A web-based intervention to promote preparedness for caregiving

A RANDOMISED CONTROLLED TRIAL AMONG FAMILY CAREGIVERS IN SPECIALISED PALLIATIVE HOME CARE

Cecilia Bauman

MARIE CEDERSCHIÖLD UNIVERSITY

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ISSN: 2003-3699
ISBN: 978-91-985807-6-1
Theses series within the field The Individual in the Welfare Society

Published by:
Marie Cederschiöld University
www.mchs.se

Cover illustration: Rosanna Emas
Printed by: US-AB, Stockholm, 2026

Institutionen för vårdvetenskap

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Akademisk avhandling
som för avläggande av filosofie doktorsexamen vid
Marie Cederschiöld högskola offentligen försvaras

fredag den 20 november 2026, kl 09.00
Marie Cederschiöld högskola

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Abstract

A web-based intervention to promote preparedness for caregiving:
A randomised controlled trial among family caregivers in specialised palliative home care

Cecilia Bauman

Family caregivers of patients with life-threatening illness report feelings of inadequacy and uncertainty, and insufficient support. This thesis explores support needs, preparedness for caregiving, and evaluates the family caregiver-targeted psychoeducational intervention 'narstaende.se' in specialised palliative home care, using a randomised controlled design employing qualitative and quantitative methods. Interview results showed that 'narstaende.se' provided reassurance and comfort (III), facilitated shared everyday life for family caregivers and patients (IV), and initiated conversations between them (III, IV). Family caregivers' accounts indicated improved preparedness for caregiving, though no statistically significant effect was demonstrated (II). Family caregivers' support needs are individual and changeable (I), and caregiving circumstances as well as the relationship with the patient were important for how relevant the intervention's content was perceived to be (III, IV). At the same time, the intervention influenced the relationship by raising awareness of different perspectives, important for promoting preparedness for caregiving (IV). Family caregivers needed support to manage their emotions (I, III) and found 'narstaende.se' helpful (III). However, engaging with certain content, such as illness progression or impending death, could be challenging, and some therefore chose to avoid this (III, IV). In conclusion, this thesis highlights the complexity and challenges of providing and evaluating web-based support, where usage is determined by individual choices. Web-based support should be viewed as a flexible complement to in-person support, tailorable to family caregivers' varying needs and circumstances.

Keywords: Family caregivers, intervention, palliative care, preparedness for caregiving, web-based support

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I. Bauman, C., Årestedt, K., Wallin, V., Fürst, P., Hudson, P., Kreicbergs, U., & Alvariza, A. (2026). Associations between support needs and preparedness among family caregivers in palliative home care. *International Journal of Palliative Nursing*, *32*(5), 232–240. doi:10.12968/ijpn.2025.0102

II. Bauman, C., Årestedt, K., Wallin, V., Tibell, L. H., Fürst, P., Hudson, P., Kreicbergs, U., & Alvariza, A. (2025). Web-based psychoeducational intervention to improve family caregiver preparedness in specialized palliative home care: A randomized controlled trial. *Psycho-Oncology*, *34*(6), e70202. doi:10.1002/pon.70202

III. Bauman, C., Wallin, V., Doveson, S., Hudson, P., Kreicbergs, U., & Alvariza, A. (2025). Resonance, self-reflection, and preparedness through a web-based intervention for family caregivers of patients with life-threatening illness receiving specialised home care. *Palliative & Supportive Care*, *23*, e48. doi:10.1017/S1478951524002086

IV. Bauman, C., Wallin, V., Doveson, S., Fürst, P., Hudson, P., Kreicbergs, U., & Alvariza, A. (2025). The family caregiver-targeted web-based intervention "narstaende.se" facilitated everyday life for couples facing life-threatening illness: A qualitative study. *Palliative Medicine*, *39*(5), 574-583. doi:10.1177/02692163251327893

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Abbreviations

Abbreviation	Term
CSNAT	Carer Support Needs Assessment Tool
IAHPC	International Association for Hospice and Palliative Care
MRC	The UK Medical Research Council
PCS	Preparedness for Caregiving Scale
RCT	Randomised controlled trial
WHO	World Health Organization

Preface

As a young teenager, I lost my mother to cancer. During the time of her illness and death, our family found ourselves in a new and unfamiliar situation. We had to adapt to new life circumstances while in a state of emotional turmoil and grief. This experience has remained with my family, and even today I cannot fully grasp the impact it has had on us. It also set me on a personal journey to understand illness and palliative care, and to do good for other families in similar situations. I have come to realise that this is partly why I have spent my professional life working as a registered nurse in palliative care.

Part of the everyday work of a nurse in palliative care involves meeting families living in the closeness of death. In my experience, how each family member handles the illness can become intertwined with the family's everyday lives and relationships. Having seen this many times has made me realise that although what my family went through was a unique experience for us, it is also an experience we share with other families facing life-threatening illness. Today, I recognise that my experiences have shaped my commitment to supporting families in palliative care.

Palliative care has metaphorically been described as being the umbrella rather than the rain. Just as an umbrella does not bring the rain, palliative care is not the source of distress but offers protection when it arises. I have come to think of preparedness and support in much the same way. They cannot prevent the challenges of caregiving, but they may help family caregivers navigate them. In line with this perspective, this thesis aims to explore family caregiver support needs and preparedness for caregiving, and to evaluate a web-based psychoeducational intervention among family caregivers of patients with life-threatening illness during specialised palliative home care.

1. Introduction

It has been recognised for some years that the need for palliative care is likely to increase in the coming decades due to increasing deaths from chronic illnesses, population ageing, and an overall increase in deaths from progressive illnesses (Etkind et al., 2017). Many patients with life-threatening illness would prefer to be cared for and die at home (Nilsson et al., 2024; Pinto et al., 2024), where family caregivers are crucial care and support providers, complementing professional health care (Challis et al., 2025). Home-based palliative care often affects family caregivers' and patients' everyday lives and daily routines, as it extends into their private sphere (Sabar et al., 2024).

Despite family caregivers' essential contributions in providing care and support to patients (Van Goethem et al., 2023), many family caregivers lack adequate support (Zavagli et al., 2022). A lack of support and a higher perceived level of care burden increase the risk that caregiving will have a negative impact on the family caregiver (Malki et al., 2025). In 2022, the Swedish government introduced a national strategy, emphasising the need for more individualised and equitable support for family caregivers across health care and social services (Socialdepartementet, 2022). Preparedness for caregiving has been identified as a protective factor against the negative impacts and perceived strain of caregiving (Gutierrez-Baena & Romero-Grimaldi, 2022; Karabulutlu et al., 2022). In this thesis, preparedness for caregiving is a key concept and refers to the self-perceived readiness across various domains of caregiving, including physical care, emotional support, and stress management (Archbold et al., 1990). Throughout the thesis, the results are framed in relation to the concept.

Today, the internet provides a platform for the dissemination of information that is accessible regardless of time and place (Tieman et al., 2023), which may be preferable for family caregivers (Coumoundouros et al., 2023). Although many web-based interventions for family caregivers have been developed and evaluated (Ploeg et al., 2018; Sherifali et al., 2018), their ability to promote preparedness for caregiving remains insufficiently studied. Against this backdrop, this thesis aims to explore family caregiver support needs and preparedness for caregiving, and to evaluate a web-based psychoeducational intervention among family caregivers of patients with life-threatening illness during specialised palliative home care.

2. Background

Palliative care is a discipline with holistic foundations, one aspect of which is recognising family caregivers, who provide vital care and support to patients. To understand contemporary palliative care and the support offered to family caregivers in home care, it is necessary to consider the historical development of palliative care and the role of family caregivers.

2.1. Palliative care from its origins to the contemporary welfare society

Cicely Saunders (1918–2005) is regarded as the initiator of palliative care philosophy (Clark, 1999). She founded the first modern hospice and coined the concept of *total pain,* which now lies at the core of palliative care. Total pain recognises pain as a holistic, lived experience with physical, psychological, social, and spiritual dimensions (Clark, 1999; Mehta & Chan, 2008). Family caregivers can be part of any dimension of pain and are therefore integral to the concept (Mehta & Chan, 2008). The work of Cicely Saunders and the concept of *total pain* have been immensely important in shaping the way patients and families facing death are cared for, and the concept remains a key tenet of palliative care (Clark, 1999). This holistic understanding of pain, focusing on both patients and their families, is reflected in the World Health Organization's (WHO) definition of palliative care as 'an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual' (World Health Organization, 2020). However, Cicely Saunders herself pointed out in her later writings that, in the early days of palliative care, the focus was largely on patients with cancer, which prevented acceptance of other conditions that could cause suffering (Saunders, 2001). Over the years, the focus has shifted towards alleviating suffering for a more diverse population of patients and family caregivers, and palliative care has evolved from being seen as an alternative to life-prolonging care to being recognised as a beneficial addition to care aimed at prolonging life (Kelley & Meier, 2010).

To reflect the expanded view on palliative care, the International Association for Hospice and Palliative Care (IAHPC) has provided an alternative definition of palliative care as: 'the active, holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially those near the end of life. It aims to improve the quality of life of patients and their families' (International Association of Hospice and Palliative Care, 2018). However, this definition has been disputed, with disagreement regarding whether it is too broad and could lead to palliative care being applied to all illnesses, including acute and transient conditions (Radbruch et al., 2020; Ryan et al., 2020). The term 'palliative approach' has been proposed to ensure access to adequate care across care facilities, based on patient and family needs (Sawatzky et al., 2016; Touzel & Shadd, 2018). Grounded in palliative care's holistic philosophy, the palliative approach has a threefold focus: the whole person, quality of life, and acknowledgement of mortality (Touzel & Shadd, 2018). There is consensus that a holistic palliative approach includes the family and applies to anyone facing a life-threatening illness (Payne et al., 2022), linking central elements of palliative care philosophy to all healthcare contexts (Touzel & Shadd, 2018). Importantly, the provision of palliative care to patients and support to their families has been described as an ethical duty for healthcare professionals (World Health Organization, 2020).

Despite the ongoing discussion about how to define palliative care, all definitions and models focus on including both patients and family caregivers, since providing holistic care also requires supporting the patient's family. Drawing on the WHO's definition of palliative care, this thesis uses the term *life-threatening illness* to describe the illness context of the participating family caregivers and patients. The term conveys both the severity of the illness and the uncertainty inherent in living close to death. However, in the context of this thesis, several definitions of palliative care could be relevant. Therefore, the choice of the term *life-threatening illness* should not be seen as rejecting other terms or definitions.

Voices have been raised that we are witnessing an ongoing medicalisation of palliative care with an increasing focus on the physical aspects of the illness, with the risk of eroding palliative care's core concept of *total pain* (Moran et al., 2021). In a report by the Lancet Commission on the Value of Death, Sallnow et al. (2022) summarise death and dying in the 21st century from a global perspective. The

report concludes that in modern society, the view of death and dying is unbalanced and contradictory: that death should be either defeated or controlled. Building on this, it is crucial to consider the impact this may have on family caregivers, since living in a society where death awareness is not emphasised can leave one unprepared when faced with caregiving responsibilities. Furthermore, in today's welfare society, access to palliative care is systematically unequal across geographical, ethnic, socioeconomic, and organisational dimensions, underscoring palliative care as a public health concern (Sítima et al., 2024).

2.2. Home-based palliative care

Home-based palliative care has significant and complex implications for family caregivers, who are central to enabling care at home (Challis et al., 2025). In this context, patient care is provided through a combination of specialised palliative care services and family caregiving, where family caregivers often remain responsible for providing emotional support to the patient (Woodworth, 2024).

Population-level studies from Sweden indicate a slight increase in deaths at home in recent years, although hospitals remain the most common place of death (Larsdotter et al., 2024). A previous review found that home is usually the preferred place of death among patients with life-threatening illness and their families (Pinto et al., 2024). This is consistent with findings from a Swedish context of patients with cancer enrolled in specialised palliative home care, showing that the majority preferred the home as the place of death, which most often also aligned with their actual place of death (Nilsson et al., 2024). However, the place of death does not necessarily correspond with the patients' preferred place for care at the end of life. Preferences regarding where to receive care and where to die are multifaceted, changeable, and heavily dependent on context and the situation of family caregivers (Pinto et al., 2024). In a Swedish context, patients receiving specialised palliative home care are also frequently transferred to inpatient care near death (Wall et al., 2024). Such transitions may reflect changing needs, increasing symptom burden, or challenges in sustaining care at home. Healthcare services can enhance family caregivers' confidence and ability to provide care and to persevere as caregivers, but a lack of continuity, availability, or clarity of responsibilities can increase the burden on family caregivers and lead to crisis-driven hospital admissions (Challis et al., 2025).

2.3. Family caregivers in palliative care

In palliative care, family members often take on the role of caregivers. A family caregiver is defined as any relative, friend, or partner with a significant personal relationship who provides assistance to a person with a life-threatening illness (Hudson & Payne, 2009). Although they may not always see themselves as caregivers, research shows that they often perform a range of supportive and caring tasks for the patient, such as providing emotional support, physical care, and practical help (Van Goethem et al., 2023). Family caregiving can be a mixed experience, and while many find it brings a sense of meaning, it can also be psychologically demanding (Van Goethem et al., 2023). Family caregivers may feel overwhelmed when expected to perform caregiving tasks they perceive as unmanageable (Midlöv et al., 2026), and taking on the role of a caregiver can evoke feelings of inadequacy, powerlessness, and uncertainty (Wang et al., 2018). This ambivalence is also evident in a Swedish context, where family caregivers of patients receiving specialised palliative home care describe the home as both a secure and a highly demanding place, sometimes experiencing insufficient support and being left with substantial responsibility for care (Söderman et al., 2026).

Existential and emotional challenges among family caregivers may manifest as distress-related symptoms, such as sadness, exhaustion, and worry (Ullrich et al., 2025), which can have a negative impact on family caregivers' physical and psychological health (Malki et al., 2025; Zavagli et al., 2022). A lack of support and confidence in caregiving, as well as higher levels of perceived caregiver burden, increase the risk of being negatively impacted by caregiving (Malki et al., 2025). Family caregivers have described feeling left out and overlooked by healthcare professionals, a lack of acknowledgement that contributes to exclusion and loneliness (Midlöv et al., 2026). As a response to the demands of caregiving, many family caregivers try to adapt to the caregiver role while continuing to struggle to balance it with their own lives (Cai et al., 2021).

Illness can have an impact on family life through its effects on previously established roles, communication, and emotional dynamics (Oliveira et al., 2024). By mirroring the patient's distress, family caregivers share the illness, making it a dyadic experience (Jacobs et al., 2017). When spouses become caregivers, the couple's everyday lives are affected, as household chores and responsibilities may

shift between them, potentially altering the power balance (Andréasson et al., 2021). Furthermore, patients may feel that they are a burden to their family, which can shift the balance in their relationship (Lilleheie et al., 2021). Family caregivers may feel that the home becomes a place where caregiving responsibilities are always at the forefront, requiring a constant presence during the care period (Midlöv et al., 2026). As family caregivers and patients share the illness experience, their ability to manage illness together is essential (Weitkamp et al., 2021). Mutual communication between family caregivers and patients could help them manage the impact of life-threatening illness (Otto et al., 2021; Weitkamp et al., 2021). However, many families commonly experience emotional barriers that hinder the initiation of such conversations (Nagelschmidt et al., 2021).

2.3.1. Preparedness for caregiving

Preparedness for caregiving is a key concept in this thesis. It was first conceptualised in the seminal work of Archbold et al. (1990), defined as 'how well prepared the family caregiver believes he or she is for the tasks and stress of the caregiver role'. A recent concept analysis by Dal Pizzol et al. (2024) proposes a refined definition of preparedness for caregiving: 'the self-confidence about current competence related to the knowledge, skills, and abilities to perform daily tasks, and to handle emotions over time'. Although the definitions overlap, Dal Pizzol et al. (2024) arguably place greater emphasis on practical caregiving activities by incorporating the terms competence, skills, and abilities, as well as adding the duration of caregiving as an important component.

Preparedness for caregiving has been described as an ongoing process throughout the illness trajectory, rather than something that can be done in advance. During this process, family caregivers may gradually realise the seriousness of the illness, adjust to the evolving challenges of caregiving, and anticipate the patient's death (Holm, Henriksson, et al., 2015; Janze & Henriksson, 2014). The process of preparedness for caregiving may need to start over as the condition changes and new situations arise (Holm, Henriksson, et al., 2015).

During this ongoing process, preparedness for caregiving also involves becoming aware of death and living with the uncertainty of when death will occur. Family caregivers have described preparedness for caregiving as trying to manage the present while at the same time preparing for an uncertain future (Janze &

Henriksson, 2014). The awareness of death may vary and can be triggered by changes in the patient's symptoms or deterioration (Janze & Henriksson, 2014). Although preparedness for caregiving and preparedness for death are separate concepts, they are also closely interrelated. Findings demonstrate a significant association between the two, including both cognitive and emotional aspects of preparedness for death, indicating that preparing to care for a patient at the end of life involves preparing for their death, with these aspects developing in parallel rather than independently (Häger Tibell et al., 2024).

