

Mealtimes in palliative care contexts

PERSPECTIVES OF PATIENTS,
PARTNERS, AND REGISTERED NURSES



Viktoria Wallin



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nurses

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Marie Cederschiöld University

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Abstract

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Viktoria Wallin

The overall aim was to explore patients', partners', and registered nurses' (RNs) experiences of mealtimes in palliative care contexts. Qualitative (studies I, II, IV and V) and quantitative (study IV) study designs were used to explore the experiences of mealtimes in palliative care from various perspectives. Three interview studies (studies I, II, V), a mixed-method systematic review (study III), and a cross-sectional study (study IV), were conducted.

The findings showed that patient's appreciated support that resembled their needs and wishes during hampered eating. Being encouraged to eat could both reduce and induce distress and well-being, social life was affected. Food and eating had existential loading (I, III). The partners described how they tried to support their dying partner by striving to maintain ordinariness around food and mealtimes, as well as finding new ways to support eating (II). RNs highlighted that food and mealtimes in palliative care cause psychosocial distress for patients and their families. Exploration implies that RNs perceptions align with patients' and families', indicating awareness of the challenges that patients and families face (IV). RNs in palliative care are well prepared to support patients with eating challenges related to physical problems, but might be less prepared to support existential, psychological, and social needs (V).

In conclusion, efforts to minimize the distress that patients and families experience in relation to mealtimes in palliative care are required. An area in need of further development is how to support RNs in communicating about food and mealtimes in palliative care to support patients', partners', and families' well-being at the patient's end-of-life.

Keywords: End-of-life, Family, Food, Mealtimes, Nursing, Nutrition, Palliative care, Partner, Patient perspectives, Registered nurses

List of Papers

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

- I. Wallin V, Carlander I, Sandman P-O, Håkanson C (2014). Meanings of eating deficiencies to people admitted to palliative home care, *Palliative and Supportive Care*. 13 (5), 1231-1239.
doi:10.1017/S1478951514001199*
- II. Wallin V, Carlander I, Sandman P-O, Ternstedt B-M, Håkanson C (2013). Maintaining ordinariness around food: partners' experiences of everyday life with a dying person. *Journal of Clinical Nursing*. 23 (19-20), 2748-2756. doi:10.1111/jocn.12518*
- III. Wallin V, Omerov P, Mattsson E, Klarare A (2021). Experiences of food and mealtime from the perspective of persons having chronic life-limiting disease: a mixed method systematic review, *Journal of Advanced Nursing*. 77 4400– 4413. doi:10.1111/jan.14927
- IV. Wallin V, Rosenblad A, Lundh-Hagelin C, Mattsson E, Klarare A, Registered nurses' perceptions of food and mealtimes in palliative care: a cross-sectional study, *in manuscript*
- V. Wallin V, Mattsson E, Omerov P, Klarare A (2021) Caring for patients with eating deficiencies in palliative care – registered nurses' experiences: a qualitative study, *Journal of Clinical Nursing*.
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*) The articles from medicine licentiate thesis (Wallin, 2015). Supervisors: Cecilia Håkanson, Ida Carlander, Per-Olof Sandman, Britt-Marie Ternstedt

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Preface

During my clinical experience as a registered nurse (RN), I met patients and their families at Ersta Hospital. I had an interest in nutrition and was given the opportunity to work full time focusing on patient nutrition. As a RN specialised in nutrition, 'nutrition nurse', I cared for patients where per oral nutrition could not fulfil their nutritional needs, and I also cared for patients with chronic life-limiting illness in situations where nutrition was obviously sustaining life. In addition, I acted as a consultant for the hospice and the specialist palliative home care services when healthcare professionals thought it could be helpful for patients to be referred to me for help. If artificial nutrition was provided, I could hopefully provide some practical advice, such as technical changes, but optimizing nutrition intake was not a goal. Sometimes, when patients knew my focus area, they would choose to talk openly, and shared thoughts about food and eating earlier in life, as well as when death was closing in.

Being given the opportunity to become a PhD student meant continuing to learn more about challenging situations when life is about to end, and mealtimes and eating are not the same as before. I believe we need to continue learning, and I am grateful to have been given the possibility to learn and contribute.

1. Background

1.1. Mealtimes in society

Mealtimes and eating are central to human well-being, both with regard to physiological aspects of human life and social interactions. Mealtimes are an important family practice (Morgan, 2013); it is mainly within families that eating habits are formed, and food preferences and identities are developed and experienced (Kaufmann & Macey, 2010). Mealtimes, eating habits and food choices are linked to identity, the image people want to convey to others (Kaplan, 2020), and how people regard each other (Morgan, 2013). During shared mealtimes, people communicate with each other and often experience social bonding (Baumeister & Leary, 2007). People are likely to eat more when eating together than when eating alone (Higgs, 2015). In social contexts, people influence each other as they communicate a guide or norm for appropriate eating behaviour. Social norms are set by peers, thereby influencing both eating and food choices (Valentine, 1999). Social support has been identified as a major factor in influencing diet quality (Ferranti et al., 2013). Desire for social acceptance, and not wanting to be different, may be an underlying cause of the social matching of food intake (Robinson et al., 2011). Conversations held when something is being eaten are perceived as better and more pleasant compared to conversations when nothing is being eaten (Louge, 2015).

