations in practice, and subsequently the use of the DöBra cards, appeared to be influence by being amenable to change through the use of reflective practice and training. Factors at an organizational level, on the other hand, may need to be addressed on a macro-level through, for example, appropriate policy-making.

7.2.1.1 Staff prerequisites: competence needed for conversations

Proactive EOL conversations were found to be complex and sophisticated conversations requiring considerable communicative, interpersonal, and listening skills. High death literacy may provide a certain level of comfort with, and preparedness for, addressing the topic, but does not necessarily reflect competence in the facilitation of conversations. The experience-based learning process outlined above might, however, contribute to making these abilities more explicit and further support their development.

Overcoming discomfort appears to be a key prerequisite for EOL conversations, found both in this thesis and in prior studies by Combes et al. (2019) and Kuusisto et al. (2020). Findings in Studies I and II indicate that introspection about one’s own difficulties with death seemed to be an important part of overcoming discomfort, which often appeared to be related to challenging prior EOL experiences, fear of mortality, or familial and/or cultural silence around death. Our results suggest a process of empowerment in which participants who initially expressed discomfort with addressing EOL matters often described this gradually dissipating and being able to challenge themselves to be ‘courageous’ in conversations in a way that they had not been before. Engaging with EOL conversations might also, therefore, have the potential to personally impact those who facilitate the conversations. This supports the finding by Somes et al. (2018) that lay ACP facilitators described increasing reflection about their own EOL care preferences and feeling being better equipped to handle death in their own lives.

As in prior research literature about EOL competence, the participants, particularly those in Study II, reported that it was sometimes difficult to verbalize their experiences or the strategies they used to facilitate the discussion (Kennedy, 1998; Robinson et al., 2017). This suggests that competence to engage in EOL conversations might involve skills that are largely tacit or intuitive. The significance of tacit knowledge has been demonstrated in studies about ACP implementation. For example, Combes et al. (2019) noted in their review that care staff need to build sufficient skills to carry out conversations but also to develop intuitive knowledge to be able to recognize and create opportunities for conducting them. Likewise, Bergenholtz et al. (2019) reported that hospital staff described their development of EOL communication skills as a process of trial and error guided by intuitive knowledge, and that conversations initially required a degree of compulsion.

In Study II, we noted that staff used various ways to approach EOL conversations. While some focused on the content, for example, addressing the topic of death in order to identify values, others appeared to focus on building interpersonal relationships and developing a sense of trust. Even though people might intuitively favor one of these approaches, practicing holding conversations using the DöBra cards might strengthen both aspects. A review by Fernandes et al. (2021) found that card-based tools are useful in overcoming reluctance and resistance to addressing EOL matters with palliative care patients and can contribute to increased engagement in ACP and self-efficacy for EOL decision-making. Likewise, in their review of EOL communication between care staff and relatives of dying patients, Anderson et al. (2019) also found support for using tools to overcome communication barriers. The findings presented in this thesis indicate that the DöBra cards could be useful for supporting the development of the ‘soft’ or ‘aesthetic’ skills (communicative, interpersonal, and listening skills) that are needed for EOL conversations among staff with limited experience of, or low self-perceived capacity for, addressing EOL issues. Such skills are said to be crucial for developing the ability to stay present and hold space for others while they reflect on EOL issues that might be emotionally charged (Kelemen et al., 2018).

7.2.1.2 Perceived mandate for EOL conversations among RCH staff

In Studies I and II we found that many participants had rarely considered proactively addressing EOL issues with residents and relatives prior to the studies. EOL communication was hindered by lack of clarity about the staff’s mandate, with findings showing that care staff, with the exception of some RNs, did not generally perceive having the responsibility to engage in EOL conversations, nor a role in supporting care decision-making. This perception is not surprising considering that in Sweden, existing routines stipulate that EOL discussions ('breakpoint conversations') are the responsibility of physicians. This finding also supports prior international research which has suggested that RNs are significantly more likely to perceive ACP conversations as part of their professional duty compared to CNAs and ANs (Gilissen et al., 2021; Ludwick et al., 2018).

Nevertheless, in Study II we chose to explore proactive EOL conversations facilitated by RNs and CNAs, and not by physicians. It has previously been argued that care staff in RCHs are well-suited to initiate EOL conversations as they have more frequent interactions with, and can establish closer relationships to, residents and their relatives compared to physicians or other consulting health professionals (Gjerberg et al., 2015). This familiarity is particularly the case for CNAs who are commonly primary care providers in elder care. Moreover, feasibility of RN-led ACP has been supported in a recent scoping review (Whitehead et al., 2022). Even though the participating CNAs in Study II appeared to be equipped for facilitating EOL conversations, questions remain the regarding varying mandate and competence across care professions. Furthermore, the feasibility of having CNAs responsible for conducting EOL conversations, for example, ACP, in RCHs needs to be further explored.

7.2.1.3 Organizational factors influencing implementation

Findings in Studies I and II point to the vital role of management in order for any effort to improve EOL communication to be successful in uptake and sustainability. Insufficient management support was described as a large barrier to EOL communication, with participants expressing that EOL care in general, and proactive EOL conversations in particular, needed to be designated as an important part of care provision. It was, however, acknowledged that services were making efforts to improve EOL care provision, primarily through staff education and the appointment of 'palliative ombudsmen' who were to act as champions of EOL care in their facilities. Even so, participants spoke of both needing more training and being given the opportunity and mandate to implement this knowledge in practice. These findings correspond with existing literature, which highlights the importance of actively engaged leadership and the provision of support from service management in EOL care interventions (Brazil et al., 2012; Frey et al., 2020; Nilsen et al., 2018). In addition, the negative attitudes of managers and their concerns about effectiveness of ACP have been shown to impede uptake and implementation in RCHs (Beck et al., 2017).

There are also several conceptual factors requiring consideration at policy level if a wider implementation of proactive EOL conversations in elder care is to be successful. The recent debate regarding the effectiveness of ACP described above underlines the need to clarify the intended purpose of proactive EOL conversations. The format for the conversations used in Studies I and II builds on the notion of conversational ACP, an iterative process aimed at social effects, such as supporting communication and strengthening relationships between care recipients and providers to promote readiness for future decision-making. Another consideration concerns timing. How far in advance should EOL conversations be conducted in order for them to be proactive and not reactive? No time limit for proactive EOL conversations has been identified in this thesis. However, it does appear that offering them as early as possible, i.e., in conjunction with RCH admission, could be a feasible strategy for maximizing the potential social effect of identifying and communicating appropriate care goals and better equipping staff to be able to support residents through declining health (deLima Thomas et al., 2018; Martin et al., 2016).

7.3 USING THE DÖBRA CARDS TO DISCUSS END-OF-LIFE CARE (I, II)

In addition to supporting reflection in various ways, the DöBra cards were found to be useful for discussing EOL care values and preferences. In both Studies I and II, participants described how the tool made them feel more comfortable addressing EOL issues and that it gave them a framework to use in conversations with residents and relatives. Study II provided insights into how using the DöBra cards stimulated interactive sharing of information, stories, and emotions, which was said to help staff develop a holistic perception of the resident as a person. Overall, the findings suggest that proactive EOL conversations with the DöBra cards might help EOL care provision become more person-centered through highlighting the care recipient’s narrative, supporting the establishing of a ‘patient-provider’ partnership, and enabling mutual agreement regarding the goals of care (Ekman et al., 2021).