Earlier literature has described how preparedness for caregiving may protect against the negative impacts of caregiving by reducing perceived strain of the caregiver role (Archbold et al., 1990; Gutierrez-Baena & Romero-Grimaldi, 2022; Karabulutlu et al., 2022). Archbold et al. (1990) developed the concept based on the idea that caregiving is self-appraised rather than an objectively measurable skill, and that preparedness for caregiving does not alter the actual stress of caregiving, but rather how the family caregiver perceives it. More recent research across different caregiving contexts is in line with this assumption, demonstrating that preparedness does not eliminate distress but influences the impact of caregiving on outcomes such as care burden, depression, and quality of life (Karabulutlu et al., 2022; Pucciarelli et al., 2022). Conceptually, preparedness for caregiving is preceded by adequate information and training from organised support, a willingness to provide care, as well as support from family, friends, and the community (Dal Pizzol et al., 2024).

2.4. Support for family caregivers

Despite the importance of considering the needs of patients and family caregivers in palliative care, a gap remains between the support needs of family caregivers and how these needs are addressed in practice, with insufficient support available (Kreyer et al., 2024; Zavagli et al., 2022). Family caregivers report extensive and multifaceted unmet needs related to both caregiving responsibilities, such as providing care and giving medications, and their own health and well-being, such as their emotions and everyday life (Kreyer et al., 2024). This has also been observed in a Swedish context, where family caregivers reported needing more support, particularly in the form of information and practical advice (Malki et al., 2025).

Support is a broad concept, often referred to as *social support* within sociology and psychology to emphasise how relationships and social contexts shape access to and experiences of support (House, 1981). However, within nursing, it has been argued that the term *support* better captures its dual nature, encompassing both practical and emotional dimensions (Stoltz et al., 2007). From this perspective, support for family caregivers includes both tangible components, such as information and assistance, and intangible components, such as emotional affirmation and opportunities to share experiences (Stoltz et al., 2007).

Although acts of support are typically well-intentioned, they may still become a source of distress (Stoltz et al., 2007; Thoits, 2011). Support that does not match the individual's needs may lead to feelings of not being seen or understood (Cutrona, 1990). Support must therefore be understood in relation to how it is perceived by the recipient, and its effectiveness depends on whether it matches the nature of the stressful situation. According to Cutrona (1990), when situations are perceived as controllable, support focused on information and esteem may be most effective, whereas uncontrollable situations call for emotional support, tangible resources, and social connection.

In a caregiving context, family caregivers face both controllable and uncontrollable challenges. While tasks such as symptom management (controllable) may benefit from knowledge and guidance, illness progression and uncertainty (uncontrollable) more often require emotional support such as reassurance and caring (Cutrona, 1990). In palliative care, the support needs of family caregivers change throughout the illness, and it is challenging to identify what support to offer when it is most needed (Marco et al., 2022). At the same time, family caregivers' increasing caregiving demands over time tend to overlap with greater support needs but also reduced time and emotional resources for seeking support (Choi et al., 2024).

Having unmet support needs as a family caregiver has been associated with poorer quality of life and health (Norinder et al., 2021). A study in a Swedish palliative home care context explored the perceptions of care and support in family caregiver–patient dyads and demonstrated that family caregivers felt less safe and supported compared to patients (Liljeroos et al., 2021), suggesting that care and support may not sufficiently target both of them. The importance of considering

family caregivers as part of the unit of care has been highlighted and recommended when providing support to family caregivers (Applebaum et al., 2024). Importantly, family caregiver-targeted support that enhances the sense of being a unit of care may also benefit patients (Norinder et al., 2017).

2.4.1. Family caregiver-targeted interventions

A wide range of interventions have been developed to support family caregivers in palliative care, varying in design, content, and mode of delivery (Alshakhs et al., 2024; Becque et al., 2023; Oliveira et al., 2022). This reflects the complexity of standardising the holistic nature of palliative care through guidelines (Oliveira et al., 2022) and also the multidimensional and diverse issues associated with family caregiving (Becque et al., 2023). This heterogeneity in study designs makes it difficult to determine why interventions may be effective and how to target specific outcomes (Alshakhs et al., 2024; Becque et al., 2023). Interventions for family caregivers in palliative home care have mainly focused on providing short-term practical and psychosocial support as part of routine care, typically delivered by healthcare professionals (Alshakhs et al., 2024). Delivering interventions in person requires time and commitment and is therefore a logistical challenge for healthcare professionals, and the in-person format may not appeal to all family caregivers (Holm, Carlander, et al., 2015). Furthermore, a perceived lack of time and difficulty leaving the home due to caregiving responsibilities present barriers for family caregivers to access in-person support (Benson et al., 2020).

Psychoeducation is a type of intervention that can be delivered in a variety of formats, commonly used in clinical research, that combines education and psychosocial support to increase knowledge, enhance coping, and improve health-related outcomes (Kusi et al., 2023). In the context of family caregivers of patients with cancer, psychoeducational interventions mainly include content related to providing patient care, self-care for the family caregiver, and relationship and coping skills (Cheng et al., 2022). Systematic reviews further show that psychoeducational interventions can influence multiple family caregiver-related outcomes, including psychological well-being, burden, and quality of life, although the timing and durability of these effects remain insufficiently studied (Cheng et al., 2022; Kusi et al., 2023).

Over the past decades, the internet has become an essential platform for the distribution of information, offering convenient accessibility and the potential to overcome geographic and time barriers (Tieman et al., 2023). Many family caregivers report using digital technology daily (Malki et al., 2025). In addition, previous research shows that family caregivers perceive digital support as favourable since this can be accessed at a convenient time (Coumoundouros et al., 2023). However, although many family caregivers share a need for practical and emotional support, education, and communication strategies, their actual needs differ, and online information is often perceived as either too general or too disease-specific (Tieman et al., 2023).

A variety of interventions for family caregivers that are either wholly or partly technology- or web-based have been developed and studied (Ploeg et al., 2018; Sherifali et al., 2018), and continued development and adaptations of web-based interventions for a diversity of family caregivers have been pointed out as a research priority (Harvath et al., 2020). A systematic review by Zhai et al. (2023) focusing on digital interventions for family caregivers across a range of conditions and contexts demonstrates that digital interventions use diverse technologies and the outcomes span multiple dimensions of caregiver well-being, with most studies indicating beneficial effects. Online environments can address the needs of family caregivers that are not easily captured by outcome measures, such as the importance of shared experiences and exploring one's identity as a caregiver (Daynes-Kearney & Gallagher, 2023).

3. Rationale

Many family caregivers take extensive responsibility when providing care and support for a patient with a life-threatening illness, and they are often essential for enabling care at home. This responsibility can be emotionally distressing and may negatively impact family caregivers both psychologically and physically. Because family caregivers and patients often share the illness experience, their ability to mutually support each other is central to managing everyday life. In this context, family caregivers' preparedness for caregiving can protect against the negative consequences of caregiving. Preparedness for caregiving is promoted when family caregivers perceive that their care responsibilities are manageable, that they have access to adequate personal and practical resources, and receive sufficient guidance and support. Despite this knowledge, family caregivers report high levels of unmet support needs related to caregiving, indicating insufficient supportive resources. However, providing individual and tailored support for all family caregivers poses a challenge for health care services, highlighting the need for accessible and flexible support interventions.

Web-based support is a potentially important complement to in-person support. Although a variety of web-based interventions for family caregivers have been developed and tested, there is still limited knowledge about whether such interventions can effectively promote preparedness for caregiving. To address this knowledge gap, this thesis explores family caregiver support needs and preparedness for caregiving, and evaluates a web-based psychoeducational intervention among family caregivers of patients with life-threatening illness during specialised palliative home care. Evaluating interventions using a robust research design may inform the clinical use and implementation of web-based support interventions for family caregivers in palliative care.

4. Theoretical perspective

Two theoretical perspectives are used in this thesis: Andershed and Ternestedt's theory of family caregivers' involvement in palliative care (2001) and Glaser and Strauss' theory of awareness of dying (1980). While Andershed and Ternestedt focus on conditions for family caregivers' involvement and how involvement is experienced, Glaser and Strauss provide a framework for understanding how awareness of dying is shaped through interaction. Together, these perspectives highlight that family caregivers' involvement is closely linked to their understanding of the situation, as awareness of life-threatening illness and impending death influences the possibilities to feel meaningfully involved.

Family caregivers' involvement in palliative care

Andershed and Ternestedt's (2001) theory of family caregivers' involvement in palliative care provides a framework for understanding how involvement is experienced and what conditions shape the experience. This is relevant for this thesis, as family caregivers' involvement may be experienced as meaningful or as limited by barriers, which is central to understanding how meaningful involvement can be supported.

A central feature of the framework is that family caregivers' involvement may be experienced *in the light* or *in the dark*. Involvement in the light is characterised by openness, confirmation, and a partnership between the family caregiver, patient, and staff. In contrast, involvement in the dark refers to caregiving carried out in isolation, where lack of information and collaboration constrain the family caregiver's ability to provide care and support (Andershed & Ternestedt, 2001). Whether involvement is experienced as being in the light or in the dark does not necessarily depend on the level of involvement but reflects the conditions for caregiving and whether it corresponds to the family caregiver's preferences. This distinction is relevant in the context of support, as it draws attention to how different supportive conditions may shape how involvement is experienced.

According to the theory, family caregivers' experience of involvement is shaped by three interrelated principal needs: *knowing*, *being*, and *doing*. *Knowing* refers to obtaining information about symptoms, the illness, prognosis, and the patient's well-being. *Being* refers to emotional presence and sharing the patient's world,

while *doing* refers to practical caregiving activities. When family caregivers are supported in achieving knowing, they are better able to make informed choices regarding their involvement, which facilitates being and doing (Andershed & Ternestedt, 1999, 2001). This is particularly relevant for this thesis, as it highlights how access to and understanding of information may shape how family caregivers experience and engage in their role.

The experience of involvement is affected by several conditions. These include the degree to which the attitudes of healthcare staff are characterised by respect, confirmation, and partnership. Involvement is also influenced by the family caregiver's sense of coherence, including their ability to find meaning in and understand the situation. In addition, a sufficiently long illness trajectory may help involvement, while a rapid or unexpected trajectory may hinder it. Resources such as support, health, and religious beliefs can also affect the experience of involvement (Andershed & Ternestedt, 2001). Together, these conditions point to key areas where support interventions may strengthen family caregivers' possibilities for meaningful involvement.

Awareness of dying

While Andershed and Ternestedt (2001) focus on how family caregivers are involved in care and how this involvement is experienced, Glaser and Strauss (1980) provide a framework for understanding how awareness of dying is shaped through interaction. Together, these perspectives highlight that family caregivers' involvement is closely linked to their understanding of the situation, as awareness of a life-threatening illness and impending death influences the possibilities for meaningful involvement. To better understand how such understanding is formed, the following section will introduce the concept of awareness of dying.

Awareness of dying refers to how knowledge about a life-threatening illness or impending death is shared among patients, family caregivers, and healthcare staff, and how these three actors understand each other's awareness (Glaser & Strauss, 1980). The theory, first developed in 1965, marked an important shift by conceptualising awareness of dying as an interactional process shaped by communication and relationships. It is important to note that the theory was developed during a time when healthcare professionals could restrict open disclosure of life-threatening illness, whereas contemporary health care,

particularly in the global north, emphasises openness and patient and family involvement. Nevertheless, awareness remains relevant as a way of understanding how communication about dying is negotiated in practice (Small & Gott, 2012).

Awareness is conceptualised as what each actor knows of the patient's illness and their respective recognition of the others' awareness (Glaser & Strauss, 1980). Therefore, awareness is not located within the individual but arises through interaction between two or more actors. In their theory, Glaser and Strauss define typical awareness contexts: in *closed* and *suspected awareness*, knowledge is unevenly distributed, as healthcare staff and family caregivers are aware of the patient's condition, whereas the patient is unaware or only suspects it; in *mutual pretence*, all actors are aware but pretend otherwise; and in *open awareness*, the life-threatening illness and impending death are jointly and openly acknowledged. According to Glaser and Strauss, a person's awareness context may change over time as the patient's condition changes.

Subsequent research has shown that access to information alone does not necessarily lead to open awareness. Timmermans (1994) argues that knowledge about impending death may not be fully understood, accepted, or integrated. Timmermans therefore differentiates *open awareness* into suspended, uncertain, and active forms. This highlights how awareness depends not only on access to information but also on how individuals interpret and emotionally engage with that information. According to Timmermans, family caregivers and patients may be in different awareness contexts, as they relate to information about life-threatening illnesses and death differently, and family caregivers may also seek information independently, which influences the awareness context in which they are situated. Further extending this perspective, Mamo (1999) emphasises that awareness is an interplay between cognitive and emotional processes, where emotional responses are both a reaction to information and shape how information about life-threatening illness and dying is understood. Awareness therefore varies between individuals depending on how they cognitively interpret and emotionally respond to the situation.

Taken together, these perspectives provide a framework for understanding how information about life-threatening illness and dying is experienced and interpreted by family caregivers, which is central to this thesis.

5. Overall aim

The overall aim of this thesis was to explore family caregiver support needs and preparedness for caregiving, and to evaluate a web-based psychoeducational intervention among family caregivers of patients with life-threatening illness during specialised palliative home care.

5.1. Specific aims

I To explore self-rated support needs and their association with preparedness for caregiving among family caregivers in specialised palliative home care.

II To investigate the effect of a web-based psychoeducational intervention on preparedness for caregiving among family caregivers of patients receiving specialised palliative home care.

III To explore how a web-based psychoeducational intervention influences family caregivers' experiences in addressing challenges while caring for a patient with life-threatening illnesses during specialised home care.

IV To explore how a family caregiver-targeted web-based psychoeducational intervention can influence couples' experiences of sharing everyday life at home while facing life-threatening illness.

6. Methods

6.1. Methodological perspectives

This thesis is informed by methodological perspectives that understand healthcare interventions as embedded within dynamic and context-dependent systems, where outcomes emerge through interactions between intervention components and contextual conditions (Greenhalgh & Papoutsi, 2018). From this perspective, intervention evaluation needs to address not only effectiveness but also how outcomes are generated within their context. Therefore, this thesis uses multiple methods to capture complementary aspects of the intervention and its effects. Methodological choices were made pragmatically, guided by the research questions and the features of the intervention under study. A pragmatic approach allows different methods to be used complementarily to generate knowledge that is useful in practice (Morgan, 2014). From this perspective, knowledge develops through the integration of different perspectives and methods, where each contributes with different insights. This approach aligns with the Medical Research Council (MRC) framework for complex interventions, which emphasises methodological diversity and attention to context when evaluating interventions (Skivington et al., 2021). Updates of the MRC framework illustrate an ongoing shift from an emphasis on standardised experimental designs towards a broader recognition of context and methodological diversity.

6.2. Design

This thesis used a randomised controlled design to evaluate the family-caregiver targeted web-based psychoeducational intervention 'narstaende.se'. To provide a comprehensive evaluation, multiple methodologies and diverse study designs were employed in the sub-studies. An overview of the included studies is presented in Table 1.

Table 1. Overview of study designs and methods.

Study	Design	Participants	Data collection	Data analysis
I	Prospective	Family caregivers (n = 153) from the intervention and control groups combined	Questionnaires at baseline and follow-up 1	Descriptive statistics, linear regression analyses
II	Randomised controlled	Family caregivers (n = 205) in the intervention (n = 103) and control (n = 102) groups	Questionnaires at baseline, follow-up 1, and follow-up 2	Descriptive statistics, hypothesis testing, linear mixed models
III	Inductive exploratory	Family caregivers (n = 17) from the intervention group	Individual semi-structured interviews	Qualitative content analysis
IV	Interpretive descriptive	Spouse-patient couples (n = 16, in total 32 participants) from the intervention group	Dyadic semi-structured interviews	Interpretive description

The MRC framework divides complex intervention research into four iterative phases that inform and guide each other: development, feasibility testing, evaluation, and implementation (Skivington et al., 2021). The studies included in this thesis are part of the evaluation phase, and multiple methods were employed to understand which parts of the intervention worked and how.

A core element of the MRC framework is the use of programme theory, which describes the intervention's key components and the sequence of activities and mechanisms that are assumed to produce change (Skivington et al., 2021). The programme theory for the 'narstaende.se' intervention (Figure 1) describes the conditions under which the intervention is expected to operate. It outlines the required resources and activities, the anticipated mechanisms of change, and the intended outcomes and longer-term impact of the intervention.

