

A person-centred approach to support family caregivers in specialised home care

THE CARER SUPPORT NEEDS ASSESSMENT TOOL INTERVENTION



Maria Norinder



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Marie Cederschiöld University

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Abstract

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Family caregivers are crucial providers of support and care for patients with life-threatening illness and many report unmet support needs. With the use of quantitative and qualitative methods this thesis aimed to evaluate the Carer Support Needs Assessment Tool (CSNAT) and explore experiences and potential effects of utilising the Carer Support Needs Assessment Tool Intervention (CSNAT-I) among family caregivers and registered nurses in the context of specialised home care. The results showed that the CSNAT tool was valid and reliable for use among family caregivers in specialised home care (I). Family caregivers reported most the need for additional support concerning “Knowing what to expect in the future” (I, II). They reported and described how higher levels of need for more support were associated with poorer quality of life (II). The intervention was effective in significantly increasing family caregivers’ preparedness for caregiving ($p = 0.002$) (IV). Participating nurses expressed that their everyday clinical practice changed while learning to use the CSNAT-I and they experienced professional and personal growth (III). Their assessments and supportive inputs shifted from reactive towards proactive and more in collaboration with family caregivers. When utilizing the CSNAT-I, family caregivers experienced their conversations with nurses as co-created, providing new perspectives and insights which increased their involvement and helped in finding solutions (V).

In conclusion, this thesis gives further weight to the importance of addressing family caregivers' support needs as a part of nursing.

Keywords: Family caregivers, Home care, Intervention, Nursing, Palliative care, Preparedness, Quality of life, Support

Till Elsa, min läromästare och största kärlek i livet

List of Papers

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

- I. Alvariza, A., Holm, M., Benkel, I., Norinder, M., Ewing, G., Grande, G., Håkanson, C., Öhlén, J. & Årestedt, K. (2018). A person-centred approach in nursing: Validity and reliability of the Carer Support Needs Assessment Tool. *European Journal of Oncology Nursing*, 35, 1-8. doi: 10.1016/j.ejon.2018.04.005
- II. Norinder, M., Årestedt, K., Lind, S., Axelsson, L., Grande, G., Ewing, G., Holm, M., Öhlén, J., Benkel, I. & Alvariza, A. (2021). Higher levels of unmet support needs in spouses are associated with poorer quality of life—a descriptive cross-sectional study in the context of palliative home care. *BMC Palliative Care*, 20, 1-11. doi:10.1186/s12904-021-00829-9
- III. Norinder, M., Axelsson, L., Årestedt, K., Grande, G., Ewing, G., & Alvariza, A. (2022). Enabling professional and personal growth among home care nurses through using the Carer Support Needs Assessment Tool Intervention - An interpretive descriptive study. *Journal of clinical nursing*, 32(13-14), 4092–4102. doi: 10.1111/jocn.16577
- IV. Norinder, M., Årestedt K., Axelsson L., Grande G., Ewing G., & Alvariza, A. (2023). Increased preparedness for caregiving among family caregivers in specialized home care by using the Carer Support Needs Assessment Tool Intervention. *Palliative & Supportive Care*, 1-7. Advance online publication. doi:10.1017/S1478951523000639
- V. Norinder, M., Axelsson, L., Årestedt, K., Grande, G., Ewing, G., & Alvariza, A. (2023). Family caregivers' experiences of talking with a nurse about their needs in a structured conversation using the Carer Support Needs Assessment Tool Intervention - a qualitative study in the context of specialised home care. *Accepted for publication in European Journal of Oncology Nursing, subject to minor amendments and resubmitted 230725.*

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Abbreviations and key terms

CBS	The Caregiver Burden Scale
CSNAT	The Carer Support Needs Assessment Tool
CSNAT-I	The Carer Support Needs Assessment Tool Intervention
EAPC	European Association for Palliative Care
IHAPC	International Association for Hospice and Palliative Care
PCS	The Preparedness for Caregiving Scale
PROM	Patient-reported outcome measures
QOLTI-F	The Quality of Life in Life-Threatening Illness – Family carer/caregiver version
WHO	World Health Organization

Family caregiver In this thesis, the term “family caregiver” refers to any relative, friend, or partner who has a significant relationship with and provides physical, social, and/or psychological support to a person with a life-threatening illness.

Global north Includes countries that are wealthy and technologically advanced and comprises of North America, Europe, Japan, Israel, South Korea, Australia, and New Zealand.

Global south Non wealthy countries with fewer resources, comprising the regions of Africa, Latin America, Caribbean Asia (excluding Japan, Israel, South Korea) and Oceania (excluding Australia and New Zealand).

Support In this thesis, the term “support” refers to support from a physical, psychological, social, and existential perspective.

Preface

Growing up, I watched my grandmother take care of my grandfather, who developed Alzheimer's disease at a working age. At first, my grandmother cared for him, but over the years his condition deteriorated, and the care became more and more demanding for my grandmother. She cared for him for over a decade at home, and he then spent his final years in a residential home.

As a teenager, I reflected on the solitude of my grandmother's responsibilities and the lack of support she received before my grandfather moved. From then on, I carried those reflections with me.

During my PhD studies, my once vibrant grandmother aged rapidly and passed away at the age of 100. When I was emptying her apartment, I found magazine articles describing how she had volunteered to raise awareness and money for research about Alzheimer's disease. Along with them were handwritten papers with her thoughts while caring for my grandfather. It served as a reminder of the importance of support to family caregivers.

"This work that we family members do in caring for our ill relatives is a huge relief for society. It seems to be forgotten that we also are affected by the disease. I have lost my husband even though he is alive. I believe that I also should receive support. I need to visit a doctor, who sees me, the person behind the patient and who does not just conclude that there is nothing wrong with me. I feel emotionally and physically drained despite good test results and blood values."

Anna Märta, 1988

My thesis, which is partly inspired by my grandmother's experiences, aims to evaluate the Carer Support Needs Assessment Tool (CSNAT) and explore experiences and potential effects of utilising the Carer Support Needs Assessment Tool Intervention (CSNAT-I) among family caregivers and registered nurses in the context of specialised home care, and is in the subject of Palliative care and in the research area "The individual in the Welfare Society."

1. Introduction

The majority of patients with life-threatening illness prefer the home as the place of death (Yamout et al., 2022) and are cared for at home towards the end of life (Tay et al., 2021). Family caregivers, for example, spouses, children, parents or others are essential for the care they provide (Khan et al., 2014; Pivodic et al., 2016). Approximately 90 000 persons die in Sweden each year (Statistiska Centralbyrån, 2023) and almost half of all deaths are caused by conditions indicative of potential palliative care needs (Håkanson et al., 2015). As more and more people with advanced, incurable disease and complex care needs are cared for at home, family caregivers take on greater responsibility (Jegermalm, 2020). Their efforts are increasing regularly, the public society in Sweden today accounts for only one third of care and family caregivers for two thirds, most of whom provide care completely without cost compensation (Nationellt kompetenscentrum anhöriga, n.d.). Research shows that 45% of citizens in Sweden have regularly performed some form of informal care (Jegermalm, 2020).

Internationally it is well known that family caregivers are crucial providers of social support (Palmer Kelly et al., 2019) and a great deal of caregiving (Holm et al., 2015) involving practical, emotional, and existential support (Holm et al., 2015; McDonald et al., 2018). Many who serve in caregiving roles report unmet support needs and insufficient knowledge of caregiving (Harding, Epiphaniou, et al., 2012; McIlfatrick et al., 2018; Sklenarova et al., 2015), and also decreased quality of life (Breen et al., 2019; Spatuzzi et al., 2017). Nurses play an important role in providing palliative care for patients and their family caregivers and must address their issues and support needs continuously (Ewing et al., 2015). Despite that the World Health Organization (WHO) (2002) strongly emphasises the importance of supporting family caregivers, there is little guidance on what such support involves or how to achieve it. Both internationally and in Sweden it has, however, been acknowledged that support to family caregivers is of importance (Payne, 2010; Payne et al., 2010; Regionala cancercentrum, 2023), and that care for the patient should be personalised to their individual needs, including support to their family caregiver (*Hälsö- och sjukvårdslagen* [HSL], 2017:30). Therefore, it is important to find an approach that can facilitate the work of assessing and addressing family caregivers' individual needs and ensure adequate support. The

Carer Support Needs Assessment Tool intervention (CSNAT-I) was developed to support family caregivers to identify, express and prioritise their support needs. The intervention may provide an evidence-based way to meet family caregivers' support needs, and previous studies have shown promising results (Aoun, Grande, et al., 2015; Aoun, Toye, et al., 2015; Aoun, Ewing, et al., 2018; Ewing et al., 2016; Lund et al., 2020). However, this intervention has not been studied in a Swedish context and more knowledge is needed to increase the understanding about potential effects as well as family caregivers and nurses' experiences of the intervention.

2. Background

2.1. Palliative care philosophy, definitions, and provision

In the development of modern palliative care, Cicely Saunders (1918-2005) played a crucial role as a pioneer in shaping hospice philosophy (Clark, 1999). Saunders established death as a natural part of life and argued that the whole patient should be seen, reflecting physical, psychological, social and/or spiritual needs. She found that social life and searching for meaning was of great importance to the dying person and emphasized that both patients and family members should be supported to live in the most optimal way as possible in the situation (Clark, 1999; Lutz, 2011). Inspired by Cicely Saunders, WHO first defined palliative care in 1990. Their updated version from 2002 ensured access to palliative care for all patients in need and has so far been the most widely used definition. Palliative care is seen as an approach that improves the quality of life of patients and their families when facing problems associated with life-threatening illness (World Health Organization, 2002). This is meant to be accomplished through the prevention and relief of physical, emotional, and spiritual suffering by means of early identification and impeccable assessment and treatment – which also includes psychosocial and spiritual support for the family. However, in a concept analysis of non-specialist palliative care, Nevin et al. (2019) highlights that the

WHO definition is unclear as it describes palliative care as an “approach to care” and at the same time states “uses a team approach to address the needs of patients and their families” (Nevin et al., 2019, p.639). This leads to confusion about whether it is to be interpreted as a philosophy of care that should be applied by all healthcare professionals or by a care team that has the possibility to work team-based. Consequently, there has been a call to update the WHO definition of palliative care to provide a clearer and transparent definition that reflects the varied nature of palliative care.

The International Association for Hospice and Palliative Care (IAHPC) recently proposed a new definition that emphasizes serious health-related suffering, rather than solely focusing on life-threatening illnesses. The new definition further expands the criteria for palliative care provision for many patients and families who endure preventive, serious, health related suffering. The definition states that: “Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers” (International Association for Hospice & palliative Care, 2018; Radbruch et al., 2020). The European Association for Palliative Care (EAPC) has criticized the new definition in the form of fears that the concept of palliative care will be eroded. The EAPC argues that the proposed linguistic change to "serious suffering from serious illness" is ambiguous and a too broad definition that could include acute or transient conditions. In addition, they are critical of the concept of suffering, which is also broad and difficult to define. According to the EAPC, the concepts need to be refined to reflect what palliative care means and to facilitate discussions about when and how palliative care should be provided (European Association of Palliative Care, 2020). The Report of the Lancet Commission on the “Value of Death: Bringing Death Back into Life” summarizes death and dying in the 21st century in a global perspective (Sallnow et al., 2022). They challenge the way that death is viewed and talked about in modern society, and argue that death is too often seen as a failure of medicine rather than a natural part of life. The commission suggests that this view of death can lead to unnecessary medical interventions and a lack of attention to the social, spiritual, and cultural aspects of dying. The Commission also proposes a new vision for

death and dying, with greater community involvement alongside health and social care services, and increased bereavement support.

Palliative care can be further understood using models and theories. Touzel and Shadd validated a conceptual model of a palliative approach that they developed by using published literature on definitions for palliative care. In total, they found 19 different definitions and could conclude that their model covered the content in the definitions (Touzel & Shadd, 2018). Their model highlights the importance of whole-person care, quality of life, and mortality acknowledgement. Another concept that was found in many definitions included the family, promoted their quality of life and help them cope by supporting them through the patient's illness and following the patient's death. Touzel and Shadd also argue and acknowledge that family support is a part of whole-person care. This model links the philosophical definitions and clinical behaviour and has the potential to facilitate a broad implementation of a palliative approach in the clinic. This can be helpful as palliative care is based on experiences from providing care for patients with cancer at the end of life and now intends to include other diagnoses.

Another conceptual model by Sawatzky et al. (2016) suggests a palliative approach to meet patients with chronic life-limiting conditions. This approach includes three overarching themes: upstream orientation towards the needs of people who have life-limiting conditions and their families, adaptation of palliative care knowledge and expertise, and operationalization of a palliative approach through integration into systems and models of care that do not specialize in palliative care. This approach can help healthcare systems integrate a palliative care approach into the care of people with chronic, life-limiting conditions. This may be helpful as palliative care should be provided regardless of where the patient is being cared for (Gamondi et al., 2013; Nevin et al., 2019; Radbruch & Payne, 2009). This means that the palliative care must be able to be provided in a variety of healthcare settings by healthcare professionals who do not have specialised training in palliative care. Some healthcare professionals in these settings perceive as difficult providing qualitative palliative care without education or experience (Hawley, 2017). Many settings that normally do not care for patients with palliative care needs have integrated a palliative care approach where the

application of palliative care is a philosophy that does not necessarily require specialised services (Nevin et al., 2019; Sawatzky et al., 2016). The healthcare professionals adapt palliative care knowledge and expertise to meet the needs of people with chronic life-limiting conditions. Traditionally, this care has been referred to as general palliative care, but lately the term non-specialist care is used. Non-specialist care shall be provided in care settings focusing on cure but with the knowledge that the disease eventually will lead to death. Healthcare professionals in these care settings shall have good knowledge of basic palliative care and provide it when needed. Specialist palliative care shall be provided in care settings whose main activity is the provision of palliative care, with healthcare professionals who have experience dealing with complex problems requiring specialised skills and competencies. This care demands a high level of coordination among a team of physicians, nurses and other professionals working together to meet the needs of the patient and family caregivers. In Sweden, palliative care is organised in a similar way. Non-specialist palliative care should be possible to provide, in most healthcare settings, to patients whose needs can be met by basic knowledge in palliative care (Regionala cancercentrum, 2023). Specialist palliative care is provided either in inpatients settings or by specialised home care teams to patients with life-threatening illness, complex symptoms or whose life situation results in special needs. The nurses in specialised home care teams are responsible for handling complex symptoms and special needs and collaborate with the municipality healthcare professionals that provide care such as personal hygiene. Importantly, however, there are no universally acceptable definitions of non-specialist palliative care and a lack of clarity surrounding the distinction between non-specialist and specialist palliative care (Nevin et al., 2019). This ambiguity can result in confusion and miscommunication among professionals, leading to challenges for healthcare practitioners on how the clinical care may be planned, delivered, and measured.

Each year, 56.8 million people are estimated to be in need of palliative care, most of whom live in low- and middle-income countries (World Health Organization, 2020). Despite progress, significant challenges remain in providing access to palliative care in different parts of the world (Clark et al., 2020). Countries with the highest levels of palliative care development contain 41.8% of the world population and are concentrated most in the Global North compared to countries

mainly in the Global South, with 53.3% of the world's population, which have very limited development of palliative care. Palliative care at the highest level of provision is available for only 14% of the global population and is concentrated in European countries. Nevertheless, there has been an improvement between 2006 and 2017, when 33 countries improved their development for palliative care. The Lancet Commission highlights that there are also inequalities at an individual level based on ethnicity, class, gender, or sexual orientation (Sallnow et al., 2022). But while it is easy to believe that inequalities exist only in low-income countries, access to palliative care varies in Western European countries, and the proportion of different specialised palliative care settings varies considerably between countries (Axelsson, 2022). Sweden is classified as a high-income country and belongs to the group of countries with the highest development of palliative care (Clark et al., 2020). Despite this, access to palliative care varies across the country and an unequal provision relating to level of care, place of residence, and age (Axelsson, 2022).

Given the lack of clarity in the different definitions, it has been recognised that it is not always apparent to health professionals how to provide palliative care in different contexts. Research shows that although the definitions and models explaining palliative care emphasise the importance of family support, many family caregivers face challenges when caring for a person with a life-threatening illness, which can lead to negative consequences. Below follows a description of currently existing research.

2.2. Family caregivers in palliative care

There is an abundance of different terms that name the person who provides support and care for the patient (Andershed, 2006). However, in this thesis, the term “family caregiver” is used based on the definition suggested from Hudson and Payne who states that “a family caregiver is as any relative, friend, or partner who has a significant relationship with and provides physical, social, and/or psychological support to a person with a life-threatening illness” (Hudson et al., 2011).

The division of responsibilities in Sweden between family, society, state, and municipality is constantly evolving, and has led to increased family care since the 1970s (Qvarsell, 1993). Recent reports show that most family caregivers are in the age group 45-64 years, the care they provide is usually to a parent (Nationellt kompetenscentrum anhöriga, n.d.). Those who spend the most time in relation to care and support are the age group 65-80 years. This group most often provides care to a spouse or partner. The majority of family caregivers (65%) provide care between one to ten hours a week. Every fifth (21%) provides a comprehensive care more than ten hours a week. In these cases, they often live together. Almost one in three are alone in their caregiving situation and don't have any possibilities to get relief or share responsibility with another, but for most informal care is not a solitary commitment. Rather, it is a shared responsibility with other people or with the help of municipal or public services such as homecare services (Jegermalm & Torgé, 2021). During spring 2022, the Government presented Sweden's first national strategy for family caregivers [svenska: Nationell anhörigstrategi] (Socialdepartementet, 2022). The strategy aims to promote the perspective of family caregivers in health and social care, and reassure that support is provided based on their specific needs. This may include information, education, respite care, financial support, or counselling. A fundamental principle is that the involvement and participation should always be voluntary.

Both national and international research shows that family caregivers are essential for patients with life-threatening illness (Cai et al., 2021; Khan et al., 2014; Pivodic et al., 2016), as many patients are cared for at home towards the end of life (Tay et al., 2021). The home is often the preferred place of care for family caregivers (Woodman et al., 2016) and despite that they often are viewed as an expected caregiver resource (Funk et al., 2010; Woodman et al., 2016), many also assume the role motivated by love and duty (Erlingsson et al., 2012; Linderholm & Friedrichsen, 2010). Although the caring experience might be rewarding, accompanied by feelings of satisfaction, and meaning (De Korte-Verhoef et al., 2014; Henriksson, Carlander et al., 2015; Higginson et al., 2020; Holtslander et al., 2017), the family caregiver can sometimes feel doubt and ambivalence and their situation has been described as exhausting and often very limiting (Wang et al., 2018).