Individuals give consideration to eating habits, and on a societal level, considerations are made in relation to science and medicine with the aim of promoting health. There have been recommendations made, especially during the 1980s with the development of the 'good eater' and adherence to food choices based on nutritional principles, with the family being the principal target of policies, strategies or campaigns, for example in schools and primary healthcare for children (Coveney, 2006). Throughout the social body, advice and knowledge based on a medical paradigm was dispersed and nutrition was interpreted accordingly (Morgan, 2004). Furthermore, commercial interests are strong regarding food trends, norms and items. Within the welfare society, the triangle of family, market and state represents the three main actors in the area

of food and mealtimes (Morgan, 2013). Healthy eating can be an ongoing behavioral project that requires the continued engagement of purposeful and planned processes (McCarthy et al., 2017). However, from a commercial perspective, food and products are sold and branded with connotations of identity (Lounge, 2015).

Eating a meal together has been described as a test, since sharing a meal may reveal the true state of relationships (Lounge, 2015). For families, the dining table is where you gather after a day away from home, and the dining table is sometimes called the 'family arena' where interactions take place (Scott, 2009). Contradictory to this, reports show that in contemporary society, people more often eat on the run, and families' hectic lives may result in not eating together. When family structures are disrupted, for example by life-limiting illness, so are the everyday practices around mealtimes (Morgan, 2013).

In this thesis, meal and mealtimes are used in their widest sense, including everything that is eaten and events where something is eaten or drank. In dictionaries the terms meal and mealtimes are defined as occasions when food is eaten that occur regularly during a day (Cambridge Dictionary, 2021). Definitions can also include the act of what occurs around the mealtimes, i.e. the planning and preparation. A wide definition was found suitable in this thesis as experiences related to mealtimes and eating were sought, irrespective of scope. No boundaries of what qualifies as mealtimes and eating were therefore set.

1.2. Palliative care

According to the World Health Organization (WHO, 2020), palliative care is an approach that aims to improve the well-being of patients and families encountering potential difficulties associated with chronic, life-limiting illness, regardless of diagnosis. An integration of physical, psychological, social and existential care interventions is emphasized, and the focus is on early detection and relief of symptoms. The philosophy of palliative care includes the family of the dying person, and family members or partners are seen as part of the care team.

Today, the expectation is that a palliative care approach is implemented by healthcare professionals early in the disease trajectory of chronic life-limiting illnesses, as well as near the end-of-life, irrespective of care setting.

Contemporary palliative care philosophies include concepts such as health-promoting palliative care (Rumbold & Grindrod, 2015), life-prolonging palliative care (Sercu et al., 2018) and life-enhancing care (MacArtney et al., 2017) that are used as descriptors during different stages of the disease trajectory. A closely related concept is chronic life-limiting disease, which includes chronic conditions where death is the likely outcome, according to the International Association for Hospice & Palliative Care (IAHPC, 2019). The term end-of-life care is frequently used, although there is no consensus regarding its definition (Gysels et al., 2013). The literature uses a diversity of definitions and end-of-life has been used in relation to the last days in life, the dying phase, and sometimes the term palliative care has been used synonymously with end-of-life care (Gysels et al., 2013; Sercu et al., 2018). End-of-life care still remains an important part of palliative care, and for many the wording has strong connotations with dying and death (Ryan et al., 2020).

In general, the concept of palliative care in Sweden also has associations with end-of-life care and knowledge about palliative care in society is limited, hence, predominantly taken to mean care shortly before death (Westerlund et al., 2018). The limited awareness and perceptions of the general public stem from a view of palliative care as being exclusively about dying and death, which may contribute to potential difficulties in comprehending and making sense of receiving palliative care when it is warranted (Öhlén et al., 2013). Ultimately, this may result in perpetuating fear and uncertainty regarding palliative care for patients and families (Gardiner et al., 2011).

Palliative care can be described as a care approach that should be gradually introduced when cure is not possible (WHO, 2020). A palliative care approach aims to relieve symptoms and enhance well-being; death is embraced as a normal process and the care approach is characterized by embracing holistic perspectives of being human. The organisation and scope of palliative care can be either general or specialised. The provision of general palliative care requires basic palliative care knowledge and skills, and it can be provided in settings for patients with diseases that will eventually lead to death, but where cure and

treatment of the disease are the main focus. Specialised palliative care is provided by multi-professional teams with expertise regarding complex palliative care needs. The care can be provided in hospital settings, long-term care or in the patients' homes, and given by regular care providers receiving support from palliative care consultants (Radbruch & Payne, 2009).