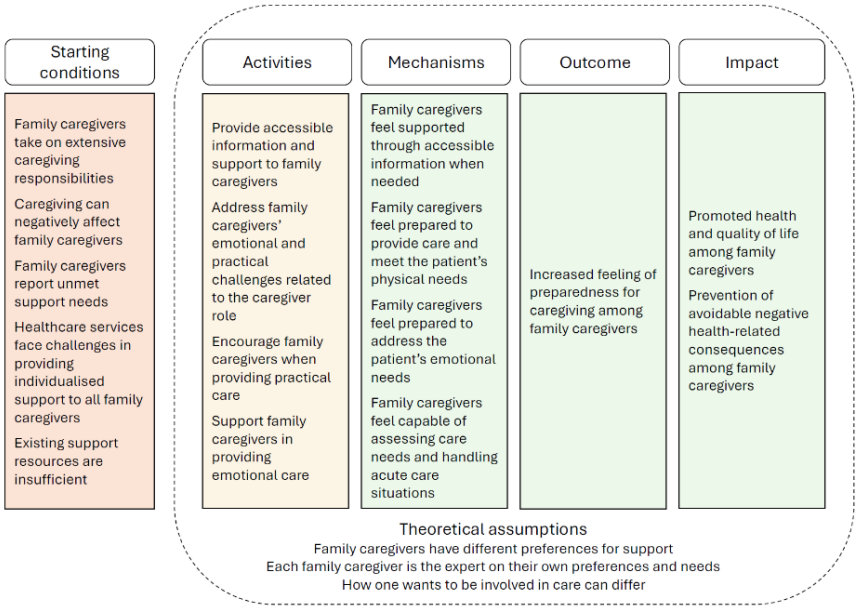

Figure 1. Programme theory of the 'narstaende.se' intervention.

6.3. Setting

All specialised home care services in the Stockholm metropolitan area were invited to participate in the trial. Of the six major services operating at the time, five agreed to participate and served as the basis for recruitment. Together, the five services comprised 18 local home care offices, each caring for 35-220 patients, and their total catchment area included most of the Stockholm region. The services provided a home-based alternative to inpatient care, available 24 hours a day to enable patients with a range of advanced or chronic illnesses to remain at home. Generally, while patients admitted to these services can have a range of diagnoses, the majority have cancer. Specialised medical and nursing care was delivered, requiring high competence and availability. The home care was provided by multi-professional teams, including registered nurses, nursing assistants, physicians, physiotherapists, occupational therapists, and healthcare social workers. Each local home care office comprised approximately 15-100 healthcare professionals. For patients with limited life expectancy, the services offered palliative care at a specialised level. Home care visits were scheduled according to patient and family needs, ranging from once per week to several

times per day, with additional acute visits if required. Support to family caregivers was part of the services' mandate, and standard support commonly entailed that family caregivers were offered a consultation upon admission, were informed that they could contact the home care office at any time, and could have appointments scheduled with a social worker, physician, or nurse.

6.4. The intervention 'narstaende.se'

The intervention 'narstaende.se' was delivered via a website in Swedish. It was fully web-based and specifically targeted family caregivers of patients with life-threatening illness and palliative care needs, to promote preparedness for caregiving and preparedness for death. The website was developed in collaboration with researchers, clinicians, information systems developers, digital communication strategists, and IT consultants. Its content was built on earlier research about long-term health consequences of bereavement (Hauksdottir et al., 2010; Valdimarsdottir et al., 2004), and in-person interventions during ongoing family caregiving (Henriksson et al., 2013; Holm et al., 2016). The content was theoretically grounded in the Andershed and Ternestedt (2001) framework on family caregivers' involvement in care.

The intervention website featured short videos illustrating interactions between family caregivers and healthcare professionals, in which they discuss concerns common to family caregivers. While all family caregivers in the videos were actors, the healthcare professionals were authentic. The website content was organised into three main domains: *Support for you – being a family caregiver*, covering how illness can affect a family caregiver, and the challenges in supporting the patient while adjusting to a new situation; *How to give support*, covering how family caregivers can support and care for the patient, both by being present and by helping with practical everyday needs; *Talk about it*, covering spending time together and having conversations about illness, death, and life. There were 23 videos in total, ranging from 2.5 to 8.5 minutes. All videos were labelled with descriptive titles, allowing family caregivers to choose topics based on their personal preferences. The videos were supplemented by informative texts offering further reading, and additional links to relevant stakeholder organisations were provided. Table 2 presents the domains and content.

Table 2. Overview of domains, videos, and texts in the intervention website.

Domain	Videos	Texts
Support for you – being a family caregiver	Many different emotions	To ask for help
	Meeting others	Living with a severely ill person
	Asking for help	Children and young people as close relatives
	Finding energy	As death is closing in
	Continue working or not	After death
	Concerns about the future	Grief
	May I be happy?	
	Being me	
	Breathing exercise	
How to give support	Nutrition and weight	Respiratory distress
	Appetite loss	Loss of weight and appetite
	Pain relief	Constipation
	Little helpful things	Assistive devices
	Fatigue and rest	Nausea
	Being a family member and a family caregiver	Worry, anxiety, sadness
	Relieve the bad and find the good	How to assist with personal hygiene
		Pain
		Tiredness and fatigue
Talk about it	Nice to have talked about	Children and young people as close relatives
	Talk about dying	Funeral and memorial ceremonies
	The loss	Death and dying
	Withdrawal of treatment	Family member – family caregiver
	Thoughts when terminating active illness treatment	Society's support system, financial/legal aspects
	When death is closing in	
	Funeral and memorial ceremonies	

The feasibility of the intervention has previously been evaluated in terms of usability and acceptability among spousal caregivers of patients with life-threatening illness (Tibell et al., 2024), showing that spouses found the website easy to use and welcoming, and that they would recommend it to others in a similar situation. Furthermore, the videos were the most used content, and spouses found the intervention timely introduced and the web-based format flexible. While the intervention was feasible, it was not suitable for everyone, as some spouses would have preferred in-person support.

During the feasibility phase, an unmoderated chat forum was available but not used. Based on participant feedback (Tibell et al., 2024), the chat forum was moderated during the randomised controlled trial (RCT), however, it remained unused and was removed after the trial ended.

Family caregivers were given free access to the intervention website, where they could select the content they wanted to use and decide how extensively they wanted to engage with it. Videos and texts could be watched or read as many times as desired. Family caregiver logins and engagement with the website were not monitored in real time. Instead, all usage data relied on self-reports. Figure 2 presents a schematic overview of the 'narstaende.se' research project.

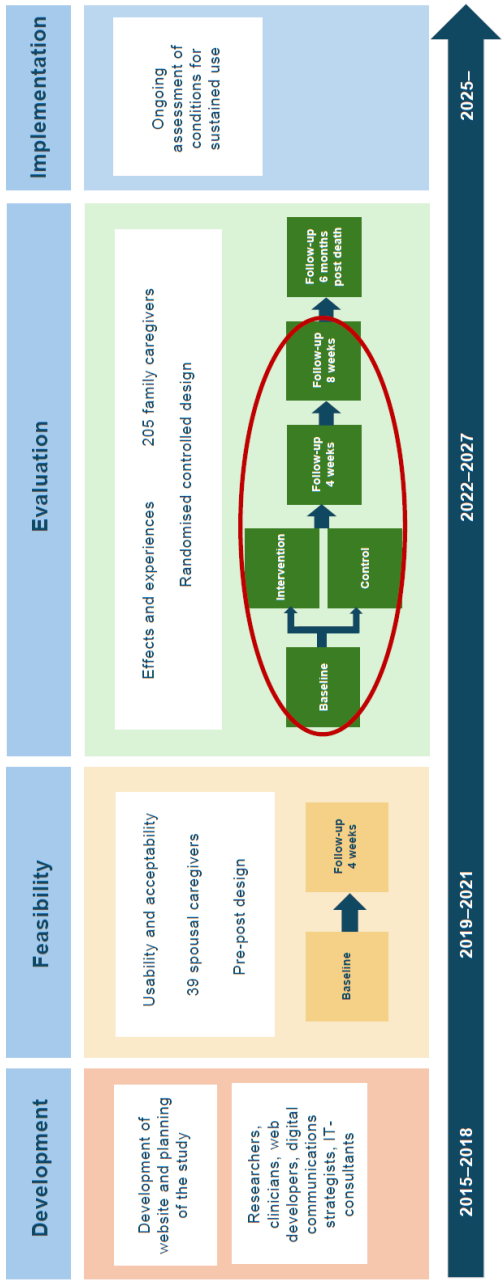

Figure 2. Schematic overview of the 'narstaende.se' project, illustrating its main phases, with the part included in this thesis circled.

6.5. Inclusion criteria and procedure

The inclusion criteria were being a family caregiver of a patient with a life-threatening illness and palliative care needs and being enrolled in specialised home care. Furthermore, both the patient and the family caregiver had to be aged 18 or over. The family caregivers were required to be able to communicate in Swedish.

The manager of each home care service approved the recruitment of eligible participants through patient medical records, conducted by three members of the research group, all with clinical employment. Eligible patients were sent a letter of information about the trial, along with an information letter they could forward to a family caregiver of their choosing. About a week later, patients were contacted by telephone and received verbal information about the trial. Through a written consent form, patients nominated one or more family caregiver(s) to be invited to participate. Patients also consented to the retrieval of their age and diagnosis from their medical records. Once the patient's consent form was returned, the family caregiver was contacted by telephone to receive verbal information. Participants were recruited between October 2022 and December 2023.

6.6. Data collection, randomisation, and participants

Data were collected through questionnaires for studies I and II and through interviews for studies III and IV.

6.6.1. Questionnaires and measures

Data were collected through questionnaires between October 2022 and March 2024. Participating family caregivers received questionnaires at three time points: baseline, 4 weeks (follow-up 1), and 8 weeks (follow-up 2). All questionnaires were distributed online, and written consent was provided upon completion of the baseline questionnaire. Family caregivers who did not respond to questionnaires were sent text message reminders up to three times. If a patient died, the family caregiver remained in the trial and was sent questionnaires adapted to their situation as a bereaved person. The questionnaires were developed based on previous research (Hauksdottir et al., 2010; Holm et al., 2016; Valdimarsdottir et al., 2004) and included socio-demographic questions, single-

item questions about illness-related communication and involvement in care, and validated instruments and tools. The two measures used in this thesis assessed preparedness for caregiving and support needs, respectively.

The *Preparedness for Caregiving Scale* (PCS) is a unidimensional measure of family caregivers' self-rated preparedness (Archbold et al., 1990). The scale comprises eight items covering various aspects of caregiving, presented in detail in Table 3. Each item is responded to on a five-point Likert-type scale with descriptive labels and response categories: *not at all prepared* (0), *not too well prepared* (1), *somewhat prepared* (2), *pretty well prepared* (3), and *very well prepared* (4). It is valid for use in palliative care and for evaluating interventions intended to meet family caregivers' needs (Henriksson et al., 2012; Henriksson et al., 2015). Responses are summed to a total score of 0–32. Cronbach's alpha for the study sample was 0.92.

Table 3. Aspects covered in PCS

How prepared do you think you are…
.. to take care of your relative/friend's physical needs?
.. to take care of your relative/friend's emotional needs?
.. to find out about and set up services for your relative/friend?
.. for the stress of caregiving?
.. to make caregiving activities pleasant for both you and your relative/friend?
.. to respond to and handle emergencies that involve your relative/friend?
.. to get the help and information you need from the health care system?
Overall, how well prepared do you think you are to care for your relative/friend?

The *Carer Support Needs Assessment Tool* (CSNAT) is a research tool to identify family caregivers' support needs. The tool comprises 15 items representing different support domains, presented in Table 4. The domains are theoretically divided into enabling domains, that is, support for providing care to the patient, and direct domains, that is, support for family caregivers' own well-being (Ewing et al., 2020; Ewing et al., 2013; Micklewright & Farquhar, 2022). Family caregivers respond to each item by indicating their perceived need for more support using three response categories: *no more support*, *a little more support*, and *very much more support*.

Table 4. Domains of support needs in CSNAT

Enabling support for providing care for the patient	Direct support for the family caregiver
Do you need more support with…	Do you need more support with…
.. understanding the patient's illness	.. having time for yourself in the day
.. managing symptoms and giving medicines	.. your financial, legal, or work issues
.. providing personal care for the patient	.. dealing with your feelings and worries
.. knowing whom to contact when concerned	.. managing relationships
.. equipment to help care for the patient	.. your own physical health concerns
.. talking to the patient about their illness	.. your beliefs or spiritual concerns
.. knowing what to expect in the future	.. practical help in the home
	.. overnight break from caregiving

6.6.2. Randomisation and statistical power

After returning the baseline questionnaire, family caregivers were randomised to either the intervention or control group. An unblinded computer-based stratified block randomisation procedure was used, with participants randomised in blocks of four and an allocation ratio of 1:1. Statistical power was calculated for the primary outcome, preparedness for caregiving, using a two-way repeated-measures ANOVA with three assessments and two groups. It was calculated that a total of 134 participants were required. Based on previous experience from studies conducted within this context (Henriksson et al., 2013; Holm et al., 2016), a 30% attrition rate was expected, therefore, the target sample size was set at 180 participants. Following randomisation, both the intervention and control groups continued to receive standard support from the home care service where the patient was admitted. Family caregivers in the intervention group were in addition given access to the intervention.

6.6.3. Participants

Once randomised, all participating family caregivers allocated to the intervention group were contacted by telephone to ensure successful login to the website. A total of 205 family caregivers were included at baseline, linked to 193 patients. Of the participating family caregivers, 103 were allocated to the intervention group, and 102 to the control group. In total, 162 family caregivers completed follow-up

1, and 131 completed follow-up 2. Since this thesis focuses on ongoing caregiving, family caregivers of patients who had died during the study period were excluded, leaving 155 family caregivers for analysis at follow-up 1 and 117 at follow-up 2. Stating a reason for withdrawal from the study was not required, and most participants who withdrew did so by not completing follow-up questionnaires. The inclusion and data collection process is summarised in Figure 3.

Among the participating family caregivers, 62.4% were female, and 37.1% were male. Their mean age was 64.0 years (19–88), and the most common relationship to the patient was partner (68.8%), followed by being an adult child (22.9%). The patients' mean age was 70.1 years (21–93), and the vast majority had a cancer diagnosis (94.1%). Family caregivers' participation in patients' physical care varied. During the month before responding to the questionnaire 15.1% had never provided physical care, 19.0% had done so occasionally, 16.6% 1–2 times per week, 27.8% every day, and 20.0% several times per day. Self-reported active intervention use at follow-up 1, was reported by family caregivers as not at all (54.1%), once (18.9%), 2–4 times (20.3%), and five times or more (6.8%). At follow-up 2, active intervention use was self-reported as not at all (50.0%), once (13.0%), 2–4 times (24.1%), and five times or more (13.0%).

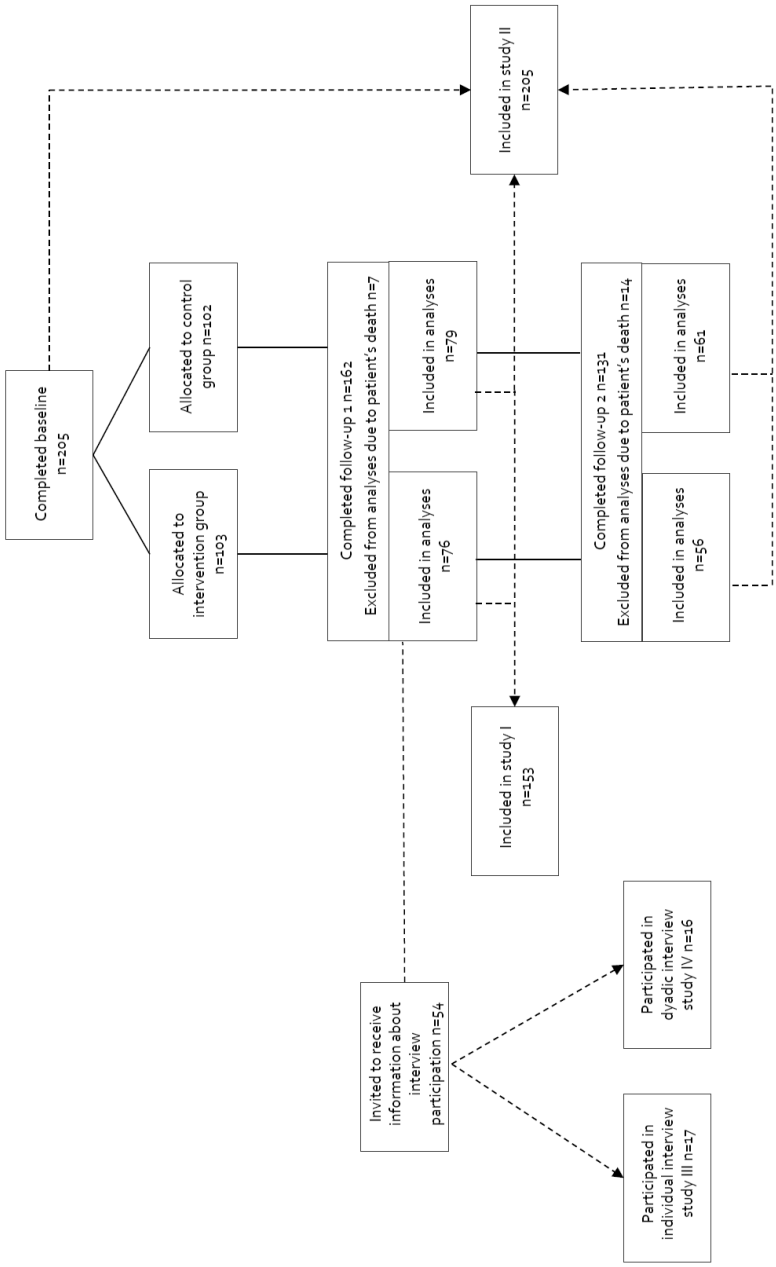

Figure 3. Flowchart of participant inclusion and data collection

6.6.4. Interviews

In parallel with questionnaires, data were collected through individual interviews (study III) and dyadic interviews (study IV). The questionnaire at follow-up 1 asked participants in the intervention group whether they were interested in receiving information about participation in an interview. Of the 54 participants who received the offer, 29 were interested and were contacted by telephone for verbal information. Among those who accepted participation, spouses, cohabiting partners, or partners who lived separate from the patient (all hereafter referred to as spouses) were invited to participate in a dyadic interview together with the patient. Family caregivers who expressed interest in a dyadic interview were asked to discuss it with the patient and thereafter contacted again a few days later for verbal consent and to schedule a time and place for the interview. Thus, the family caregivers could participate in both an individual and a dyadic interview. Written consent from all participants was obtained before each interview commenced. Sampling for the interviews was conducted consecutively as questionnaires were completed. When the data were considered sufficiently rich, the invitation to participate was excluded from the remaining questionnaires.