7.3.1.1 Elucidating individual variation in end-of-life values and preferences

The variability of statements in the DöBra cards, covering a range of physical, practical, existential, and social matters, might contribute to a discussion about EOL preferences beyond that of medical treatment options available. This is an important advantage of the DöBra cards, since many other existing EOL conversation tools focus primarily on either medical or psychosocial aspects (Sussman et al., 2020).

The DöBra cards have previously been found useful for discussing EOL care values with Indigenous Sámi in Sweden (Kroik et al., 2022), indicating cultural sensitivity of the DöBra card statements in that context. Furthermore, the DöBra cards were found feasible to reflect on EOL values with staff for varying cultural backgrounds in Studies I and II. This is an important consideration in terms of the usability of the DöBra cards in elder care overall; the proportion of the older Swedish population who are foreign-born is increasing, which is expected to influence future provision of elder care in terms of language and cultural preferences (National Board of Health and Welfare, 2020). Prior research has shown that cultural and religious perspectives can influence EOL care values as well as patterns of communication (Cain et al., 2018; Fang et al., 2016). The relevance of using the DöBra cards with people with diverse cultural backgrounds should be explored.

7.3.1.2 Shaping and supporting conversations about end-of-life care

The DöBra cards were primarily found to help RCH staff facilitate proactive EOL conversations by providing a structure for addressing the topic according to the steps in the instructions. The individual cards served as visual prompts and the statements provided a starting point for reflection and discussion. The benefit of the physical format of the DöBra cards has been previously described by Eneslätt (2021) and Delgado-Guay et al. (2016). Study II showed that by discussing reasoning behind the choice of particular cards, often through telling personal stories, a more in-depth exploration of EOL values and preferences was enabled. Similarly, Zwakman et al. (2021) describe in their study about ACP readiness among patients with advanced cancer that narratives about prior experiences were used to communicate care preferences and identify related concerns and feelings.

Study II also demonstrated that proactive EOL conversations provided an opportunity to strengthen connections and build trusting relationships between staff, residents and relatives. This corresponds to findings by Pedrosa Carrasco et al. (2021), suggesting that ACP conversations between cancer patients and their caregivers can contribute to empathic communication within families, the development of coping skills, and empowerment for future decision-making. However, the authors note that conversations could also expose tensions in relationship dynamics.

7.3.1.3 Adaptability of use

Even though the large number of DöBra cards provides the possibility for exploration of a wide range of care preferences, this might also limit their usefulness with residents affected by cognitive decline, for example due to dementia. As the prevalence of dementia is growing (Sleeman et al., 2019), this is an important aspect to consider. One possible solution, suggested by a participant in Study II could be to reduce the number of cards. This raises the question, however, about which cards should be removed and how this should be decided. Selection according to staff's perspectives of what is important could defeat the purpose of the tool. In a recent study by Olsson Möller et al. (2022), a reduced version of a card-based EOL conversation tool (see Olsson Möller et al., 2020) was created based on the cards most commonly chosen by patients. While the large number of DöBra cards may limit their suitability for use with some care recipients, I would argue that if the intention is to explore individual variations in EOL preferences, creating a norm-based tool for EOL conversations would be counterproductive. Different ways of using the DöBra cards might instead be a way to adapt to various needs, as indicated by findings in Study II showing that participants developed various strategies to simplify or expedite the procedure.

. However, not completing the default task, i.e., prioritizing and ranking the DöBra cards, was found to be challenging for participating staff to accept at times. Ashana et al. (2022) reported that narrow views of when an EOL conversation is "successful" or "completed" could even hinder discussions altogether. Fan et al. (2019) pointed out that people facilitating EOL conversations must keep in mind that the goal is to initiate reflection on, and discussion of, matters of importance at the EOL and not necessarily to make decisions. This perspective is also used by those who characterize ACP as a process rather than a product (Abel et al., 2020; Hopkins et al., 2020; Moody, 2021).

In summary, the original instructions for the DöBra cards provided a helpful structure for EOL conversations, but the findings of Study II strongly suggest that there is no one optimal method. The combination of structure and adaptability of the DöBra cards appeared to promote a collaborative exploration of EOL values and preferences, enabling residents and relatives to actively influence the direction and depth of the discussions. Allowing them to choose how much they wish to disclose is an essential ethical aspect of the voluntary nature of conducting EOL conversations, as also stated by Zwakman et al. (2021). Other script-based EOL conversation tools might not allow preferences to be as freely explored. The adaptability of the DöBra cards therefore appears to be central for their usability in the elder care setting, which supports the previously highlighted need for EOL conversations to be flexible (Evans et al., 2012; Hall et al., 2019; Holland et al., 2017).

7.4 PERFORMANCE OF THE SWEDISH DEATH LITERACY INDEX (III, IV)

The findings in Study III supported the validity of the DLI-S, suggesting that the DLI is an instrument suitable for measuring death literacy in Sweden.

7.4.1.1 Content of the Death Literacy Index

The DLI-S was found to be acceptable in terms of content, since the participants in the cognitive interviews did not consider the items to be distressing or too sensitive. Instead, the interview participants described the process of completing the DLI-S as an interesting and thought-provoking task that helped them realize the extent of their own knowledge. These findings support earlier research showing that people can find it rewarding to talk about the EOL (Eneslatt et al., 2020; Tishelman et al., 2022) and that opportunities to consider difficult topics that might otherwise be avoided may contribute to participants' empowerment and learning (Alexander et al., 2018). In addition, we found in Studies I and II that reflection on prior experiences is an important step for death literacy development (Johansson et al., 2021; Johansson et al., 2022). Thus, if the DLI-S can promote reflection about EOL experiences, the instrument itself may constitute an educational exercise supporting death literacy development.

The potential impact of the Swedish language lacking a word for 'community' should, however, be acknowledged, especially since a large portion of the DLI focuses on 'community capacity'. There is no direct Swedish equivalent with the same breadth of meaning as the word in English; 'community' can be translated into Swedish by emphasizing either a social context, i.e., a group of people with a shared sense of belonging based on self-identity or interests (e.g., '*intressegrupp*', '*samhällsgrupp*', or '*subkultur*'), or a geographical area, i.e., a neighborhood ('*närsamhälle*', '*grannskap*'). Following a discussion with the original developers about the intended focus of the DLI-S, we used the latter alternative. Even though this is a common translation of the term and we no problems with comprehensibility were identified in the cognitive interviews, it is possible that the scope of items in the scale became narrower or more specific in the Swedish version. In contrast, Chung et al. (2019)found in their review of community-based EOL care initiatives that ‘community’ was generally conceptualized as something beyond place, i.e., based on culture or identity.

7.4.1.2 Applicability of the six-factor death literacy model

While we found evidence supporting the validity of the DLI-S, some items concerning access to, and interactions with, care services (specifically the scales *Factual knowledge* and *Accessing help*) did not perform as well as the other scales in the Swedish context. For example, the cognitive interviews showed that lack of clarity or inconsistent interpretation of item content often referred to these two scales. In addition, the CFA showed that these scales were highly correlated, which could mean that, in the Swedish context, they measure one underlying factor rather than two distinct dimensions of death literacy. The *Accessing help* scale also demonstrated a floor effect, indicating that it has limited ability to differentiate between responses at the lower end of the response scale, which reduces its reliability (Terwee et al., 2007).