Palliative home care is provided by professionals but between their home visits family caregivers are crucial providers of social support (Palmer Kelly et al., 2019). They also perform a great deal of caregiving consisting of extensive assistance with personal care, medication and symptom relief, maintaining contact with the health care service (Alam et al., 2020; Barlund et al., 2021; Higginson et al., 2020; Holm et al., 2015; Pollock et al., 2021), as well as existential support (Alam et al., 2020; Holm et al., 2015; McDonald et al., 2018). In addition, family caregivers increasingly take over the household chores and some family caregivers have little opportunity to leave the home when the ill family member needs constant attention (Holm et al., 2015). Thus, their situation is interwoven with that of the patient (Hudson & Payne, 2011; Norinder et al., 2017) and as the illness progresses and the patient deteriorates, more demands are often placed on family caregivers (Cai et al., 2021; Candy et al., 2011). Family caregivers usually need to reframe their own lives and must cope with an uncertain future and the impending death of a family member (McDonald et al., 2018). Furthermore, the family caregivers' own existential concerns are often evoked, forcing them to confront life's fragility and their own mortality.

Although there are variations, family caregivers' quality of life is often negatively affected as they put their own lives on hold and attend to the patient's needs (Breen et al., 2019; Gotze et al., 2018). Their quality of life seems to decrease as the patient deteriorates (Breen et al., 2019). Family caregivers are known to suffer from sleep disturbances with a substantial reduction in total sleep time (Maltby et al., 2017), in association with factors such as anxiety (Gotze et al., 2018), depression, fatigue (Perpina-Galvan et al., 2019), emotional distress, and physically, socially and financially related problems (McDonald et al., 2018). All of these factors contribute to a reduced quality of life. Of importance to note, however, is that quality of life is a complex concept as it has different meanings for people (Fayers & Machin, 2015) and each family caregiver's experience of grief and loss is unique. This may necessitate a need to systematically assess family caregivers' quality of life through an approach that supports their unique narrative in practical, emotional, existential, and social terms (Holtslander et al., 2017). Quality of life is a vital part of palliative care and is highlighted as an essential concept that always should be in focus when meeting patients and their family caregivers (Touzel & Shadd, 2018). A frequently used definition is WHO:s (1997)

which defines quality of life as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment” (p. 1).

Preparedness is important in reducing negative consequences for family caregivers (Henriksson & Årestedt, 2013; Holm et al., 2016; Tang et al., 2021). Being prepared for caregiving has been defined as having a perceived readiness for multiple domains of the caregiving role, such as providing physical care, emotional support and dealing with the stress of caregiving (Archbold et al., 1990). Family caregivers who feel more prepared may experience less burden (Gutierrez-Baena & Romero-Grimaldi, 2022; Karabulutlu et al., 2022), and they also tend to report more positive experiences of caregiving with higher levels of hope and reward as well as quality of life (Henriksson & Årestedt, 2013; Rochmawati & Prawitasari, 2021).

A family caregiver's situation during the caring trajectory can be seen and understood through the Penrod et al. theoretical model of caregiving through the end of life (Penrod et al., 2012). They describe a transitional process that starts when the health problem is recognized, then continues to the phase focused on treatment and family caregivers taking on an assistant role; when diagnosis becomes palliative and the family caregiver transitions to a new phase with an active caregiving role; the final transition for the family caregiver is when the patients dies, and they grieve and begin to assemble a new pattern of normality. All phases have different levels and amount of caring and the family caregiver follows and responds to the changeability of the disease during this period. During the transitions, they have a need for new knowledge, change in behavior and support (Meleis, 2010). Family caregivers have information and educational needs at all points in the illness trajectory (Flemming et al., 2019). These needs fluctuate as caregivers are required to adapt to the changes to their role caused by progressing illness. In their new caring role, many family caregivers experience that they lack sufficient knowledge to care for someone with a life-threatening illness and have unmet needs, which creates a demand for information and support from the professional healthcare (Collins et al., 2018; Harding, List, et al.,

2012; McIlfatrick et al., 2018; Sklenarova et al., 2015). Many express that they need more information about the illness' prognosis, progression and treatment (Collins et al., 2018; Harding, Epiphaniou, et al., 2012; Holm et al., 2015; McIlfatrick et al., 2018; Sklenarova et al., 2015). In addition, they also communicate the need for emotional support from the healthcare professionals (Harding, List, et al., 2012; McIlfatrick et al., 2018; Sklenarova et al., 2015). Time with healthcare professionals, a chance to share views and opinions and an opportunity to talk to someone who understands their situation - all exemplify perceived support.

Existing research clearly indicates great challenges to achieve sufficient support to family caregivers according to philosophy definitions and models of palliative care.

2.2.1. Support to family caregivers

According to the literature described above, family caregivers seem to risk their quality of life when caring for an ill person. It is therefore crucial that healthcare professionals support family caregivers systematically and holistically. Timely and tailored support for family caregivers at all stages of the caring trajectory will enable them to best care for the patient, and to maintain their own health and wellbeing (Aoun, Ewing, et al., 2018).

Care at home can be complex, creating challenges for both family caregivers and healthcare professionals as it involves meeting both the patient's and the family's needs. The home environment can however enable normality, a sense of control and individualised care which family caregivers often perceive as contributing towards a good death (Pottle et al., 2020).

Existing literature contributes with knowledge concerning the need for support among family caregivers (Wang et al., 2018). Family caregivers experience healthcare professionals acting as both barriers and facilitators to the provision of information and education, thereby affecting their ability to manage their caring role. To feel confident in managing care, family caregivers require timely access to information and support, particularly out of hours (Flemming et al., 2019). In a recent literature review published from 2004 to 2020, Becqué et. al (2023) found that almost all interventions to support family caregivers in palliative care reported

beneficial effects, mainly in the psycho-emotional and social dimensions. Most interventions were provided by nurses and primarily aimed at supporting family caregivers' self-care, sometimes in combination with patient care and family care. Two other reviews show that the most common design of family caregiver interventions the last 15 years were psychosocial, educational, and psycho-educational (Ahn et al., 2020; Ferrell & Wittenberg, 2017). The support interventions varied in design, with some being couples-based involving both the patient and the family caregiver and others were offered to either the patient or the family caregiver. The majority of interventions have used a combination of face-to-face visits and telephone contact, some group formats, video/audio materials or web-based education and support. Research on these interventions shows that there has been an increase in randomized controlled trials (RCTs) since the 2010 meta-analysis by Northouse et al. (2010) but that the psychoeducational interventions remain the predominant approach to family caregiving intervention research.

However, it has been found that there is a vast heterogeneity concerning context, delivery, outcome measures or timing of assessment in support interventions for family caregivers the last two decades (Oliveira et al., 2022). Discussions around this heterogeneity point to the multidimensional and complex nature of palliative care causing the lack of consensus and effective guidelines for this type of intervention. This is in accordance with a Cochrane review that concluded that the low study quality and varying study designs make it difficult to draw conclusions about the effects of psychosocial interventions for caregivers. Supportive interventions can address some of the family caregivers' negative effects and reduce them, such as burden and anxiety and promote family caregivers' preparedness for caregiving and their competence (Ahn et al., 2020; Bilgin & Ozdemir, 2022; Candy et al., 2011; Ferrell & Wittenberg, 2017; Holm et al., 2016; Singer et al., 2016) so that the caring experience can be meaningful (Alvariza et al., 2018; Henriksson, Carlander, et al., 2015; Higginson et al., 2020). However, despite the increased attention to interventions aimed to support family caregivers and the development of different models and designs, Ferrell and Wittenberg (2017) argue that translation for realistic application into clinical practice is highly necessary. Importantly, different family caregivers have various needs and cope with information in different ways (Røen et al., 2018). Therefore,

knowing the exact time and way to provide support to family caregivers is not always clear. When it is not clarified how support for family caregivers can be provided in the context of everyday work, there is a risk that the care will focus on task-oriented work. Individual efforts to provide person-centred support will then have limited impact on overall care and hence, a shared vision and a collective team approach is needed.

2.2.2. Nurses' role in supporting family caregivers

Nurses play a key role in palliative care, and their approach and preparedness to it is an important factor in ensuring quality care for the patient and the family (Hawley, 2017). Nurses are in the unique position of being the primary link between the patient, the family caregivers and other professionals in the palliative care team (Sekse et al., 2018). It has been shown, however, that resource constraints (e.g. lack of time) implies that nurses give lower priority to communication (Ball et al., 2014; Pottle et al., 2020), the basis for being able to support family caregivers. They describe frustration when resource constraints also affect their ability to address the different needs of the dying patient and their family. In addition to this, nurses experience barriers to truth-telling when the family caregivers and the patients' needs and wishes are in opposition (Noble et al., 2015). The nurses find themselves in the dilemma of having to choose between meeting family caregivers' or patients' wishes. In particular, nurses in home care must master a range of activities, often alone, in the immediacy of the patient's home. They face complex challenges in practical, relational and moral dimensions of care, which demand a comprehensive approach to the care they provide. This may contribute to situations in which nurses need to focus often on the patient and therefore do not find possibilities to address the situation or needs of family caregivers (Wittenberg et al., 2018). Nurses have an important role to play in both helping family caregivers to care for the patient, and directly supporting them to preserve their own health and well-being (Ewing et al., 2015). The identification of needs and support for family caregivers has been found to be mainly based on intuition and experience, rather than on a systematic approach (Becqué et al., 2021). Therefore, Becqué and co-authors (2021) conclude that the support provided by nurses can vary, and this variation is based on nurses' interpretation rather than on the needs reported by caregivers. In addition, nurses' ability to

meet the caregiver's needs are also affected by factors such as their knowledge and experience, the way in which care is organised, laws and regulations.

Nurses in non-specialised palliative care are commonly inadequately prepared to cope with patients with life-threatening illnesses (Zheng et al., 2018) and express that it can be experienced as challenging (Hawley, 2017; Pottle et al., 2020). Communication is highlighted as a major barrier to care and can generate family-related problems (Blaževičienė et al., 2020). Palliative care also requires more time addressing the patient's physical needs, leaving less time to attend to the patient's and family's spiritual and psychological needs. Nurses who don't usually work with palliative care can often experience it as emotionally demanding (Zheng et al., 2018). To be able to manage the care for a dying patient, nurses may use various coping strategies such as debriefing, showing emotions or avoidance. Dobrina et al. (2014) identified three models for palliative care nursing in a literature search and through a content analysis found ten core concepts that fell into three categories: patient, nurse and therapeutic relationships. Most of the themes and values in the nursing models were congruent with palliative care philosophy and the core concept that emerged could help the nurses to feel confident in their role and improving their practice in enhancing quality in palliative care. Through their relationship to the patient and their family, nurses have a special and specific role in providing quality of life and support in palliative care. However, based on the challenges described above, nurses might benefit from finding structured ways to supporting family caregivers as a part of their daily work.

2.3. The Carer Support Needs Assessment Tool Intervention

This thesis focuses on the Carer Support Needs Assessment Tool Intervention (CSNAT-I) which was developed in 2013, by Gail Ewing and Gunn Grande in the United Kingdom, with an intention to address the needs of family caregivers. The constructors first developed an assessment tool as a response to the absence of existing evidence-based family caregiver assessment tools feasible to use in clinical practice. The tool was developed based on interviews with family

caregivers concerning their perspectives of support needs during the provision of palliative care at home (Ewing & Grande, 2013). The tool was uniquely developed to directly assess and address practical, emotional, existential, and social support needs in family caregivers, rather than act as an indicator of caregiving difficulty. It was found to be valid for direct measurement of family caregiver support needs, with good face, content, and criterion validity (Ewing et al., 2013).

Initially, the constructors presented the CSNAT tool and how it should be used in a person-centred process with five stages. These stages provided a framework for a process of assessment and support for healthcare professionals. The CSNAT tool received much attention in the United Kingdom and other countries, and it has been developed over time. Today the tool and the five-stage process are named the Carer Support Needs Assessment Tool Intervention (CSNAT-I). The addition of the word “intervention” was meant to ensure that the tool is not used as an instrument, but instead understood as an opportunity to initiate a conversation with family caregivers by using the five-stage process and to gain family caregivers’ own perspective on their support needs and what they would find supportive. The intervention thus comprises two parts: (1) an evidence-based tool, and (2) a five-stage person-centred process of assessment and support.

2.3.1. The CSNAT tool

For the studies included in this thesis, the CSNAT tool (v2.0) was used. It is structured around 14 broad support domains formulated as questions concerning practical, emotional, existential, and social support needs in family caregivers. In addition, there is also an “Anything else” question, which allows the family caregiver to raise any aspect of support required that is not already covered by the existing questions. (Table 1). The CSNAT tool takes into account the dual role of the family caregiver. Seven questions address what support the caregiver needs to be able to care for the patient (enabling support) and seven questions about what support family caregivers need for their own health and well-being (direct support). Family caregivers can respond by using four response categories on the CSNAT by indicating how much more support they need, ranging from ‘no more support’ to ‘very much more support’. The CSNAT is not developed to be summed into a total score. The questions cover broad domains in which family

caregivers generally need support as for example; providing personal care, managing symptoms, dealing with feelings and worries, and looking after their own health (Ewing & Grande, 2013).

At the time of writing this thesis the CSNAT tool has undergone further development. The tool was tested for family caregivers to patients with long-term conditions, such as MND/ALS, and that study revealed the importance of discussing support needs related to relationships. Therefore, an additional question concerning relationships was added and the tool thus now consists of 15 questions, CSNAT tool (v3.0) (Ewing et al., 2020; Micklewright & Farquhar, 2020, 2021). Also, in version 3.0, the response categories were reduced from four to three. However, CSNAT tool (v2.0) was used for the entirety of this thesis.

Table 1. The Carer Support Needs Assessment Tool questions (v.2.0).

Do you need more support with:

1. understanding your relative's illness?
2. having time for yourself in the day?
3. managing your relative's symptoms, including giving medicine?
4. your financial, legal or work issues?
5. providing personal care for your relative (e.g. dressing, washing, toileting)?
6. dealing with your feelings and worries?
7. knowing who to contact if you are concerned about your relative (day and night)?
8. looking after your own health (physical problems)?
9. equipment to help care for your relative?
10. your beliefs or spiritual concerns?
11. talking with your relative about his or her illness?
12. practical help in the home?
13. knowing what to expect in the future when caring for your relative?
14. getting a break from caring overnight?
15. anything else (please write in)

2.3.2. The CSNAT-I five-stage person-centred process

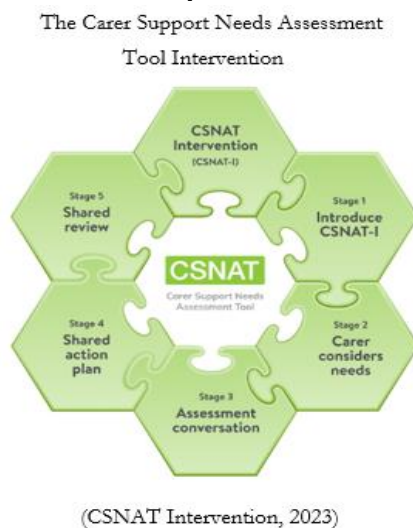
1) The CSNAT-I five-stage process starts with an introduction, as a conversation starter about the support the family caregiver may need (CSNAT Intervention, 2023; Ewing et al., 2015). The family caregiver receives the CSNAT tool to be completed and the 14 question domains provide visibility about needs and facilitate reflection. This step is the beginning of a continuous assessment process.

2) Time for the family caregiver to consider the questions in the CSNAT tool and if they need more support in any of the domains. In addition, they prioritise which of the questions they most want to focus on in the conversation with the healthcare professional. The CSNAT-I five-stage process provides a framework for the family caregiver to express and prioritise their support needs.

3) An assessment conversation takes place, focusing on the prioritised questions by the family caregiver. This stage is vital to explore individual support need(s) in each of the prioritised questions and what supportive inputs the caregiver would find helpful meeting those needs.

4) A shared action plan is formulated based on the assessment conversation. The family caregivers identified needs and the agreed supportive inputs, for example information giving or active listening, are documented at the backside of the CSNAT tool.

5) A continuous shared review is required as the family caregivers' needs change over time. Consideration should be given to repeating the whole CSNAT-I five-stage process at another point in time. Both the nurse and the family caregiver can initiate a shared review.



2.3.3. Theoretical underpinning of the CSNAT-I

The CSNAT-I uses a person-centred approach and is described by the original constructors to build on a theoretical foundation by Collins (Collins, 2014). Four principles underpin person-centred care, support or treatment, and for the CSNAT-I the theoretical underpinning is adapted in relation to family caregivers:

- The person is treated with dignity, compassion, and respect – These ‘experience standards’ are basic human rights and should always be taken into consideration.
- Support is personalised – What matters for the family caregiver?
- Support is coordinated – Services should appear seamless – Support should be offered across multiple episodes and over time.
- Support is enabling – Supporting family caregivers to recognise and build upon their own strengths and/or to recover from setbacks so that they can develop their own unique range of capabilities and have a fulfilling life.

The principles are the essential ingredients and will be blended in different proportions according to the context and will not necessarily be enacted in every encounter. A person-centred approach guides the person in practical actions and is a general concept often used in healthcare. The approach fosters collaboration between the family caregiver and the nurse, based on careful listening to the family caregiver’s story. The person's unique perspective is given validity to the professional perspective, and professionals take a step back from being the “expert” in the care relationship (Collins, 2014; Ewing et al., 2015).

2.3.4. International research on the CSNAT-I

The CSNAT tool and related materials for CSNAT-I have been translated into 16 different languages, including Arabic, French, Sami, Thai, Dutch, and Chinese (CSNAT Intervention, 2023). As the CSNAT tool is copyrighted a license is required for translation and as of today, 27 different countries have the license. CSNAT-I has been tested in different contexts and populations of family caregivers, such as people living with cancer (Aoun, Grande, et al., 2015), chronic obstructive pulmonary disease (Micklewright & Farquhar, 2021), motor neurone disease (Ewing et al., 2020), dementia (Aoun, Toye, et al., 2018), or stroke (Darley et al., 2021) in their family. The intervention has been found to have a positive

effect during caregiving by significantly reducing caregiver strain (Aoun, Grande, et al., 2015), decreasing distress (Aoun, Grande, et al., 2015; Lund et al., 2020), and increasing satisfaction with support (Aoun, Ewing, et al., 2018; Lund et al., 2020). Positive effects also included improved attention to family caregivers', quality of information and communication, and assistance in managing burdens and appropriate support according to their needs (Lund et al., 2020). Additionally, it was found to improve mental and physical health in bereavement (Grande et al., 2017) as well as facilitate the grief process (Grande et al., 2017) among family caregivers in a palliative home care context. A study by Toye et al. (2016) also found a positive impact on preparedness for family caregivers of older people discharged home from a medical assessment unit, when CSNAT-I was used as part of an overall discharge support package. The CSNAT tool has also been modified to a paediatric version, CSNAT (Paediatric) for use with parent caregivers in paediatric palliative care (Lyon et al., 2022) and shown good feasibility (Aoun et al., 2022).

From the nurses' perspective, CSNAT-I has proved to be beneficial, providing them with guidance and structure for discussions with family caregivers about their specific support needs. The intervention also seems to legitimise the nurses' work in supporting family caregivers, as CSNAT-I enabled nurses to share dedicated time with family caregivers, demonstrating an interest in supporting and meeting their needs (Aoun, Toye, et al., 2015). In addition, nurses experienced that CSNAT-I helps convey to family caregivers that their needs are important, legitimate and distinct from those of patients (Ewing et al., 2016).