While working on this thesis, the definition of palliative care has evolved and broadened, and concepts used in palliative care are continuously being refined and discussed. The original definition from 2002 by the World Health Organization (2002) has been criticized for being narrow since it is aimed at younger people who die of cancer, while people who die of other diseases or conditions, such as cardiovascular, liver or kidney diseases or dementia, can also be in need of palliative care (Connor & Sepulveda Bermedo, 2014). The updated definition does not indicate any specific diagnosis groups or contexts, making it applicable for any context, however, the inclusion of cancer populations was considered natural (WHO, 2020). Despite ambitions to widen the application of palliative care to all diagnoses where there is a need, specialised palliative care is still predominantly used to apply to people with incurable cancer (Sawatzky et al., 2016; Walter, 2017). According to a Swedish review, research on palliative care has increased and a greater focus on people who die from diagnoses other than cancer has been identified (Henoch et al., 2016), indicating increasing interest in expanding the scope of palliative care provision. At least from a theoretical point of view, the use of a palliative care approach is emphasized early in the disease trajectory of chronic life-limiting illnesses, irrespective of care setting (WHO, 2020). However, there is considerable room for improvement to make this a practical reality, both nationally and internationally.

In this thesis palliative care is used and understood according to the latest updated definition from the WHO (WHO, 2020). Furthermore, the wording end-of-life care is used to underline when the period close to death is in focus.

1.2.1. Palliative care in Sweden

In Sweden, most of the palliative care is provided outside of hospitals, either by primary care or specialist home care services (Håkanson et al., 2015). Potential inequalities in Sweden regarding the availability and/or utilization of healthcare services at the end of life have been emphasised (National Board of Health and

Welfare, 2016). Based on cause of death, nearly half of the people who died (45 percent) in 2012 would most likely have benefitted from palliative care interventions (Håkanson et al., 2015).

Variables, such as location, age and diagnosis, influence care at the end of life. Geographical location matters since healthcare in Sweden is governed at regional level giving rise to regional differences in care priorities, e.g. specialist care is not distributed equally on a national level (National Board of Health and Welfare, 2016). Higher age has been associated with lower access to palliative care in general, lower access to specialised palliative care, and insufficient pain relief. Furthermore, higher age was associated with a lack of communication with patients' families about death and dying (Lindskog et al., 2015). Studies have also shown that diagnosis is linked to access to palliative care and patients with diseases other than cancer, such as COPD (Chronic Obstructive Pulmonary Disease) (Ahmadi et al., 2015) or stroke (Eriksson et al., 2016), are less likely to be admitted to specialised palliative care and thereby risk receiving less than optimal symptom relief and communication about end-of-life issues.

The development of palliative care services worldwide has resulted in the availability of palliative care services in most countries, although to varying extents (Centeno et al., 2016); globally, palliative care is not available to everyone. Many individuals who would benefit from palliative care either do not receive it at all or receive it solely at the end of life. In Sweden, as in many other Western European countries, mapping has indicated significantly improved access to palliative care services. The areas that are still in need of development to meet the palliative care needs of the population are inpatient palliative care services, home care teams, and hospital support teams. Another factor is that life expectancy is increasing in Sweden (Beureau of Labour Statistics 2020). Together, improved living conditions and more highly developed care and medical treatments contribute to more people living longer with chronic diseases, and life expectancy is therefore expected to continue to increase (United Nations Population Division, 2019).

1.3. Death in society

Sweden has gone through changes in the way illness, health and dying are understood in society, from illness and death being something managed in people's homes to a societal change comprising hospitalization and medicalization of illness and death, consequently managed by professionals in hospitals and care homes. This represents a shift from a tradition where religion and the priest had a prominent role, to a society where the doctor and medical science became an authority (Walter, 2012). People started dying in hospitals and this meant that death was not as visible in society compared to before. In the past decades, people's autonomy has been emphasized in Sweden and this might be one reason contributing to the reduction in hospital beds in acute care settings (OECD, 2019), ultimately leading to increased outpatient care. At the same time, a parallel process has been ongoing with reforms and policies to gradually enable people to be cared for in their own homes (National Board of Health and Welfare, 2015). With this shift, dying at home became a realistic choice. Death has become more present in society, for example it is generalized in movies, which contributes to raised awareness of death, but seldom in a way that is close to the realities of dying and death (Walter, 2017). Dying and death have become individualised projects, for example through being shared on social media and by writing books, and people make plans for how they want to die. In effect, people design their deaths to a greater extent, with farewell parties or preparations of what to wear in death (Gellie et al., 2014). Even though death is not as hidden as it might have been in the latter part of the 20th century, there still seems to be a dominant paradigm where curing is the goal and incurable diseases and death are seen as a failure (Gellie et al., 2014; Walter, 2012).