Between January and December 2023, a total of 33 interviews were conducted: 17 individual interviews (study III) and 16 dyadic interviews (study IV). Of the participating family caregivers, nine took part in an individual interview only, eight in both a dyadic and an individual interview, and eight in a dyadic interview only, resulting in 25 unique family caregivers interviewed. Study-specific interview guides were developed and included open-ended questions with follow-up and probing questions adapted to follow the natural course of the conversation. During the interviews, there was openness to both positive and negative experiences. For study III, the interviews started with family caregivers being asked to openly describe how they had used the website. Questions such as '*Can you tell me about your experience of using the website?*' and '*Was there anything on the website that made you reflect or that raised questions for you?*' were asked to gain further insight into their experiences. For study IV, the interviews started with the couples being asked to describe their expectations and thoughts when the family caregiver was invited to take part in a web-based intervention. Questions such as '*What has it been like for you [the patient] to know that your spouse has access to the website?*' and '*Could the website support you [the family caregiver] in talking to [the patient] about difficult topics? If*

so, how?' were asked. During the dyadic interviews, questions were directed to the couples for joint responses and to each partner separately.

The participants were able to choose the preferred interview format: face-to-face (study III: n = 11, study IV: n = 13), telephone (study III: n = 5, study IV: n = 1), or via video conferencing software (study III: n = 1, study IV: n = 2). Those who participated in both individual and dyadic interviews could choose whether to conduct the two interviews in a single session or schedule them for separate occasions. On average, the interviews lasted 61 minutes for study III, and 55 minutes for study IV. The sample sizes for studies III and IV were continuously reassessed based on information power, which is the principle that the more relevant information a sample contains, the fewer participants are needed, dependent on the study aim, sample specificity, use of theory, quality of dialogue, and analysis strategy (Malterud et al., 2016).

In study III, 12 of the participating family caregivers were women, and five were men. They were aged 42 to 85 years (mean age = 67 years) and had different types of relationships to the patient they cared for, either spouse (n = 13), adult child (n = 2), parent (n = 1), or sibling (n = 1), and were either employed (n = 9) or retired (n = 9).

In study IV, the median age of family caregivers was 72.5 years (range 46–85); 10 were women, and six were men. They were either retired (n = 10) or employed (n = 6). The patients had a median age of 75.0 years (range 46–85), of whom 10 were men and six were women. They were either retired (n = 13) or on sick leave (n = 3). The patients had been diagnosed with an incurable illness a median of 1.5 years prior, with a range from 0 to 13 years.

6.7. Analyses

6.7.1. Statistical analyses

Missing items for the main outcome, preparedness for caregiving, were imputed if they did not exceed 25% of the scale. In total, 9 items were imputed listwise across 8 individuals using the person mean score.

Study I

For study I, only data from baseline and follow-up 1 were used. Participants with complete responses for both the PCS and the specific CSNAT item included in each analysis at both time points were included.

Descriptive statistics were used to present participants' background characteristics. Appropriate measures of central tendency and variability were applied according to the level of measurement. For categorical variables, frequencies and percentages were reported. For continuous variables, median, mean, standard deviation, and minimum–maximum values were reported. A dropout analysis comparing included and non-included participants showed no difference between groups. The distribution and changes in family caregivers' reported support needs across the 15 CSNAT domains were examined using cross-tabulation.

Associations between family caregivers' self-reported support needs and their preparedness for caregiving were examined using simple linear regression analyses. The responses for each CSNAT item were dichotomised for analysis. Responses indicating no support need were coded as 0, while responses indicating any level of support need were coded as 1. Associations were analysed in three sequential steps. First, support needs for each CSNAT item were included as explanatory variables, and the baseline preparedness score measured by the PCS was used as the outcome variable. Second, the same regression models were used, only this time with the difference score in the PCS from baseline to follow-up 1 as the outcome variable. In the third step, changes in each CSNAT item between baseline and follow-up were transformed into dichotomous variables to indicate whether the support need had been met (1) or not met (0). Each variable was entered separately as the explanatory variable in a linear regression model, with the PCS difference score from baseline to follow-up as the outcome variable.

A sensitivity analysis was performed for each CSNAT baseline score to account for the randomised group assignment. No significant differences were observed between the two groups, confirming that the data could be combined.

Study II

The analysis followed the intention-to-treat (ITT) principle, meaning that all enrolled participants were included. For analysis purposes, the variable describing family caregivers' participation in physical care was dichotomised, with responses *never* and *occasionally* coded as 0, versus responses *1–2 times/week*, *every day*, and *several times/day* coded as 1. The variables describing family caregivers' active intervention use at follow-up 1 and 2 were combined and dichotomised, with responses *not at all* coded as 0, and *once*, *2–4 times*, and *five times or more* coded as 1.

Baseline characteristics were explored using descriptive statistics and compared between groups. Based on sample size, Fisher's exact test and Chi-squared tests were applied to categorical variables. For continuous variables, independent samples *t*-tests or Mann-Whitney *U* tests were applied depending on the level of measurement and distribution of the data. To analyse intervention effects on preparedness for caregiving, linear mixed models were used. The models included group and time as fixed effects, individuals as random effects, and the group × time interaction. A sensitivity analysis was performed to evaluate the need for adjustment for baseline differences in participants' relationships, which proved unnecessary.

After analysing the entire group, subgroup analyses were performed in several steps. First, the sample was divided based on participants' baseline preparedness for caregiving. Three cut-offs based on quartiles of the sample's reported baseline preparedness scores were used to divide the sample into subgroups. Values above Q3 were excluded, as improvement in this group was considered unlikely. The remaining three subgroups were analysed separately for effects and then combined with family caregivers' reported participation in the patient's physical care and their reported active intervention use.

6.7.2. Qualitative analyses

Study III

Qualitative content analysis (Graneheim & Lundman, 2004) was employed for study III. This analytical approach aims to identify variations in experiences and to give voice to participants (Graneheim & Lundman, 2004; Lindgren et al., 2020). The interview transcripts were read, first while listening to the audio recordings,

and then again without audio. This was done to identify verbal nuances and gain an overall sense of the data. The analysis then proceeded to extract meaning units, which are parts of the text pertinent to the study aim (Graneheim & Lundman, 2004). These meaning units included several sentences to capture their context, which is necessary when studying complex phenomena (Lindgren et al., 2020). The meaning units were condensed while striving to maintain their essence. To preserve the original meaning and nuances, movement was made between the meaning units and the text as a whole, with adjustments made to ensure that the essence of the original text was maintained. The condensed meaning units were given descriptive codes to abstract the underlying meaning (Graneheim & Lundman, 2004). These codes were then sorted into categories based on similarities in content, while also capturing variations in patients' experiences within that category. The categories were adjusted or collapsed as the analysis progressed. As the data were considered sufficiently rich to allow further abstraction and interpretation (Graneheim et al., 2017; Lindgren et al., 2020), they were formed into themes based on an interpretation of their interrelatedness. These themes were then merged to ensure they were both internally consistent and mutually exclusive, ultimately forming the final result. Throughout the analysis, there was an ongoing adjustment to ensure consistent interpretation.

Study IV

For study IV, interpretive description was used as an analytical approach. Interpretive description has its epistemological roots in the nursing discipline and draws on the researcher's clinical experience as an interpretive lens. This links the research question to the study's contribution to knowledge relevant to clinical practice (Thorne, 2025). This approach was considered appropriate given that the study aimed to explore a complex and dynamic issue that could potentially be illuminated by interpretation informed by clinical experience. In line with the interpretive descriptive approach (Thorne, 2025), data analysis began during the data collection phase through reflection on initial patterns in the data and adapting the approach to the research questions for subsequent interviews. Lengthy data units deemed relevant to the study aim were extracted and assigned descriptions that carefully interpreted their meaning. The data were then sorted into broad, tentative themes based on observed patterns, a process that evolved throughout

the analysis (Thompson Burdine et al., 2021; Thorne, 2025). The original data were used to validate the interpretations until the final results were obtained.

7. Ethical considerations

This thesis was conducted in accordance with the Swedish Act concerning the Ethical Review of Research Involving Humans (SFS 2003:460). Ethical approval was obtained from the Regional Ethical Review Board in Stockholm (No. 2018/1893-31), and subsequent amendments were approved by the Swedish Ethical Review Authority (Nos. 2019-02242, 2021-00235, 2022-02218-02, and 2022-06623-02). The research process was guided by the principles of biomedical ethics: *autonomy*, *nonmaleficence*, *beneficence*, and *justice* (Beauchamp & Childress, 2019). Adherence to the Declaration of Helsinki (World Medical Association, 2025) and guidelines on good research practice (Swedish Research Council, 2024) ensured that ethical considerations were continuously taken into account.

Potential risks and benefits

Family caregivers of patients with life-threatening illness could be in a particularly vulnerable position due to the emotional strain of their situation. It is important to acknowledge the risks associated with including potentially vulnerable groups in research, which requires sensitivity on the part of the researcher. Protecting those involved in research should take precedence over the research interest (Swedish Research Council, 2024). However, the risks associated with including family caregivers and patients in palliative care research are sometimes exaggerated, resulting in researchers being reluctant to involve these groups (Chambers et al., 2019). Failing to represent all voices in research could be considered a violation of *justice*. Assuming that all family caregivers are vulnerable may be too simplistic and overlook individual variations. Earlier research has shown that family caregivers often want to participate in research and that their motives can be both personal and altruistic (Chatland et al., 2023). Therefore, viewing vulnerability as contextual, rather than as a fixed property of a group, could enable more tailored measures to safeguard participants' rights to make autonomous decisions about their participation in research (Gordon, 2020).

Completing questionnaires, participating in interviews, and engaging in the content of the intervention under study might provoke distress for participants. To comply with the principle of *nonmaleficence*, it was considered important that the family caregivers could easily contact the research group at any time. Therefore, names and contact details of research group members were provided

to all participants. Furthermore, all videos and texts on the website have clear, descriptive titles and an introductory text, allowing family caregivers to address only the issues they wish to. Moreover, family caregivers in both groups continued to receive standard support from their home care service. The risk of burden should be weighed against the potential benefits of the research (World Medical Association, 2025). In accordance with the principle of *nonmaleficence*, care was taken to minimise the risk of placing an undue burden on the participants. The questionnaires were kept as brief as possible, while ensuring that the necessary amount of data to address the research question was obtained. Furthermore, close attention was paid during interviews to ensure that participants felt comfortable and safe, and no indications called for additional measures.

The RCT design of this thesis means that only half of the participants got access to the intervention during the trial period, which brings the principles of *justice* and *beneficence* into focus. According to the World Medical Association (2025), research involving humans should have a scientifically sound and rigorous design, such as an RCT, to be justified. Support offered to family caregivers should be evidence-based; however, there is insufficient evidence to support the effectiveness of web-based interventions in the palliative care context. The expected contribution to knowledge and potential benefits for family caregivers were therefore considered to justify the study design. Furthermore, once the data collection for the RCT had ended, the intervention was made accessible to the public, thereby making it accessible to all family caregivers.

Informed consent

Patients nominated their family caregiver to be invited to participate in the study. Participation was therefore only possible if both the patient and their family caregiver actively opted in. This creates a potential dependency relationship, whereby the family caregiver may feel expected to participate in the study as part of their support for the patient. According to the Swedish Research Council (2024) guidelines on good research practice, researchers must pay attention to situations where relationships can create feelings of obligation that affect the voluntary nature of consent. Therefore, all information emphasised that each participant gave their consent individually and voluntarily. It is important to note that the recruitment procedure also poses a risk of patients acting as gatekeepers, hindering family caregivers from participating in the study, which could

compromise the *autonomy* and *justice* of the family caregivers. Nevertheless, this was deemed the most ethical approach to recruitment.

The principle of *autonomy* was upheld by providing eligible participants with written and verbal information about the study, including its purpose, the intervention, and randomisation to either the intervention or control group. This information also covered the voluntary nature of participation and the right to withdraw from the study at any time without having to provide a reason, and that doing so would not affect the care or support provided to the patient or themselves. Each participant was contacted by telephone so that information could be tailored to their individual needs, questions could be answered, and comprehension of consent could be ensured.

Integrity and Data Protection

In accordance with the principle of *nonmaleficence*, personal data were handled in a way that minimised the risks to integrity and safeguarded confidentiality. Data were collected and handled in accordance with the General Data Protection Regulation (Regulation (EU) 2016/679, 2016) and applicable Swedish data protection legislation (SFS 2018:218). Accordingly, the personal data collected was limited to the information necessary for the research specified in the ethical approval. In the RCT, data were collected using an online survey platform that complies with the requirements for the General Data Protection Regulation. Participants completed the questionnaires confidentially and were identifiable only by a personal code. It is important to recognise that, during their participation, family caregivers could share information that reveals personal details about the patient or their medical care. To protect integrity and uphold *nonmaleficence*, all patients were able to choose which family caregiver they wanted to invite to participate in the trial and consented to their family caregiver being approached. For confidentiality purposes, all participants' names and potential identifiers were replaced by a code and the encryption key stored with access restrictions. All data are kept in locked storage or on a secure server.

8. Results

The results of the four studies included in this thesis have been synthesised to provide a broader understanding of how the intervention 'narstaende.se' was experienced and its effects in terms of preparedness for caregiving. Study I contributes to an understanding of the diversity of family caregivers' support needs and how these needs relate to preparedness for caregiving. Study II investigates the effect of the intervention on preparedness for caregiving. Studies III and IV illuminate how the intervention supported family caregivers and patients in addressing caregiving challenges and sharing everyday life. When viewed together, the studies demonstrate that although the intervention was generally perceived as supportive, some elements evoked emotionally challenging responses. Despite the largely positive experiences, no statistically significant effect on preparedness for caregiving was found. The synthesised results are presented in three themes.

8.1. The intervention's relevance for the caregiver role

Family caregivers found the intervention relevant to their caregiver role. It guided them in adapting their approach to caregiving, shifting their perspective, and alleviating some of their frustration related to caregiving (III). While family caregivers described that the intervention addressed relevant caregiving issues (III, IV), this was not reflected in the statistical results, which showed no measurable effect on preparedness for caregiving. Notably, when family caregivers with the highest baseline preparedness levels were excluded, it was evident that across all subgroups, preparedness for caregiving had increased in both the intervention and control groups ($p < 0.01$ to $p < 0.001$) (II).

Preparedness for caregiving depended, in part, on the ability of family caregivers to have their support needs met. Across most support domains, having unmet support needs also meant having lower levels of preparedness (13 out of 15 domains, $p < 0.05$). Importantly, preparedness for caregiving generally increased when support needs were met (11 out of 15 domains, $p < 0.05$) (I). Having access to the web-based intervention was described as a relief, since the caregiver role entailed extensive responsibilities that made it difficult to find time for support

outside the home (III). The need to have time for oneself during the day was not only common among the family caregivers overall, but also the support need that most often emerged between baseline and follow-up, reported by 25% (I). The intervention allowed family caregivers to access support at a time and a place that suited them and for as long as was required (III). However, despite the accessibility of the intervention, no statistically significant effect was observed even among the family caregivers who reported having actively used it (II).