The average inter-item correlations (AIC) for all DLI-S scales slightly exceeded the recommended upper range (Clark & Watson, 2019) but were considerably higher for the scales *Accessing help* and *Community support groups*. The AIC is an indicator of internal consistency and while it is a more robust measure than Cronbach’s α, an acceptable AIC does not necessarily imply a unidimensional scale. For these scales, however, the AIC values showed that the items are too highly inter-related. This finding indicates item redundancy, i.e., there are items that do not contribute enough new information to measure the construct (Clark & Watson, 2019). Even though these issues were not major threats to the validity of the DLI-S’, the findings suggest that it might perform better in the Swedish context if one or several items from the community-focused scales were removed. Taken together, the high inter-item correlations between all four items in the *Community support groups* scale and responses from the cognitive interviews for these items indicate that the scale might work better as one, overarching, item. Consequently, this could mean that a five-factor model of death literacy would fit the DLI-S better. The performance of a revised version of the DLI-S should therefore be examined in the Swedish context to further explore the cross-cultural validity of the dimensions in the death literacy model and refine their operationalization in different contexts. Similar revisions of the DLI might also be relevant in other contexts.

To summarize, the findings show that the scales that focused on *Factual knowledge* and *Community capacity* featured many of the more problematic items in terms of comprehensibility, affecting both content and response process validity. This could mean that these items do not sufficiently relate to a shared perception of the role care services play in EOL care provision in a Swedish setting. Compared to the other DLI-S scales, these scales also performed worse in the psychometric evaluation of internal structure validity. While these findings could indicate problems in the performance of the DLI-S, they could also reflect differences between the Swedish and Australian settings, particularly in the organization of the care systems, an aspect known to be particularly difficult to translate in surveys (Squires et al., 2013).

Consequently, the contextual differences might be a result of varying awareness and expectations of care and support services in Australian and Swedish populations. For example, trust in health care providers and institutions has been found to be notably high in the Swedish population (Lindstrom & Pirouzifard, 2022). Similarly, our findings show that some participants in the cognitive interviews described that, if they needed guidance in the care of someone at the EOL, they would confidently turn to their primary care clinic for support or call *1177*, the Swedish national hub for information regarding health and healthcare services. Such sentiments suggest that participants did not perceive a need to possess some forms of knowledge themselves, as this was seen to be the responsibility of formal care services and providers. It is possible that the DLI would perform differently in countries without universal welfare or with lower trust in public institutions, and where people might be more accustomed to caring for others at the EOL.

Studies III and IV have resulted in an international collaboration being established to investigate the cross-cultural viability of the DLI and the death literacy construct. This will shed more light on whether the contextual factors found to be relevant in the comparison between Sweden and Australia might also be generalizable to other settings.

7.5 METHODOLOGICAL CONSIDERATIONS

This section, some key methodological considerations of the studies are discussed to highlight strengths and limitations of this thesis.

7.5.1 Selection of participants

7.5.1.1 Selection bias

All four studies in this thesis used non-probability sampling, i.e., the samples were not randomly selected. This can introduce a risk of selection bias whereby participants in a study differ in a meaningful way from the population of interest, leading to a systematic error in the outcome. This creates problems with generalizing study findings to the population of interest. Random sampling, or probability sampling, is an effective means of avoiding selection bias, but depends on the aim of the study (Pasek, 2016). As the studies in this thesis address exploratory research questions and aim for theoretical, rather than probabilistic, generalization of findings, study validity is not dependent on randomized samples. However, selection bias can still threaten rigor, i.e., research quality, of the studies.

In Studies I and II, the participants were invited to the workshop series by managers or contact persons in their services. We have, therefore, little insight in how this part of the recruitment process was performed and on what basis staff were selected. In addition, we do not know how many declined the study invitation. During the joint planning meetings, managers or contact persons would sometimes describe having particular staff in mind to invite to the studies, usually due to a known interest for EOL care or involvement in training or change processes. Such statements suggest a risk that recruited participants might have been more positive to EOL communication than staff who were not invited. Also in cases where contact persons used a wider recruitment procedure, e.g., distributing information about the study to all staff in a service, it could be that staff who respond first to the invitation are more positive to EOL communication. Furthermore, the follow-up interviews in Study II were only conducted with staff who reported having used the DöBra cards. It is possible that staff not making contact might have used the tool and had more negative experiences. This could mean that such experiences are under-represented.

The longitudinal design of Studies I and II introduced another form of self-selection due to attrition over time. PAR processes can be especially labor-intensive and resource-demanding, which might lead to situations where staff who perceive EOL conversations as challenging are more likely to opt out, whereas those more interested in, and feeling more empowered to, initiate change are likelier to continue their participation (Freshwater, 2005).

A biased selection would limit the findings' transferability since the conclusions would be based on data from participants who do not reflect the overall population. This does not appear to have been the case in Studies I and II. Service and participant characteristics were heterogenous and views expressed regarding the value and feasibility of EOL conversations were generally diverse. In summary, selection bias was not a major threat in these studies.

The use of convenience sampling to recruit expert reviewers in Study III also introduced a risk for selection bias. Since participants were accessed via the researchers' networks, there was some personal connection between those reviewing the translated instrument and the research group responsible for the translation. This might have affected the experts' reviews, for example by increasing social desirability in their responses. However, the expert review was conducted using an online survey that allowed the participants to respond anonymously, thus limiting the potential impact of personal connection. The expert review was also only one of multiple steps in the validation process and the risk that the reviewers' responses would threaten the validity assessment of the DLI-S is, therefore, low.

7.5.1.2 Quota sampling from panels

The survey data collection in Studies III and IV used non-probability quota sampling from an online panel. These types of volunteer panels can be affected by self-selection at two steps. The decision to become a panel member has been shown to be linked to a number of characteristics that could impact the outcomes, such as age and education (Fricker, 2017). Within this panel sample, the quota sampling method can introduce a second selection bias as panel members with little interest in EOL matters might have been less likely to accept the survey invitation (Fricker, 2017; Vehovar et al., 2016). While Vehovar et al. point out that recruitment from survey panels shares similar limitations with other forms of non-probability sampling, they also state that contemporary panels work well for a variety of research topics, especially if care is taken to select appropriate quotas or stratification at the second step of sample selection.

In Studies III and IV, the quota sampling from the online panel was stratified to reflect the Swedish population in relation to gender, age, and geography, and the panel sample corresponds to official population statistics with regard to these variables. However, the panel deviates from Statistics Sweden's population data concerning two important variables. The first is education since the panel is more highly educated compared to the population average. For example, 36% of the panel have completed one year or more of tertiary education,[9] compared with 23% of the general population (Statistics Sweden, 2022). This positive skewness was also noticeable in the survey sample. The second variable is place of birth; 19.7% of the Swedish population are born outside of Sweden (Statistics Sweden, 2021), compared to only 7.2% of the survey participants. Since native-born Swedish people are generally more highly educated than immigrants (Bussi & Pareliussen, 2017), the underrepresentation of foreign-born people in the panel might be one reason for the skewed the distribution of education. The demography of the survey sample is a limitation for the internal validity of Studies III and IV, as it is not known whether education or place of birth are significant precursors of death literacy.