However, research indicates that for the CSNAT tool to be meaningful it needs to be used as part of a person-centred intervention, rather than as a simple checklist. The five stages in the CSNAT-I enables family caregivers to consider, express and prioritise their support needs, and discuss these with a healthcare professional and thereby gain tailored support. (Austin et al., 2017; Darley et al., 2021; Horseman et al., 2019). A transition to a new way of working can be facilitated by training in the underlying principles of CSNAT-I (Austin et al., 2017) and internal facilitators that can communicate the evidence and provide legitimacy for changing practice (Diffin et al., 2018).

3. Rationale

Almost half of all deaths in Sweden are caused by conditions indicative of potential palliative care needs. Family caregivers are central to the support and care of patients, especially when the patient is cared for at home. Being a family caregiver can pose serious challenges and they often express feeling exhausted and limited, resulting in a reduced quality of life. Many family caregivers report unmet needs and strong interest in receiving more support. Palliative care literature and research emphasises the importance of supporting family caregivers and recommends that improvement is needed, such as assessment and addressing of support needs. Registered nurses play an important role in providing support to the family caregiver. To facilitate the work of supporting family caregivers the Carer Support Needs Assessment Tool Intervention (CSNAT-I) was developed. The use of the CSNAT-I aims to enable family caregivers themselves to identify their own support needs. The person-centred process can foster collaboration between family caregivers and nurses, and they are given equal validity as the professional takes a step back from being the “expert” in the care relationship. In clinical care, the use of the CSNAT-I may facilitate the work of assessing needs and ensuring adequate support for family caregivers and enhance their quality of life. This thesis focuses on the CSNAT-I and the use of the intervention in a Swedish specialised home care context. Of specific interest is to evaluate the CSNAT tool and explore experiences and potential effects of the intervention from both family caregivers and nurses’ perspectives. There is a need for increased understanding of the CSNAT-I to guide everyday clinical work to enhance possibilities for supporting family caregivers.

4. Theoretical Perspectives

4.1. Involvement in the light and in the dark

A person-centred approach is a prerequisite for palliative care overall and family caregiver support specifically. Andershed and Ternestedt's theoretical framework of involvement, "Involvement in the light - involvement in the dark" is therefore appropriate to guide this thesis (Andershed & Ternestedt, 2001; Andershed & Ternestedt, 1999). The framework focuses on the involvement in the patients' care and principal needs of family caregivers in palliative care (Andershed & Ternestedt, 2001; Andershed & Ternestedt, 1999). The framework should not be considered as an explanation, but rather for increased understanding for family caregivers' situation. It is based on two main assumptions: the first- involvement in the light- is when good collaboration between the family caregiver and the professional healthcare can promote the possibility of better quality of life for both the patient and family caregivers and increase the conditions for meaningful care and an appropriate death. If, on the other hand, this is not met and family caregivers feel isolated and unseen and experience a lack of communication from the professional healthcare, an exclusion occurs – involvement in the dark, which results in decreased meaningfulness, a less good death and a more difficult grieving process. A trusting relationship develops between the family caregiver and the healthcare professional when the family caregiver feels well informed, treated with respect and validated. In this way, the care could constitute a buffer and increase the family caregiver's possibilities for involvement in the light (Andershed, 2006; Andershed & Ternestedt, 2000). On the other hand, if the interaction is characterized by insufficient respect, avoidance, exclusion, and a lack of sincerity it is characterized as involvement in the dark and complicates a family caregiver's involvement in the patient's situation. Thus, nurses' approaches, attitudes, competences, and possibilities are of great importance for family caregivers' experiences. CSNAT-I can increase the possibility for the nurses to provide structural support to family caregivers systematically during the care period and the increased communication brought by this approach can facilitate involvement in the light.

Involvement has three key concepts: Knowing, that represents the family caregivers informational needs; Being, that represents their existential and emotional needs; and Doing, that is a practical/task oriented need and reflects the activities that the family caregiver does for the patient that he or she is incapable of doing due to their illness (Andershed & Ternestedt, 2001; Andershed et al., 2013). The three key concepts are interrelated and interdependent. Knowledge is a prerequisite for the choice of being and doing, but being and doing also increase the possibility of knowing (Andershed, 2006).

Andershed's and Ternestedt's framework takes a stand in caring science and is inspired by Swanson's (1991) middle range theory of caring. The main purpose of the theory of caring is to help health care professionals to deliver nursing care that focuses on the needs of individuals in a way that promotes their dignity, respect and empowerment (Wojnar, 2017). Family caregiver's involvement and care for the patient can be compared with the professional healthcarer's work (Andershed & Olsson, 2009). Care is a key concept and is seen as a belief in persons and their capacity to cope with events and transitions and face a meaningful future (Swanson, 1993, Wojnar; 2017). The theory was developed with five caring processes, Knowing, being with, doing for, enabling, and maintaining belief, that overlap and describe how care is delivered.

Knowing is a striving to understand the other person's experiences of an event and what is meaningful to him or her. Listening carefully to the other person, seeking cues and avoiding assumptions. Both the caregiver and patient are engaged in this process (Andershed & Olsson, 2009; Wojnar, 2017).

Being with is to be emotionally present. By giving time, authentic presence and attentive listening, increases the possibility of understanding the other person's situation (Andershed & Olsson, 2009; Wojnar, 2017).

Doing for refers to taking actions that are helpful, protective, increase comfort, and preserve dignity, that the other person normally would perform him/herself (Andershed & Olsson, 2009; Wojnar, 2017).

Enabling is facilitating the other person's passage through life transitions and/or unfamiliar events. The purpose is to facilitate the other person's capacity to grow, heal and/or practice self-care. This means focusing on the event, informing,

explaining, supporting, allowing and validating feelings and the other's reality, creating alternatives, and giving feedback (Andershed & Olsson, 2009; Wojnar, 2017).

Maintaining belief is maintaining faith in the other person's capacity to get through transitions, supporting the other person to find and maintain strength, capacity, and face future with meaning (Andershed & Olsson, 2009; Wojnar, 2017).

All five of the caring processes can be found in Andershed's and Ternstedt's three concepts: Knowing (knowing), Being (being with and maintaining beliefs) and Doing (doing for and enabling). In addition, the CSNAT questions correspond to these concepts. However, it is important to recognise that there is not a simple direct relationship between the three key concepts and the CSNAT-I questions. Rather, one question may have more than one underlying support need that is reflected in the different key concepts (Knowing, Being and Doing). For instance, "Support with knowing what to expect in the future" may be about a need for information (knowing), but could also pertain to emotional support and existential concerns in terms of anxiety about an uncertain future (being), or about finding out what practical measures need to be put in place as the patient deteriorates (doing). Such is the broad nature of the CSNAT-I questions that further information, and emotional or practical support may be required for any of the questions, depending on the underlying support needs that the caregiver expresses. Thus, the assessment conversation is vital to understand the family caregiver's individual need for support.

In recent years, the original authors of the theory have problematised the concept of involvement (Andershed, 2020). They have discussed that the involvement process consists of more than "making" the family caregiver involved, the process can rather be described as a basis for person-centred care. A basis that takes for granted that the other person is always regarded as an adult individual with his or her own mandate. "Involving" caregivers is an obsolete concept and healthcare must assume that they are involved in extensive informal care and that co-creation and partnership are the concepts we must now apply. This is in line with the CSNAT-I process, where the intervention is facilitated by healthcare professionals but is caregiver-led and the assessment conversation is carried out in co-creation.

5. Overall aim

The overall aim of this thesis was to evaluate the Carer Support Needs Assessment Tool (CSNAT) and explore experiences and potential effects of utilising the Carer Support Needs Assessment Tool Intervention (CSNAT-I) among family caregivers and registered nurses in the context of specialised home care.

5.1. Specific aims

I

To translate and evaluate the validity and reliability of the CSNAT in a sample of Swedish family caregivers and nurses in a palliative home care context.

II

To explore associations between family caregivers' support needs and quality of life when caring for a spouse receiving specialized palliative home care.

III

To explore nurses' experiences of supporting family caregivers in specialised home care while learning to use the Carer Support Needs Assessment Tool Intervention.

IV

To explore potential effects of CSNAT-I on preparedness for caregiving, caregiver burden, and quality of life among Swedish family caregivers in specialised home care.

V

To examine family caregivers' experiences of discussing their needs with a nurse during specialised home care, utilizing the Carer Support Needs Assessment Tool Intervention.

6. Methods

6.1. Design

This thesis comprises two parts. First, the CSNAT tool was translated and evaluated (I) and then used to explore family caregivers' support needs (II). In the second part, potential effects of the CSNAT intervention were explored (IV) and experiences were studied from the perspectives of nurses (III) and family caregivers (V).

The studies are underpinned by Campbell's framework for the design of complex interventions to improve health (Campbell et al., 2000). A complex intervention is defined as involving more than one component and that the active ingredient could be hard to specify. Evaluation of complex interventions benefits from using both qualitative and quantitative evidence. An overview of this thesis study design and methods are presented in Table 2.

Table 2. Overview of the study designs and methods.

Paper	Study design	Participants	Data collection	Data analyses
I	Validation design	Translation-procedure: Family caregivers (n = 8) and nurses (n = 10) Evaluation of the CSNAT tool: Family caregivers (n = 114)	Cognitive and focus groups interviews Questionnaire with close-ended questions	Comments were analysed based on relevance, clarity and sensitivity. Descriptive statistics and polyserial correlation analysis.
II	Descriptive cross-sectional design	Family caregivers (n = 114)	Questionnaire with close-ended and open-ended questions	Descriptive statistics, multiple linear regression analyses, and qualitative content analysis
III	Longitudinal interpretive descriptive design	Nurses (n = 12)	Individual interviews	Interpretive description
IV	Pre-post intervention design	Family caregivers (n = 33)	Questionnaire with close-ended questions	Descriptive statistics and Wilcoxon signed-rank test
V	Inductive qualitative descriptive design	Family caregivers (n = 10)	Individual interviews	Framework analysis

6.2. Study I and II

6.2.1. Study context

For Studies I and II, data was collected at two specialised home care services in two large cities in Sweden. Both services provided care at home for patients with complex palliative care needs and limited survival expectancy, regardless of diagnosis. Patients in these services had needs such as symptom management, emotional and existential support, as well as assistance with personal care. Both services were staffed by multi- professional teams, including physicians, social workers, physical and occupational therapists, and nurses (who constituted the largest group of professionals).

6.2.2. Inclusion criteria

Inclusion criteria for family caregivers were being a spouse or partner to and living with a person who had a life-threatening illness and received specialised home care, 18 years or older, and able to read and understand the Swedish language. Inclusion criteria for nurses were not limited to anything other than being employed at one of the two services.

6.2.3. Procedure and data collection

Study I

For Study I, data was collected during 2016. The study was conducted in three stages to reach conceptual, semantic, operational and measurement equivalence between the original UK version of the CSNAT and the Swedish version.

Translations process

When translating the CSNAT from English to Swedish the suggested translation procedure from the European Organization for Research and Treatment of Cancer, including forward- and backward-translation was used (Koller et al., 2007). Initially, translation from English to Swedish was done independently by two forward-translators and then checked and discussed among the research group members. The first version was then back-translated into English by two independent additional backward-translators to ensure that the provisional forward-translation was an adequate representation of the English original. The

two back-translations were reviewed and discussed among the authors of the study, which also included the original constructors of the CSNAT-I, one of whom understands the Swedish language.

Cognitive interviews

Cognitive interviews with a think-aloud approach (Willis, 2004) were performed with 8 family caregivers and 10 nurses from October to December 2016. Initially, ten family caregivers were telephoned by one of the authors, given verbal information about the study, and were invited to take part in an interview. One of them declined and another withdrew from the study after accepting because the patient's condition had unexpectedly been impaired. The remaining eight family caregivers then received written information about the study, its aim, what to expect about the interview situation, and the principles of confidential and voluntary participation. At the time of the interview, all eight family caregivers gave their written informed consent. Altogether, eight family caregivers, five women and three men, aged 66 to 87, participated. The sample also consisted of 10 registered nurses. All nurses were women aged 35 to 55, each with more than eight years of experience in palliative care nursing. The same procedure was followed when nurses were approached and invited to participate, and all agreed to participate.

The participating family caregivers and nurses were asked to reflect on the relevance, clarity, and sensitivity of the wordings as they went through the CSNAT tool. Individual face to face interviews were conducted with the family caregivers. The goal was to gain an understanding about the CSNAT tool from the perspective of family caregivers living close to a patient who received palliative home care. The nurses were interviewed in groups as the format provided the possibility for interactions between nurses. The purpose was to explore how the nurses perceived the CSNAT tool for their work as professional providers of care and support. All interviews were audio-recorded and lasted between 15 and 35 minutes.

Measurements properties

To evaluate measurements properties, all eligible family caregivers at the two home care services (n = 342) were approached by two of the researchers. A letter

sent by post included information about the study, a request for their participation, as well as a questionnaire (described in the section below). Family caregivers consented to participation by completing and returning the questionnaire in a pre-paid stamped envelope for direct return to the researchers. In total, 114 family caregivers completed the questionnaire, a response rate of 33%. Ninety percent of the participants were born in Sweden, 61% were women, and the mean age was 67.5 (SD = 10.9, range = 33–90) years. In general, the participants were well educated, and 42% had a university degree. A majority was retired (61%), while 27% worked full-time, and 12% had children in their household. One-fifth (20%) reported receiving care benefits, i.e., they received allowances by the Swedish Social security Office to provide care for the patient at home. Most of the patients had a cancer diagnosis (84%).

The Questionnaire

The questionnaire consisted of demographic questions, such as gender, age, and relation to the patient and an open-ended question at the end of the questionnaire: “Do you have any thoughts about your situation, not covered in the questionnaire, that you want to share?”. Additionally, it included the *Carer Support Needs Assessment Tool (CSNAT)*, validated instruments measuring preparedness for caregiving, caregiver burden, and quality of life.

The Preparedness for Caregiving Scale (PCS) measures family caregivers' perceived readiness to provide care (Archbold et al., 1990). The scale consists of eight items answered on a five-point Likert-type response scale ranging from ‘Not at all prepared’ (0) to ‘Very well prepared’ (4). The responses are summed into a total score with a possible range between 0 and 32. The instrument has demonstrated good measurement properties in the context of palliative care (Henriksson et al., 2012; Henriksson, Hudson, et al., 2015).

The Caregiver Burden Scale (CBS) was originally developed to measure self-perceived burden in caregivers of stroke patients (Elmståhl et al., 1996). It consists of 22 items divided into five subscales: General strain, Isolation, Disappointment, Emotional involvement, and Environment. The items are answered on a 4-point Likert-type scale, ranging from ‘Not at all’ (1) to ‘Often’ (4), where higher scores indicate greater caregiver burden. The item scores of each subscale are summed, and a mean value for each subscale is calculated, with scores ranging from 1 to 4.

The Quality of Life in Life-Threatening Illness – Family carer/caregiver version (QOLLTI-F) (Alnjadat et al., 2014; Cohen et al., 2006; Schur et al., 2014) version 2, includes a total of 17 items divided into 7 subscales assessing different domains of quality of life: Environment, Patient condition, Family caregiver's own state, Family caregiver's outlook, Quality of care, Relationships, and Financial worries. It also includes 1 item about overall Quality of life. All items are scored on an 11-point numeric rating scale, ranging between 0–10 with a descriptive anchor at each extreme. Each domain is calculated by adding the responses and dividing the sum by the number of items in each domain. Thus, each domain can range between 0–10, and after reversed items have been rescored, higher scores indicate higher levels of quality of life (Cohen et al., 2006). The content validity of the QOLLTI-F has shown to be satisfactory among Swedish family caregivers to patients with life-threatening illness (Axelsson et al., 2020)

Study II

Study II is based on the same sample who completed the questionnaire in study I. To explore family caregivers' support needs and quality of life as well as associations, the CSNAT tool and QOLLTI-F was used. In addition, family caregivers who had answered the open-ended question about their experiences. Comments were provided from 43 family caregivers, who shared stories that varied in length from a few lines to two extra pages.

6.2.4. Analyses

Study I

The recorded cognitive interviews were listened to and comments from family caregivers and nurses on each of the CSNAT items were summarized. The content was analysed based on relevance, clarity, and sensitive content and wordings. Descriptive statistics were used to present the sample, item score distribution (ceiling and floor effects), and missing data patterns. To evaluate construct validity, the CSNAT items were correlated (polyserial correlation coefficients) with external constructs expected to be related to support needs (caregiver burden, preparedness for caregiving, and quality of life).

Study II

Quantitative data were analysed using descriptive statistics and multiple linear regressions analyses to explore associations between support needs and quality of life. The QOLTI-F scales were used as outcome variables while the CSNAT items were used as explanatory variables. As the CSNAT response scale contains one category that implies no support need while the other categories reflect various levels of support need, the CSNAT items were dichotomized into 'No support need' (= 0) and 'Support need' (= 1). The regression models were adjusted for sex (female= 0; male = 1), age, and education (no university degree = 0; university degree = 1). Missing data was treated using listwise deletion. For all tests, $p < 0.05$ was considered to be statistically significant. All analyses were conducted in Stata 17.0 (StataCorp LLC, College Station, TX, USA).

Content analysis was used to analyse the open-ended question (Hsieh & Shannon, 2005). The initial review of the comments found that they contained stories about family caregivers' support needs and / or quality of life. Next step was to read the text thoroughly to search specifically for various expressions. Finally, associations between support needs and quality of life were searched using the CSNAT tool and QOLTI-F to identify expressions concerning support needs and quality of life. Data was coded and grouped into categories that consisted of descriptions illustrating the associations.

6.3. Study III, IV and V

6.3.1. Study context

For Studies III, IV and V, six specialised home care services in various parts of Sweden participated. These services' work and organization resembled the services in Studies I and II; they provided care for patients with complex needs and limited survival expectancy, regardless of diagnosis, through utilisation of a multi- professional team of physicians, nurses, social workers, and physical and occupational therapists.

6.3.2. Inclusion criteria

Inclusion criteria for family caregivers were the same as in Studies I and II, i.e., being a spouse or partner to and living with a person who had a life-threatening illness and received specialised home care, 18 years or older, and able to read and understand the Swedish language. For Study V, family caregivers also needed to have experienced the CSNAT-I five stage process at least one time. Inclusion criteria for nurses were working in one of the participating specialised home care services and be able and willing to participate in learning and working with the CSNAT-I.

6.3.3. Procedure and data collection

The heads of the departments at the care services approved participation after having received written and oral information about the study. They also identified registered nurses at each of the services who were interested in participating. This resulted in a convenience sample of 12 nurses, one to three per service. The interested nurses were all contacted by the researchers who provided them with written information about the study. Next, two of the researchers held a digital video meeting for oral information and opportunity to ask questions with the 12 nurses who all agreed to take part.