Death as a natural part of life and a condition of life, needs to be further highlighted. In the late 1960s, this was emphasized by Kübler-Ross (2014), yet there is still continued trust in a medical cure and a sense of fighting death, whereby the dying process is associated with failure. This may be one obstacle to achieving peace in death (Gellie et al., 2014). The Swedish welfare system is expected to provide adequate help if health or social care is needed, and inherent in this are expectations of receiving external help from outside the family that is provided by the state. In Sweden, the individual's freedom of choice is prominent (Trägårdh, 2010). This may be questioned since prioritizing

the patient's or the families' choice, when they stand in opposition, is challenging. Furthermore, the extent of autonomy and choice regarding the provision of health and social care to different stakeholders is tricky since all preferences cannot be satisfied simultaneously. For instance, in palliative care, the families' abilities and possibilities to care for a family member vary. A common conundrum is when a patient adamantly wants to be cared for at home, but the partner does not have either the energy or resources to do so, consequently requesting transfer to a hospital or a hospice. Furthermore, the age of an ill person and the place where they live also influences care provision during the last period of life (Håkanson et al., 2015). It is often registered nurses (RNs) who are responsible for care planning and practical care provision in palliative care settings, but it is problematic that there are fewer RNs in nursing homes than in other care contexts. Community home care is mainly provided by persons with shorter non-university educations.

1.4. Being a person with palliative care needs and eating deficiencies

The situation of being confronted with one's own mortality is demanding, where distress and anxiety are common (Kübler-Ross, 2014). Having palliative care needs entails a gradually increasing dependency on others and includes changes that have to be adapted to (Candela et al., 2020). The person's increasing dependence on family members and limitations in performance of activities of daily life can make them feel responsible for causing distress to the family (Tishelman et al., 2010). Needing care from others may evoke feelings of being a burden for others, and experiences of guilt and frustration are common (McPherson et al., 2007). When a person must rely on others during mealtimes and eating, they can experience that their autonomy has been reduced or lost (Plow & Finlayson, 2012). On the other hand, knowing that life is about to end in the near future could also heighten their appreciation for small, familiar things in everyday life, things that were earlier taken for granted (Johansson-Melin et al., 2006). Living with the awareness of impending death entails existing in a movement between existential uncertainty and everyday life situations, where living in the present is a strategy for endurance (Karlsson et al., 2014). The

meaning of interactions with others is recurrently emphasized, relationships with family and friends are highly valuable and may provide a link to life as it used to be before illness (Johansson-Melin et al., 2006; Sand et al., 2009).

Living with the symptoms and signs of hampered eating, or eating deficiencies, is common during the illness trajectory, and among the symptoms most frequently described are loss of appetite and weight loss (Potter et al., 2003; Solheim et al., 2014; Tan & Fearon, 2008). These are often related to cancer cachexia, which is a wasting syndrome seen among persons with cancer (Arends, 2018; Fearon et al., 2011). Cachexia induces metabolic muscle breakdown and hampers the person's ability to assimilate food. It is also common in diagnoses other than cancer (von Haehling et al., 2016) and several conditions themselves can cause eating deficiencies, for example chronic obstructive pulmonary disease or heart failure. In this thesis, *eating deficiencies* is used as an overarching term that includes the various illness-related signs and symptoms of hampered eating. The concept implies a lack of eating, but also encompasses the complex challenges around eating and mealtimes.

Several studies show that weight loss is stressful and that failing in their efforts to gain weight involves emotional tension for patients (Del Río et al., 2012; Oberholzer et al., 2013). Patients may experience anger or sadness due to their reduced ability to eat (Ellis, 2018; Lize et al., 2021). Conflicts around mealtimes can be experienced (Ellis, 2018; Oberholzer et al., 2013) sometimes as being worse than the eating challenges themselves (Shragge et al., 2006), and support from healthcare professionals with difficulties concerning food has been described as limited (Reid et al., 2010). Today, many people with chronic life-limiting illness are living longer than previously, and with the worldwide trajectory of aging populations (Cristea et al., 2020), conditions with multi-morbidity and frailty are increasing (Vetrano et al., 2018). There is therefore an increased need for palliative care incorporating an understanding and awareness of aspects related to mealtimes.

1.5. Being partner and family to a person with palliative care needs and eating deficiencies

The illness trajectory and dying process inevitably impacts everyday life for dying persons and their families (Grande et al., 2009; Sowerbutts et al., 2019). Family members of a person with palliative care needs often take on care responsibilities, and the scope of such responsibilities increases as the illness progresses. It is often considered natural to take a caring role (Linderholm & Friedrichsen, 2010); however, experiences of pressure and expectations to become a family caregiver and feelings of obligation have been described (Wilson et al., 2018). Family caregivers may wish to be seen and acknowledged for their efforts since, in general, the focus is on the dying person (Linderholm & Friedrichsen, 2010). Support given to family caregivers around food and mealtimes has been found valuable and yet is sometimes missed (Amano et al., 2019; Del Río et al., 2012). People often want to live life as ordinarily as possible until death and being cared for at home facilitates the maintenance of habits and customs of everyday life. Ordinarity is highly valued when the death of a family member is closing in, and being at home together can thus be experienced as important (Hutchinson & Van Wissen, 2017), even though the meaning of home changes as medical devices move into the home and the previously safe and familiar environment becomes a medical environment (Sowerbutts et al., 2019). Caring for a family member who is dying has been described as both rewarding and burdensome (Martín et al., 2016); however, the responsibilities can be challenging and may lead to ill health for the family caregivers (Funk et al., 2010). Compared to the general population, family caregivers have higher levels of anxiety and depression (Götze et al., 2018). Families of persons with life-limiting illness put their own lives on hold in order to be available for the patient's needs. They face, and are expected to manage, the patient's uncertain future and impending death (McDonald et al., 2018). Existential concerns are often evoked and family members experience life's fragility in addition to their own mortality (Vachon, 2020).