One additional limitation regarding the survey data concerns the test-retest reliability assessment, since the participants were not asked whether they had experienced any additional EOL-related situations in the time interval between baseline and re-test measurement. Such information could otherwise have allowed us to explore within-subjects changes in death literacy among those who had had new EOL encounters.

7.5.2 A reflexive note on the generation and collection of data

7.5.2.1 Participatory action research

One major strength of Studies I and II is the use of PAR with a heterogenous group of staff to explore the acceptability of the DöBra cards and co-develop strategies for how EOL conversations can be conducted, both informing and learning from practice (Hockley et al., 2013). Collaboration with people with various professions and roles in the RCH workforce and management improves study validity and sustainability of impact. In addition, the use of a multi-case design in these studies enabled identification of similarities and differences between services, thus increasing the transferability of findings (Fletcher et al., 2015). This was critical since the influence of organizational factors, such as different staff mandate and available resources was a recurring topic and a prominent part of the findings in Study II.

Participation

Intentions and strategies used for achieving partnerships between researchers and participants can differ, as highlighted in a systematic review by Greenhalgh et al. (2019) exploring frameworks for public and patient involvement in research. A key motivation for the choice of PAR in Studies I and II was to establish a collaborative process of inquiry where participating services and staff would feel a sense of ownership of the research. In retrospect, however, the partnership primarily involved participating staff. While we received input from

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[9] Panel statistics from personal communication

the strategist at the central management for Stockholm City Elder Care Bureau during initial study planning, it proved more challenging to actively involve service management. In the joint planning meetings, managers and contact persons expressed their interest in and the urgency concerning the research focus and gave input on practical matters regarding performance of the workshops, such as time and place, although they generally provided little input on the research design. The lack of input, however, was not necessarily indicative of managers' commitment to the research, but likely, at least in part, a consequence of being unfamiliar with participatory research processes and expecting the study design to be finalized by the researchers.

It is possible that PAR jargon created some confusion, as some participants in Studies I and II expressed expectations of receiving formal education in the studies rather than engaging in collaborative learning. This might have been due to using the term workshop, which could imply a didactic approach. Despite repeated efforts to emphasize the participants' expert knowledge, the participants initially considered us, the facilitators, to be authority figures on the study topic. Downplaying one's own experience was not uncommon: during the workshop series in Study I, several participants initially said they could not understand what we would be able learn from them. This might reflect the hierarchical structure of the care system Fryer et al. (2016) have shown that in multi-professional discussions, CNAs and ANs can experience that their knowledge being less valued than that of more qualified health professionals. However, participants in both Studies I and II described having learned a lot about themselves and from each other during the PAR process. Thus, even though there were some power differentials, participants expressed appreciation of having their capabilities for EOL care highlighted, and their reflections and suggestions taken seriously, indicating that we achieved to incorporate elements of appreciative inquiry into the PAR process (Hockley et al., 2013).

The iterative discussions about data and preliminary findings with participating staff and managers adds strength to the findings in Studies I and II. While this form of member-checking does not verify results, general agreement and recognition of findings among participants contributes to study validity (Mays & Pope, 2000). At the same time, none of the participants were involved in the formal data analysis or writing of scientific articles. This can be considered a limitation in terms of the PAR ideal of participation throughout the entire research process. However, participants in Study I expressed little interest in joining the analytic process and although participants in Study II were invited to collaborate with the write-up, none wished to do so.

Prolonged engagement

Another strength in Studies I and II is the longitudinal design and the prolonged engagement, which Polit and Beck (2004) argue can help generate more honest and richer information. I found our prolonged engagement to be an important means of building trust and rapport with the participants, thereby establishing a safe space in which participants could discuss sensitive or uncomfortable experiences. For example, in Study I, some participants who were initially reserved about their views on problematic aspects of EOL care provision, became more forthcoming over the course of the workshop series. Similar to findings by Antoft and Petersen (2014), the facilitators' ability to create safe spaces in Studies I and II appeared crucial for enabling open and inquiring discussions. However, Dickson-Swift et al. (2006) cautions that personal interaction over time can risk blurring the boundaries in the researcher-participant relationship, which they argue can lead to detrimental effects for the researchers in terms of emotional exhaustion. In addition, blurred boundaries may affect data analysis and the interpretation of results. Prolonged engagement can thus constitute both a strength and a limitation for research validity.

7.5.2.2 Qualitative data collection

Qualitative data provided depth in the exploration of the research questions. In Study II having RCH staff facilitate EOL conversations using the DöBra cards meant that a qualitative study design was essential to meaningfully explore their experiences. Furthermore, in Study III, qualitative data were fundamental to being able to assess the comprehensibility, relevance, and contextual suitability of DLI-S items. However, qualitative data collection comes with certain challenges since the presence of researchers influences data collection, even when they aim to remain 'neutral' (Malterud, 2001). This challenge relates to the collection of data in both individual and group situations.

Anyan (2013) notes that in relation to qualitative interviews, asymmetrical power distributions between participant(s) and interviewer(s), due to, for example, socioeconomic status, education, professional background, gender and ethnic identity can lead to perspectives of the other person, or their possibility to express them, becoming constrained. A concrete example of this would be an interviewer who asks questions and steers the interview in a way that hinders the interviewee from sharing reflections that they had wished to address. Less obvious situations of interviewer influences include providing feedback, both verbal and non-verbal, to suggest that the interviewee has talked about something that is interesting, or conversely, not interesting.

With focus group discussions, group composition constitutes an additional factor that can facilitate or inhibit dialogue and affect power dynamics between participants. The decision to mix professions in Study I was motivated by the exploratory aim and indications that EOL care experiences varies across professions (Kaasalainen et al., 2017). However, it has been recognized that group heterogeneity may possibly increase tendencies for social desirability (Bergen & Labonte, 2020). Importantly, this approach might also involve a greater risk of introducing hierarchies that affect group interaction (Barbour, 2005). This might influence how perspectives are received and accepted by various participants, as suggested by Fryer et al. (2016) above.

7.5.3 Statistical analysis

7.5.3.1 Accuracy of data

According to Fricker (2017), there is almost always a trade-off between the amount of data that can be collected in a survey and the accuracy of these data. One major strength in the survey data collection in Studies III and IV was the assessment of the response processes using cognitive interviews to test and revise DLI-S items. According to Zumbo and Chan (2014), this is an underused element in instrument validation. Not only did this assessment contribute to a more comprehensive understanding of how DLI-S functioned in a Swedish context, but likely also reduced the risk of measurement error in the DLI-S survey, i.e., when survey responses do not reflect the participants' true responses because they have misinterpreted questions or made errors when answering (Fricker, 2017).