Study III

Data was collected through 22 interviews with 12 nurses over a 15-month period between October 2020 and January 2022. To explore potential changes, ten nurses were interviewed twice, with the first interview carried out after they had completed CSNAT-I training and the follow-up interview after they had used CSNAT-I at least twice, i.e., with two different family caregivers. All nurses were women, aged 28–64 (median = 48) and they had worked in specialised palliative home care for between five and 26 years (median = 14).

The participating nurses completed training, provided by two of the researchers, to learn how to use CSNAT-I. The training was completed before they used the intervention in their meetings with family caregivers. Training consisted of a 30-minute video, based on the original CSNAT-I online toolkit (<https://arc-gm.nihr.ac.uk/training/register>). Initially, the video presented a short summary of research about family caregivers' situation. This was followed by a detailed

description of CSNAT-I, including the CSNAT, the person-centred process, and details of each of the five stages. The video also included reflective questions to facilitate the learning process. When possible, participating nurses working at the same services were encouraged to watch the video together to enable reflective discussions. This digital training also gave opportunities to watch the video presentation repeatedly. In addition to the video, nurses were given an informative booklet and an accompanying written presentation with guidance on how to work with the intervention. During the study, one of the researchers was in continuous contact with the nurses and digital meetings were arranged to provide opportunities to discuss issues concerning training in using CSNAT-I. These meetings aimed to ensure that nurses understood how to deliver the intervention as intended.

Study IV

Data was collected between October 2020 and January 2022 through questionnaires. The 12 designated nurses informed family caregivers at their service about the study and invited them to participate. Family caregivers who had accepted participation were requested to answer questionnaires, concerning support needs, preparedness for caregiving, quality of life, and caregiver burden, at two time points. A total of 70 family caregivers answered a questionnaire at baseline and returned it along with a written consent form. After completed intervention, a follow-up questionnaire was sent to the family caregiver and 33 finished and returned it. Family caregivers' mean age was 68.6 (SD = 8.3) years. A majority were retired (n = 26, 81%), women (n = 19, 58%) and two-fifths had a university degree (n = 13, 41%). Most family caregivers had been offered professional support from the healthcare before CSNAT-I (n = 22, 69%) was delivered. About one-fourth (n = 8, 25%) of the family caregivers had sought healthcare for themselves and more than one-third (n = 12, 37%) had visited a curator or psychologist on their own due to the patient's illness.

Questionnaires

The questionnaire in Study IV included the same instruments as in Studies I and II, i.e. *The Carer Support Needs Assessment Tool (CSNAT)* (Ewing et al., 2013), *Preparedness for Caregiving Scale (PCS)* (Archbold et al., 1990; Henriksson et al., 2012; Henriksson, Hudson et al., 2015), *Caregiver Burden Scale (CBS)* (Elmståhl et al.,

1996), and *Quality of Life in Life-Threatening Illness – Family carer/caregiver version (QOLLTI-F)* (Alnjadat et al., 2014; Cohen et al., 2006; Schur et al., 2014). In addition, the questionnaire consisted of demographic questions such as gender, age, education and single items about their own health-care contacts. Family caregivers answered the questionnaire at two timepoints; before the CSNAT-I (baseline), after the CSNAT-I (follow-up).

Study V

Data was collected through interviews during 2020 to 2022. Family caregivers were asked in the follow-up questionnaire if they wanted to participate in an interview and 21 agreed. Those who had used CSNAT-I recently ($n = 13$) were contacted via e-mail including information about the interview study, confidentiality, possibility to withdraw at any time and contact details to the researchers conducting the study. Three of those who had agreed could not be reached by e-mail or telephone. Altogether, 10 family caregivers, from four of the six services, agreed to participate, 9 of whom were women (spouses of the patients). Their age ranged from 39 to 75 with median age of 66. A majority had a university degree and were retired.

6.3.4. Analysis

Study III

Data collection and analysis were done concurrently, as interviews were transcribed verbatim after the interview, each interview informing the following in an iterative process (Thompson Burdine et al., 2021; Thorne, 2016). In the initial phase of analysis, the first author listened to each of the interviews several times to develop a comprehensive understanding of it in its entirety. At the same time, notes taken during the interviews were read and reflected upon to deepen the understanding of the data, following the immediate impression (Thorne, 2016). Then, questions close to the study aim, for example, 'How do the nurses describe their support to the family caregivers?' were asked of the data, and units of text were extracted and broadly coded. In the third phase, the text was condensed into shorter descriptions of the broad codes. Memos about ideas and preliminary interpretations were documented in the margins of the text. The memos were utilised to support the interpretation of data and themes. In the

subsequent interpretive phase, patterns of similarities and variations within the data were identified (Thorne, 2016). Segments of data with similar themes were then grouped together. Initially, the data was organised into several themes. This phase involved identifying patterns and their inherent variations of nurses' work in supporting family caregivers. This was carried out for all the interviews and then the analysis moved on to using themes to reflect changes in the nurses' way of providing support to the family caregivers. As the analysis progressed, the themes merged and a change in support for the family caregivers was identified over time in the final results.

Study IV

Descriptive statistics were used to present the sociodemographic and study variables, mean and standard deviations for continuous variables, median and quartiles for ordinal variables, and frequencies for categorical variables. Given the ordinal nature of data, based on the self-reported instruments, the Wilcoxon signed-rank test was used to identify changes in preparedness for caregiving, caregiver burden, and quality of life between the baseline and follow-up assessments. The level of statistical significance was set at $p < 0.05$. All statistical analysis was carried out using Stata 17.0 (StataCorp, College Station, TX, USA).

Study V

The Framework analysis (Goldsmith, 2021) guided the qualitative analysis process and was chosen as it is developed for use in applied qualitative research to enhance usefulness for clinical and social policy application. The interviews were transcribed verbatim and de-identified. Transcripts were read while listening to the audio recordings. To familiarise with the content, the first author read and re-read each interview, with consistent notetaking of thoughts and recurring major themes in the data. Ideas for the initial thematic framework were discussed with the last author, who had also read all the interviews. An analytic framework manual was developed with four preliminary themes, as a tool for the analysis to methodically identify and describe key patterns, including notable variations, within and across the themes. Next, the framework was applied to all data and the framework was discussed and adapted. The authors iteratively analysed the data and the developing thematic framework, discussing and re-sorting the data

as needed. The final step involved abstracting the data to create the final themes (Goldsmith, 2021).

7. Ethical considerations

This thesis was conducted according to the ethical principles for medical research involving human research in the Declaration of Helsinki (WMA, 2013). The studies have received ethical approval (Approval number Study I-II: 2015/1517-31/5, Approval number study III-V: 2020-00133).

There is always a need for ethical considerations when involving persons in research. In this thesis a group of family caregivers, i.e., spouses to patients with life-threatening illnesses, were approached and could be viewed as a vulnerable study population. It is likely that their participation could elicit strong emotions and add an extra burden to their life situation. However, to label a whole group as vulnerable can oversimplify their experiences and needs, overlook their agency, expertise, and diverse experiences, potentially undermining their contributions and autonomy. Excluding this population based on perceived vulnerability risks excluding capable persons from research opportunities. This exclusion would be an unjust and paternalistic form of discrimination that may contribute to further marginalisation perpetuating inequalities and hindering their opportunity to have a voice in healthcare decision-making processes (Beauchamp & Childress, 2013). Earlier research has shown that family caregivers might appreciate the opportunity to participate in research and benefit from their involvement (Aoun et al., 2017; Dempsey et al., 2016).

Nevertheless, this thesis emphasised the recommendations of good research practice (Swedish Research Council, 2017) and the principles of biomedical ethics: *autonomy*, *beneficence*, *non-maleficence*, and *justice* (Beauchamp & Childress, 2013). To honour the principles of *autonomy* the project practice informed consent to the participants. Both patients and family caregivers received written and oral information about the study before inclusion. The information underlined that their participation was voluntary and that their consent could be withdrawn at any time without any consequences for themselves or their ill family members' care. An ethical dilemma that arose was that there were family caregivers who wished to participate but found it stressful to answer the questionnaires on their own while they had to care for their ill family member. This ethical challenge was carefully considered and the significance of in ensuring that participating in the studies should not become burdensome for these caregivers and that their wishes

to participate were respected. It was essential to offer support and assistance in responding to the questionnaire, aiming to alleviate any potential burden and make the process as accessible and manageable as possible. By doing so, the study upheld the principles of *autonomy* and respect for the participants' well-being throughout the research activity. To respect the patients and protect their autonomy, they were asked to give their consent before the family caregiver was approached. This was considered the most ethical approach. *Non-maleficence* and *Beneficence*, i.e., avoiding unnecessarily or unjustifiably harm and promote the well-being of participants as well as balancing risks against benefits, has been considered. Family caregivers can be considered to be in a dependent position to the recruiting nurse, and to reduce this risk it was important that the recruiting nurse underlined that the study was voluntary and that declining participation did not present any disadvantages for the care of their family member or their own support. To participate in research and in this case also in an intervention takes time away from family caregivers in a situation where the patient's time is limited. It is important to recognise that the participating family caregivers are offered an intervention that aims to meet their support needs. In addition, in the written comments from the participating family caregivers in the questionnaires for study IV, many expressed their appreciation for receiving support for themselves and expressed a desire for this opportunity to have been offered earlier in the patient's disease trajectory.

Another ethical consideration concerned the questionnaires, which may raise questions or elicit strong feelings for family caregivers. To address this, phone numbers were specified in both the informational letter and the questionnaire so that the family caregiver easily could contact the research group if needed. The recruited nurses for the research project and the researchers maintained an ongoing dialogue with family caregivers to ascertain their willingness to participate. Both the recruited nurses and the interviewing researcher had clinical experience in communicating with individuals in vulnerable situations. *Justice* was considered in the research study as the intervention was provided to the patient's spouse or partner. This decision was based on research showing that spouses or partners often serve as the primary caregiver, providing significant care and support. In addition, they often report higher levels of distress and more physical and psychological burden than other family caregivers. Offering the intervention

only to the patient's spouse or partner enabled allocation of the project's resources and the nurses' support to the persons who were most in need of it, in order to hopefully help other family caregivers in the future. The intervention itself has no such limitations but is intended to support any family caregivers who are in need.

Apart from the family caregivers, the studies also include nurses at the specialised homecare services. The CSNAT-I could potentially lead to an increased workload for the nurses as it brought a new approach to their work, which may have created internal conflict and added pressure and feelings of stress for the nurses if they perceived that they were unable to fulfil or address the family caregivers needs. Notably, the studies were carried out during the Covid-19 pandemic when the workload was already strained. The project was therefore carried out in collaboration with the home care services and they were given the opportunity to influence how many nurses could participate in the project and how the CSNAT-I best could be integrated into their daily work.

All data has been handled with confidentiality. Data were pseudonymised and a code list was developed for participating family caregivers and nurses, and stored separately from the data. All data, including audio recordings, transcriptions, and statistical data files, was encrypted and stored at a protected computer server and in a locked storage facility at the Marie Cederschiöld University. Data was handled according to the General Data Protection Regulation (Swedish Authority for Privacy Protection, 2022).

8. Results

The results of the five studies included in this thesis have been synthesised and are described under two headings: Evaluation of The Carer support needs assessment tool (CSNAT), and experiences and potential effects of The Carer support needs assessment tool intervention (CSNAT-I).

8.1. Evaluation of the Carer Support Needs Assessment Tool (CSNAT)

The CSNAT tool was considered relevant and useful to identify support needs among family caregivers in Swedish specialised home care (I). Through cognitive interviews it was found that both family caregivers and nurses considered the questions in the tool relevant for assessing support needs, facilitating opportunities for family caregivers to express their needs. Nurses experienced that the tool could be supportive to them, in their profession, when communicating with family caregivers. This was also confirmed in Study V, which found that family caregivers experienced the questions as a helpful starting point for a conversation about their support needs. The questions also made it easier for caregivers to determine what support they wanted to focus on. Family caregivers also noted that they earlier found it difficult to know what kind of support was actually available to them, but that the use of the CSNAT tool clarified those options (V).

Nurses on their hand, experienced that the pre-formulated questions enabled them to be truly present in their meetings with family caregivers (III). Further, the questions helped them address support needs that they normally did not discuss. Another advantage was highlighted that the CSNAT tool could be used repeatedly during the period of care (I, III).

In the evaluation of the CSNAT tool, neither family caregivers nor nurses considered any of the questions to be upsetting, offensive or evoking emotions that were difficult to cope with (I). Some nurses, however, believed that asking questions to identify support needs that they are not able to help with would be challenging. This can be compared with what the participating nurses in study III,

who worked with CSNAT-I, expressed. They believed that professionalism and nursing skills were needed as some of the questions could evoke strong feelings and cause harm to family caregivers.

Even though the questions were considered easy to understand by both family caregivers and nurses, a main concern was raised during the validation (I). Both nurses and caregivers reacted on the word “care” (“to care for” in English). It was perceived as implying an expectation that family caregivers should fulfil the role of a care worker as the word initially was translated into a Swedish expression denoting “to deliver care to.” Therefore, the wording of CSNAT questions relating to “care” was changed to reflect more specifically Swedish vernacular in defining this word. Family caregivers also considered it difficult to understand what the question “what to expect in the future” referred to and wondered whether it concerned physical, emotional, or economic aspects (I).

The evaluation of the CSNAT tool showed satisfactory measurement properties regarding data quality and construct validity (I). All the questions’ response categories were used and there were few missing values observed. The evaluation of data quality showed that the distribution of the scores was positively skewed and floor effects were observed in all questions. Construct validity was overall supported as all questions in the CSNAT tool, except “Understanding your relative's illness,” correlated significantly with the other instruments, i.e., lower levels of needs correlated with lower burden and with higher levels of preparedness for caregiving and quality of life (I).

8.1.1. Support needs

As a part of the evaluation of the CSNAT tool, family caregivers reported their support needs. In Study I, more than 60% of the family caregivers reported that they needed more support concerning “Knowing what to expect in the future,” “Having time for oneself in the day,” and “Dealing with feelings and worries” (I). They needed more support related to all the CSNAT questions with a variation between 11% to 69% (I, II).

In Study II, data were analysed to specifically show both direct and enabling support needs. Results showed that family caregivers reported having direct support needs, i.e., needs for their own health and well-being. This was shown in

the questions: “Having time for oneself in the day” (66%) and “Dealing with feelings and worries” (63%). Further, enabling support needs, i.e., needs to be able to care for the ill family member was reported and shown in the questions: “Knowing what to expect in the future” (69%) and “Understanding your relative’s illness” (46%) (Fig. 1) (II).

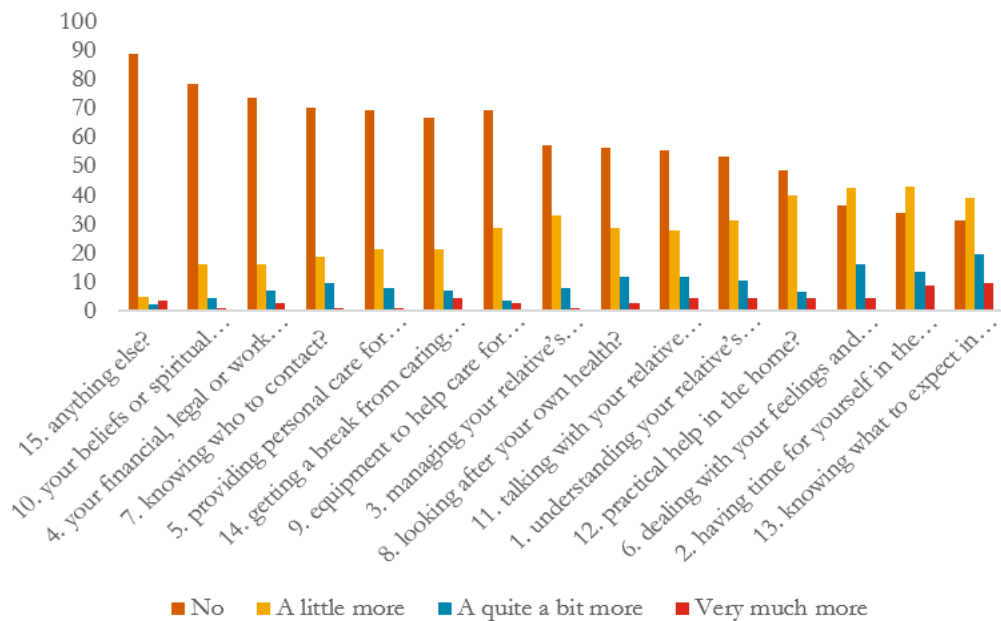


Figure 1. Family caregivers’ support needs assessed by the CSNAT

8.1.2. Associations between support needs and quality of life

Study II showed that all of the of support needs were significantly associated with one or more quality of life domains, in particular: “Practical help in the home” (CSNAT 12, B = -1.31 to -2.33), “Dealing with feelings and worries” (CSNAT 6, B = -1.17 to -1.51), and “Talking with your relative about his or her illness” (CSNAT 11, B = -1.03 to -1.82). None of the support needs were significantly associated with the quality of life domain that is related to distress linked to

“Patient condition,” while 11 of 14 were associated with the domain “Family caregiver’s own state” (B = -0.93 to -1.59) (Table 3).

Table 3. Associations between domains of support needs and quality of life reported as unstandardised slope coefficients from the multiple linear regression analyses, adjusted for age, sex and education. Only significant associations ($p < 0.05$) are reported.

	Overall quality of life	Environment	Patient condition	Family caregivers' own state	Family caregivers' outlook	Relationships	Quality of care	Financial worries
CSNAT 1							-1.43	
CSNAT 2	-1.88	-1.86		-1.59	-1.25	-1.64		
CSNAT 3	-0.95							-1.77
CSNAT 4				-1.02				-3.44
CSNAT 5	-1.14	-0.97		-1.10				-1.73
CSNAT 6	-1.51	-1.20		-1.40	-1.17	-1.34	-1.32	-1.47
CSNAT 7		-0.96		-0.93			-1.85	-1.67
CSNAT 8	-0.99	-1.27		-1.00				
CSNAT 9	-0.98	-1.08		-1.18			1.87	-1.53
CSNAT 10	-1.40	-1.10		-1.47			-1.18	-2.65
CSNAT 11	-1.57	-1.03		-1.10	-1.32		-1.82	-1.52
CSNAT 12	-1.31	-1.58		-1.47	-1.34	-1.56	-1.50	-2.33
CSNAT 13					-1.05	-0.99	-1.36	-1.62
CSNAT 14	-1.39	-1.03		-1.37				-1.63

CSNAT = Carer Support Needs Assessment Tool

Using the free comments section in Study II, family caregivers wrote and shared their own stories about how their lives were disrupted and thus their quality of life was impaired, both physically and emotionally, by their family member's life-threatening illness. Related to their support need of looking after their own health, family caregivers described how they placed all their attention towards supporting and caring for the patient. Increased responsibility for the home and reduced sleep affected their quality of life. In addition, some already had health problems of their own that had worsened due to their situation. During the cognitive interviews in Study I, some family caregivers reacted to the question that related to more support to look after their own health. They expressed that as the specialised home care service was not designated to help them and they needed to visit their own doctor, the question was not relevant. Despite this, one-fifth (20%) of family caregivers reported that they wanted more support with their own health (I, II). The free comments also revealed that they needed more support to deal with feelings and worries for the unknown future and how things would be if the situation did not improve (II). Family caregivers expressed that they feared their support and care would not be sufficient to relieve the patient's symptoms. Further, they described how they, due to their caregiving situation, needed support to find time for themselves during the day. Some could not leave the patient alone at home and those who were parents of minor children also had the main responsibility for them.