Family caregivers perceived that the intervention helped them feel more capable in their caregiver role by providing a sense of direction through the complexities of caregiving. For some, the intervention provided emotional support by increasing self-awareness of feelings and experiences. However, others had primarily sought practical information and tailored advice on specific caregiving issues, and they described how the intervention was unable to sufficiently provide this information (III). Family caregivers and patients expressed that their support needs varied depending on personal preferences and the most pressing consequences of the illness at that time (IV). This variability was evident as, over time, the support needs reported by family caregivers changed. These needs either emerged, persisted, were met, or never arose (I). Support needs also differed between individuals and could involve several areas relevant to their everyday lives as family caregivers (I, III, IV).

Family caregivers considered the intervention's content to be relevant when it made them feel that they shared experiences with other family caregivers. They described recognising their own caregiving experiences because the topics addressed in the intervention were things they had encountered firsthand. This provided them with comfort and reassurance and made them realise that they were not alone in struggling with the caregiver role. However, the intervention did not resonate with all family caregivers. When the patient they cared for was less ill than those portrayed in the videos, the intervention was perceived as less relevant for them as caregivers (III). It is not known how perceived relevance affected engagement with the intervention, as active engagement was not required to remain in the study (II). For some, merely seeing a resemblance to their own situation was insufficient. Instead, they sought personal contact with other family caregivers, which the intervention could not provide (III).

8.2. The intervention's influence on the relationship

Some family caregivers engaged with the intervention not primarily for their own personal benefit, but in the hope that it would help them feel more confident in providing care and, in turn, make things easier for the patient (III). Both family caregivers and patients described how family caregivers' engagement in the intervention influenced their relationship dynamics by providing insights into how they might adjust to changes in their relationship as the patient's illness progressed (IV). The most common type of relationship between family caregivers and patients was spousal (68.8%) (II). In this group, family caregivers struggled to manage their dual roles as family caregivers and spouses (IV). Lower preparedness for caregiving was seen among those who reported a need for support related to managing relationships ($p < 0.001$). Notably, more than half (56%) of family caregivers reported at baseline and/or follow-up that they needed support to manage relationships. Those for whom this need was met experienced a greater increase in preparedness for caregiving between these time points ($p = 0.018$) (I).

The content of the intervention gave family caregivers encouragement to take time away from caregiving to restore their energy levels, thus reminding them to prioritise their own needs (III, IV). Family caregivers and patients described how they had separate experiences of their shared life situation related to illness, which made it difficult for them to understand each other's perspectives. Patients worried that their illness might take priority over their family caregiver's needs, and they hoped that the intervention would allow their family caregiver to focus more on themselves (IV). Importantly, most family caregivers (60.0%) had, at baseline and/or follow-up, needed support to have time for themselves. Although this was not significantly associated with their level of preparedness for caregiving (I), family caregivers described having time for oneself as essential for continuing to provide care to the patient (IV). Support related to providing personal care was the least common need, reported by 21% of family caregivers (I). Although almost half of the family caregivers (47.8%) had participated in the patient's care daily, no intervention effect was found in this subgroup (II).

Both family caregivers and patients described how the strategies they used to manage illness and everyday life differed depending on whether they were a patient or a family caregiver (IV). Following the intervention, family caregivers and patients had begun to reflect on their own strategies, as well as each other's, and on the impact of the illness on their everyday life (III, IV). Patients had also realised that they had not fully understood their family caregivers' caregiving experience before. However, among family caregivers and patients who were spouses, it was suggested that the intervention might have had a greater impact on their relationship if they had been invited to participate together. This would have given them a better understanding of how the illness affected them as a couple (IV).

Family caregivers described that the intervention contributed to their awareness of issues they felt were urgent to discuss with the patient (III, IV). This provided a starting point for communication, enabling family caregivers and patients to share their feelings and experiences (IV). The permissive environment encouraged family caregivers to raise topics that they had previously found challenging or forbidden, such as feelings of frustration towards the patient (III, IV). Notably, lower levels of preparedness for caregiving were observed among those who reported needing support to talk to the patient about their illness ($p < 0.001$). This need was reported by 59% of family caregivers at baseline and/or follow-up, and a greater increase in preparedness was seen among those whose need was met ($p < 0.001$) (I). Although communication was deemed important for the relationship, family caregivers and patients had become aware that their need to talk things through could differ, as one might feel a stronger need to talk than the other (IV).

8.3. The intervention evoked emotional responses

To prepare for how the illness might come to affect the patient, and what future caregiving demands they as caregivers could be faced with, family caregivers described it as important to know what lay ahead (III, IV). At baseline and/or follow-up, family caregivers commonly reported needing more support to know what to expect in the future (86%) and to understand the patient's illness (75%). Notably, for most family caregivers, these needs either persisted or emerged

between these time points (I). The intervention was described as helpful for accessing information that supported family caregivers in understanding or processing emotionally challenging aspects of the patient's illness, even when engaging in these reflections was difficult (IV). Using the intervention to reflect and process provided a degree of stability in an otherwise worrisome and insecure life situation (III). Importantly, family caregivers' preparedness for caregiving increased if the need to know what to expect and the need to understand the illness were met ($p < 0.001$ and $p = 0.010$, respectively) (I). Although these needs were common and important for preparedness for caregiving, some family caregivers felt that the intervention did not align with their personal way of preparing for caregiving, or that they were so preoccupied with their caregiving responsibilities that they felt they lacked the emotional capacity to actively prepare (III).

Most family caregivers (64.0%) had provided care for a patient with an incurable illness for up to two years (II). Caring for a patient with a life-threatening illness made family caregivers aware of the patient's inevitable illness progression and their impending death (III). This insight was described as an essential part of the process of preparing, but also as emotionally difficult to face (III, IV). The videos that addressed end-of-life issues were considered important for preparedness, as they served as a reminder of the limited remaining time together. However, taking active measures to prepare for future caregiving responsibilities and for the patient's death could be perceived as inappropriate or shameful. Therefore, the fact that the intervention offered a way to prepare privately was considered supportive. Family caregivers expressed mixed feelings about reflecting on caregiving and the future through the intervention. Although this was helpful for their role as caregivers, it was also emotionally challenging, as it made them think of things they sometimes avoided but also knew they perhaps needed to face (III). This duality is reflected in the fact that, at baseline and/or follow-up, 75% of family caregivers reported needing support to deal with their own feelings and worries (I). While the importance of preparing for future caregiving demands and inevitable illness progression was recognised, some family caregivers deliberately postponed preparing as they found it too emotionally challenging. Overwhelmed by thoughts and emotions, they avoided certain parts of the intervention, despite acknowledging that this might leave them unprepared (III).

Patients acknowledged their family caregivers' need to prepare and hoped that the intervention could help them manage their thoughts about the future and the prospect of living life alone (IV). However, some family caregivers did not feel the need to engage with the intervention because they wanted to postpone preparing for caregiving and the future until a time closer to the patient's death, or because they already felt sufficiently prepared (III).

9. Discussion

This thesis explores family caregiver support needs, preparedness for caregiving, and evaluates the web-based psychoeducational intervention 'narstaende.se' among family caregivers of patients with life-threatening illness during specialised palliative home care. The results suggest that the intervention did not increase preparedness for caregiving at the group level, although it provided valuable experiences that were important for individual family caregivers' preparedness. The specific support needs, shaped by caregiving responsibilities and relationship with the patient, were important factors in how relevant the intervention's content was perceived to be. At the same time, the intervention shed light on their separate perspectives on the illness and their shared situation, affecting the relationship. Family caregivers needed support to manage their own emotions and found 'narstaende.se' helpful. However, engaging with certain content could be challenging, and some therefore chose to avoid it.

9.1. Relevant support for the caregiver role

Recognising oneself in the support content

The results show that family caregivers perceived the intervention content as relevant because it addressed issues which they had experienced firsthand, reinforcing a sense of not being alone (III, IV). Online support can reduce loneliness among family caregivers when they recognise their own experiences in others', even without direct interaction (Daynes-Kearney & Gallagher, 2024). In the 'narstaende.se' intervention, family caregivers became aware of their own feelings and felt comforted and reassured when they engaged with videos and texts (III). This suggests that recognising oneself in others can provide valuable emotional support. Evidence suggests that to promote preparedness for caregiving, intervention content is more critical than intervention duration or setting (Bilgin & Ozdemir, 2022). However, results from this thesis indicate that intervention content alone may not have been sufficient to promote preparedness for caregiving, as this increased in both the intervention and control groups (II). This is consistent with previous research showing that, although digital interventions may support aspects of care such as communication and information sharing, evidence for measurable effects on broader caregiver and

patient outcomes remains heterogeneous and inconclusive (Finucane et al., 2021). Sustained use of family caregiver-targeted digital interventions largely depends on whether the intervention is perceived as providing tailored support, aligns with the stage of the illness, and validates the caregiving experience (Coumoundouros et al., 2022; Premanandan et al., 2024). The lack of effect observed in the subgroup who reported active use in the 'narstaende.se' trial (II) suggests that sustained engagement alone may be insufficient to promote preparedness for caregiving. Rather, the intervention content may need to align with family caregivers' changing and individual support needs. In line with Timmermans (1994), becoming aware of illness progression and impending death involves more than access to information; the information also needs to be meaningful and interpretable in relation to one's own situation. Recognising oneself in the content may therefore indicate that the information resonates with how family caregivers understand and make sense of their circumstances.

Support without interaction

Family caregivers described that the digital format allowed them to access support at a time and place that suited them, and for as long as required (III), suggesting that the web-based format aligned with their preferences and everyday caregiving reality. When comparing nurse-led and digital support for family caregiver and patient dyads, a recent multinational RCT found that a web-based intervention did not result in improvements in any outcomes, whereas a nurse-led intervention showed positive effects on dyadic processes and caregivers' problem-focused coping (De Vleminck et al., 2025), suggesting that professional, face-to-face facilitation may have added value beyond the psychoeducational content alone. Importantly, a secondary analysis of that same multinational trial showed that digital competence was not associated with participant retention in the web-based intervention, indicating that the lack of effect was not explained by difficulties using digital technology (Van Goethem et al., 2025). In the 'narstaende.se' trial, participants did not interact with peers, yet they described that the intervention supported them in providing care and that they felt a connection to the family caregivers featured in the videos (III, IV). This aligns with previous research, demonstrating that family caregivers can feel supported by online resources, even without peer interaction (Daynes-Kearney & Gallagher, 2023). Taken together, this suggests that support from digital interventions may be present without

simultaneous peer interaction, although interaction may be an important feature to promote effects in certain outcomes.

New perspectives on caregiving

Family caregivers perceived that the 'narstaende.se' intervention provided new perspectives on what it meant to be a caregiver, which helped them adapt their approach to caregiving (III, IV) and enhanced their capability to navigate the complexities of caregiving (III). These findings align with broader research on preparedness for caregiving, showing that preparedness may be promoted if family caregivers have access to educational, relational, and practical support that allows them to perceive caregiving tasks as manageable and meaningful (Zimami & Darwish, 2024). This resonates with Andershed and Ternestedt's (2001) emphasis on knowing as a central condition for involvement in care, suggesting that enhanced understanding may support family caregivers' adaptation to the caregiver role. From a broader societal perspective, palliative care is understood as a relational and collective responsibility within health and welfare systems rather than resting solely on individuals or families (Sallnow et al., 2022). Accordingly, in palliative care contexts, digital interventions should address holistic needs and facilitate relationships and care processes that are grounded in patients' and family caregivers' values and preferences (Finucane et al., 2021), consistent with the philosophy of palliative care. In the 'narstaende.se' trial, increased understanding may have occurred primarily at the individual family caregiver level, as no group-level effects were found (II).

Changing support needs over time

Increased preparedness for caregiving depended, in part, on family caregivers' ability to have their support needs met (I). Previous research indicates that the feeling that support is available enables preparedness to be translated into caregiving ability by strengthening family caregivers' confidence and engagement in care-related activities (Teng et al., 2025). This resonates with Andershed and Ternestedt's (2001) emphasis on support as a prerequisite for involvement *in the light*, suggesting that feeling supported may enable family caregivers to engage with their role in more meaningful and manageable ways. Consistent with this, across most support domains, having support needs met was associated with a greater increase in preparedness for caregiving (I). Addressing family caregivers' support

needs may promote the feeling of being seen and guided, and strengthen the overall confidence in providing care, which may positively affect preparedness for caregiving (Caetano et al., 2024). Importantly, this thesis shows that family caregivers' support needs changed over time and according to personal preferences. Across domains, some needs could be met, while new needs emerged as caregiving demands evolved (I). For family caregivers, the emotional and practical challenges are constantly shifting, as are their support needs (McCarthy et al., 2024). This arguably complicates the matching of support to individual needs, as this requires support to be continuously tailored. The advantage of flexible, needs-based interventions over one-size-fits-all designs has therefore been highlighted (Kirvalidze et al., 2023). This aligns with the intention behind the design of the 'narstaende.se' intervention, which allowed family caregivers to select content based on individual needs. At the same time, a person is not always able to articulate their support needs, particularly in stressful situations (Cutrona, 1990). Therefore, placing the responsibility on family caregivers to identify relevant content may lead to the intervention being perceived as overly general if they are unable to identify what content they need the most. Consistent with this, this thesis found that, when seeking support for specific caregiving concerns, family caregivers sometimes experienced the content as insufficiently tailored (III). This is important in relation to the assumptions in the programme theory of this intervention. If family caregivers are uncertain about their support needs or unable to identify relevant content, they may be less likely to engage with content that could help them feel prepared to provide care. Consequently, the mechanisms through which the intervention was expected to promote preparedness may not have been fully activated.

9.2. The role of support in navigating relationships

Supporting the caregiver role

Some family caregivers engaged in the intervention primarily because they sought support in providing care that would ease the patient's situation (III). This aligns with findings by Nysaeter et al. (2024) where family caregivers expressed support needs related to providing care, while setting their own needs aside. Assuming the caregiver role can be an important source of making meaning of the caregiving

experience (Washington et al., 2021). Andershed and Ternestedt (2001) conceptualise meaning as a prerequisite for involvement *in the light*, emphasising that family caregivers' involvement is dependent on their ability to make sense of and find meaning in the caregiving situation.

A common need among family caregivers was to have time for themselves (I). When using the intervention, family caregivers felt encouraged to take time away from caregiving to restore their energy levels (III, IV). To prioritise time for oneself can evoke feelings of guilt, and family caregivers may need to be encouraged not to be constantly available (Nysaeter et al., 2024). Such encouragement may support family caregivers to sustain their role as the ones providing care and support to the patient (McCauley et al., 2024). From this perspective, the videos and texts on 'narstaende.se' that validated the importance of taking time for oneself may have had a dual function by supporting stress reduction and strengthening family caregivers' sense of caregiving capacity, thereby facilitating continued caregiving.

The intervention had prompted reflection on differing strategies to manage illness and shared everyday life among family caregivers and patients (III, IV), and some patients described that they had not fully understood their family caregivers' experiences before (IV). This suggests that patients and family caregivers may differ in how they understand and make sense of the illness situation. Such differences are consistent with the concept of awareness contexts, where individuals may have different understandings of illness progression and impending death based on how knowledge is distributed, communicated, and interpreted (Glaser & Strauss, 1980; Timmermans, 1994). This also relates to research showing that discrepancies between what patients wish for and what family caregivers believe they are capable of and what they consider appropriate to do can create strains in the relationship (Caetano et al., 2024).

Relational adaptation to illness

Family caregivers and patients described how family caregivers' engagement in the intervention influenced their relationship dynamics by helping them adjust to how the patient's illness changed their relationship (IV). These findings align with earlier research describing caregiving relationships as reciprocal, where family caregivers and patients support each other (McCauley et al., 2023), and where

changes in the illness can affect both partners' well-being over time (Keswa et al., 2026). Furthermore, mutuality within the caregiving relationship has been described as a central resource for family caregivers' ability to cope with caregiving demands and to feel prepared for the caregiving role (Zimami & Darwish, 2024). When caregiving takes place within supportive and reciprocal relationships, family caregivers have been shown to report higher self-efficacy, which in turn is associated with greater preparedness for caregiving (Keswa et al., 2026). From this perspective, the 'narstaende.se' intervention can be understood as supporting preparedness through relational conditions, rather than purely strengthening family caregivers individually.

The intervention provided support to initiate conversations, enabling family caregivers and patients to share their feelings and experiences about topics that previously had felt challenging or forbidden (III, IV). In the Andershed and Ternestedt (2001) framework, communication between family caregiver and patient can be understood not only as a prerequisite for *knowing*, but also as supporting *being*, enabling family caregivers to share and remain present in the patient's world. When facing life-threatening illness, patients and family caregivers may not routinely openly share their distress in order to protect one another or to postpone dealing with issues that are perceived as challenging (Nagelschmidt et al., 2021). From the perspective of awareness of dying, this may reflect awareness contexts in which knowledge about the situation is not openly acknowledged or shared. This may be, for example, in the case of *mutual pretence* where both partners are aware of the illness severity but avoid discussing it (Glaser & Strauss, 1980). Importantly, both open disclosure and concealment can be expressions of mutual support, intended to alleviate the other person's burden (McCauley et al., 2023).