Family in this thesis aligns with Wright and Leahey's (2013) definition where the concept of family is viewed in a systemic perspective. In this system, each member represents one part, and all members together are more than the sum of the parts (Wright & Leahey, 2013). Family is used broadly and is defined as a

social construction, where family members themselves outline who is part of the family. This is in contrast to earlier definitions where family was defined as blood relation or legal status, for example marriage.

As mentioned, eating deficiencies are common when living with life-limiting illness, especially as the illness trajectory progresses and death is closing in. Illness trajectories will, at some point, entail challenges in eating (Cooper et al., 2015), and family members will experience significant changes in the patient's oral intake at the end of life (Raijmakers et al., 2013). Families can feel obliged to support eating and may experience conflicts in the process (Weaver et al., 2022; Wheelwright et al., 2016). Seeing a loved ones' illness trajectory and decreasing body weight is distressing for families (Hilário & Augusto, 2021; Pettifer et al., 2019). In summary, given the central role mealtimes have in everyday life, issues related to mealtimes and eating can cause substantial distress for patients, partners and families (Del Río et al., 2012; Hopkinson, 2016; Lize et al., 2020).

1.6. Registered nurses caring for patients with palliative care needs and eating deficiencies

Everyday ethical nursing practice is guided by core responsibilities to alleviate suffering and to provide care that is respectful of human rights (ICN, 2012). Giving information and providing support to families are vital dimensions of palliative care (IAHPC, 2019; WHO, 2020). RNs meet patients and families with palliative care needs and independently provide palliative care according to the needs identified (Sekse et al., 2018). However, Larsen and Uhrenfeldt (2013) revealed a lack of professional assistance during mealtimes and insufficient guidance concerning how specific nutritional problems could be managed. Patients experiencing challenges with reduced intake of food and fluids during illness expect committed nursing care with regards to nutritional advice and assistance in meal-related situations (Larsen & Uhrenfeldt, 2013; Oberholzer et al., 2013).

RNs are independently responsible for clinical decisions to provide people with increased opportunities to improve their health, maintain or regain their health,

manage health problems, illness or disability, and also to achieve the best possible well-being and quality of life until death (Svensk sjuksköterskeförening, 2021). The importance of nutritional support is repeatedly stressed in the scientific literature (Cederholm et al., 2017; McClement, 2021; Zhao et al., 2021) and supporting food intake is a vital aspect of nursing. However, RNs experience challenging situations and ethical dilemmas regarding food and nutrition intake in palliative care; in particular with regards to artificial nutrition (Geppert et al., 2010; Jones, 2007), and in situations when worried families push a dying person to eat (Hopkinson, 2016). The medicalisation of care has also been highlighted and artificial nutrition, the administration of iv fluids and the use of feeding tubes to reduce family distress, have been described (Guérin, 2016). Decision-making concerning when to withdraw artificial nutrition is a challenge that is recurrently described (Blakely & Millward, 2007; Leheup et al., 2015).

Guidelines concerning nutrition in relation to, for example, cancer, non-surgical oncology, dementia, chronic intestinal failure and home parental nutrition are available (European society of Enteral and Parenteral Nutrition and Metabolism, 2021), but there are no specific guidelines for palliative care or end-of-life care. The ESPEN guidelines on ethical aspects of artificial nutrition and hydration (Druml et al., 2016) state that individual decisions are needed and ‘overall benefits’ should be valued in palliative care, i.e. possible treatment results, quality of life, psychological and existential well-being. The ESPEN guidelines on the definitions and terminology of clinical nutrition describe a similar focus, adding ‘palliative nutrition’ as a form of nutritional care and therapy provided to patients in the late phases of end-stage disease (Cederholm et al., 2017), focusing on improving quality of life. The recommendations underscore that, in early palliative care, proteins and nutrients should be provided in the most feasible way, whereas in later phases of illness, psychosocial support for both patients and relatives is a priority. To reduce stress around mealtimes, parenteral nutrition could be considered; however, assessments and weight control can add to stress and should be avoided. Guidelines regarding nutrition at the end of life are vague and it is not known whether medically assisted nutrition helps patients with palliative care needs to feel better or to live longer (Good et al., 2008; Good et al., 2014). A recent randomized controlled study showed that for