8.2. Experiences and potential effects of The Carer Support Needs Assessment Tool Intervention (CSNAT-I)

The results showed that the learning and use of the CSNAT-I changed how nurses supported family caregivers (III). Prior to using the CSNAT-I, they experienced difficulties in finding privacy when talking to family caregivers, and often ended up having ad hoc meetings. Important conversations were often carried out in hallways when they were on their way out to the next patient visit. With the use of CSNAT-I, nurses instead scheduled appointments with family caregivers which enabled trustful conversations. The nurses strived to be flexible

concerning the family caregivers' wishes about how to conduct the conversation so that the caregiver could feel safe. Similarly, family caregivers expressed that they valued the opportunity to talk in privacy with the nurse, and the scheduled meetings signalled to them that nurses also had time to care for them as family caregivers, enabling a feeling of security as a member of the care team (V).

Before learning to use the CSNAT-I, nurses supported family caregivers in a more reactive way, and often only when the patient had a short time left to live (III). Support was usually provided to those family caregivers who asked for help. It was not unusual that family caregivers, by the time their support needs were noticed, were already overwhelmed by the situation. By using CSNAT-I, nurses experienced that their support methods changed and became more proactive. They felt that they had an opportunity to get to know the caregiver and their situation better, which facilitated timely, individualised support (III). Family caregivers experienced this as well (V). They appreciated that the CSNAT-I gave them an opportunity to talk about their situation and their related support needs. The CSNAT-I conversation facilitated a deeper relationship with the nurse, and caregivers felt reassured and more secure in talking with the nurse, who had knowledge about their ill partner and was familiar with their situation at home.

The nurses' experiences about the division of responsibilities between themselves and the family caregivers changed after they learnt to use CSNAT-I (III). They went from feeling that it was their professional responsibility to acknowledge and identify family caregivers' support needs, towards feeling a shared responsibility based on family caregivers' own expert knowledge of their current situation. Likewise, family caregivers expressed that they appreciated that the CSNAT-I gave them the opportunity to reflect over their own support needs so that the conversation was not based on the nurse's experiences and assumptions about their needs (V). They also described that the nurse empowered them to take an active role in the conversation about their support needs and that they took more responsibility for certain supportive inputs.

Family caregivers who talked with a nurse about their support needs and beneficial supportive inputs during the intervention increased their preparedness for care (IV). They reported significantly higher levels of preparedness at the

follow-up compared to the baseline assessment ($p = 0.002$). In addition, family caregivers also reported descriptively higher levels of quality of life regarding Distress related to the patient's condition, Own state, Quality of care, and Relationships. In contrast, they reported lower levels of quality of life at follow-up regarding Financial worries. This was also expressed by family caregivers who described that they had not prioritised this question in the CSNAT tool as they did not know what the question meant (V). Family caregivers wished that that they would have received more guidance from the nurse during their conversation as their caregiving situation later resulted in legal issues that affected their finances. By comparison, less than 30% of family caregivers in Studies I and II reported the need for support concerning financial, legal, or work issues, or with their beliefs or spiritual concerns.

Even if family caregivers in Study V said that they previously had not been able to reflect on their own needs due to their intense situation, CSNAT-I gave them the opportunity to express their feelings and discover new perspectives with the nurse, generating new thoughts and solutions that helped them to move forward. These family caregivers felt reassured to receive support with different needs when needed in the future. In comparison, nurses in Study III found that using CSNAT-I enabled them to proactively discuss potential future needs and support, rather than reacting to needs as they arose. They believed this could contribute to providing support earlier, prior to a time when family caregivers were exhausted. By contrast, some family caregivers were ambivalent as to how much they wanted to know in advance, as their way of managing the situation was to live day by day (V).

Both family caregivers and nurses described that nurses used different strategies, such as using probing questions and acting as a sounding board during the assessment conversation (III, V). Nurses also used various kinds of clarifications or reformulations to ensure that the family caregiver understood the questions correctly and shifted to focus on their own needs. Nurses explained that these strategies enabled the family caregivers to reflect upon and express their needs (III). Similarly, the family caregivers experienced the strategies to promote further reflection and dialogue between them and the nurses (V). In addition, they expressed that the conversation gave new valuable insights regarding their support needs and inputs.

Despite all the positive aspects that the nurses experienced when working with CSNAT-I, they also expressed that the conversations affected them emotionally and could be draining (III). In addition, a concern was raised about the time this of kind of support might require.

9. Discussion

This thesis focuses on a person-centred approach to support family caregivers in specialised home care. More specific, the CSNAT tool was evaluated and potential effects as well as experiences of the CSNAT-I were studied. The results showed that both family caregivers and nurses found the CSNAT tool relevant and useful to assess and address support needs. Family caregivers reported most need the need of support concerning knowing what to expect in the future but also concerning having time for themselves during the day. Further, higher levels of unmet support needs were associated with poorer quality of life. Nurses experienced that their way of supporting family caregivers changed from ad hoc contacts in the hallway towards scheduled, trustful conversations. Consequently, family caregivers experienced being seen and heard, creating a feeling of belonging to the care team. The CSNAT-I facilitated discussions and collaboration around support needs leading to possibilities for proactive support and new perspectives. Further, the results showed that after taking part of CSNAT-I, family caregivers' preparedness for caregiving increased and a slight improvement in caregiver burden and quality of life was found.

9.1. The CSNAT tool – relevant and useful to identify support needs among family caregivers

The results showed that the Swedish version of the CSNAT tool has sound measurements properties with satisfactory data quality and construct validity. The CSNAT tool has been validated according to the procedure of testing of instruments, though the constructors have made efforts to clarify that the tool is not an instrument and should not be used to measure the levels of need (CSNAT Intervention, 2023; Ewing et al., 2013). Instead, it should be seen as a communication tool. However, as assessment tools may be used directly in clinic with patients or families or as quality indicators to evaluate interventions in research studies, they need to be reliable and valid. Otherwise, the tool may not truly reflect what is being measured and the intervention lacks in meaningfulness (Aslakson et al., 2017). The translated German version of the CSNAT tool has also been validated (Kreyer et al., 2020), showing good feasibility and validity as

well as both the traditional and simplified Chinese versions, which also showed good validity and reliability. Just as in the Swedish evaluation, the Chinese version showed positive correlations with caregiving burden (Cheng et al., 2021; Zhou et al., 2021) and negative correlations with preparedness for caregiving and quality of life (Zhou et al., 2021).

Cognitive interviews with the targeted population can play an important role in ensuring equivalence between the translated and original instruments (Epstein et al., 2015). Cognitive interviews enable the researcher to detect misunderstandings and interpretations when the respondent reflects over the instrument. In Study I, cognitive interviews with both family caregivers and nurses suggested that the questions in the Swedish tool were considered relevant. However, there were reactions from both groups on the word “care” and it became evident that the word could be interpreted differently in Swedish compared to English. Initially, the expression “to care for” was translated to “to deliver care for,” which was perceived as implying an expectation that family caregivers should fulfil the role of a care worker. Therefore, the wording in the CSNAT tool that related to “care” were changed to, for example, “to be a support for.” Translation difficulties may arise if two languages do not have equivalent words with the same meaning (Epstein et al., 2015) and therefore it is important to make cultural adaption of an instrument (Carvajal et al., 2011). Both the German and Chinese versions of the CSNAT tool involved cultural adaptation, making adjustments to account for differences in language (Kreyer et al., 2020) and cultural differences (Zhou et al., 2021). In the German version, several adjustments were made, for example, there was no equivalent word for “practitioner” and an alternative wording was chosen. Both family caregivers and healthcare professionals requested a comprehensible German title and “KOMMA” for “Kommunikation mit Angehörigen” was chosen as it described the core target, communication with family caregivers. Also, in the Swedish version adjustments were made for the word “practitioner” to healthcare professionals as there are no equivalent word in Swedish. The CSNAT-I and the tool were given the title “Ditt behov av stöd” to be more understandable for family caregivers and the CSNAT tool is mentioned in text as a basis for conversation. In the Chinese version, during the content validity, experts did not find question 12 (practical help in the home) clear. An explanation was added that clarified that the question referred to help to manage housework or

help around the home from various sources, not just family members. Family caregivers, due to the culture, had difficulties understanding the part of question 4 that referred to legal issues and therefore “legal issues” was removed from the question (Zhou et al., 2021).

The pre- formulated questions in the CSNAT tool enabled nurses to be truly present in their meeting with family caregivers (III). Nurses in a stepped wedge cluster trial in Australia also expressed that the CSNAT tool facilitated closer relationships with caregivers, allowing further conversations where they could gain insights into family caregivers’ needs (Aoun, Toye, et al., 2015), resulting in identified support needs and inputs that otherwise would not have emerged. The CSNAT-I facilitated the nurses to spend more time and focus specifically on the family caregiver. These results can be reflected upon in relation to a review by Dobrina et al. (2014) who highlights “Presence” and “Uniqueness” as core concepts in palliative care nursing. To work in accordance with these concepts, the nurse must have a genuine desire to be present and focused in the caring moment. It is important that the nurse finds space to be there for the other person both in time and physically, and to treat each person as unique with different needs, hopes, values, and preferences. However, the tool can be viewed as a risk for potentially blocking the relationship between the nurse and the family caregiver if too much is asked too soon (Ewing et al., 2016). This concern is related to the fact that the nurses did not fully work according to the CSNAT-I person-centered process, where the approach is that the intervention is introduced by the nurses, but family caregiver led. If the intervention is used correctly, allowing family caregivers themselves to express and prioritise their support needs, the nurse may pose questions and provide information based on those needs, which might reduce the risk of unwanted information. The tool alone does not bring about benefits described above; rather, the mechanism of action creates space and presents opportunity for family caregivers to express and prioritise their needs. Therefore, the constructors have focused on the importance of learning the CSNAT process when implementing the intervention in practise (CSNAT Intervention, 2023; Ewing et al., 2015). To help healthcare professionals through this transition to a new way of working, training and support is required (Austin et al., 2017).

Both family caregivers and nurses appreciated the CSNAT tool as a valuable aid when communicating about and identifying support needs (I, III, V). These results may also be relevant regarding other assessment tools or instruments and patients. For example, the Integrated Patient care Outcome Scale (IPOS) is an instrument that provides a multidimensional perspective on the patient's situation (Beck et al., 2017). The instrument has been found to facilitate discussions between patients and nurses about care needs and enable person-centered care (Högberg et al., 2019). Patients have expressed an appreciation for the opportunity to talk about their needs with a nurse when using IPOS but they also highlighted that it was important having their needs met (Beck et al., 2017). In the description and presentation of the IPOS, no theoretical underpinning is presented but is intended to be used as a base for conversation which can facilitate reflection on their situation (Högberg et al., 2019). However, healthcare professionals have expressed uncertainty about how to approach severely ill patients and their family members, which hindered their use of IPOS with patients with palliative care need in acute settings (Lind et al., 2019). Questions regarding psychosocial and emotional issues were experienced as being difficult to discuss, especially when the healthcare professional did not know how to respond. Gatekeeping has been associated with the use of patient-reported outcome measures (PROM) in palliative care, as the healthcare professionals approach a vulnerable person and are worried that they can harm them (Bausewein et al., 2011). Hence, there may be a need to incorporate the tool into a process that may safeguard against this challenge, which is what the constructors of CSNAT-I attempt to do by the use of the five-stage process (Ewing et al., 2015). Then when the conversation is family caregiver-led and based on what the person in need wants to talk about, the self-perceived burden on the healthcare professional may ease. It is also known that one of the main barriers for healthcare professionals often consists of lack of training and guidance on how to use and implement PROMs, as a consequence, professionals may not understand the value of PROMs and therefore choose to not use them (Bausewein et al., 2011; Foster et al., 2018). This indicates the importance of supporting healthcare professionals if PROMs are to be a part of routine clinical care. One way of doing this can be to follow the example of the CSNAT-I constructors. They offer a free of charge online CSNAT-I training by all those implementing CSNAT-I in an organisation

and require that it should be completed before a licence is approved (CSNAT Intervention, 2023).

The CSNAT tool also made available support visible for family caregivers, helping them focus on the support need they considered most important at that time (V). For nurses, the questions facilitated addressing support needs that they normally did not discuss with family caregivers (III). This is in line with earlier research showing that nurses experienced the CSNAT tool as useful in making support needs visible (Ewing et al., 2016; Lund et al., 2022), helping caregivers keep the focus on the conversation and enabled them to identify need(s) that would otherwise not have been identified (Lund et al., 2022) or discussed (Ewing et al., 2016).

9.2. Paying attention to family caregivers' support needs

Family caregivers reported a need for increased support in their dual roles as both a provider of care and a person in need of care themselves. Specifically, they reported more need for support in knowing what to expect in the future, having time for oneself in the day, dealing with feelings and worries and understanding the illness (II). These results are consistent with results from similar studies conducted in the United Kingdom (Ewing et al., 2013), Denmark (Lund et al., 2022), and Australia (Aoun, Grande, et al., 2015). In all of these countries, knowing what to expect in the future was the highest ranked need, except for in China, where it was having time for oneself during the day. A recent systematic review of reviews conducted between 2010-2020, with the aim to identify the most commonly expressed needs of family caregivers of people with an advanced disease, assess the quality of current evidence, and set an agenda for future research and clinical practice, found similar results. The most common needs of family caregivers were emotional support, disease-specific education, role responsibilities education and training, and self-care needs. These needs are often related to one or more of three different types of needs often described in the literature: information, practical, or psychosocial. As an example, needs related to medication or treatment were found both in the information needs and practical

needs. Practical support was the most requested, followed by information and then psychosocial support (Marco et al., 2022). The CSNAT-I was designed to explore individual needs within the question(s) that are seen as broad domains (Ewing et al., 2015). This means that family caregivers who prioritised the same question still may have completely different support needs, requiring tailored support for each caregiver based on their specific needs. This can be better understood by using Andershed and Ternestedt's framework of involvement for family caregivers. Three key concepts: Knowing (information needs); Being (existential and emotional needs); and Doing (practical needs) has to be met for the family caregiver to gain an Involvement in the light (Andershed & Ternestedt, 2001; Andershed & Ternestedt, 1999). However, it is important to note that support is a complex concept and the type of support needed varies from person to person (Marco et al., 2022; Payne, 2010). The unpredictable nature of caring for a person with a life-threatening illness can make family caregivers' needs vary over time. In addition, the caregiver role can last for a relatively short time but for others it might be for a longer period of time. These variations may also affect the need for support (Payne et al., 2010). Additionally, the support has to match the family caregivers' needs to be supportive, and the challenge in knowing how to deliver support remains (Cohen et al., 2000). Andershed and Ternestedt's framework as well the CSNAT-I are based on person-centredness. This provides opportunities and enables family caregivers themselves to reflect on and express their support needs and what support inputs they think would help them. The Andershed and Ternestedt framework, together with CSNAT-I five-stage process, can guide the healthcare professional when delivering support so that it corresponds to what the family caregiver perceives as beneficial.

The results in Study II showed that higher levels of unmet support needs were significantly associated with poorer quality of life for family caregivers. This is consistent with earlier research that has shown that support needs negatively affect quality of life during the caregiving period, and also change over the illness period (Kim & Carver, 2019). Family caregivers reported their caregiving experience as overwhelming and this was consistently associated with their support needs being unfulfilled during the trajectory. Spousal caregivers reported greater unmet needs. Some family caregivers in Study V managed their situation by living day to day and were ambivalent about how much information about the

disease and its effects they wanted to know. However, abstaining from attending to their own support needs in order to care for an ill family member is often seen as natural by the family caregiver, even though it affects their quality of life (Tranberg et al., 2021). Family caregivers expressed that the situation was something they were supposed to handle and endure; some even avoided thinking or talking about their own needs. This avoidance may eventually lead to depression and/or burnout syndrome. Therefore, it is important to make support more visible and to continuously assess and address individual support needs throughout the care period.

Finally, the family caregivers' reported support needs and their associations to poorer quality of life could again be compared with the results of Andershed and Ternestedt's framework (Andershed & Ternestedt, 2001; Andershed & Ternestedt, 1999). If family caregivers experience a lack of communication with healthcare professionals, support needs can be unmet as they either are not expressed or understood. This can result in that family caregivers do not feel involved in the care of the patient or in their own support leading to a sense of exclusion and involvement in the dark. This can lead to family caregivers feeling less meaningfulness in the difficult situation, a less good death, and a more difficult grieving process that can affect their quality of life.

9.3. A new way of attending to support needs and increasing preparedness for caregiving

9.3.1. Facilitating communication

Nurses in Study III expressed that they changed the way they supported family caregivers while learning to use CSNAT-I, allowing family caregivers to be more involved in their own support. The nurses strived to be flexible in accommodating the family caregivers' preferences for conducting conversations, thereby creating a safe and trusting environment for dialogue. Nurses have also earlier expressed that dialogue with family caregivers is of great importance through the whole course of the disease as it can increase their ability to provide compassionate care (Skorpen Tarberg et al., 2020). In addition, family caregivers themselves have

expressed that establishing a dialogue with nurses is essential for improving their own involvement (Tarberg et al., 2019). While family caregivers in Study V valued having conversations with the nurse, they described the conversations as either caregiver-led, nurse-led, or performed in a mutual way. This is however not in line with the design of CSNAT-I and how it is intended to be used, where each stage of the process is facilitated by healthcare professionals but is caregiver-led. It is known that family caregivers are in a multiple disadvantage in healthcare, including organizational, knowledge-based, and existential challenges (Ekman, 2020). This can be understood as the family caregiver is positioned at the bottom of a hierarchical healthcare organisation when he or she is already at a disadvantage due to an exposed and vulnerable situation in which the patient's life is threatened. In addition, the family caregiver is often at a knowledge disadvantage. It could be assumed that it is not easy for family caregivers to change their perspective of adapting to the healthcare systems' hierarchy to becoming part of a partnership between themselves and the nurse, and leading conversations about their support needs. However, the nurses in Study III seemed to consciously apply a variety of strategies and adjust their role to ensure that the conversation was based on the needs of the family caregiver, resulting in enhanced dialogue and new insights regarding their support needs and inputs. Communication has been described as a skill that is critical to the nursing role and it is important to adjust and support the communication to meet the communicational needs of the other person (Daly, 2017). Communication has also been found to be a main competency for nurses in palliative care (Hökkä et al., 2020). Nurses need to be able to facilitate dialogue with the family caregiver and be willing to listen actively. However, people differ in their needs for communication and it is not always obvious what type of communication a given situation requires of the nurse. Some persons expect or require active listening, without expecting answers while others want a knowledge and explanations for everything that happens to them (Kourkouta & Papathanasiou, 2014). Communication is further described as a cornerstone in establishing a person-centred care (Kourkouta & Papathanasiou, 2014) that may contribute to viewing the family caregivers as persons with unique needs and diversities, avoiding generalisations (Daly, 2017).