In this thesis, family caregivers and patients acknowledged that their respective needs to talk things through could differ, as one might feel a stronger need to talk than the other (IV). When communication primarily focuses on problem-solving and leaves little room for emotional expression, family caregivers may be left alone with unexpressed feelings, which can increase caregiver burden (Otto et al., 2021). In the 'narstaende.se' trial, the need for support to talk to the patient about the illness was common, and having this need met was associated with a greater increase in preparedness for caregiving (I). This is confirmed by previous research

showing that couples express needs for support to talk about the illness, uncertainty, and the end of life (Francis et al., 2023), and preparedness for caregiving can be supported if patients clearly communicate their concerns and needs to their family caregiver (Otto et al., 2021).

9.3. The importance of emotional responses to support

Becoming aware of illness progression and death

Caring for a patient with a life-threatening illness made family caregivers aware of the patient's inevitable illness progression and impending death (III). Family caregivers described awareness of the patient's impending death as an essential part of the preparedness process, but also as emotionally demanding (III, IV). In line with Andershed and Ternestedt (2001) conceptualisation of *knowing* as a foundational condition for involvement, such awareness can be understood as necessary for family caregivers to make sense of and adapt to the caregiving situation, even though it may be emotionally challenging. As the illness progresses, family caregivers may experience increasing existential and emotional stress and require emotional, informational, and practical support to prepare for both caregiving and impending death (Caetano et al., 2024). From the perspective of awareness of dying, this process can also be understood as dynamic, as awareness changes in relation to the progression of illness (Glaser & Strauss, 1980).

Family caregivers described the importance of knowing what to expect to prepare for future caregiving demands (III, IV). They also reported a need for support to understand the patient's illness (I). Although not in a palliative care context, a large meta-analysis by Kuai et al. (2025) shows that uncertainty about illness is a key reason for low preparedness for caregiving among family caregivers. The information on 'narstaende.se' supported family caregivers in understanding and processing emotionally challenging aspects of the patient's illness, even when such reflections were difficult (III). This is important as previous research shows that family caregivers report a need to understand the patient's diagnosis, prognosis, and symptoms to interpret what the illness means for daily functioning and future care needs (Washington et al., 2021). Feeling uncertainty in these areas may hinder

planning and delay family caregivers' preparedness process (Kuai et al., 2025). From an awareness perspective, such uncertainty may reflect situations where knowledge is not fully shared or integrated, and where family caregivers may move between different awareness contexts, for example, between suspected awareness and forms of uncertain or suspended open awareness (Glaser & Strauss, 1980; Timmermans, 1994). This implies that knowing what lies ahead is an essential foundation for preparedness for caregiving and is in line with the findings of the 'narstaende.se' trial, where family caregivers had a greater increase in preparedness for caregiving when their need to know what to expect and to understand the illness was met (I). However, being cognitively aware of the future does not ensure that individuals feel prepared, and preparedness also requires an emotional aspect, which does not necessarily follow the same course (Tang et al., 2021). From this perspective, awareness is not only a matter of knowing but also of how individuals emotionally respond to and make sense of that knowledge (Mamo, 1999).

Engagement with emotionally demanding content

While the importance of preparing for future caregiving demands and inevitable illness progression was recognised, some family caregivers deliberately postponed preparing through the intervention (III). In a guided, manualised intervention, family caregivers reported no increased emotional strain from engagement in difficult topics, but rather a greater sense of confidence (Theißen et al., 2024). In contrast, in the 'narstaende.se' trial, family caregivers engaged with the intervention on their own, resulting in more varied usage; while some tended to avoid sections that were perceived as emotionally demanding, others actively sought and engaged with the same topics (III). Family caregivers have described a need to talk to someone about their fear regarding the future and the impending loss (Nysaeter et al., 2024), consistent also with the results from this trial, where family caregivers reported a need for support to deal with their feelings and worries (I). In the modern welfare society, death and dying tend to be marginalised, reducing opportunities to engage with illness and death as shared and ongoing aspects of everyday life (Sallnow et al., 2022). From the perspective of Andershed and Ternestedt (2001), avoidance of emotionally demanding content may not reflect unwillingness to be involved but rather a strategy for managing information that is emotionally difficult. Since *knowing* is understood as a prerequisite for *involvement in the light*, avoiding content may limit opportunities

to gain the knowledge and understanding needed for meaningful involvement. Family caregivers may therefore risk involvement *in the dark* if they are not sufficiently supported in handling knowledge of illness and death. This thesis shows that while some family caregivers engaged in the intervention in this avoidant way, others did not, indicating that emotional and existential support may not have been sufficient for all participants.

Some family caregivers did not feel that the intervention aligned with how they wanted to prepare (III). When interpreting this finding, it is important to recognise that support can cause distress, depending on how it is perceived by the person it is intended for (Stoltz et al., 2007; Thoits, 2011). Contrary to the assumptions in the programme theory, access to support did not lead to statistically significant improvements in preparedness for caregiving. Importantly, some family caregivers expressed mixed feelings about reflecting on caregiving and the future through the intervention because it made them think of things they usually avoided (III). From the perspective of awareness of dying, this can be understood as an interplay between knowledge and emotional responses, where emotions shape how information is received, interpreted, and engaged with (Mamo, 1999). In this sense, family caregivers may not only respond to the intervention content but also to its emotional implications, which may influence whether it is experienced as supportive. Importantly, Andershed and Ternestedt (2001) conceptualise *knowing* as a prerequisite for meaningful involvement. However, based on the avoidance described in this study, this could also be interpreted as family caregivers avoiding certain knowledge to maintain involvement *in the light*. This is also supported by Zhang et al. (2023), who describe how family caregivers actively prepare by seeking information and arranging practical matters, whilst also protecting themselves emotionally through avoidance and distancing.

10. Methodological considerations

10.1. My pre-understanding as a researcher

For a researcher, pre-understanding can be a useful resource, while also a potential source of bias. My clinical background as a palliative care nurse has helped me to formulate relevant questions about what I need better understanding of, how different aspects are connected, and how the knowledge is relevant for clinical practice. This clinical background has also made me comfortable talking to family caregivers and patients about their deeply personal experiences. Although research interviews have a different focus than conversations in nursing care, my background has been a valuable tool to help find ways to reach those personal experiences during interviews. Of course, being familiar with the context inevitably carries the risk of letting my pre-understanding confirm what I assume to be true rather than what is grounded in the data. To address this, I have striven to maintain a reflexive and critical approach throughout the research process. This has included continuously considering alternative explanations for the findings.

Apart from my clinical background, my pre-understanding also stems from my personal experience of losing a parent to cancer as a child. Throughout life, we all develop pre-understanding from previous encounters, personal values, social norms, or significant life events. While my personal experience is closely related to the subject of this thesis—support for family caregivers in a palliative care context—I acknowledge that my experience is not a template against which to compare family caregivers. Rather, it is part of my foundation that rests on the idea that life-threatening illness affects the patient and the family, influencing relationships and life.

10.2. Overall design

A complex intervention shaped by context

The 'narstaende.se' intervention can be understood as complex, as it comprises multiple components targeting diverse needs of family caregivers (Skivington et al., 2021). These components include, for example, practical information, emotional support, self-care strategies, and guidance for navigating the health-care system. However, complexity is not only related to intervention design but

also to the context in which it is used (Moore et al., 2019; Skivington et al., 2024). The 'narstaende.se' intervention was intentionally designed to be flexible and user-driven, allowing family caregivers to adapt their use over time in response to shifting needs and circumstances. This flexibility is central in support for family caregivers in a palliative care context, which is characterised by diversity and continuous change, elements that Moore et al. (2019) identify as important features of complex context dynamics. From this perspective, 'narstaende.se' is not an isolated programme but an event introduced into a context where family relationships, resources, and established norms may shape how the intervention is perceived and used.

The RCT applied to evaluate the 'narstaende.se' intervention provides scientific robustness. However, the use of fixed outcomes and time points, as required in an RCT, may not fully capture the complexity of family caregiving. As Moore et al. (2019) argue, interventions interact dynamically with their context, and effects may emerge or shift unpredictably, not capturable through fixed measurement. Consequently, an RCT does not provide a complete account of an intervention's effects. Therefore, the evaluation is strengthened by the use of multiple methods that illuminate the changeability in family caregivers' support needs, and their experiences of the intervention in relation to caregiving, relationships, and thoughts about the future.

A pragmatic evaluation trial

The design of this RCT is consistent with the pragmatic orientation of this thesis, where design and methodological choices are guided by the expected real-world use of the intervention and the expected usefulness of the findings (Morgan, 2014). Thus, pragmatism has guided both the overall trial design and the selection of methods.

The intervention 'narstaende.se' was delivered without a set structure, based on the assumption that each family caregiver is the expert on their own preferences and needs. During the trial, participants were not prompted or monitored to ensure dosage or fidelity. This allowed complete variation in how the intervention was used, corresponding to a highly pragmatic trial design (Loudon et al., 2015). Pragmatic trials aim to determine whether an intervention works under real-world conditions, thereby maximising applicability for clinical practice (Le-Rademacher

et al., 2023; Loudon et al., 2015). However, as Ford and Norrie (2016) note, the same trial design features that enhance clinical relevance can also reduce the ability to detect effects. The PRECIS-2 tool (Loudon et al., 2015) assesses how pragmatic a trial is across nine domains. Based on a subjective assessment, several domains of the 'narstaende.se' trial were highly pragmatic. Of these domains, flexibility in *delivery* and *adherence* likely had the strongest impact on the main outcome, as they directly shape intervention use and variability in participant exposure (Ford & Norrie, 2016).

Flexibility in delivery. A defining feature of the 'narstaende.se' trial was the absence of a pre-determined sequence, timing, or minimum dose of use. Family caregivers could access the intervention whenever and however it suited them, reflecting a highly pragmatic approach in delivery consistent with anticipated real-world use (Loudon et al., 2015). However, such flexibility introduces a high degree of variation in participants' exposure, which may reduce the observed effect (Ford & Norrie, 2016; Le-Rademacher et al., 2023).

Flexibility in adherence. No adherence monitoring or prompts for engagement were used in the 'narstaende.se' trial. Engagement relied entirely on family caregivers' own willingness and motivation, reflecting a highly pragmatic approach consistent with how family caregivers could be expected to use the intervention outside a research context (Loudon et al., 2015). At the same time, this introduces substantial variation in intervention use, which complicates the interpretation of results since low or unmonitored adherence risks underestimating potential benefits (Ford & Norrie, 2016).

10.3. Quantitative methods

The following section discusses the internal and external validity of studies I and II. Internal validity refers to the extent to which a study's results are reliable and not attributable to alternative factors. External validity, on the other hand, refers to the degree to which study results can be generalised to other settings or samples (Flanagan et al., 2025).

10.3.1. Sampling strategy and participants

The trial was conducted within a specialised palliative home care context where patients generally receive comprehensive care, and family caregiver support is part of the services' mandate. This context may differ significantly from settings with fewer resources and less focus on family caregiver support. In a different context, where family caregivers receive less support, the intervention could have had a greater effect. Furthermore, most patients in the study had a cancer diagnosis (94.1%), which may limit the generalisability of the results to family caregivers of patients with other diagnoses and thus poses a threat to external validity. This may also have reduced the variation in family caregivers' experiences, potentially limiting the possibility of observing an intervention effect that might have been possible in a more diverse sample.

Previous research has shown that family caregivers in palliative care often decline participation in research because they are unwell or preoccupied by caregiving responsibilities (Hudson et al., 2023). Consequently, the family caregivers who accepted participation and were included in this trial may have been somewhat better off than what is typical in this context. This could imply that the included family caregivers have comparatively less need for a supportive intervention, which could influence their engagement with the intervention and the observed outcomes. Contextual and sample characteristics should therefore be considered when interpreting the results, as this may limit the external validity and generalisability to other care settings.

10.3.2. Data collection

The outcome measure used in this trial was the PCS. This is a valid, reliable, and commonly used measure in palliative care research, sensitive to change in preparedness for caregiving over shorter time intervals (Henriksson et al., 2012; Henriksson et al., 2015), making it suitable for the time points that were applied in this trial. In previous studies, the PCS has been used to evaluate interventions in palliative care where effects have been detected (Holm et al., 2016; Norinder et al., 2024). Although an instrument's psychometric properties are important, they are insufficient when deciding if an instrument is fit to measure what the intervention is intended to change. The outcome measure's fit depends largely on how well it captures the type of change that the intervention is expected to

generate within the trial's timeframe (Coster, 2013). The intervention 'narstaende.se' offered accessible information, support, and encouragement for caregiving. This was, according to the programme theory, intended to support family caregivers in feeling prepared to meet the patient's emotional and physical needs, and was ultimately expected to increase their preparedness for caregiving. The domains of the PCS are closely related to the main parts of the intervention categorised in the three main domains *Support for you – being a family caregiver*, *How to give support*, and *Talk about it*, which motivates its use in this trial.

Another aspect of the outcome measure's fit concerns the conceptual level it is intended to capture. The PCS covers both emotional and practical aspects of caregiving, which are also present in the content of the 'narstaende.se' intervention, as articulated in the programme theory. While the intervention addressed certain practical aspects of caregiving, particularly within the *How to give support* domain, the videos may not have been sufficiently concrete or focused on tangible caregiving tasks to influence this outcome. The texts on the website, provided in addition to the videos, offered more detailed information and practical advice on caregiving. However, the feasibility study shows that the videos were the most used content (Tibell et al., 2024), and family caregivers may therefore not have been exposed to the text-based content related to practical hands-on caregiving. Conceptually, preparedness for caregiving includes emotional aspects but is largely related to the family caregiver's perceived ability to perform daily caregiving tasks (Archbold et al., 1990; Dal Pizzol et al., 2024). It is worth acknowledging that this intervention may not have provided sufficient support related to practical, tangible caregiving, which may explain why the chain of events in the programme theory did not fall out as anticipated.

In addition to the PCS, the questionnaires included the CSNAT, which is primarily intended to be used as a conversation tool as part of a five-stage intervention. However, it can also be used as a research tool to collect data on unmet support needs (Carer Support Needs Assessment Tool Intervention, n.d.). The project has been granted a licence to use the CSNAT as a research tool to describe the self-reported support needs of family caregivers.

Studies that rely on personal experiences and reflections, such as in this thesis, carry an inherent risk that the research procedure itself affects the results.

Previous research has shown that participants can experience increased reflection and insight simply by answering questionnaires (Miles et al., 2020). This suggests that the control group may also have been influenced by their participation. All participants completed questionnaires, which may have increased their awareness of what they considered important and encouraged them to reflect on different aspects of caregiving. This potential measurement effect could have reduced between-group differences, thereby underestimating the intervention's effect.

The follow-up questionnaire included a question about the use of the intervention. This question was phrased, '*To what extent have you used narstaende.se?*' However, this phrasing was suboptimal, as the word 'use' can be interpreted differently, influencing the internal validity of the results drawn from this variable. For participants, having 'used' the website may have implied anything from logging in once to deeper engagement and active application of the content in everyday caregiving situations. In study II, this question served as a variable to categorise participants into subgroups. As the question suggested some form of active engagement, this variable was labelled as 'active use'. The purpose of this subgroup analysis was to examine whether an intervention effect could be detected based on participants' engagement with the intervention. However, due to the ambiguity of the question's phrasing, the conclusions that can be drawn from these analyses are limited.

10.3.3. Data analysis

In analyses for study I and II, the PCS was used as the outcome variable. Since this instrument uses a Likert-type scale for responses, by definition, it is an ordinal measurement (Zlokovich et al., 2023). However, in the analyses, this variable was treated as an interval measurement, and parametric statistics were applied accordingly. If certain conditions are met, both non-parametric and parametric analyses can be applied to Likert-type scales, especially when the instrument allows a sum score of responses (Tanujaya et al., 2022), which is the case for the PCS. Therefore, after establishing that assumptions of normality were met, parametric statistics were applied.

The analyses for study I included the 15 CSNAT domains. The CSNAT is designed to allow family caregivers to express and describe their support needs. According to the constructors, when the CSNAT is used as a research tool,

responses should not be summarised into a total score or treated as an outcome measure. It may, however, be used descriptively or to compare outcomes based on reported support needs (Carer Support Needs Assessment Tool Intervention, n.d.). In line with this, in study I, each CSNAT domain was analysed reported individually, both descriptively and as explanatory variables (thus, not as the outcome).

In study II, the data were analysed using linear mixed models. Mixed models were considered appropriate since this allows for analysing repeated measurements over time and considering individual differences through random effects, accounting for variation between individuals (McCoach et al., 2023). In study II, the random effects are represented by individual differences in baseline levels of preparedness for caregiving, allowing variation in family caregivers' starting values. Mixed models can account for participants with missing measurement points without excluding them from the analysis (Chan, 2004). Altogether, this makes linear mixed models useful for longitudinal studies involving missing data and individuals who develop independently.

In study II, the results were not adjusted to account for participants nested within the same family. This may have affected the internal validity, as such an adjustment could have helped isolate an effect. However, this was not performed because the number of participants nested within a family was small (12 out of 205) and was therefore considered unlikely to meaningfully influence the results.