patients with palliative care needs, quality of life and survival were not improved by parenteral nutrition, and for patients with advanced cancer and cancer-related cachexia, it caused more serious side effects (Bouleuc et al., 2020). Neither is there any clear evidence concerning enteral feeding (Sánchez-Sánchez et al., 2021). Furthermore, conducting nutritional research in palliative care contexts is delicate; randomised controlled trials are sparse in the palliative context, evaluation of the harm and benefits of hydration and nutrition are challenging in light of the inherent complexities near the end of life (Good et al., 2014). Clinical practice in palliative care settings concerning the use of enteral and parenteral nutrition seems haphazard. A recent review emphasized RNs' responsibilities and possibilities as core members of the palliative care team in meeting patients' nutritional issues concerning food and mealtimes (Zhao et al., 2021). To achieve this, RNs need to be familiar with screening tools as well as how to identify the need for psychosocial support. However, RNs have been found to be uncertain about how to talk about issues with eating and what advice they should give to patients, partners and families (Dewey & Dean, 2007; Millar et al., 2013); in other words RNs feel uncertain about how to help (Scott et al., 2016). Considering the absence of evidence and practice guidelines, this is not surprising.

2. Rationale

In the Swedish welfare society, the healthcare system is expected to provide the care that is needed. Additionally, in Sweden, as in other western countries, an increasing number of people live longer with chronic life-limiting conditions, meaning that an increased need for palliative care is expected. Mealtimes and eating are central for human well-being, both considering the physiological aspects of human life and social interactions. Mealtimes are often cornerstones of family life and have links to identity. Living with life-limiting illness entails eating deficiencies, and eating patterns and mealtimes change, especially as the illness trajectory progresses and death is closing in. When everyday structures are disrupted, for example by a persons' life-limiting illness, so are the practices around mealtimes with the family. Given the central role mealtimes have in everyday life, issues related to mealtimes and challenges with eating can cause substantial distress for patients, partners and families. Supporting food intake is a vital aspect of nursing. However, RNs experience challenging situations and ethical dilemmas regarding food and nutritional intake in palliative care and also seem uncertain about how to talk about issues concerning food and mealtimes, and what advice they should give. The goal of all palliative care is to alleviate suffering, based on the needs of patients and family, and promote well-being up to the end of life. This also applies to challenges that are experienced related to mealtimes. An increased need for palliative care, incorporating an understanding and awareness of aspects regarding mealtimes and eating, is anticipated.

There is, therefore, a need for studies elucidating the phenomenon, i.e. mealtimes and eating in palliative care, from various perspectives to broaden and deepen knowledge for use in clinical practice. In this thesis, patients, partners and RNs are considered to have unique experiences and perspectives of care at the end of life, and can thereby be significant sources of experiential knowledge concerning mealtimes and eating in palliative care.

3. Aim

The overall aim of this thesis was to explore how mealtimes influenced daily life for patients and partners, as well as RNs' perspectives of mealtimes, in palliative care contexts.

3.1. Specific aims

The specific aims were to:

- explore the meanings of living with eating deficiencies at the end of life among people admitted to specialist palliative home care (study I).
- explore partners' experiences of everyday life in caring for a dying person with eating deficiencies at home (study II).
- describe and synthesise experiences of food and mealtimes from the perspective of patients with chronic life-limiting disease (study III).
- investigate RNs' perceptions of mealtimes in palliative care, including the clinical perspectives of patients and families. An additional aim was to investigate associations between socio-demographic variables and RNs' perceptions of food and mealtimes (study IV).
- explore RNs' experiences of caring for patients with eating deficiencies in palliative care (study V).

4. Methods

4.1. Context and design

The starting point for the present doctoral thesis was a thesis for a licentiate degree, *Food and mealtimes at the end of life – Patients' and partners' experiences of eating deficiencies* [*Mat och måltider vid livets slut – Patienter och närståendes erfarenheter av ättsvårigheter*] (Wallin, 2015).

In studies I and II from the licentiate project, experiences of eating deficiencies in everyday life from the perspectives of patients and partners were in focus. In the continuing PhD studies, broader and deeper perspectives regarding experiences of food and mealtimes from the perspectives of patients with chronic life-limiting disease were pursued. Studies describing patients' experiences had yet to be systematically reviewed and synthesised. A mixed-method systematic review was therefore performed, exploring how eating deficiencies affected patients' everyday lives, in order to contribute to clinically relevant knowledge and future research foci in palliative care (study III). Based on findings from the review, a study specific questionnaire for RNs was constructed, since they are key caregivers in palliative care (Kobleder et al., 2017). The questionnaire was used in an online survey about RNs' perceptions of food and mealtimes in palliative care (study IV). At the end of the survey, RNs were invited to participate in interviews to further explore their perspectives on food and mealtimes (study V). See Table 1 for an overview of the studies.

The design of the included studies was explorative and descriptive. Both qualitative (studies I, II, IV and V) and quantitative methods (study IV) were used to explore aspects of mealtimes in palliative care from various perspectives. When exploring a phenomenon relevant to healthcare, combining methods may contribute to a more comprehensive overview of the phenomenon (Polit & Beck, 2016). Study III was a mixed-method systematic review of the literature, aiming to describe and synthesize experiences of food and mealtimes from the perspectives of patients with chronic life-limiting disease. The mixed-method design was selected to allow findings from a diverse range of research methods

and to provide a breadth of perspectives with comprehensive understanding of the studied phenomenon (Noyes et al., 2019).