7.5.3.2 Hierarchical multiple regression analysis

Hierarchical regression analyses have numerous purposes and the variation in their use has led to contention regarding the methods used to build regression models (Field, 2018; Hoyt et al., 2008; Petrocelli, 2003). In Study IV, the explanatory variables were entered into the regression model on the basis of theoretical importance and causal priority. This means that probable 'causes' should be entered before their assumed 'effects'. The process of variable selection was helped by the visualization of posited causal paths generated by the DAG (Williamson et al., 2014). However, since there was only one published article about factors influencing death literacy at the time (Leonard et al., 2022), there was limited empirical and theoretical insight to guide the hierarchical regression analysis. For this reason, the inferred temporal aspect of explanatory variables influenced how both the DAG and the regression model were built. The attention paid to causal priority can be considered a strength (Petrocelli, 2003), particularly as the study aimed to explore which, and to what extent, explanatory variables were associated with death literacy (Hoyt et al., 2008). The explanatory aim also means that the use of non-experimental cross-sectional data is not a threat to study validity, although it does limit the possibility of drawing conclusions regarding mediation and confounding variables (Rosopa & Stone-Romero, 2008).

Regarding the statistics analysis of the regression model in this study, R^2 is the measure of variance in the outcome that the model accounts for. However, this statistic is influenced by the number of variables in the model, i.e., it will increase even if the variable is not contributing to explaining the variance and there is, therefore, a greater risk of overfitting the model. Adjusted R^2, on the other hand, adjusts for the number of variables and is a method for assessing the generalizability of a regression model since it measures the loss of predictive power (Field, 2018). Even though adjusted R^2 is always lower than R^2, Field (2018) argues that these values should ideally be as close to each other as possible. In the regression model for death literacy that is presented in Study IV, the values of R^2 and adjusted R^2 differ by approximately 0.2, suggesting that if the model was derived from the population it would account for about 20% less variance in the outcome. This is a rather large loss of predictive power, although it is expected considering the large number of variables in the model.

7.5.4 Researcher reflexivity

In her influential guidelines on qualitative research methods, Malterud (2001) recognizes reflexivity as a key criterion for rigor. Researcher reflexivity involves having a self-critical and self-appraising perspective, as well as means of questioning findings, and their interpretations, to recognize possible bias. Malterud argues that the idea of an objective researcher, uninfluenced by preconceptions, personal perspectives, or scientific traditions is implausible regardless of the research field or method. However, the issue of reflexivity is particularly important in qualitative research since the researchers are the "instruments" for both data collection and analysis. For this reason, it is recommended that the researcher provides information about professional and personal aspects that might have affected them (Malterud, 2001; Polit & Beck, 2004). In the articles and the in method sections for Studies I and II, characteristics of the researchers involved in collecting and analysing data have been briefly described. I now aspire to discuss my own background in more detail and consider ways it might have affected the research process, as well as describe the efforts made to counter-act bias.

Before being enrolled as a PhD student in 2018, I had gained years of research experience as a research assistant in different projects and primarily working with quantitative research. I joined the DöBra research program as a research assistant in 2016 and by the time I started my doctoral education, I had conducted 53 qualitative interviews and was very familiar with the DöBra cards. Coming from a background in theoretical psychology and having no professional health or social care experience, the context in which my first studies were conducted was new to me, which I also informed the participants about when introducing myself. Being naive to the context can be considered a strength rather than a limitation, however, particularly since the research used a new public health approach rather than a professional or clinical perspective. Not being familiar with terms and procedures, routines for daily care practice, or organizational and administrative aspects of care services, such as documentation systems, meant that participants had to describe these aspects for me in detail. In the multi-professional group discussions in Studies I and II, this was particularly helpful, since such explanations also highlighted situations in which the participants had different understandings of, and prerequisites for, care provision. My naivety also seemed to emphasize the participants' own expertise, demonstrating that they had experience and skills that were not common knowledge. This might have contributed to creating an open and permissive atmosphere in the groups. These experiences reflect Berger's (2013) idea of the 'unfamiliar' researcher enabling empowerment of study participants.

Throughout Studies I and II, I made reflective notes about data collection, my early understanding of the data, and ideas for data analysis. Such documentation can, according to Malterud (2001), help distinguish researchers' own reflections and preconceptions regarding study findings. The note-taking also enabled an iterative analytic process since the reflective notes sometimes became the basis for codes in subsequent formal analysis. Furthermore, listening to the audio-recordings of discussions and interviews provided an additional opportunity for reflexivity, allowing critical review of my own and IG's interviewing styles and roles. Polit and Beck (2004) argue that such self-critical listening can contribute to refining one's interviewing technique by increasing awareness of how questions were posed and the dynamics between the researchers and the participants.

My involvement in both data collection and analysis in each study in this thesis can be considered a strength as this allowed me to become more immersed in the data (Polit & Beck, 2004). However, there is also a risk of confirmation bias. To reduce this risk and avoid unsubstantiated claims and selective interpretations, we established a practice of discussing and reviewing preliminary findings. This occurred both internally in the author groups—in which there was always a mix of authors who had participated in data collection and those who had not, and externally with research group colleagues or through open article seminars at the university. Examining the findings in this manner allowed me to consider alterative explanations or patterns in the data that I might have overlooked (Calman et al., 2013; Hsieh & Shannon, 2005).

While reflexivity is less emphasized in quantitative research, researchers often play an active part in shaping data collection and it is equally important to recognize undue influence due to personal interests, assumptions, and biases in these studies (Malterud, 2001; Ryan & Golden, 2006). For me, such influence was exemplified by the various linguistic choices made during the design of Studies III and IV. The validation of the DLI in Sweden was part of an international collaboration involving researchers from Sweden, Australia, Belgium, and the Netherlands. This meant that few "standard formulations" could be used for collecting background questions, since terms such as civil status, education, and employment differed between countries. The process of specifying the socio-demographic questions became a form of joint reflexive process which showed that, as researchers, we perceive and value different things in the data. Similarly, a joint reflexive process was performed during the development of the DLI-S in Study III, and it became clear that the researchers' different backgrounds influenced how words and concepts were understood. Keeping notes from the consensus meetings proved vital for clarifying the reasoning behind decisions made about translation. Including a literacy review in the translation and validation process further demonstrated how, as researchers, we shaped the data collection through our choice of language. There was an intricate balance between deciding which difficult or uncommon words were important for capturing the subtleties of a latent construct, death literacy, and which were due to being blind to our use of academic terms. In summary, these examples show how researchers' perspectives might alter the questions, which in turn may affect the accuracy of the data, as discussed above.

8 FUTURE PERSPECTIVES

8.1 IMPLICATIONS OF FINDINGS

I will now describe some study processes and findings that have already had an impact and consider potential future implications of the thesis findings for policy, practice, and research.

8.1.1.1 Implications for policy

This thesis addresses a subject which is of considerable societal importance, since death affects us all and the provision of EOL care constitutes a public health issue. The COVID-19 pandemic has further highlighted the necessity of societal preparedness for EOL care, for example making informed decisions in line with a care recipient's individual values. In Sweden, this recognition has had an impact at policy level. The findings of this thesis align with several recent suggestions for policy changes regarding EOL care in Swedish elder care, such as implementation of coordinated and proactive approaches to palliative care (Nyholm & Björkman, 2021; Swedish Association of Local Authorities and Regions, 2020) and the need to strengthen care recipients' involvement in care planning (Swedish Government Official Reports, 2020).