9.3.2. Enhancing person-centeredness

Through utilising the CSNAT-I, nurses learned to take on less responsibility for acknowledging and identifying support needs toward a partnership where family caregivers' own knowledge and insights guided the assessment, content of the conversation and the results (III). Since the CSNAT-I is theoretically underpinned by a person-centred approach, these results can be compared with the concept of person-centred care, where the person's experience is prioritised and the importance of their own narrative for care is emphasised (Ekman et al., 2011). The person's unique perspective is given equal value as the professional perspective and the person's narrative lays the ground for a partnership in care and sets the person's views about his/her life situation irrefutably and always at the centre of care. There are several definitions of person-centred care, but no universally used definition within the nursing profession (Byrne et al., 2020). However, the core themes are that care is co-created by the person and the healthcare professionals (Kristensson Ugglå, 2014). Family caregivers experienced the needs assessment to be an opportunity for co-created and flexible dialogue, gaining new insights, and finding possible solutions (V). They found that the conversations with nurses validated their role and they felt empowered to take on a more active role. The CSNAT-I has been found to empower family caregivers (Aoun, Toye, et al., 2015). Nurses have expressed that giving one-to-one time to family caregivers provided them with more information, involved them in the decision-making and gave them courage to ask for support. From these results, it could be assumed that CSNAT-I may facilitate and safeguard a transition to person-centred care and support.

9.3.3. Potential barriers

Even though nurses' experiences of the CSNAT-I were predominantly positive, they also expressed that the CSNAT-I required them to possess high levels of professionalism and nursing skills. They also expressed that the conversations affected them emotionally and could be draining (III). A recent review about a nurse's role and how they uphold their nursing values in palliative care found that nurses sometimes developed strategies and skills in preserving their personal integrity when they were overwhelmed by emotions (Moran et al., 2021). It is a balancing act between the nurse, the other person, and their feelings, and this can be simultaneously draining and enriching. Being with the person is considered

part of holistic care and presence with the person is “not about doing, it’s about being”. To achieve true presence and protect privacy, nurses must find a balance between having a professional and relationship approach.

Nurses in Study III also expressed concern about the amount of time this kind of support might require. Time is of the essence in palliative care, as both patient's and family caregiver's needs are unique (Hemberg & Bergdahl, 2020). In addition, the ethical sensitivity of the situation at home requires more time. However, nurses often have little time to prioritise the psychosocial needs of patients and family caregivers due to organisational and cultural structures that prioritise medical interventions (Glasdam et al., 2020). The authors discuss that these findings challenge nurses to take on a more ethical approach to ensure that patients and their family caregivers receive good palliative care with a focus on more than medical issues and logic, strengthening the nurses' profession in the field of palliative care. The CSNAT tool legitimises nurses' work in supporting family caregivers as it reinforces nurses' interest in them (Ewing et al., 2016) and may help nurses to prioritise family caregivers' psychosocial needs.

9.4. Methodological considerations

This thesis includes five studies using different study designs and research methods. This variation has enabled a broad and deep understanding related to the overall aim. Both qualitative and quantitative methods have been used to evaluate the CSNAT tool and explore the CSNAT intervention. I have emphasised transparency concerning the many choices made throughout the research process and have strived to describe them thoroughly in the separate articles and in this thesis. However, there are some strengths and limitations to consider. My considerations are structured below. At first there is a discussion concerning the various study designs. Following that, I have sorted my considerations related to participants, data collection and data analyses within the section's Qualitative methods and Quantitative methods.

9.4.1. Overall design

This thesis consists of two parts and various designs are applied. The first includes a validation design to translate and evaluate the validity and reliability of the CSNAT tool (I), which provided a solid ground for following studies and strengthened the results. A cross-sectional design was applied in Study II, which does not allow for any conclusions to be drawn about the causal relationships between the variables (Polit, 2021), a possible limitation. It is therefore important to bear in mind that we cannot exclude the possibility that the relationships have an opposite direction, i.e. that the outcome variable (QOLTI-F) has affected the explanatory variable (CSNAT). However, the descriptive qualitative results served to deepen one's understanding of how family caregivers' support needs affect their quality of life and complimented the quantitative results.

Part two of this thesis employs an intervention design to explore potential effects of the CSNAT-I for family caregivers as well as experiences from both nurses and family caregivers. In Study III, due to the Covid-19 pandemic, the specialised home care services participated with fewer nurses than intended, resulting in less participating family caregivers and thus a decreased amount of data. Consequently, a longitudinal design with repeated interviews with participating nurses was chosen to ensure quality. During the course of this study, it was evident that this design was advantageous, as it allowed time for reflections between interviews, both for researchers and nurses, which also increased the

chances for verbal validity (Patton, 2015). In addition, the understanding of the changing experiences might have resulted in enriched data (Morse, 2015). The pre- and post-design without a control group, used in Study IV, provided data about changes between baseline and follow up among the participants. However, this design is limited in its ability to establish cause (support through CSNAT-I) and effect (preparedness for caregiving). Therefore, the results must be interpreted with caution. With the use of inductive qualitative descriptive design in Study V it was possible to provide a deeper understanding of family caregivers' experiences of discussing their needs utilising the CSNAT-I with a nurse.

9.4.2. Qualitative methods

Trustworthiness is important in qualitative research and is evaluated through the quality of data and procedures throughout a study. In this thesis, trustworthiness is discussed through the concepts traditionally used in discussing qualitative methods: (1) *credibility* (how well data and processes of analysis address the intended focus), (2) *dependability* (data stability over time and alterations made in the researcher's decisions during the analysis process), (3) *transferability* (the extent to which the findings can be transferred to other settings or groups), and (4) *authenticity* (the extent to which researchers, fairly and faithfully, show a range of realities) (Graneheim et al., 2017; Graneheim & Lundman, 2004).

Participants

The inclusion criteria for family caregivers remained the same throughout the five studies. A purposeful choice was made to include cohabiting spouses based on research indicating that they often spend more time and extensive care and support to a seriously ill partner than other family caregivers. Applying purposive recruitment can be a strength as it can provide both depth and variety in the studied phenomenon (Polit, 2021), that resulted in participants with different experiences of being a family caregiver. However, due to practical issues such as the questionnaires and information provided were written in Swedish, only Swedish speaking spouses could be included in the studies. Such an exclusion may have eliminated participants with diverging experiences, which may be considered a limitation. To strengthen credibility, family caregivers in part 1 of this thesis were included from two different specialised home care services in two large cities in Sweden (I, II) and in part 2 from sex different specialised home care services

in 3 geographic locations in Sweden, including urban, suburban, and rural areas (III, V). Drawing from a wider range of participants is done to increase the likelihood of capturing diverse experiences. This, in turn, increases the potential for comprehending the research questions from multiple viewpoints, thereby bolstering the transferability of the findings.

Furthermore, another limitation due to the Covid -19 pandemic, was that nurses in Study III were chosen by the heads of the departments at the care service. These nurses had a special interest in supporting family caregivers and extensive experience working in palliative care. This may not be representative of the nurses working in specialised home care. However, qualitative research by design does not aim for replicability, rather it seeks to understand a wide range of truths (Stahl & King, 2020).

Data collection

To establish credibility in the studies using qualitative methods, different data collection methods (written open-ended questions, individual interviews, group interviews) were chosen depending on the aim (Graneheim & Lundman, 2004). The open-ended question in the questionnaire in part 1 of this thesis was developed to generate depth and capture experiences that might not be fully encompassed by the questionnaire instruments. There are different views on the benefits of using a general open-ended question at the end of a questionnaire (Decorte et al., 2019; O'Cathain & Thomas, 2004). For example, the comments to these open-ended questions could potentially elaborate or corroborate answers to closed questions and give an opportunity to voice the participants reactions or opinions but may be difficult to analyse. The written comments provided by the family caregivers to the open questions used in the questionnaires provided a deeper understanding of family caregivers situation and enriched the results.

The aims of Studies III and V led to the conclusion that individual interviews were an appropriate method. The interviews were based on semi-structured study-specific interview guides with open questions. In addition, probing questions were used to encourage participants to elaborate and discuss both positive and negative experiences. It may be regarded as a limitation in Studies III and V that the interviews were conducted over telephone or Voice over Internet Protocol (VoIP) technologies, such as Teams, due to the Covid-19 pandemic.

These types of interviews may risk that body language and nuances are more easily missed. However, in the performed interviews, family caregivers and nurses frequently shared their personal experiences, resulting in rich and varied data. Some of them actually expressed that they preferred the interview being conducted by phone or Teams as it then was easier to find the time needed. Also, in the literature telephone interviews and VoIP have been described as good complements that can provide the same nature and depth of responses as face-to-face interviews (Lo Iacono et al., 2016; Sturges & Hanrahan, 2004). Other positive aspects of this method of interview are the flexibility, reduced disruption of the day and cost-effectiveness (Sturges & Hanrahan, 2004). However, a few family caregivers declined to be interviewed remotely for Study V due to hearing problems, thus delineating one weakness, as it consequently excluded some family caregivers.

Data analysis

Selecting an appropriate analysis method with regard to the data collection and the amount of data are also important in establishing credibility (Graneheim & Lundman, 2004). Four different data analysis methods have been used depending on the aim and quality of data. Altogether, careful decisions have been made and appropriate analyses were chosen, i.e. a summarising analysis based on relevance, clarity and sensitivity (Willis, 2004) for study I, content analysis (Hsieh & Shannon, 2005), for Study II, interpretive description (Thorne, 2008) for Study III and framework analysis (Goldsmith, 2021) for Study V. The same analysis method in studies III and V might have deepened the understanding on how family caregivers and nurses experienced CSNAT-I.

Credibility in Study I was strived for by choosing a widely used qualitative method for evaluating how individuals mentally process and respond to questionnaires (Meadows, 2021). In addition, the use of both standardised versus free-form probes during the interview potentially enabled participants to provide rich information and, at the same time, it did not constrain the collected data through scripted probes (Meadows, 2021). Dependability was addressed by discussions among co-authors, who had various knowledge and different preunderstandings of the context, when the data were summarised and analysed. However, the think-aloud approach can place a burden on participants when they are asked to

formulate an opinion on issues that may involve emotions or preferences (Meadows, 2021). To ensure that participants felt secure, they choose the time and place for the interview.

In Study II, 38% of the participating family caregivers responded to the open-ended question and comments varied in length from a few sentences to two pages and contained various experiences of their situation. Open-ended questions can have limitations for analysis, due to the variation in the answers and data often consists of few words or sentences (Decorte et al., 2019). The methodological literature focusing on this issue is relatively scarce, providing unclear guidance on how to analyse these questions, resulting in many researchers failing to analyse or present the data. Content analysis was considered to be appropriate as it can provide opportunities to explore relationships between support needs and quality of life (Hsieh & Shannon, 2005). The length of the comments varied, and the amount of data was relatively small. However, the comments provided a sufficient amount and depth of data, and were found to describe how family caregivers' support needs were associated with quality of life. All authors read and discussed the codes and categories, enabling a critical examination throughout the analysis process and strengthened the dependability. By quotations in the result section, readers will hopefully be able to assess confirmability and the authenticity of the interpretations made in the analysis. Finally, the use of methodological triangulation, i.e. using more than one method of collecting or analysing data, may have strengthened the credibility of the overall results (Stahl & King, 2020).

In Study III interpretative description was used to analyse the data. This method is described by Thorne (2008) as especially suitable to use for addressing complex experiential questions while producing practical outcomes. Moreover, the resulting outcome is knowledge with the potential to change clinical practice. When using this method, having clinical experience is considered a strength, a factor that both my main supervisor and I shared. This knowledge was used to refine aim, choose data collection methods, and interpret data. However, this could also bias the results and risk the trustworthiness (Thorne, 2008). To strengthen dependability, a thorough description of the analyses was given. Additionally, to manage the remaining risk of bias, an open dialogue was

conducted among co-authors, with thorough reflection on how our own values and experiences affect the research process, data analysis and interpretation (Thompson Burdine et al., 2021).

Using framework analysis in Study V provided the opportunity to analyse data through a created framework which was then applied to the data in an organised manner without losing flexibility (Goldsmith, 2021). This analysis was chosen as it can be shaped by existing ideas (Ward et al., 2013). Data were addressed through specific questions which enabled a systematic analyse. The authors discussed varying interpretations throughout the analysis, which strengthens credibility. In addition, the quotations presented in the results were chosen to show variations of experiences. The framework analysis is known for providing a structure that can accomplish analysis quickly (Ward et al., 2013). However, in this case, the method was perceived as both resource and time consuming to switch between the data, the thematic framework and re-sorting the data to reach a result.

9.4.3. Quantitative methods

The quantitative research methods will be discussed in terms of participants, data collection and data analysis and its importance for external validity, i.e., the degree to which the results can be generalised to other settings or samples than studied (Polit, 2021)

Participants

Participants in Studies I and II were recruited from two different home care services in two different cities. The reason for this was to be able to include more people and to increase generalisability, as support for family caregivers can vary between regions and health care units. One challenge entailed by this sample set was that the samples were made in two large cities, where the level of education is generally higher than in small towns. People with high socio-economic status often have better conditions to cope with stresses (Oechsle et al., 2019), and therefore this may have affected the generalisability. Although only large cities were included, a large majority of participants were born in Sweden. Therefore, in Study IV more units were included divided into three geographical areas. Despite this, the same skewed distribution regarding educational level and

proportion of Swedish-born participants remained. It is a known fact that people with higher socio-economic status are overrepresented in research (Addington-Hall et al., 2007), which can negatively affect generalisability. In addition, research shows that those family caregivers who are already coping well or are well-supported are more likely to take part in research than those who are more vulnerable, which may affect the results (Addington-Hall et al., 2007; Holm et al., 2017). Support needs may therefore have been underestimated. However, descriptive statistics have been used to present the characteristics of the participating family caregivers and study variables to be transparent and give the reader clear picture of generalisability.

A limitation in Study IV was that family caregivers were identified by the participating nurses. This may have resulted in some family caregivers being excluded due to gatekeeping. Furthermore, before approaching the family caregiver, patients were asked for approval. This could possibly have excluded family caregivers who wanted to participate in the study.

The response rate in Studies I and II was 33%, though participation may have been higher if reminders were sent out. However, it was decided not to send out a reminder as the target group of participants could conceivably be considered extra vulnerable. It is also known that survey fatigue exists, and response rates have generally declined over the years. Response rates around 50% are common in normal populations (Story & Tait, 2019). In a palliative context, response rates are often lower and are often explained by challenges and sensitivities of recruiting this population into research studies (Addington-Hall et al., 2007). A high non-response rate does not necessarily pose a problem for generalisability as long as the respondents are representative of the population. Unfortunately, there was no data for those who did not participate and therefore no opportunity to examine any differences between these groups. This should be taken into account when interpreting the results of Studies, I, II and IV.

No sample size calculation was made for Studies I, II and IV and the samples can be considered small. This can likely be explained by the high dropout rate (I, II) and partly due to the Covid-19 pandemic (IV). In Study IV, the patients deteriorated significantly in their illness and 27% died before the intervention was

completed. In addition, to the threat for the external validity, the small sample size increased the risk for type I errors, e.g., failure to identify changes in quality of life and caregiver burden. Relatedly, some missing data were presented which reduced the numbers of observations further. However, since the number of missing data was low, no imputation was used. This can be a problem for the generalisability if participants with missing data is not representative. Therefore, different imputations methods, such as multiple imputation, are commonly recommended (Jäger et al., 2021). Despite these limitations, the results in Study II revealed subtle and nuanced relationships between family caregivers' needs for more support and their quality of life. In addition, significant effects were found for preparedness in Study IV. Yet, it is not possible to be entirely sure what influenced these effects. It is difficult to know how family caregiver's preparedness for caregiving might have been affected by the fact that they received help or that, for example, the patient's illness improved. It is also important to consider that time in itself could have influenced their preparedness.

Data collection

Questionnaires including validated instruments and background questions were used in Studies I, II and IV. Response bias is a potential threat in survey studies. In this thesis there was a particular risk for social desirability and recall bias, that is giving answers that are consistent with prevailing social views or unable to adequately recall past events. This implies that participants may have given answers to the instruments (PCS, QOLLTI-F, CBS) that correspond to what they assume is expected of them or that they want to show that they manage the situation well. In addition, participants are likely to live in a stressful situation and may not perceive the questions in the same way as they would in another less stressful one. To minimise social desirability and recall bias, the chosen instruments consisted of relatively few questions and participants who expressed that it was burdensome to answer the questionnaire were provided help to answer them. Family caregivers commented in the questionnaires that they considered research about support to family caregivers as important, indicating an interest of being part of research. There are also advantages of questionnaires as they enable large data collections while being cost and time efficient, which make them important to use in nursing research (Siedlecki, 2020).

Data analysis

The quantitative data were analysed with different types of statistical methods. There is no consensus on the statistical procedures for analysing ordinal scales, as they are typically based on a summation of questions scored on a scale consisting of ordered categories. Some argue that they should be treated as ordinal variables and analysed with non-parametric statistics (Norman, 2010) while others argue that this type of scales can be treated as continuous variables and analysed with parametric statistics as long as the other conditions for analysis are met, such as the condition of normal distribution (Williams, 2021). In the present thesis, self-reported data were analysed with non-parametric statistics except in Study II, where linear regression analyses were used to explore associations between family caregivers' support needs and quality of life. There are currently no good alternatives to linear regression, the alternatives offered are different types of logistic regression, all of which mean that the variable must be divided into two values, such as "yes" or "no" (Williams, 2021). This, in turn, increases the risk of individuals being misclassified, especially those with a score close to the cut-off point. These responses can then be "censored," and the recorded responses are biased, which represents a form of measurement error. Using linear regression where the outcome measure is an ordinal scale can therefore be seen as both a strength and a limitation, depending on how one chooses to view this type of variable.

9.4.4. Reflections on my role as a researcher

It is essential in the research process to acknowledge the researcher's own experience in the studies context and how it influences the construction of the study and the work (Patton, 2015). As a registered nurse I have been working within palliative care for 17 years and during my PhD studies I have lost my father and grandmother. In that sense I have experiences of being both a nurse and a family caregiver who supports and cares for an ill person. It has been argued that pre-understanding should be bracketed as it can have a negative influence on research validity (Palmér et al., 2022). Others, like Thorne (2008) argues that pre-understanding has a positive input in research and should be used as a tool during the research process. Thorne also highlights that the nurse's theoretical, empirical and clinical knowledge can constitute an important knowledge base for designing

clinically relevant research questions (Thorne, 2008). It is possible that both my private and professional knowledge and clinical experience of palliative care has influenced my analysis and interpretation, and perhaps also limited me from seeing alternative interpretations. During interviews I have, however, strived to be open-minded and asked the participants to explain how they feel or mean and summarised at the end to avoid misunderstandings and premature interpretation due to my pre-understanding. Discussing and reflecting with the research group has served as an important resource that challenged my interpretations and added other perspectives.