Table 1. Overview of studies.

Study	Design	Setting and sample	Data collection	Data analyses
I	Qualitative design	Specialist palliative home care Patients (n=12)	Repeated face-to-face interviews	Interpretive description
II	Qualitative design	Specialist palliative home care Partners (n=9) of a deceased person	Single face-to-face interviews	Interpretive description
III	A mixed-method systematic review	24 articles from UK (n=7), Canada (n=4), Sweden (n=4), USA (n=2), Australia (n=1), Brazil (n=1), China (n=1), Japan (n=1), New Zealand (n=1), Singapore (n=1) and Switzerland (n=1) including patients (n=1013) with chronic life-limiting disease, 83% in palliative care settings	Systematic database searches	Thematic analysis
IV	Quantitative design	Palliative care RNs (n=100)	Online survey	Descriptive statistics, linear regression analysis and deductive content analysis
V	Qualitative design	Palliative care RNs (n=19)	Single telephone interviews	Qualitative content analysis

Studies I, II, IV and V were conducted in Sweden, and studies I and II in specialist palliative home care. This is indicative of a somewhat unique or focused perspective within a palliative care context that is not available for everyone. In studies I and II, palliative care is provided by multi-professional

teams tasked with meeting complex palliative care needs throughout the illness trajectory approaching death.

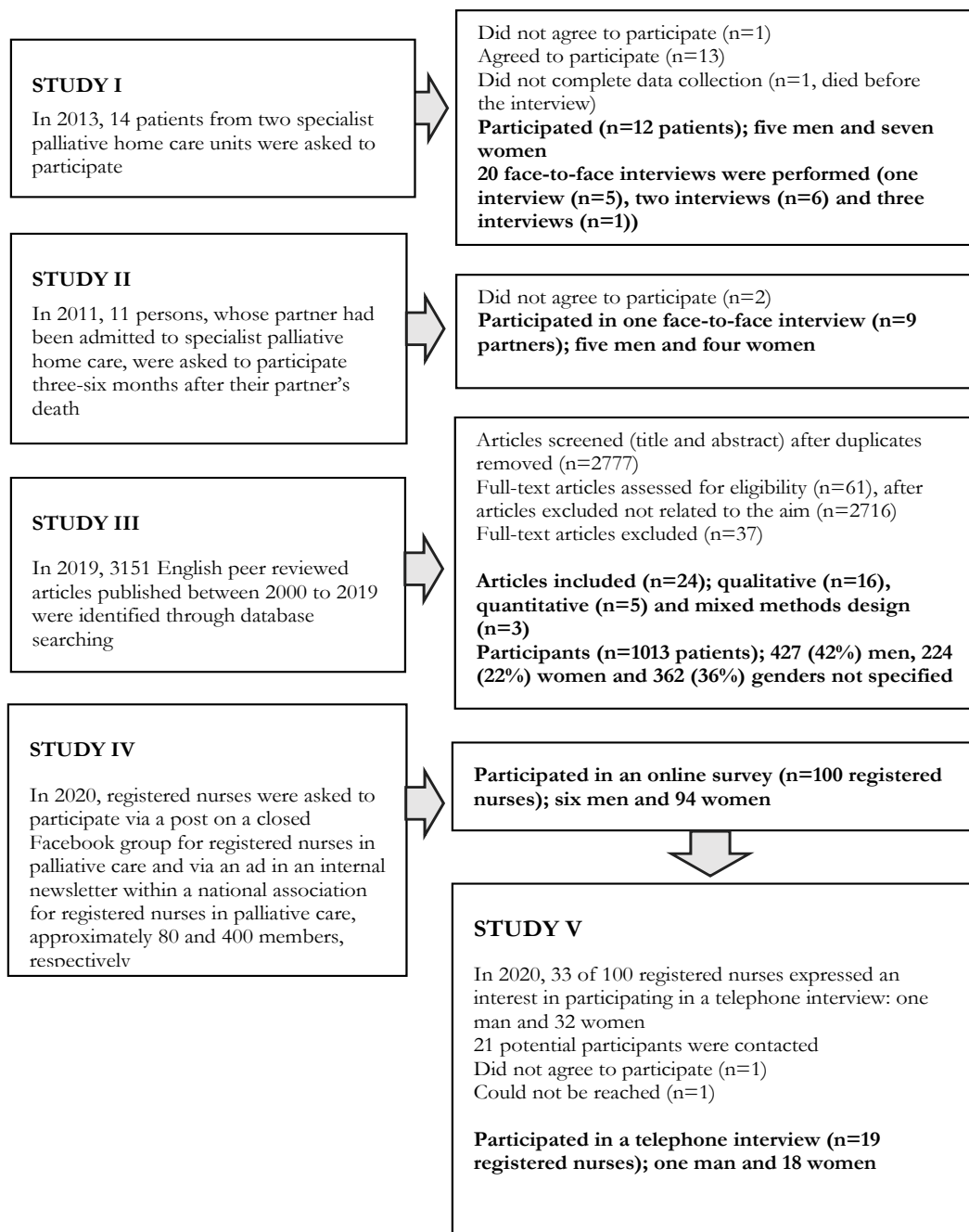
4.2. Participants and studies

See Figure 1 for an overview of recruitment of participants to the studies, and participants/articles included (I-V), and reasons for exclusion of articles in study III.