In summary, based on this thesis, I would suggest two specific policy recommendations for improved practice:

- Awareness of the importance of proactive palliative care, and the necessary competence for its provision, needs to be strengthened among staff workingin residential elder care
- Person-centered care at the EOL cannot be achieved without active communication about EOL issues with those who are affected, i.e., residents and their relatives

8.1.1.2 Implications for practice

The PAR processes generated engagement and continued action and collaboration among participants and stakeholders in elder care. As mentioned above, the workshops in Study I resulted in several staff-led initiatives in which the DöBra cards were used in different ways, for example for staff reflection and education, or to discuss EOL care preferences with residents and relatives. These spin-off effects led to wider dissemination of the DöBra cards both within and across elder care services.

Throughout Studies I and II, findings were disseminated primarily through follow-up meetings and presentations, which stimulated and informed stakeholders at an organizational level to initiate changes in practice. One example is the practical guide for proactive EOL conversations using the DöBra cards, which was developed by the project group in Study II. To date, this guide has been distributed to 141 RCHs in the Stockholm city region as part of a wider promotion of proactive EOL conversations. Availability of such guidance might encourage and assist RCH staff in becoming more engaged in EOL communication, which might in turn contribute to the normalization among both staff, residents, and relatives of proactively addressing EOL care. The effects of this, however, remain to be seen.

In summary, the findings in this thesis indicate that proactive EOL conversations are feasible in the RCH context and can be facilitated in a way to meet the particular needs that are common in the resident population, such as cognitive decline. Furthermore, this thesis shows that participating in conversations about EOL issues can contribute to developing death literacy through accumulative experience-based competence-building. The findings also identify some issues concerning implementation in care practice which need further exploration. These include whether, how, and where information generated in proactive EOL conversations should be documented, and how to best support communication about EOL care preferences across multi-professional teams.

8.1.1.3 Implications of using participatory action research

Discussion about the use of PAR integrates findings, methodological considerations, and implications; however, I will focus here on the impact of PAR on participating staff and services. The use of PAR in this thesis mainly demonstrated impact on two levels. On the individual level, we noted changes in awareness, attitudes, and interest, which supported learning. For example, the workshops in Study I generated suggestions for improvement and identified areas in which staff felt they needed more support to develop their communicative abilities. This finding highlights the value of participants' engagement in PAR processes in enabling them to identify tacit knowledge, their own strengths, and areas for development that are important for enacting change (Hockley et al., 2013; Koshy et al., 2010). These individual processes in turn prompted action at group level, mainly in the form of staff-led initiatives using the DöBra cards in the participating services. The variety of individually driven spin-off uses of the DöBra cards supports prior findings by Eneslätt et al. (2021), which showed a breadth of strategies in the dissemination of the DöBra cards after they became publicly available in Sweden.

Taken together, Studies I and II support Kleijberg et al.'s (2022) description of how PAR can inform and bring about participant-driven change. Our findings suggest that PAR impacted participants by building awareness and allowing the development of ideas from insights acquired during the study process. In addition, PAR appeared to support action-oriented impact where identified problems and suggestions for change guide practice in individual services, as well as strategy-oriented impact, where insights inform changes to practice and policy at a higher organizational level .

Nevertheless, the PAR studies in this thesis reflect a primarily bottom-up process. Bentur and Sternberg (2019) propose that for sustainable change to occur, synergy between top-down (such as legislation, policy, and documentation) and bottom-up actions (such as local initiatives and changes in routines in organizations) is required, with neither process being sufficient on its own.

8.1.1.4 Implications for research

The findings in this thesis provide a basis for a range of continued research objectives, some of which are ongoing. One contribution of this thesis is the translated and validated version of the DLI to measure EOL competence in the Swedish context. The DLI-S is a needed addition to the currently existing tools, since instruments to measure overarching EOL competence with good psychometric properties have been lacking in Sweden. The broad set of knowledge and skills in relation to different aspects of EOL care captured in the DLI may make it applicable for use in a variety of settings with both professional and family caregivers. This would be especially useful in light of the increasing interest in EOL competence-building initiatives outside of formal care settings (Sallnow, 2018).

Identifying the factors that influence death literacy is helpful in understanding the construct and how it develops, which is of particular relevance for future educational interventions. This thesis has generated new knowledge about the cross-cultural viability of the death literacy model and the use of the DLI to measure it, and therefore provides a foundation for further research. For example, the DLI scores reported in Study III can provide a point of comparison for death literacy levels in future studies. In addition, the explanatory model constructed in Study IV might inform future studies aiming to further investigate death literacy.

Furthermore, experiences and insights from the participatory research process and findings in Studies I and II constitute the foundation for an addition, ongoing, project in the DöBra research program led by doctoral student Åsa Olsson. The findings in Studies III and IV also informed the choice of using the DLI-S as a measure for EOL competence in an educational intervention with staff facilitators of proactive EOL conversations in RCHs.

8.2 FUTURE RESEARCH

During my work with this thesis, several new questions for further research have been developed, which will be presented here.

8.2.1.1 Death literacy and its development

The findings presented in this thesis suggest that direct EOL encounters play a central role in building death literacy. However, further research, particularly predictive studies, is needed to assess the proposed explanatory model for death literacy development presented here, and better understand factors that influence this process. Given the inconclusive findings regarding the link between competence and actual behavior described earlier, future studies might also investigate whether higher death literacy translates into changes in practice, such as increased involvement in EOL conversations and which factors might support this process. Another related issue to study is whether changes in death literacy can be sustained long-term and the possible facilitators and inhibitors for this to occur.

Furthermore, it is theorized that death literacy is indicative of caregiver capacity, especially among family caregivers (Leonard et al., 2022). At the same time, it is known that family caregivers perceive a significant burden from care provision at the EOL. Future studies could explore whether there is a connection between death literacy levels and perceived burden in order to further build on research aiming to better prepare and equip family caregivers for EOL care (Becque et al., 2019).

8.2.1.2 Implementation of proactive end-of-life conversations in elder care

This thesis has contributed to better understanding of how to overcome individual barriers for EOL conversations, primarily discomfort and perceived lack of skills. Still, additional research is needed to also identify and examine strategies to overcome organizational barriers and strengthen institutional leadership. Such barriers have been noted in this thesis as well as in prior research about implementing proactive EOL conversations in elder care (Baughman et al., 2015; Beck et al., 2017). PAR approaches might be helpful for evaluating such strategies (Froggatt & Hockley, 2011).

Experimental studies with longer follow-up periods are needed to investigate whether use of proactive EOL conversations can lead to concrete changes in outcomes for care recipients and relatives, including concordance of care preferences, as was suggested in a recent study by Towsley et al. (2022). Satisfaction with communication and involvement in decision-making are other outcomes that might be examined. Future research should also investigate outcomes for staff following participation in EOL conversations, for example improvements in communication skills, confidence, and attitudes.

8.2.1.3 Usability of the DöBra cards

It should be noted that the residents invited to take part in EOL conversations by the participants in Study I and II were primarily cognitively competent. Previous studies with the DöBra cards have also focused on generally healthy older adults (Eneslätt, 2021). Thus, it is important for future studies to investigate the usability and value of the DöBra cards to discuss EOL care with residents with moderate and severe cognitive impairment in order to better understand the potential impact of the tool among a broader population of RCH residents. Fhe research in this thesis has focused on staff perspectives of using the DöBra cards in EOL conversations. Further studies should, therefore, explore residents' and relatives' perspectives and whether proactive EOL conversations might support death literacy development among these stakeholders. The use of the DöBra cards could also be investigated in other settings, such as informal EOL conversations facilitated by lay-people.