10. Conclusions

The results from the present thesis provide new knowledge about the Carer Support Needs Assessment Tool Intervention in a specialised home care context in Sweden. The results complement earlier international studies on the intervention and add to the validity of the CSNAT tool demonstrating its reliability for use among Swedish family caregivers. This thesis contributes to further understanding of family caregiver's situation, showing that they need more support than they often receive and that higher levels of support needs are associated with poorer quality of life. The use of CSNAT-I can facilitate communication and collaboration between nurses and family caregivers, leading to person-centred support. The intervention enabled a co-created dialogue that increased family caregivers' possibilities of new valuable insights and adequate supportive inputs. The intervention provided increased opportunities for family caregivers to be seen and listened to. This empowered them to be involved in their own support, which might have enhanced their sense of security. Utilising the CSNAT-I increased the family caregiver's preparedness for caregiving, and thus the intervention may be implemented as a way to prepare them for their caregiver role.

11. Clinical implications

Supporting family caregivers is increasingly important, as the trend in recent years has been that patients with life-threatening illnesses are cared for at home by healthcare professionals and their families. There has been a call in the international research for applicable interventions in clinical care. In Sweden, the Government has presented the first National strategy to strengthen family caregivers' position and to ensure that they receive adequate support. Knowledge drawn from this thesis demonstrates that the CSNAT-I is an evidence-based intervention that could be applied in the Swedish specialised home care to address family caregivers' support needs and increase the provision of support needed. By becoming more aware of family caregiver's situation and how it impacts their quality of life, healthcare professionals may be better prepared to support family caregivers through this time. Furthermore, the results indicate that CSNAT-I can

guide nurses to work in collaboration with family caregivers when they identify and address support needs and finding beneficial inputs. The CSNAT-I can enhance nurses' support, increasing the likelihood of proactive person-centred support that may prepare family caregivers for their new situation and caregiver role. Addressing family caregivers' individual support needs is crucial in making it possible for patient to be cared for at home.

The results underscore the importance of involving family caregivers in their own support needs to increase their possibilities for adequate support. Knowledge about how family caregivers experience discussing their support can be useful both for nurses and services when implementing CSNAT-I.

The knowledge achieved in this thesis offers a deeper understanding of the complexities of supporting family caregivers in palliative care and provides an intervention that may facilitate individual support, enhancing the possibilities to increase family caregivers' preparedness for caregiving. This may be helpful for home care services and healthcare professionals in their efforts to improve family caregiver support.

12. Future research

There is a need for more research on the unrecognised work family caregivers perform. The support and care for the ill patient affects the caregiver's need for support and what supportive inputs they perceive as helpful for enhancing their quality of life. As family caregivers' support needs change over the patient's trajectory, it would be valuable to expand the knowledge of how family caregivers experience the support throughout this period. In addition, more knowledge is needed about nurses' experiences of using the intervention repeatedly to address family caregivers' changing needs for support. It would also be valuable to test CSNAT-I in a randomised controlled trial (RCT) to draw more reliable conclusions about the effects of the intervention.

As the majority of patients receiving palliative care are not cared for in the specialised palliative care, our results should also be supplemented by research from other contexts, for example the primary home care (non- specialised).

Today's society has become more technologically advanced and many services can be provided online from the computer at home. Even in health care, more data is registered digitally and the use of paper is being phased out. Therefore, it would be valuable to conduct further research on CSNAT-I when incorporated into a digital platform to study the experiences of both family caregivers and healthcare professionals.

Sammanfattning

Många patienter med livshotande sjukdomar vårdas i hemmet mot livets slut (Tay et al., 2021) och närstående blir ofta nödvändiga för den sjuke (Khan et al., 2014; Pivodic et al., 2016). Närstående ger ofta den sjuke både socialt (Jegermalm, 2020; Palmer Kelly et al., 2019), emotionellt, och existentiellt stöd samtidigt som de ibland utför omfattande vård i form av personlig omvårdnad (Holm et al., 2015; Jegermalm, 2020; McDonald et al., 2018). I den situationen, rapporterar många närstående att de har behov av stöd och upplever otillräcklig kunskap för att vårda en svårt sjuk person (Harding, Epiphaniou, et al., 2012; McIlfatrick et al., 2018; Sklenarova et al., 2015), samt en försämrad livskvalitet (Breen et al., 2019; Spatuzzi et al., 2017). Sjuksköterskan har en central roll i den palliativ vården och måste kontinuerligt bemöta närståendes svårigheter och behov av stöd (Ewing et al., 2015). Världshälsoorganisationen (WHO, 2002) betonar vikten av att stödja närstående och det finns modeller och teorier (Sawatzky et al., 2016; Touzel & Shadd, 2018) som sätter fokus på närstående. Dock finns det idag inte mycket vägledning om vad sådant stöd innebär eller hur man uppnår det. The Carer Support Needs Assessment Tool Intervention (CSNAT-I), på svenska Ditt behov av stöd, har utvecklats för att främja närståendes möjligheter att identifiera, uttrycka, och prioritera sina stödbehov. Interventionen består av två delar, ett samtalsunderlag (The Carer Support Needs Assessment Tool/CSNAT) och en personcentrerad process i fem steg. Interventionen kan vara ett evidensbaserat sätt att bemöta närståendes behov av stöd, och tidigare studier har visat lovande resultat med minskad upplevd påfrestning/börda, ökad tillfredsställelse med stödet och högre grad av rätt stöd (Aoun, Grande, et al., 2015; Aoun, Toye, et al., 2015; Aoun, Ewing, et al., 2018; Ewing et al., 2016; Lund et al., 2020). Detta har dock inte studerats i en svensks sjukvårdskontext och mer kunskap behövs för att öka förståelsen för potentiella effekter samt närståendes och sjuksköterskors erfarenheter av interventionen.

Det övergripande syftet med avhandlingen var att utvärdera samtalsunderlaget (CSNAT) och utforska erfarenheter och potentiella effekter av att använda interventionen Ditt behov av stöd (CSNAT-I) bland närstående och sjuksköterskor i specialiserad hemsjukvård. Avhandlingen omfattar fem

delstudier med olika design, och både kvantitativa och kvalitativa metoder har använts.

Resultatet visade att samtalsunderlaget (CSNAT) var valid och tillförlitligt för att använda bland närstående i den specialiserade hemsjukvården (I). Närstående rapporterade mest behov av att få veta vad de kunde förvänta sig av framtiden (I, II). Högre nivåer av ej tillgodosedda behov av stöd hos närstående var signifikant associerat med sämre livskvalitet vilket även stärktes av deras beskrivningar om hur deras liv och livskvalitet påverkades av sjukdomens konsekvenser (II). Närstående rapporterade även signifikant ökad förberedelse för att vårda efter att ha tagit del av interventionen samt en liten förbättring gällande börda/påfrestning och livskvalitet. Sjuksköterskornas kliniska vardag förändrades när de lärde sig att använda interventionen och de upplevde professionell och personlig utveckling (III). Stödet förändrades och utvecklades från tillfälliga kontakter i hallen till schemalagda förtroendefulla samtal. Deras bedömningar och stödjande insatser skiftade från att vara reaktiva till att bli mer proaktiva. Även deras förhållningssätt ändrades och istället för att själva ta på sig ett stort professionellt ansvar för att identifiera närståendes behov av stöd tillämpade de istället ett samarbetsinriktat förhållningssätt med ett delat ansvar med närstående. Dock uttryckte sjuksköterskorna en oro över den tid och energi denna typ av stöd kunde kräva av dem i deras ofta stressfyllda arbetssituation. Närstående å andra sidan uppskattade dessa schemalagda möten de hade med sjuksköterskan. Det gav dem möjlighet att fokusera på det som var viktigt för dem (V). De upplevde att samtalen var samskapade med en flexibel dialog. Samtalen gav nya perspektiv och insikter som hjälpte dem att hitta möjliga lösningar på deras stödbehov. Närstående upplevde sig stärkta av samtalen och tog på sig en mer aktiv roll i samtalet.

Sammantaget ger avhandlingen ytterligare tyngd till betydelsen av att möta närståendes behov av stöd som en del av omvårdnaden.

Då majoriteten av patienter med behov av palliativ vård inte vårdas inom specialiserad hemsjukvård skulle ytterligare forskning kring interventionen Ditt behov av stöd (CSNAT-I) i andra vårdkontexter, som till exempel allmän hemsjukvård, vara betydelsefullt.

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Appendices

Enkät 1 och 2, samt intervjuguider

Närståendes situation och behov av stöd

Enkät 1



Kodnummer: _____

Mottaget datum: _____

Instruktion till enkäten

Frågeformuläret består av ett antal frågor och påståenden att ta ställning till och beräknas ta ca 20 minuter att besvara. För att resultatet ska bli så tillförlitligt som möjligt är det angeläget att du svarar så uppriktigt du kan på frågorna. Det är också angeläget att du försöker att besvara samtliga frågor. Enkäten består av några inledande frågor om dig och din livssituation samt frågor kring ditt behov av stöd, förberedelse för att vårda, din situation som närstående och livskvalitet. Enkäten kan besvaras i omgångar och du kan pausa när du behöver.

Har du frågor om forskningsstudien eller att fylla i enkäten är du välkommen att ta kontakt med Maria Norinder, se kontaktuppgifter nedan.

Vi vill börja med att be dig underteckna ditt samtycke till att delta i denna forskningsstudie:

Jag har fått muntlig och skriftlig information samt haft möjlighet att ställa frågor. Jag accepterar deltagande i den beskrivna studien och jag känner till att mitt deltagande är frivilligt. Jag godkänner att de uppgifter som samlas i denna enkät får behandlas enligt Personuppgiftslagen.

Namnunderskrift

Ort och datum

Namnförtydligande

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Inledande frågor

Dessa frågor handlar om dig och din livssituation. Försök om möjligt att besvara samtliga frågor.

1. Är du

- ☐ Kvinna
- ☐ Man
- ☐ Annan könsidentitet

2. Din ålder? _____

3. Födelseland

- ☐ Sverige
- ☐ Annat land i Norden
- ☐ Annat land i Europa
- ☐ Annat land utanför Europa

4. Civilstånd

- ☐ Gift eller registrerad partner
- ☐ Ogift
- ☐ Änka/Änkling
- ☐ Skild
- ☐ Annat: _____

5. Den som är sjuk är din/ditt:

- ☐ Maka/Make/Partner
- ☐ Barn
- ☐ Förälder
- ☐ Syskon
- ☐ Vän
- ☐ Annan: _____

6. Var vårdas din sjuka närstående just nu?

- ☐ Hemmet
- ☐ Palliativ vårdavdelning eller hospice
- ☐ Annan vårdavdelning
- ☐ Vård och omsorgsboende

7. Vilken är den högsta utbildningsgrad som du avslutat?

- ☐ Lägre än grundskoleexamen
- ☐ Grundskoleexamen eller motsvarande
- ☐ Gymnasieexamen eller motsvarande
- ☐ Högskole- eller Universitetsexamen

8. Vilken sysselsättning har du för tillfället? Flera alternativ kan anges.

- ☐ Heltidsarbetande
- ☐ Deltidsarbetande
- ☐ Arbetssökande
- ☐ Sjukskriven
- ☐ Pensionär
- ☐ Studerande
- ☐ Annan: _____

9. Har du närståendepenning?

- ☐ Ja
- ☐ Nej

10. Har du för egen del sökt hälso- och sjukvård under de senaste 6 månaderna med anledning av din närståendes sjukdom?

- ☐ Nej
- ☐ Ja, 1–2 gånger
- ☐ Ja, 3–5 gånger
- ☐ Ja, fler än 5 gånger

11. Har du haft någon samtalskontakt med kurator, psykolog eller motsvarande med anledning av din närståendes sjukdom?

- ☐ Ja
☐ Nej

12. Har du från hälso- och sjukvården blivit erbjuden någon form av stöd under tiden som din närstående varit sjuk?

- ☐ Nej
☐ Ja, beskriv gärna:

Närståendes behov av stöd

Vi vill veta vad du behöver för att vara ett stöd till din närstående samt vilka behov av stöd du har för din egen skull. Kryssa för det alternativ som bäst stämmer överens med dina behov i nuläget.

	Behöver du mer stöd med...	Nej	Lite mer	Ganska mycket mer	Väldigt mycket mer
1	..att förstå din närståendes sjukdom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	..att få tid för dig själv under dagen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	..att hantera din närståendes symtom, inklusive att ge medicin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	..dina ekonomiska, juridiska eller arbetsrelaterade frågor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	..att hjälpa din närstående med personlig vård och omsorg (tex påklädning, hygien, toalettbesök)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	..att hantera dina egna känslor och oro?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	..att veta vem du kan kontakta om du är bekymrad för din närstående (dag som natt)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	..att sköta din egen hälsa (fysiska problem)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	.. hjälpmedel för att underlätta vården och omsorgen om din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	..din tro, livssyn eller existentiella/andliga funderingar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	..att prata med din närstående om hans eller hennes sjukdom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	..praktisk hjälp i hemmet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	..att få veta vad du kan förvänta dig för dig och din närstående i framtiden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	..att få vila från vård och omsorgsansvar under natten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	..något annat (vänligen beskriv här)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Förberedelse för att vårda en närstående

Följande frågor handlar om hur förberedd du känner dig för att vårda din närstående. 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
1	Hur väl förberedd tror du att du är för att tillgodose din närståendes fysiska behov?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Hur väl förberedd tror du att du är för att möta din närståendes känslomässiga behov?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Hur väl förberedd tror du att du är för att identifiera hjälpbehov hos din närstående och att hitta lösningar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Hur väl förberedd tror du att du är inför den påfrestning som vårdandet medför?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Hur väl förberedd tror du att du är för att göra vårdandet så bra som möjligt för både dig själv och din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Hur väl förberedd tror du att du är på att hantera akuta situationer som rör din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Hur väl förberedd tror du att du är för att hitta hjälp och information du behöver från hälso- och sjukvården?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Generellt sett, hur väl förberedd tror du att du är för att vårda din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Din situation som närstående

Följande frågor handlar om hur du ser på din situation som anhörig. Besvara varje fråga genom att sätta ett kryss i den ruta som bäst överensstämmer med dina upplevelser.

		Nej, inte alls	Nej, knappast	Ja, i viss mån	Ja, i hög grad
1	Känner du dig trött och utarbetad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Känner du dig ensam och isolerad pga din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Tycker du att du får ta för mycket ansvar för din anhöriges väl och ve?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Känns det ibland som om du skulle vilja fly undan hela den situation du befinner dig i?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Ställs du inför rent praktiska problem i vården som du tycker är svåra att lösa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Kan du bli sårad och arg på din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Tycker du att din hälsa har blivit lidande pga att du tagit hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Har din anhöriges problem lett till att umgänget med andra, t ex släkt och vänner, minskat för dig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Finns det något i din anhöriges bostad som gör det besvärligt att ta hand om honom eller henne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Känner du dig bunden av din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Känner du dig besvårad av din anhöriges beteende?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Leder din anhöriges problem till att du inte kan göra det du hade tänkt göra vid denna tid i livet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Tycker du att det är fysiskt påfrestande för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14	Tycker du att din anhörige tar så mycket tid att du inte får tillräckligt med tid för dig själv?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Oroar du dig över att du inte ska kunna ta hand om din anhörige på rätt sätt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Kan du ibland skämmas över din anhöriges uppförande?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Finns det något i omgivningen runt din anhöriges hem som gör det besvärligt att ta hand om honom eller henne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Har det inneburit någon ekonomisk uppoffring för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Tycker du att det är psykiskt påfrestande för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Har du ibland en känsla av att livet behandlat dig orättvist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Hade du tänkt dig att livet skulle vara annorlunda i den ålder du är i nu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Undviker du att bjuda hem vänner och bekanta pga din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Livskvalitet

Formuläret innehåller en rad påståenden som vart och ett följs av två motsatta svar. De utgör ytterligheter på en skala från noll till tio. Ringa in den siffra som stämmer bäst för dig. Det finns inga svar som är rätt eller fel, men det är viktigt att du besvarar frågorna så ärligt som möjligt.

EXEMPEL:

Jag är hungrig:

inte alls	0	1	2	3	4	5	6	7	8	9	10	extremt
------------------	---	---	---	---	---	---	---	---	---	---	----	----------------

- Om du inte är det minsta hungrig ringar du in 0.
- Om du är lite hungrig (som när du precis har ätit, men har fortfarande plats för dessert), ringar du in 1, 2, eller 3.
- Om du är ganska hungrig (som när det snart är dags att äta), ringar du in 4, 5, eller 6.
- Om du är väldigt hungrig (som när du inte ätit på hela dagen), ringar du in 7, 8, eller 9.
- Om du är extremt hungrig, ringar du in 10

START

Var vänlig och besvara frågorna utifrån hur du har känt **DE SENASTE TVÅ (2) DYGNEN**.

DEL A **Allmän livskvalitet**

A. Om jag ser till alla delar i mitt liv (till exempel fysiskt, emotionellt, socialt, spirituellt och ekonomiskt) tycker jag att min livskvalitet under de senaste två dygnen (48 timmarna) har varit:

mycket dålig	0	1	2	3	4	5	6	7	8	9	10	utmärkt
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Fortsätt på nästa sida...

DEL B Omgivning

1. Under de senaste två dygnen (48 timmarna) har jag varit nöjd med den plats där min närstående vårdas (hem, sjukhus, annat):

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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2. Under de senaste två dygnen (48 timmarna) har jag haft den avskildhet jag önskat:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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DEL C Din närståendes tillstånd

3. Under de senaste två dygnen (48 timmarna) har jag varit påtagligt orolig över min närståendes tillstånd:

sällan	0	1	2	3	4	5	6	7	8	9	10	alltid
---------------	---	---	---	---	---	---	---	---	---	---	----	---------------

DEL D Ditt eget tillstånd

4. Under de senaste två dygnen (48 timmarna) har graden av kontroll jag haft över mitt liv:

inte varit något problem	0	1	2	3	4	5	6	7	8	9	10	varit ett enormt stort problem
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Fortsätt på nästa sida...

5. Under de senaste två dygnen (48 timmarna) har jag haft tid att ta hand om mig själv:

aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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6. Under de senaste två dygnen (48 timmarna) har jag kunnat tänka klart:

sällan	0	1	2	3	4	5	6	7	8	9	10	alltid
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7. Under de senaste två dygnen (48 timmarna) har jag fysiskt mått:

extremt dåligt	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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8. Under de senaste två dygnen (48 timmarna) har jag känslomässigt mått:

extremt dåligt	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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DELE Ditt perspektiv

9. Att kunna ta hand om eller vara sällskap åt min närstående som är sjuk har under de senaste två dygnen (48 timmarna) fått mig att må bra:

sällan eller aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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Fortsätt på nästa sida...