The only statistically significant baseline difference between the intervention and control groups was the type of relationship between the family caregiver and the patient. This was sensitivity-tested in study II, which confirmed that the findings were robust. This approach is consistent with the methodological recommendations by Flanagan et al. (2025) on how to address potential selection bias and strengthen internal validity. Furthermore, a dropout analysis was performed in study I through group comparison of the sociodemographic characteristics of included and non-included participants. The analysis did not reveal any statistically significant differences between included and non-included participants, thereby addressing attrition bias (Flanagan et al., 2025).

10.4. Qualitative methods

In this thesis, two qualitative methodological approaches were used based on each study's respective research question. Study III employed qualitative content analysis, which assumes that data contain multiple layers of meaning (Graneheim et al., 2017), making the method well-suited to explore distinct aspects of participants' experiences, as was the aim of study III. Study IV employed interpretive description, an approach that assumes that reality is contextual and relational, and that knowledge is constructed through subjective experience and interpretation (Thorne, 2025). Its applied context-sensitive nature aligned with the relational focus of study IV. Both approaches rest on compatible epistemological assumptions, as each supports interpretive analyses aimed at illuminating meaning in human experiences while offering both structure and analytic flexibility (Graneheim & Lundman, 2004; Thorne, 2025).

Despite these shared epistemological starting points, quality is understood or assessed differently within the two approaches. In qualitative content analysis (study III), *trustworthiness* is often used as a quality criterion (Graneheim & Lundman, 2004). Trustworthiness comprises credibility, transferability, dependability, and confirmability (Morse, 2018). In interpretive description (study IV), quality is assessed through four criteria: epistemological integrity, representative credibility, analytic logic, and interpretive authority, which together constitute *rigour* (Thorne, 2025).

10.4.1. Sampling strategy and participants

For study III, a consecutive sampling strategy was employed. Family caregivers were approached as follow-up questionnaires were completed, and those who first accepted participation were included. This approach was deemed appropriate because the family caregivers had already been included in the RCT based on inclusion criteria that were also relevant for study III. Consequently, it was expected that all family caregivers would have experiences relevant to this study. In line with qualitative content analysis, emphasis was placed on obtaining variation in experiences (Graneheim & Lundman, 2004) to enhance the breadth and depth of the results, which was considered feasible through consecutive sampling. Consecutive sampling reduces the risk of selection bias, as all eligible

individuals within the accessible population are invited to participate over a predefined time period (Flanagan et al., 2025).

For study IV, purposeful sampling was employed, with only spouses being approached. This approach added to the study's representative credibility and epistemological integrity, as spouses were expected to provide relevant information to generate contextual, experience-based insights relevant to applied practice (Thorne, 2025).

In both studies III and IV, there is a potential risk that family caregivers who were outspoken or resourceful may have been more inclined to participate in an interview. Although the sampling strategy aimed to capture variations and generate rich data, it is important to acknowledge that this cannot be fully predetermined at the sampling stage.

10.4.2. Data collection

Emphasis was placed on developing interview guides that could support open exploration of participants' experiences. The interview guides were constructed to cover broad thematic areas while including multiple specific questions, which made it possible to capture a diversity of experiences. At the same time, the structure allowed enough flexibility for participants to share what they themselves regarded as most important. This approach strengthens credibility, as it helps ensure that the accounts reflect the participants' own experiences rather than the researcher's preunderstanding (Morse, 2018). The approach is also consistent with the epistemological integrity central to interpretive description, which emphasises that methodological choices must be aligned with the phenomenon under study (Thorne, 2025). By allowing participants to guide the direction of the interview, the risk of unintentionally shaping their responses through the interview guide was reduced, contributing to confirmability (Morse, 2018). As much as possible, closed-ended questions were avoided in the interview guide to facilitate rich and nuanced narratives. However, this may have contributed to some questions being positively framed and implicitly focused on the potential impact of the intervention. As Thorne (2025) highlights, in qualitative interviewing, the researcher should 'learn not to lead', as the framing of questions may shape participants' responses. Therefore, it cannot be excluded that the framing of the questions influenced the data generated. At the same time, efforts

were made during interviews to maintain an open stance and allow space for both positive and negative experiences, including descriptions of limited usefulness or lack of impact of the intervention.

For study II, data were collected through dyadic interviews, which provided unique narratives based on the couples' interactions during the interviews. This strengthens the epistemological integrity, since the method of data collection was designed to logically align with the study's purpose (Thorne, 2025), in this case to generate an understanding of relational aspects related to family caregivers' participation in the intervention. However, a limitation to acknowledge is that the dyadic format may have limited participants' openness, out of mutual concern or relational dynamics (Bayuo et al., 2026). Although this was never explicitly stated by the participants, my impression is that the dynamic differed between the individual and dyadic interviews and that certain topics were more cautiously approached during dyadic compared to individual interviews. Some couples even reflected on the fact that during the interview they discussed issues they usually did not talk about, which naturally required a certain degree of sensitivity. An advantage of dyadic interviews is that they combine depth and interaction (Bayuo et al., 2026). This was seen in interviews for study IV, where family caregivers' and patients' joint reflections complemented and elaborated individual accounts that provided a shared perspective, contributing insights into the relational aspects of caregiving. In this sense, the dyadic format can be understood as both a potential limitation and a methodological strength because it may have constrained openness, but also illuminated shared experiences about caregiving in everyday life.

10.4.3. Data analysis

In both study III and IV, the results are presented as themes, which is a level of analysis involving a degree of interpretation. According to Thorne (2025), the researcher is a co-creator of data and therefore cannot be detached from it. In line with this, Morse (2018) argues that a degree of reflexivity is warranted to ensure confirmability and safeguard that interpretations are grounded in the data and not biased. To ensure credible interpretations, each step of the analytical process was discussed amongst the authors. This triangulation between researchers encouraged reflection and enabled alternative interpretations to be considered.

However, interpretation is always based on the researcher's deliberate choices (Thorne, 2025), and one interpretation is always chosen over others. It is important to acknowledge that alternative interpretations were possible in both study III and IV, which could have altered the results.

Member checking was not employed in the qualitative studies included in this thesis, despite it being viewed as a means to ensure credibility (Morse, 2018). However, the methodological contribution of member checking has been debated in the literature, as it is arguably unrealistic to expect participants to validate an analytical process once data have been transformed through interpretation (Thomas, 2017). In line with this, Thorne (2025) argues that member checking is not appropriate for interpretive description, since participants' individual perspectives do not necessarily provide meaningful insight into the broader analytical patterns. Although no strict member checking was employed, the results were discussed with family caregiver representatives as members of the 'narstaende.se' research team to stimulate reflection on the findings.

Within interpretive description, pre-understanding is regarded as an analytic lens that supports the researcher in detecting clinically meaningful patterns rather than something to be bracketed (Thorne, 2025). In study IV, my clinical background functioned as an analytic resource by helping me critically question and refine my initial interpretations. This approach enabled looking beyond participants' sometimes cautious formulations, which were particularly common in the dyadic interview format. In combination with continuous verification of each step by comparison with the original data, my familiarity with the clinical context thus enhanced my ability to detect and identify relevant information with strong interpretive authority (Thorne, 2025).

10.5. Declaration on the use of generative AI

This thesis was written with the help of Generative AI tools to ensure linguistic accuracy by suggesting synonyms and alternative phrases and improving overall grammatical clarity. Generative AI was not used for any transcribing, data analysis, or literature searches. All AI-generated content was carefully reviewed and, as the author, I take full responsibility for the content of this thesis.

11. Conclusions

This thesis contributes to a deeper understanding of the complexity involved in providing and evaluating self-directed, web-based support for family caregivers in specialised palliative home care, where individual choices entirely drive intervention usage. The results indicate that the perceived relevance and use of the intervention were not given; rather, they depended on the extent to which the content resonated with family caregivers' individual support needs and caregiving circumstances. The intervention also appeared to support preparedness for caregiving by facilitating understanding between family caregivers and patients.

The results further demonstrate that engagement with emotionally challenging content varied. While some family caregivers avoided such content, others actively sought it out. This highlights an essential tension in self-directed interventions, where content perceived as most meaningful may also be the most emotionally difficult to engage with. The results, therefore, suggest that family caregivers may need encouragement and support to engage with potentially beneficial content. Overall, the thesis underscores the importance of flexible and responsive web-based support that meets varying needs, preferences, and emotional responses.

12. Clinical implications

Supporting family caregivers is a core component of palliative care. In home-based palliative care, many family caregivers experience emotional strain and difficulties related to the caregiver role, indicating a need for support that is responsive to these circumstances.

From a clinical perspective, this thesis suggests that the 'narstaende.se' intervention may be most useful when integrated into clinical care. When used to complement in-person support, web-based interventions may enable healthcare professionals to reach a broader group of family caregivers and tailor support to individual preferences and needs. Facilitating opportunities for family caregivers to reflect on the intervention content together with a healthcare professional may further support the translation of insights into practical caregiving. Such guided reflection could also encourage engagement with emotionally challenging content.

13. Future research

Despite extensive research on support for family caregivers, there remains a need for research to better understand how and under what circumstances web-based interventions produce beneficial outcomes among family caregivers. One way to achieve this would be to design a trial that allows for more detailed assumptions about how the processes initiated by family caregivers' intervention engagement may lead to desired outcomes. While this thesis contributes insights into family caregivers' preferences when engaging with web-based interventions, there is a need for future research on factors influencing engagement patterns and decision-making processes in self-directed formats, including how family caregivers select and engage with or disengage from different types of intervention content.

Future research should also address the limitations related to inclusion in this trial. There is a need to explore how web-based interventions can be adapted to better meet the needs of family caregivers from diverse ethnic backgrounds, including those with limited fluency in Swedish, who may be at increased risk of reduced access to support. Additionally, children and young adults affected by life-threatening illness within the family represent a group whose needs and engagement with digital support require separate investigation. Web-based interventions such as 'narstaende.se' need ongoing adaptation to remain relevant based on societal changes, population diversity, and technical progress. Since the chat forum was not used during the trial, a future research area would also be to explore what interactive features family caregivers want from interventions, and how this could be integrated into the 'narstaende.se' website.

Future research should also evaluate the intervention as part of clinical care, combining digital support with opportunities for reflection with healthcare professionals, to promote preparedness for caregiving.

Sammanfattning

När patienter med livshotande sjukdom vill vårdas hemma är närståendes insatser ofta en förutsättning för att detta ska vara möjligt. Att vara närstående kan innebära betydande fysisk och psykisk påfrestning och ge känslor av osäkerhet och otillräcklighet. Möjligheten till förberedelse för att vårda kan minska risken för stress och ohälsa. Samtidigt upplever många att de saknar tillräckligt stöd. Att delta i fysiska stödinterventioner kan dock vara svårt på grund av tidsbrist, svårigheter att lämna hemmet eller en ovilja att dela sin situation med andra. Webbaserade interventioner kan därför vara ett värdefullt komplement som når fler närstående och kan anpassas efter individuella behov, men kunskapen om deras effekt på förberedelse för att vårda är begränsad.

Avhandlingens övergripande syfte var att utforska stödbehov och förberedelse för att vårda samt att utvärdera en webbaserad psykoedukativ intervention bland närstående till patienter med livshotande sjukdom inom specialiserad palliativ hemsjukvård. En randomiserad kontrollerad design har använts med olika metoder i delstudierna för en bred utvärdering.

Den webbaserade interventionen Närstående.se ('narstaende.se') syftar till att öka närståendes känsla av förberedelse för att vårda. Den bestod av en webbplats innehållande 23 korta filmer som skildrar samtal där närstående och vårdpersonal pratar om sådant som närstående ofta har tankar och frågor kring. Därtill fanns fördjupande texter och länkar till andra aktörer för vidare information. Innehållet baserades på tidigare forskning och klinisk erfarenhet.

Via specialiserade hemsjukvårdsenheter tillfrågades närstående om att delta i studien. Totalt deltog 205 närstående som slumpmässigt fördelades till interventions- eller kontrollgrupp. Interventionsgruppen fick fri tillgång till webbplatsen och båda grupperna besvarade enkäter vid tre tillfällen.

Resultaten visar att interventionen gav närstående nya perspektiv och stöd i rollen som närståendevårdare, men statistiskt påvisades ingen effekt på förberedelse för att vårda, eftersom en ökning sågs i både interventions- och kontrollgruppen. Ökad förberedelse hade samband med att närståendes stödbehov blev mötta.

Interventionens flexibilitet och tillgänglighet uppskattades, men innehållet mötte inte alltid närståendes individuella behov. Samtal om sådant som kunde kännas svårt att ta upp underlättades, men påverkades av att närstående och patienten inte alltid hade samma behov av att prata om eller bearbeta situationen. Interventionens innehåll väckte känslor hos närstående. Innehållet kunde kännas som en hjälp för att förstå och hantera ovissheten om framtiden och skapa en känsla av stabilitet i en annars osäker situation. Innehåll om sjukdomsförloppet och döden upplevdes som viktigt, men också känslomässigt svårt att ta till sig. Därför valde vissa närstående att undvika delar av interventionen och användningen påverkades av hur redo närstående kände sig att ta till sig innehållet.

Sammantaget visar avhandlingen på komplexiteten i självstyrt webbaserat stöd. Nyttan beror på hur väl innehållet svarar mot egna stödbehov och situation. Även meningsfullt innehåll kan vara utmanande att ta till sig, vilket påverkar användningen och interventionens möjlighet att påverka förberedelse för att vårda. Självstyrt webbaserat stöd kan därför behöva kompletteras med personlig vägledning och reflektion.

Acknowledgements

I wish to express my gratitude to everyone involved in the PhD programme at **Marie Cederschiöld University** for allowing me to pursue these PhD studies.

I also wish to thank all the participating family caregivers and patients who shared their time, experiences, thoughts, and feelings. You all made this work possible.

This thesis would never have been written if it weren't for some fantastic people in my life to whom I would like to extend my special thanks. First, what an absolute dream team of supervisors I've had:

Anette Alvariza – you have steadily guided me every step of the way, always with enthusiasm, kindness, and sincerity. No matter has ever been too small, and I have valued our conversations on life, death, palliative care, and research over these years. You are fantastic at making me feel supported, yet you have always pushed me to try my own wings and fly even in moments when I doubted that I could.

Viktoria Wallin – I wish to express my deepest gratitude for your warm personality. You inspire me in research, nursing, and as a person. With you beside me, these past four years have been the most joyful journey. Besides, there will never be a travel companion as fun as you!

Ulrika Kreicbergs – I am grateful for your ever-giving generosity, sharing your experience, network, and not least, your home. You have dared me to aim high and made me see and value what I accomplish.

Pelle Fürst – thank you for always cheering me on and for being positive and encouraging. Your belief in my abilities and your kind feedback have been greatly appreciated.

A big thank you also to **Kristofer Årestedt** for generously sharing your wisdom and enthusiasm for statistics and quantitative methods.

To my fantastic colleagues at Marie Cederschiöld University: My dear friend, **Kerstin Ivéus**, whose workspace has been just behind mine in our shared PhD

students' room. Being able just to turn around and talk to you has been priceless – you've literally had my back these past four years. I can't imagine this journey without you. All our shared experiences, conversations, joint reflections, and sometimes moments of confusion have been such an important part of this time. **Caroline Andersz**, to whom I want to express how lucky I feel to have had you as a companion on this journey. To have someone who asks how I feel – in body, soul, and spirit – not everyone is so fortunate to have a colleague and friend like that! **Maria Norinder**, with whom I have shared paths for some years now, as fellow nurses, master's students, and PhD students. Thank you for walking the path before me.

To my family: **Elliot** and **Dante**, my two favourite people in the world. Thank you for giving me joy, perspective in life, and for just being you. Being your mother is the greatest privilege of all, and I love you both so much! **Jocke**, my life companion since forever. Thank you for being my anchor and for encouraging me to grow. I wouldn't want anyone else as my teammate in life.

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Appendices

Baslinjeenkät

Till dig som närstående

Obligatoriska frågor är markerade med en stjärna (*)

1. Jag har fått muntlig och skriftlig information om studien och har haft möjlighet att ställa frågor. *

□ Jag samtycker till deltagande och har samtycke från den person som är sjuk att delta i studien närstående.se

□ Jag samtycker till att uppgifter om mig behandlas på det sätt som beskrivs i studieinformationen ovan

2. Ange den studiekod som vi skickat till dig *

3. Vilket år är du född?

4. Vilket år är den person som är sjuk född?

5. Är du....

□ Kvinna
□ Man
□ Annat
□ Vill inte uppge

6. Är den person som är sjuk....