8.2.1.4 Theoretical understanding of the Death Literacy Index and its usefulness in practice

With further validation, the DLI could become a multifaceted instrument for future cross-cultural research about EOL competence-building, which could be vital for advancing the field of PHPC. Prerequisite cross-cultural validation is the focus of an ongoing comparative study within the international collaboration described above. In addition, the validity of the DLI should be explored in the elder care context, especially if it is to be used to evaluate outcomes for EOL interventions with elder care staff. This would be particularly relevant to investigate since the need for comparable outcome measures for EOL education in elder care was recently pointed out in a review by Iida et al. (2021). However, there are currently no published cut-off values in the DLI for low and high death literacy, and it is not clear how care provision may vary according to different DLI scores. These questions remain for future studies to investigate.

Future research could also examine convergent validity of the DLI-S and theoretically related measures that have been validated in the Swedish context, such as the Swedish version of the Frommelt Attitude Toward Care of the Dying Scale (Henoch et al., 2014), which measures positive or negative attitudes towards caring for dying people. In addition, two instruments measuring EOL competence have recently been translated and validated in the Swedish context, the Swedish version of the Palliative Care Self-Efficacy (Andersson et al., 2022) and the Self-efficacy in Palliative Care Survey (Granat et al., 2022), both of which measure health care professionals' self-perceived abilities and confidence concerning various palliative care tasks.

9 CONCLUSIONS

This thesis contributes with new knowledge about how EOL competence and preparedness can be supported, which is valuable for designing competence-building interventions and informing future research in the field of public health palliative care.

The findings offer insights into specific means to stimulate and support EOL competence-building and how these can be promoted in practice. In particular, the thesis adds new knowledge about how staff can conduct proactive EOL conversations in residential elder care in a manner that is appropriate for the setting, and ways in which the DöBra cards can support this. These findings are central to continued efforts to improve and strengthen preparedness for EOL care provision in elder care practice.

This thesis adds theoretical knowledge about EOL competence-building to the research field from the examination of whether the conceptualization of EOL competence in the death literacy model is applicable cross-nationally. In addition, new knowledge has been gained about the viability of the DLI for measuring broad EOL competence that is not context- or profession-specific. This finding fills an important knowledge gap since there is a lack of validated instruments for evaluating such EOL competence, particularly outside specialized palliative care settings.

The following conclusions can be drawn from this thesis:

- Experience-based learning is central for building EOL competence. Specifically, a process integrating introspection and extrospection about past experiences and personal values, feelings, and opinions about dying, enables people to re-evalutate and learn from prior EOL encounters, and make tacit knowledge and assumptions explicit.
- The DöBra cards were found to be a useful tool for stimulating and structuring reflection about the EOL among elder care staff, thereby promoting experience-based learning and, on a broader perspective, death literacy development. The DöBra cards were also found to help staff facilitate proactive EOL conversations in elder care practice. Key features for the tool’s usability in the elder care setting included its physical format, which provided a visual and shared structure and vocabulary for exploring EOL values and preferences, and its flexibility in relation to individual needs of residents and relatives.
- The Swedish-language version of the DLI is a valid and psychometrically sound measurement, with findings supporting the six-factor multidimensional death literacy model. However, some items performed less well, likely due to differences in the organization of care systems between Swedish and Australian settings. The potential impact of such differences on the operationalization of death literacy in Sweden, and other countries, should be investigated further.

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12 APPENDICES

12.1 APPENDIX 1. DÖBRA CARD STATEMENTS

Swedish DöBra card statements	English translation of DöBra statements
Att vara fri från smärta	To be free of pain
Att inte ha svårt att andas	Not being short of breath
Att få vara ren och snygg	To be clean and neat
Att inte känna oro eller ångest	To be free of anxiety
Att känna mänsklig beröring	To have a human touch
Att mina närmaste är förberedda på min död	To have those close to me be prepared for my death
Att dö hemma	To die at home
Att ta avsked av personer som är viktiga för mig	To say goodbye to important people in my life
Att minnas det jag gjort/åstadkommit i livet	To remember personal accomplishments
Att reda ut oavslutade saker med andra	To take care of unfinished business with others
Att bli behandlad på det sätt jag önskar	To be treated the way I want
Att behålla min värdighet	To maintain my dignity
Att behålla min humor	To keep my sense of humor
Att omges av goda vänner	To have close friends near
Att ha någon som lyssnar på mig	To have someone who will listen to me
Att inte vara en börda för mina nära	Not being a burden to those who are close to me
Att kunna hjälpa andra	To be able to help others
Att kunna prata om sånt som gör mig orolig eller rädd	To be able to talk about what scares me
Att ha mina närmaste omkring mig	To have those I am close to around me
Att jag fått leva mitt liv fullt ut	To have lived my life to the fullest
Att ha en läkare som känner mig väl	To have a doctor who knows me well
Att inte dö ensam	Not dying alone
Att vara klar och redig	To be mentally aware
Att kunna be	To pray
Att ha kontakt med en företrädare för min religion	To meet with a representative of my religion
Att kunna samtala om vad döden innebär	To be able to talk about what death means
Att finna frid med min Gud	To be at peace with God
Att ha ordning på min ekonomi	To have my financial affairs in order
Att veta hur jag kommer att förändras kroppsligt	To know how my body will change
Att undvika konflikter genom att se till att mina närmaste vet vad jag vill	To prevent arguments by making sure my family knows what I want
Att ha någon som vet om mina värderingar och prioriteringar och kan föra min talan	To have an advocate who knows my values and priorities
Att ha förtroende för min läkare	To trust my doctor
Att vårdas av personal som jag trivs med	To be cared for by staff I feel comfortable with
Att min begravning är planerad	To have my funeral arrangements made
Att inte bli kopplad till medicinska apparater	Not being connected to machines
Att det finns någon som talar mitt språk	To have someone who speaks my own language
Valfritt alternativ	WILD CARD

Table adapted from Eneslätt et al. (2020) © Oxford University Press (CC BY 4.0) & Eneslätt (2021)

12.2 APPENDIX 2. THE DEATH LITERACY INDEX (LEONARD ET AL., 2021)

1. Practical knowing

1.1. Talking support

Please rate how difficult or easy you would find the following talking support (on a scale of 1-5 between Not at all able to Very able)

1. Talk about death, dying or grieving to a close friend
2. Talk about death, dying or grieving to a child
3. Talk to a newly bereaved person about their loss
4. Talk to a GP about support at home or in their place of care for a dying person

1.2 Hands-on care

Please rate how difficult or easy you would find the following hands-on care duties for the dying (on a scale of 1-5 between *Not at all able* to *Very able*)

5. Feeding a person or assisting them to eat
6. Bathing a person
7. Lifting a person or assisting to transfer them
8. Administering injections

2. Learning from experience

*Please rate how much each of the below statements sound like you (*on a scale of 1-5 between *Very untrue of me* to *Very true of me).*