10. Under de senaste två dygnen (48 timmarna) har min livssyn, tro eller andlighet varit till tröst:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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11. För närvarande känner jag att mitt liv har mening:

väldigt lite mening	0	1	2	3	4	5	6	7	8	9	10	väldigt mycket mening
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DEL F Vårdkvalitet

Om du inte behövt fatta några viktiga beslut eller inte haft behov av hälso- och sjukvård under de senaste två (2) dygnen ber vi dig svara (frågorna 12-14) för de senaste gångerna du/ni gjorde det.

12. Under de senaste två dygnen (48 timmarna) har jag tyckt att beslut beträffande min närstående har fattats på ett bra sätt:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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13. Under de senaste två dygnen (48 timmarna) har vi fått hälso- och sjukvård när vi behövt det:

aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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14. Under de senaste två dygnen (48 timmarna) har kvalitén på den hälso- och sjukvård vi fått varit:

otillfredsställande	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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Fortsätt på nästa sida...

DEL G Relationer

15. Under de senaste två dygnen (48 timmarna) har jag känt att samspelet med min närstående som är sjuk varit:

mycket avslappnat	0	1	2	3	4	5	6	7	8	9	10	ansträngt
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16. Under de senaste två dygnen (48 timmarna) har jag på det stora hela känt att samspelet med de personer som är viktigast för mig varit:

mycket avslappnat	0	1	2	3	4	5	6	7	8	9	10	Mycket ansträngt
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DEL H Oro för ekonomi

17. Under de senaste två dygnen (48 timmarna) har min ekonomiska situation varit stressande:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

Tack för din medverkan!

Närståendes situation och behov av stöd

Enkät 2



Kodnummer: _____

Mottaget datum: _____

Instruktion till enkäten

Du deltar i forskningsstudien ” Personcenterat stöd till närstående inom palliativ vård – en intervention” och har tidigare besvarat en enkät. Vi skickar dig nu enkäten återigen för att förfölja studien och för att se om din situation har förändrats. Enkäten består av ett antal frågor och påståenden att ta ställning till och beräknas ta ca 20 minuter att besvara. För att resultatet ska bli så tillförlitligt som möjligt är det angeläget att du svarar så uppriktigt du kan på frågorna. Det är också angeläget att du försöker att besvara samtliga frågor. Enkäten består av några inledande frågor om dig och din livssituation samt frågor kring ditt behov av stöd, förberedelse för att vårda, din situation som närstående och livskvalitet. Enkäten kan besvaras i omgångar och du kan pausa när du behöver.

Har du frågor om forskningsstudien eller att fylla i enkäten är du välkommen att ta kontakt med Maria Norinder, se kontaktuppgifter nedan.

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Leg Mastersjuksköterska, Doktorand
Studieansvarig
Ersta Sköndal Bräcke högskola,
Institutionen för vårdvetenskap
E-post: maria.norinder@esh.se
Mobil: 076-6365072

Anette Alvariza
Leg sjuksköterska, Professor
Forskningsledare
Ersta Sköndal Bräcke högskola,
Institutionen för vårdvetenskap
E-post: anette.alvariza@esh.se
Mobil: 076-6365073

Inledande frågor

Dessa frågor handlar om dig och din livssituation. Försök om möjligt att besvara samtliga frågor.

1. Var vårdas din sjuka närstående just nu?

- ☐ Hemmet
- ☐ Palliativ vårdavdelning eller hospice
- ☐ Annan vårdavdelning
- ☐ Vård och omsorgsboende

2. Vilken sysselsättning har du för tillfället? Flera alternativ kan anges.

- ☐ Heltidsarbetande
- ☐ Deltidsarbetande
- ☐ Arbetssökande
- ☐ Sjukskriven
- ☐ Pensionär
- ☐ Studerande
- ☐ Annan: _____

3. Har du närståendepenning?

- ☐ Ja
- ☐ Nej

4. Har du för egen del sökt hälso- och sjukvård under de senaste 6 månaderna med anledning av din närståendes sjukdom?

- ☐ Nej
- ☐ Ja, 1–2 gånger
- ☐ Ja, 3–5 gånger
- ☐ Ja, fler än 5 gånger

5. Har du haft någon samtalskontakt med kurator, psykolog eller motsvarande med anledning av din närståendes sjukdom?

- ☐ Ja
☐ Nej

6. Har du från hälso- och sjukvården blivit erbjuden någon form av stöd under tiden som din närstående varit sjuk?

- ☐ Nej
☐ Ja, beskriv gärna:

Närståendes behov av stöd

Vi vill veta vad du behöver för att vara ett stöd till din närstående samt vilka behov av stöd du har för din egen skull. Kryssa för det alternativ som bäst stämmer överens med dina behov i nuläget.

	Behöver du mer stöd med...	Nej	Lite mer	Ganska mycket mer	Väldigt mycket mer
1	..att förstå din närståendes sjukdom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	..att få tid för dig själv under dagen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	..att hantera din närståendes symtom, inklusive att ge medicin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	..dina ekonomiska, juridiska eller arbetsrelaterade frågor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	..att hjälpa din närstående med personlig vård och omsorg (tex påklädning, hygien, toalettbesök)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	..att hantera dina egna känslor och oro?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	..att veta vem du kan kontakta om du är bekymrad för din närstående (dag som natt)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	..att sköta din egen hälsa (fysiska problem)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	.. hjälpmedel för att underlätta vården och omsorgen om din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	..din tro, livssyn eller existentiella/andliga funderingar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	..att prata med din närstående om hans eller hennes sjukdom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	..praktisk hjälp i hemmet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	..att få veta vad du kan förvänta dig för dig och din närstående i framtiden?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	..att få vila från vård och omsorgsansvar under natten?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	..något annat (vänligen beskriv här)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Förberedelse för att vårda en närstående

Följande frågor handlar om hur förberedd du känner dig för att vårda din närstående. 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
1	Hur väl förberedd tror du att du är för att tillgodose din närståendes fysiska behov?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Hur väl förberedd tror du att du är för att möta din närståendes känslomässiga behov?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Hur väl förberedd tror du att du är för att identifiera hjälpbehov hos din närstående och att hitta lösningar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Hur väl förberedd tror du att du är inför den påfrestning som vårdandet medför?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Hur väl förberedd tror du att du är för att göra vårdandet så bra som möjligt för både dig själv och din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Hur väl förberedd tror du att du är på att hantera akuta situationer som rör din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Hur väl förberedd tror du att du är för att hitta hjälp och information du behöver från hälso- och sjukvården?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Generellt sett, hur väl förberedd tror du att du är för att vårda din närstående?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Din situation som närstående

Följande frågor handlar om hur du ser på din situation som anhörig. Besvara varje fråga genom att sätta ett kryss i den ruta som bäst överensstämmer med dina upplevelser.

		Nej, inte alls	Nej, knappast	Ja, i viss mån	Ja, i hög grad
1	Känner du dig trött och utarbetad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Känner du dig ensam och isolerad pga din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Tycker du att du får ta för mycket ansvar för din anhöriges väl och ve?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Känns det ibland som om du skulle vilja fly undan hela den situation du befinner dig i?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Ställs du inför rent praktiska problem i vården som du tycker är svåra att lösa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Kan du bli sårad och arg på din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Tycker du att din hälsa har blivit lidande pga att du tagit hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Har din anhöriges problem lett till att umgänget med andra, t ex släkt och vänner, minskat för dig?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Finns det något i din anhöriges bostad som gör det besvärligt att ta hand om honom eller henne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Känner du dig bunden av din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Känner du dig besvårad av din anhöriges beteende?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Leder din anhöriges problem till att du inte kan göra det du hade tänkt göra vid denna tid i livet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Tycker du att det är fysiskt påfrestande för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14	Tycker du att din anhörige tar så mycket tid att du inte får tillräckligt med tid för dig själv?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Oroar du dig över att du inte ska kunna ta hand om din anhörige på rätt sätt?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Kan du ibland skämmas över din anhöriges uppförande?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Finns det något i omgivningen runt din anhöriges hem som gör det besvärligt att ta hand om honom eller henne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Har det inneburit någon ekonomisk uppoffring för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Tycker du att det är psykiskt påfrestande för dig att ta hand om din anhörige?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Har du ibland en känsla av att livet behandlat dig orättvist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Hade du tänkt dig att livet skulle vara annorlunda i den ålder du är i nu?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Undviker du att bjuda hem vänner och bekanta pga din anhöriges problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Livskvalitet

Formuläret innehåller en rad påståenden som vart och ett följs av två motsatta svar. De utgör ytterligheter på en skala från noll till tio. Ringa in den siffra som stämmer bäst för dig. Det finns inga svar som är rätt eller fel, men det är viktigt att du besvarar frågorna så ärligt som möjligt.

EXEMPEL:

Jag är hungrig:

inte alls	0	1	2	3	4	5	6	7	8	9	10	extremt
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- Om du inte är det minsta hungrig ringar du in 0.
- Om du är lite hungrig (som när du precis har ätit, men har fortfarande plats för dessert), ringar du in 1, 2, eller 3.
- Om du är ganska hungrig (som när det snart är dags att äta), ringar du in 4, 5, eller 6.
- Om du är väldigt hungrig (som när du inte ätit på hela dagen), ringar du in 7, 8, eller 9.
- Om du är extremt hungrig, ringar du in 10

START

Var vänlig och besvara frågorna utifrån hur du har känt **DE SENASTE TVÅ (2) DYGNEN**.

DEL A **Allmän livskvalitet**

A. Om jag ser till alla delar i mitt liv (till exempel fysiskt, emotionellt, socialt, spirituellt och ekonomiskt) tycker jag att min livskvalitet under de senaste två dygnen (48 timmarna) har varit:

mycket dålig	0	1	2	3	4	5	6	7	8	9	10	utmärkt
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Fortsätt på nästa sida...

DEL B Omgivning

1. Under de senaste två dygnen (48 timmarna) har jag varit nöjd med den plats där min närstående vårdas (hem, sjukhus, annat):

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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2. Under de senaste två dygnen (48 timmarna) har jag haft den avskildhet jag önskat:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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DEL C Din närståendes tillstånd

3. Under de senaste två dygnen (48 timmarna) har jag varit påtagligt orolig över min närståendes tillstånd:

sällan	0	1	2	3	4	5	6	7	8	9	10	alltid
---------------	---	---	---	---	---	---	---	---	---	---	----	---------------

DEL D Ditt eget tillstånd

4. Under de senaste två dygnen (48 timmarna) har graden av kontroll jag haft över mitt liv:

inte varit något problem	0	1	2	3	4	5	6	7	8	9	10	varit ett enormt stort problem
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Fortsätt på nästa sida...

5. Under de senaste två dygnen (48 timmarna) har jag haft tid att ta hand om mig själv:

aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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6. Under de senaste två dygnen (48 timmarna) har jag kunnat tänka klart:

sällan	0	1	2	3	4	5	6	7	8	9	10	alltid
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7. Under de senaste två dygnen (48 timmarna) har jag fysiskt mått:

extremt dåligt	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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8. Under de senaste två dygnen (48 timmarna) har jag känslomässigt mått:

extremt dåligt	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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DELE Ditt perspektiv

9. Att kunna ta hand om eller vara sällskap åt min närstående som är sjuk har under de senaste två dygnen (48 timmarna) fått mig att må bra:

sällan eller aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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Fortsätt på nästa sida...

10. Under de senaste två dygnen (48 timmarna) har min livssyn, tro eller andlighet varit till tröst:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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11. För närvarande känner jag att mitt liv har mening:

väldigt lite mening	0	1	2	3	4	5	6	7	8	9	10	väldigt mycket mening
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DEL F Vårdkvalitet

Om du inte behövt fatta några viktiga beslut eller inte haft behov av hälso- och sjukvård under de senaste två (2) dygnen ber vi dig svara (frågorna 12-14) för de senaste gångerna du/ni gjorde det.

12. Under de senaste två dygnen (48 timmarna) har jag tyckt att beslut beträffande min närstående har fattats på ett bra sätt:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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13. Under de senaste två dygnen (48 timmarna) har vi fått hälso- och sjukvård när vi behövt det:

aldrig	0	1	2	3	4	5	6	7	8	9	10	alltid
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14. Under de senaste två dygnen (48 timmarna) har kvalitén på den hälso- och sjukvård vi fått varit:

otillfredsställande	0	1	2	3	4	5	6	7	8	9	10	extremt bra
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Fortsätt på nästa sida...

DEL G Relationer

15. Under de senaste två dygnen (48 timmarna) har jag känt att samspelet med min närstående som är sjuk varit:

mycket avslappnat	0	1	2	3	4	5	6	7	8	9	10	ansträngt
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16. Under de senaste två dygnen (48 timmarna) har jag på det stora hela känt att samspelet med de personer som är viktigast för mig varit:

mycket avslappnat	0	1	2	3	4	5	6	7	8	9	10	Mycket ansträngt
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DEL H Oro för ekonomi

17. Under de senaste två dygnen (48 timmarna) har min ekonomiska situation varit stressande:

inte alls	0	1	2	3	4	5	6	7	8	9	10	helt och hållet
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[illegible]

☐ Ja
☐ Nej

Tack för din medverkan!

Intervjuguide studie I

Intervjuerna inleds med en kort presentation av frågeformuläret och hur intervjun är tänkt att gå till. Deltagarna ombeds att tänka högt då denne besvarar formuläret. Frågor ställs allteftersom och deltagaren får möjlighet till att utveckla sina tankar. Efter att formuläret fyllts i ställs frågor från intervjuguiden. Samtalet spelas in.

Hur uppfattade du frågeformuläret som helhet?

Hur uppfattar du formuläret gällande antal frågor och tiden att fylla i formuläret?

Är det någon fråga som borde ha ställts på ett annat sätt? Kan du beskriva?

Hur uppfattade du svarskategorierna?

Om det är det någon fråga du saknar rörande din situation och dina behov av stöd, kan du berätta hur du tänker?

Om du uppfattar någon av frågorna som överflödiga, kan du motivera varför?

Hur ser du att frågeformuläret skulle kunna användas i vården?

Hur ser du på att fylla i formuläret i din kontakt med vården?

Hur ser du på att fylls i formuläret vid upprepade tillfällen för att identifiera ditt behov av stöd?

Vad ser du för fördelar med att använda formuläret?

Vad ser du för nackdelar?

Något annat du vill tillägga om frågeformuläret?

Intervjuguide studie III

Intervju 1

På vilket sätt tycker du att stöd till närstående ingår i ditt arbete och ansvar?

Hur brukar du arbeta för att identifiera och möta närståendes behov av stöd?

Varför vill ni förändra hur ni arbetar med stöd till närstående?

Vad kände du till om interventionen Ditt behov av stöd sedan tidigare?

Vilka förväntningar hade du?

Vilka möjligheter och utmaningar såg du med interventionen Ditt behov av stöd?

Hur gick det till när ni gick igenom utbildningen?

Kan du beskriva vad som var bra och mindre bra med utbildningen?

På vilket sätt upplever du utbildningen kan vara till hjälp inför arbetet med Ditt behov av stöd?

I och med Covid-19 gjordes utbildningen digital, vilka för och nackdelar var det med det?

På vilket sätt skiljer sig arbetssättet med interventionen Ditt behov av stöd från hur du tidigare arbetat med stöd till närstående?

Är det något du vill berätta som vi inte har pratat om idag?

Intervju 2

Hur resonerade du kring vilka du skulle tillfråga om deltagande?

Beskriv hur du har arbetat med Ditt behov av stöd?

Hur gick samtalen till?

Hur upplevde du det var att genomföra samtalen?

Kan du berätta lite om dina erfarenheter av samtalen?

Hur har du och närstående diskuterat angående andra resurser runt dem som de kan få stöd av?

Hur gjorde du för att underlätta för den närstående så att hen kunde reflektera och prioritera kring sina behov av stöd?

Kan du beskriva hur ni upprättade handlingsplanen?

Vilka är de vanligaste svårigheterna med interventionen Ditt behov av stöd enligt din erfarenhet?

Vad skulle kunna hjälpa till att lösa dessa svårigheter?

Hur har det skilt sig och vad har varit bra med att arbeta med Ditt behov av stöd tillskillnad från ert tidigare stöd till närstående?

Hur upplevde du att interventionen Ditt behov av stöd gick att integrera i ditt arbete?

Vad tänker du kring interventionen i relation till övrigt stöd till närstående i det dagliga arbetet?

Hur har arbetssättet tagits emot av närstående?

Hur tror du att detta arbetssätt påverkar relationen mellan dig och den närstående?

Kan du berätta vad som är viktigt att tänka på för andra enheter som vill starta upp och att arbeta med interventionen Ditt behov av stöd?

Är det något du vill berätta som vi inte har pratat om idag?

Intervjuguide studie V

Kan du berätta hur du tänkte när du fick frågan om att delta i det här forskningsprojekt?

Berätta gärna lite om din situation som närstående och det stöd du har omkring dig?

Kan du berätta om ditt samtal med sjuksköterskan som ni hade utifrån samtalsunderlaget Ditt behov av stöd?

Hur upplevde du samtalet?

Vad är bra och mindre bra med att det fanns ett samtalsunderlag med frågor att utgå från som du/ni kunde reflektera kring?

Upplever du att samtalet varit till hjälp för dig att reflektera kring det stöd du behöver och i så fall på vilket sätt?

Väckte det några nya tankar hos dig?

Kan du berätta om vilket stöd som du mest behöver?

Kan du berätta hur ni använde handlingsplanen?

Kan du berätta om stödåtgärder som hjälpt dig?

Hur tycker du att detta sätt att samtala kring dina stödbehov fungerade?

Är det något du vill berätta som inte kommit upp i intervjun idag?

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A person-centred approach to support family caregivers in specialised home care

The Carer Support Needs Assessment Tool Intervention

This thesis reports results from the Carer Support Needs Assessment Tool Intervention (CSNAT-I) among Swedish family caregivers and registered nurses in the context of specialised home care. The CSNAT-I led to a significant increase in family caregivers' preparedness for caregiving and a slight improvement in caregiver burden and quality of life. Nurses' everyday clinical practice changed in relation to supporting family caregivers through training and use of CSNAT-I. Nurses felt more secure in working in collaboration with family caregivers and their support became more person-centred. Family caregivers appreciated the CSNAT-I as it promoted co-created conversations with a nurse about their support needs and solutions. This thesis gives further weight to the importance of addressing family caregivers' support needs as a part of nursing.



Maria Norinder is a registered nurse with a Degree of Master of Science in Nursing with Specialisation in Palliative Care and has comprehensive experience working in both specialist home- and inpatient care. She is employed at Marie Cederschiöld University as a lecturer, teaching nursing students in palliative care at the Department of Caring Sciences.

Marie Cederschiöld University has third-cycle courses and a PhD programme within the field The Individual in the Welfare Society, with currently two third-cycle subject areas, Palliative care and Social welfare and the civil society. The area frames a field of knowledge in which both the individual in palliative care and social welfare as well as societal interests and conditions are



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