□ Kvinna
□ Man
□ Annat
□ Vill inte uppge

7. Vilken är din relation till den person som är sjuk? Det är...

□ Min make/maka/registrerad partner
□ Min sambo
□ Min särbo
□ Mitt barn
□ Min förälder

□ Min vän
□ Annan

8. I allmänhet, hur skulle du säga att din hälsa är

□ Dålig □ Någorlunda □ God □ Mycket god □ Utmärkt

9. Om du ser till alla delar i ditt liv (till exempel fysiskt, emotionellt, socialt, spirituellt och ekonomiskt) tycker du att din livskvalitet under de senaste två dygnen (48 timmarna) har varit

Mycket dålig										Utmärkt
□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8	□ 9	□ 10

10. När fick personen som är sjuk sin diagnos?

11. Bedömer du att den person som är sjuk har haft något/några av följande symptom under den senaste månaden?

Symtom	Inte alls	Måttligt	Mycket
A. Smärta	□	□	□
B. Trötthet	□	□	□
C. Illamående	□	□	□
D. Oro eller ångest	□	□	□
E. Sömnsvårigheter	□	□	□
F. Nedstämdhet	□	□	□
G. Förvirring	□	□	□
H. Nedsatt tankeförmåga	□	□	□
I. Aptitlöshet	□	□	□

12. Andra förekommande symptom hos den person som är sjuk och dina egna kommentarer om symptom:

13. Har du, under den senaste månaden, haft samtal med läkare eller sjuksköterska, om prognosen av sjukdom?

□ Nej
□ Ja, en gång
□ Ja, två till tre gånger
□ Ja, fyra gånger eller mer

14. Följande frågor handlar om hur förberedd du känner dig för att vårda och hjälpa den person som är sjuk. Att vårda kan innebära t.ex. att vara sällskap, ge känslomässigt stöd eller hjälp med personlig hygien. Sätt ett kryss i den ruta som överensstämmer med dina upplevelser.

	Inte förberedd alls	Ganska dåligt förberedd	Till viss del förberedd	Väl förberedd	Mycket väl förberedd
A. Hur väl förberedd tror du att du är för att tillgodose fysiska behov hos den person som är sjuk?	□	□	□	□	□
B. Hur väl förberedd tror du att du är för att möta känslomässiga behov hos den person som är sjuk?	□	□	□	□	□
C. Hur väl förberedd tror du att du är för att identifiera hjälpbehov hos den person som är sjuk och hitta lösningar?	□	□	□	□	□
D. Hur väl förberedd tror du att du är inför den påfrestning som vårdandet medför?	□	□	□	□	□
E. Hur väl förberedd tror du att du är för att göra vårdandet så bra som möjligt för både dig själv och den person som är sjuk?	□	□	□	□	□
F. Hur väl förberedd tror du att du är på att hantera akuta situationer som rör den person som är sjuk?	□	□	□	□	□
G. Hur väl förberedd tror du att du är för att hitta hjälp och information från hälso- och sjukvården?	□	□	□	□	□
H. Generellt sett, hur väl förberedd tror du att du är för att vårda den person som är sjuk?	□	□	□	□	□

15. Hur många dygn har den person som är sjuk vistats hemma under den senaste månaden?

16. Hur ofta, under den senaste månaden, har du deltagit i vård eller omsorg om den person som är sjuk?

□ Aldrig
□ Vid enstaka tillfällen
□ Ungefär 1-2 gånger i veckan
□ Varje dag
□ Flera gånger per dag

17. Hur väl stämmer följande påståenden med din uppfattning? Sätt ett kryss på varje rad för det alternativ som bäst stämmer med din uppfattning.

	Stämmer inte alls	Stämmer delvis	Stämmer till stor del	Stämmer helt
A. Jag tillbringar så mycket tid som jag önskar tillsammans med den person som är sjuk	□	□	□	□

B. Jag önskar vara delaktig i vård eller omsorg av den person som är sjuk	□	□	□	□
C. Tid är inte ett hinder för mig att delta i vård eller omsorg	□	□	□	□
D. Jag orkar känslomässigt delta i vård eller omsorg	□	□	□	□
E. Jag orkar fysiskt i vård eller omsorg	□	□	□	□
F. Den person som är sjuk vill att jag deltar i vård eller omsorg	□	□	□	□
G. Vårdpersonalen underlättar min delaktighet i vård eller omsorg	□	□	□	□

18. Här kan du skriva om dina erfarenheter av att delta i vård och omsorg av den person som är sjuk:

19. I vilken utsträckning har ditt behov av egentid kunnat tillgodoses under den senaste månaden?

Inte alls tillräckligt										Tillräckligt
□ 0	□ 1	□ 2	□ 3	□ 4	□ 5	□ 6	□ 7	□ 8	□ 9	□ 10

20. Hur ofta, under den senaste månaden, har du ägnat dig åt någon form av aktivitet för egen del, t.ex. promenader, träning, bio, fika?

□ Aldrig
□ Vid enstaka tillfälle
□ Ungefär en gång i veckan
□ Ungefär tre gånger i veckan
□ Varje dag

Nedan följer ett antal frågor om ditt behov av stöd. Ordet närstående syftar här på den person som är sjuk, detta för att underlätta formuleringen av frågorna.

21. Behöver du mer stöd med:

	Nej	Lite mer	Mycket mer
A. Att förstå din närståendes sjukdom?	□	□	□
B. Att få tid för dig själv under dagen?	□	□	□
C. Att hantera din närståendes symtom, inklusive att ge medicin?	□	□	□
D. Dina ekonomiska, juridiska eller arbetsrelaterade frågor?	□	□	□
E. Att hjälpa din närstående med personlig vård och omsorg (t.ex. påklädning, hygien, toalettbesök)?	□	□	□
F. Att hantera dina egna känslor och oro?	□	□	□
G. Att hantera relationer?	□	□	□
H. Att veta vem du kan kontakta om du är bekymrad för din närstående (dag som natt)?	□	□	□

I. Att sköta din egen hälsa (fysiska problem)?	□	□	□
J. Hjälpmedel för att underlätta vården och omsorgen om din närstående?	□	□	□
K. Din tro, livssyn eller existentiella/andliga funderingar?	□	□	□
L. Att prata med din närstående om hans/hennes sjukdom?	□	□	□
M. Praktisk hjälp i hemmet eller någon annanstans?	□	□	□
N. Att få veta vad du kan förvänta dig för dig och din närstående i framtiden?	□	□	□
O. Att få vila från vård och omsorg under natten?	□	□	□
P. Något annat? (vänligen beskriv här)	□	□	□

22. Om du har fyllt i att du har stödbehov kan du berätta mer om dem här:

23. Ange i vilken utsträckning du har tagit del av följande stödformer under den senaste månaden. Sätt ett kryss på varje rad för det alternativ som bäst stämmer med din uppfattning.

	Aldrig	Vid enstaka tillfällen	Ungefär 1-2 gånger i veckan	Varje dag	Flera gånger per dag
A. Stöd från läkare, sjuksköterska eller annan sjukvårdspersonal	□	□	□	□	□
B. Stöd från professionell samtalspartner, till exempel kurator, psykolog eller annan	□	□	□	□	□
C. Stöd från religiös företrädare, till exempel präst, diakon, imam eller annan	□	□	□	□	□
D. Känslomässigt stöd från familj och vänner	□	□	□	□	□
E. Praktiskt stöd med hushållssysslor från hemtjänst eller annan	□	□	□	□	□
F. Praktiskt stöd med hushållssysslor från familj och vänner	□	□	□	□	□
G. Stöd från arbetsgivare	□	□	□	□	□

24. Har du någon att dela dina tankar och känslor kring sjukdomen med, i så fall vem? Sätt ett kryss på varje rad för det alternativ som bäst stämmer med din uppfattning.

	Aldrig	Ibland	Ofta	Inte aktuellt
A. Den person som är sjuk	□	□	□	□
B. Mitt/mina barn	□	□	□	□
C. Övrig familj	□	□	□	□
D. Vänner	□	□	□	□

E. Professionell samtalspartner, till exempel kurator, psykolog eller annan	□	□	□	□
F. Religiös företrädare, till exempel präst, diakon, imam eller annan	□	□	□	□
G. Deltagare i en stödgrupp	□	□	□	□
H. Annan – Ange vem:	□	□	□	□

25. Har du och den person som är sjuk, under den senaste månaden, samtalat om hur sjukdomen påverkar honom/henne fysiskt, till exempel med smärta, illamående, andfåddhet, eller andra symtom?

□ Nej
□ Nej, men vi har gjort det tidigare under sjukdomstiden
□ Ja, men jag önskar att vi pratar mer
□ Ja

25. Har du och den person som är sjuk, under den senaste månaden, samtalat om hur sjukdomen påverkar honom/henne känslomässigt, till exempel med nedstämdhet och nedsatt tankeförmåga?

□ Nej
□ Nej, men vi har gjort det tidigare under sjukdomstiden
□ Ja, men jag önskar att vi pratar mer
□ Ja

27. Undviker du att samtala om praktiska, ekonomiska och juridiska saker med den person som är sjuk?

□ Nej, vi har samtalat klart om detta
□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

28. Undviker du att samtala om känslomässiga saker med den person som är sjuk?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

29. Är du beroende av den person som är sjuk inom något av följande områden? Sätt ett kryss på varje rad för det alternativ som bäst stämmer med din uppfattning.

	Stämmer inte alls	Stämmer till viss del	Stämmer till stor del	Stämmer helt	Inte aktuellt
A. Hushållssysslor, t.ex. matlagning, tvätt och städning	□	□	□	□	□
B. Ekonomi, t.ex. betalning av räkningar och användande av internet	□	□	□	□	□
C. Transporter, t.ex. bilkörning	□	□	□	□	□

D. Fastighetsunderhåll, t.ex. gräsklippning, snöskottning och reparationer	□	□	□	□	□
E. Sociala kontakter med familj och vänner	□	□	□	□	□
F. Formella kontakter med myndigheter	□	□	□	□	□

30. Har ni genomfört några förändringar för att minska ditt beroende?

□ Inte aktuellt, jag är inte beroende
□ Nej
□ Ja

31. Beskriv gärna vilka förändringar ni i så fall har gjort:

Många som vårdas inom specialiserad sjukvård i hemmet har en sjukdom som är långvarig och obotlig. Nedan följer ett antal frågor relaterade till obotlig sjukdom.

32. Har den person som är sjuk fått besked om att sjukdomen är obotlig?

□ Nej, sjukdomen är inte obotlig
□ Nej
□ Vet ej
□ Ja

33. Om sjukdomen är obotlig, när fick den person som är sjuk besked, år:

34. Om sjukdomen är obotlig, när fick den person som är sjuk besked, månad:

35. Har du och den person som är sjuk, under den senaste månaden, samtalat om att sjukdomen är obotlig?

□ Nej, sjukdomen är inte obotlig
□ Nej, vi har inte samtalat
□ Nej, men vi har gjort det tidigare under sjukdomstiden
□ Ja

36. Har du, under den senaste månaden, tänkt på att den person som är sjuk kan ha en begränsad tid kvar att leva?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, hela tiden

37. Har du, under den senaste månaden, tänkt på hur du ska klara dig utan den person som är sjuk?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, hela tiden

38. Har du och den person som är sjuk, under den senaste månaden, samtalat om hur du praktiskt och ekonomiskt ska klara dig i framtiden?

□ Inte aktuellt
□ Nej

□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

39. Har du och den person som är sjuk, under den senaste månaden, samtalat om hur du känslomässigt ska klara dig i framtiden?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

40. Har du förnuftsmässigt (intellektuellt) tagit till dig information om att sjukdomen är obotlig?

□ Inte aktuellt, sjukdomen är inte obotlig
□ Jag har inte fått någon information
□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

41. Har du känslomässigt tagit till dig informationen att sjukdomen är obotlig?

□ Inte aktuellt, sjukdomen är inte obotlig
□ Jag har inte fått någon information
□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

42. Känner du dig förnuftsmässigt (intellektuellt) förberedd på att tillståndet möjligen snabbt kan försämras?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

42. Känner du dig känslomässigt förberedd på att tillståndet möjligen snabbt kan försämras?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

44. Känner du dig förnuftsmässigt (intellektuellt) förberedd på att den person som är sjuk kan ha begränsad tid kvar att leva?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

45. Känner du dig känslomässigt förberedd på att den person som är sjuk kan ha begränsad tid kvar att leva?

□ Nej
□ Ja, till viss del
□ Ja, till stor del
□ Ja, helt

46. Vilken är din högsta utbildning?

□ Grundskola, folkskola eller motsvarande
□ Gymnasium, fackskola, realskola eller motsvarande
□ Eftergymnasialutbildning, folkhögskola eller motsvarande
□ Universitets- eller högskoleutbildning

47. Vad är din huvudsakliga sysselsättning för närvarande?

□ Yrkesarbetande, anställd
□ Yrkesarbetande, egen företagare
□ Ålderspensionär
□ Förtidspensionär
□ Studerande
□ Arbetssökande
□ Föräldraledig
□ Annat, ange vad

48. Har du varit sjukskriven den senaste månaden?

□ Nej
□ Ja, delvis
□ Ja, helt

49. Har du avstått från att arbeta för att delta i vård och omsorg av den person som är sjuk och fått ersättning via Försäkringskassan i form av närståendepenning?

□ Nej
□ Ja, delvis
□ Ja, helt

50. Var är du född?

□ I Sverige
□ I annat land i Norden
□ I annat land i Europa
□ I annat land utanför Europa

51. Har du några tankar om din situation eller om enkäten som du vill dela med dig av och som inte har fått utrymme i enkäten? Skriv gärna nedan:

Intervjuguide studie III

Användning av webbsidan Kan du berätta hur det har varit för dig att ta del av webbsidan? I vilken utsträckning har du använt webbsidan? I vilka situationer har du använt sidan? Vad var dina förväntningar och förhoppningar med att ta del av webbsidan? Kan du berätta om hur det har varit att ta del av ett *webbaserat* stöd? Hur tänker du generellt kring stöd på webben? Är det något på webbsidan som har gjort dig fundersam eller väckt tankar hos dig? Hur kände du då? Hur påverkade det dig? På vilket sätt har det påverkat din fortsatta användning av webbsidan?	**Betydelsen av webbsidan för rollen som närstående** Vad på webbsidan har du upplevt som värdefullt för dig? På vilket sätt har det varit värdefullt för dig? Vad har webbsidan haft för betydelse för dig i rollen som närstående? Att du tagit del av webbsidan, vad har det haft för betydelse för personen som är sjuk, tror du? Vad har webbsidan haft betydelse för dig att förbereda dig för framtiden? Kan du ge något exempel? Om nej: Vad kan det bero på? Varför har den inte haft betydelse? Vad behöver du för stöd som närstående? Hur stöttar ni varandra i den här situationen?
Samtal och kommunikation På vilket sätt har webbsidan betydelse för dig i hur du pratar med NN? Hur pratar man med varandra om sådant som är svårt? På vilket sätt skulle webbsidan kunna hjälpa dig att prata med NN om det du egentligen tycker är svårt? Hur blev det? Skulle du vilja? På vilket sätt har webbsidan haft betydelse för dig att prata med andra personer om din situation?	**Fortsatt användning** I vilka situationer tror du att webbsidan kommer att vara till hjälp för dig framöver? Om du skulle berätta för någon i samma situation om webbsidan vad skulle det vara? Inför att vi skulle träffas, var det något som du funderade på som du vill berätta om?

Intervjuguide studie IV

Inbjudan, förväntningar och anledningar att delta Vad tänkte du (patienten) när du fick information och förfrågan om att bjuda in (närstående) att delta i studien? Hur tänkte du? (närstående) Hur resonerade ni tillsammans kring eventuellt deltagande? Vad var era förväntningar och förhoppningar angående deltagandet?	**Stöd av webbsidan ur patientens perspektiv** Hur har det varit för dig (patienten) att (närstående) haft tillgång till webbsidan? Hur tror du (patienten) att det har varit för (närstående) att ta del av webbsidan under den här tiden? Har du (patienten) uppfatttat att (närstående) fått stöd från webbsidan? Har det i så fall varit ett stöd för dig?
Användning av webbsidan Hur har du (patienten) fått ta del av webbsidan? Har din närstående berättat eller visat för dig vad som finns på webbsidan? Är det något på webbsidan som ni tittat på tillsammans?	**Ömsesidigt stöd till varandra** Hur stöttar ni varandra nu när (patienten) är sjuk? Vilka strategier har ni haft tidigare när ni varit i svåra situationer? Har ni kunnat använda det nu? På vilket sätt har webbsidan inneburit en hjälp för hur ni stöttar varandra? Vilken betydelse har webbsidan haft för ert dagliga liv?
Samtal och kommunikation Hur pratar ni tillsammans om det som kan upplevas som svårt i livet? Pratar ni om att (patienten) är sjuk? På vilket sätt pratar ni -om framtiden -om vardagen och livet? Vilken betydelse kan webbsidan ha haft för dig (närstående) gällande att prata tillsammans? Skulle du kunna hämta stöd från sidan för att prata med (patienten) om det som kan vara svårt? Hur pratar ni med andra i er omgivning om sådant som är svårt? Vilken betydelse har webbsidan haft för det sätt ni pratar -tillsammans? -med andra?	

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