My previous experience of grief, loss or other significant life events has

9. Increased my emotional strength to help others with death and dying processes
10. Led me to re-evaluate what is important and not important in life
11. Developed my wisdom and understanding
12. Made me more compassionate toward myself
13. Provided me with skills and strategies when facing similar challenges in the future

3. Factual knowledge

*Please rate how much each of the below statements sound like you (*on a scale of 1-5 between *Strongly disagree* to *Strongly agree)*

14. I know the law regarding dying at home
15. I feel confident in knowing what documents you need to complete in planning for death
16. I know how to navigate the health care system to support a dying person to receive care
17. I know how to navigate funeral services and options
18. I know how to access palliative care in my area
19. I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life
20. I know about the contribution the cemetery staff can make at end of life

4. Community capacity

4.1 Accessing help

*Please rate your level of agreement with the following statements (*on a scale of 1-5 between *Strongly disagree* to *Strongly agree).*

If I were to provide end of life care for someone, I know people who could help me

21. Access community support
22. Provide day to day care for the dying person
23. Access equipment required for care
24. Access culturally appropriate support
25. Access emotional support for myself

4.2 Support groups

Please rate your level of agreement with the following statements (on a scale of 1-5 between Strongly disagree to Strongly agree).

There are support groups in my community for

26. People with life threatening illnesses
27. People who are dying
28. Carers for people who are dying
29. People who are grieving

12.3 APPENDIX 3. THE SWEDISH DEATH LITERACY INDEX AND ITS ENGLISH TRANSLATION

Swedish Death Literacy Index (DLI-S)	**English translation of the DLI-S**
Detta frågeformulär undersöker kunskaper och förmågor som rör livets slut. Frågeformuläret kan användas av alla, oavsett om du har tidigare erfarenhet av livets slut eller inte. I frågeformuläret kommer du att få svara på hur väl olika påståenden stämmer in på dig. Det finns inget rätt eller fel svar, utan vi är intresserade av din uppfattning så som den ser ut idag.	This questionnaire explores knowledge and skills related to the end of life. The questionnaire can be completed by anyone, whether or not you have earlier experience related to the end of life. In this questionnaire, you will answer questions about the extent to which you agree with different statements. There are no right or wrong answers, as we are interested in your perspectives at present.
1. Praktisk kunskap	**1. Practical knowing**
1.1. Samtal om att dö, döden eller sorg	**1.1. Conversations about dying, death, or grief**
Hur beredd skulle du vara att prata om följande?	*How prepared would you be to talk about the following?*
Ange ditt svar på en skala mellan 1-5, där 1=inte alls beredd och 5=mycket beredd	*Give your answer on a scale from 1-5, where 1=not prepared at all and 5=very prepared*
1. Att prata om att dö, döden eller sorg med en nära vän	1. To talk about dying, death, or grief with a close friend
2. Att prata om att dö, döden eller sorg med ett barn	2. To talk about dying, death, or grief with a child
3. Att prata med en sörjande person om hens förlust	3. To talk with a bereaved person about their loss
4. Att prata med vårdpersonal om stöd till en person som kommer att dö i hemmet eller på den plats där hen får vård	4. Talk with care staff about support for a person who will die at home or in their place of care
2. Erfarenhetsbaserad kunskap	**2. Experience-based knowledge**
Hur stämmer följande för dig? *Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*	*To what extent do you agree with the following? Indicate your response on a scale from 1-5, where 1=do not agree at all and 5=strongly agree*
Tidigare erfarenheter av sorg, att förlora någon eller andra viktiga händelser i livet har...	***Previous experiences of grief, losing someone, or other important life events have…***
9. Gjort mig mer känslomässigt förberedd att ge stöd till andra i processer kring döden	9. Made me more emotionally prepared to support others with processes related to death and dying
10. Fått mig att fundera på vad som är viktigt och mindre viktigt i livet	10. Made me think about what is important and not important in life
11. Gjort mig mer klok och gett mig ny förståelse	11. Made me wiser and given me new understanding
12. Ökat min medkänsla för mig själv	12. Increased my compassion toward myself
3. Kännedom om processer och system relaterade till livets slutskede	**3. Knowledge about processes and systems related to the end of life**
Hur stämmer följande för dig?	*To what extent do you agree with the following?*

Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl	*Indicate your response on a scale of 1-5, where 1=do not agree at all and 5=strongly agree*
14. Jag känner till de regelsystem som rör dödsfall i hemmet	14. I know about rules and regulations regarding deaths at home
15. Jag känner till att det finns dokument som kan hjälpa en person att planera inför döden	15. I know that there are documents that can help a person plan before death
16. Jag vet tillräckligt mycket om hur vård och omsorg fungerar för att kunna stödja en person att få vård i livets slut	16. I know enough about how the health and social care systems operate to be able to support a person in receiving care at the end of life
17. Jag känner till processen inför begravning, vart jag kan vända mig och vilka val som finns	17. I know about processes for funerals, where I can turn, and which choices are available
18. Jag känner till hur jag får tillgång till palliativ vård i området där jag bor	18. I know how to access palliative care in the area where I live
19. Jag vet tillräckligt för att kunna ta beslut om medicinska behandlingar och förstå hur de kan påverka livskvaliteten i livets slut	19. I know enough to make decisions about medical treatments and understand how they may affect quality of life, at the end of life
20. Jag känner till olika sätt som personal vid begravningsplatser kan vara till hjälp vid begravning	20. I am aware of different ways that cemetery staff can be of help around funerals
4. Kunskaper om samhället där du bor	**4. Knowledge about the community where you live**
4.1. Hur andra kan hjälpa mig med vård i livets slut	***4.1 How others can help me with end-of-life care provision***
Hur stämmer följande för dig? *Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*	*To what extent do you agree with the following? Indicate your response on a scale from 1-5, where 1=do not agree at all and 5=strongly agree*
Om jag skulle ta hand om en person i livets slut, så känner jag till var jag kan vända mig för:	***If I were to care for someone at the end of life, I know where to turn:***
21. Att få stöd i området där jag bor, exempelvis från föreningar eller frivilligorganisationer	21. To get support in the area where I live, e.g., from clubs, associations, or volunteer organizations
22. Att få hjälp med att ge en person daglig vård under livets sista tid	22. To get help with providing day to day care for a person at the end of life
23. Att skaffa hjälpmedel som behövs för vård	23. To get equipment that are required for care
24. Att få tillgång till stöd som passar personens kultur	24. To get support that is culturally appropriate for a person
25. Att få tillgång till eget känslomässigt stöd	25. To get emotional support for myself
4.2. Stödgrupper	***4.2 Support groups***
Hur stämmer följande för dig? *Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*	*To what extent do you agree with the following? Indicate your response on a scale from 1-5, where 1=do not agree at all and 5=strongly agree*

Jag känner till att det finns stödgrupper för:	***I know that there are support groups for:***
26. Personer som har en sjukdom som kan leda till döden	26. People with diseases that might lead to death
27. Personer som inte har långt kvar att leva	27. People who are nearing the end of their lives
28. Personer som tar hand om någon som är döende	28. People who are caring for someone who is dying
29. Personer som sörjer	29. People who are grieving