In studies I and II, participants were recruited in 2013 and 2011, respectively, from two specialist palliative home care units in Stockholm, Sweden. At the time of the interviews, participants lived in apartments in central areas of the city. Purposive sampling was used in both studies aiming at capturing a variety of experiences concerning eating deficiencies. There were no connections between the participants included in studies I and II.

The inclusion criteria for participants in studies I and II were adults (>18 years), able to speak, read and understand Swedish, and having been admitted to a specialist palliative home care unit (study I), or being a partner to a deceased person who was cared for by a specialist palliative home care unit at the end of life (study II). A further inclusion criterion was existing eating deficiencies, i.e. appetite loss, artificial nutrition, dysphagia, nausea and/or weight loss, distress and challenges concerning food and eating documented in the patient's records/the deceased patient's records.

Figure 1. Recruitment, participants, and studies.



Patients meeting the inclusion criteria were contacted by a RN from the specialist palliative care units, either by telephone or during a home care visit (study I). Information was given and, if there was interest in participation, written information was sent and thereafter the patients were contacted by the PhD student through a telephone call. During the telephone conversation, potential participants were given the opportunity to ask questions and to make a decision regarding participation. Time and place for the interview were chosen by the participants. Fourteen patients were asked to participate in the study. One patient declined participation, and one wanted to participate but died before the planned interview. Repeated interviews were performed, and the number of interviews was determined by the patients' willingness and strength to participate. After each interview, information was given regarding repeated interviews and the patients could decide to participate in another interview or decline further participation. Twelve patients were included, five men and seven women, aged 36-80 years, see Figure 1. Cancer was the main diagnosis, ten had advanced cancer (breast, oesophagus, gynaecological, lung, pancreatic, peritoneal carcinoid, prostate, synovial sarcoma), one had a neurological disease and one a kidney disease. Two patients had children living at home.

Partners (study II), documented in patient records, were contacted by the assistant head RN in the home care units by telephone 3-6 months after their family member had died. Information was given and those interested in participation received written study information by post and were subsequently contacted by the PhD student through a telephone call. During the call, the study information was reiterated and those contacted were given the opportunity to ask questions and decide whether they wanted to participate or not. Time and place for the interview were chosen by the partners who consented to participate. Eleven partners were asked to participate in the study. Two partners declined participation; they were not asked to motivate their decision. Nine partners participated, five men and four women, aged 60-83 years, see Figure 1. Six of the participants were retired from work, and of those who were employed, all had been at home caring for their partner, full or part time, during the last period of their partner's life. All households consisted only of the couple, i.e. no children were living at home. Eight of the deceased

patients had died of some form of cancer (cardia, skin, lung, kidney, prostate, bladder, ventricle) and one had died of a neurological disease.

The inclusion criterion for Study III was articles examining experiences of food or mealtimes for adult patients with chronic life-limiting disease. Empirical studies, original quantitative, qualitative, and mixed methods research studies, and multiple case studies were considered for inclusion. The search strings comprised: (I) patients living with chronic life-limiting disease, (II) experiences OR perceptions and (III) food OR eating. The search terms used were Subject Headings. Peer-reviewed articles in English published between January 2000 and March 2019 were searched. The time frame was chosen to find more recent findings and searches were made in the following databases: Academic Search Complete, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Nursing and Allied Health Database, PsycINFO, Soc Index, PubMed, and Web of Science Core Collection. In the 24 articles included, participant numbers ranged from 4-281, and in total 1013 participants were included (427 men, 224 women and 362 genders not specified), see Figure 1. The care context in the majority of the articles was palliative care (83%), predominantly homecare (54%), and in most articles (71%) the main diagnosis was advanced cancer. The studies had been conducted in twelve different geographical locations, with a clear majority in developed countries.

RNs with experience of food and mealtimes in palliative care were included in studies IV and V. An online survey using a study specific questionnaire (study IV) was conducted. RNs were recruited by means of convenience sampling, though an advertisement via a post on a closed Facebook group for RNs in palliative care, and in an internal newsletter within a national association for RNs in palliative care (approximately 80 and 400 members, respectively). At the end of the survey, RNs were asked about interest in participating in an interview study (study V).

In study IV, 100 RNs agreed to participate and completed the online survey. Most of the RNs were female (n=94), six were men, see Figure 1. The RNs were on average 48 years of age and had completed their nursing degree nineteen years ago (range 3-50 years). Four out of five RNs (81%) worked in a specialist

palliative care unit, 41% had a post-graduate degree in palliative care, and 43% had worked for more than ten years in palliative care.

Thirty-three RNs volunteered to participate in an interview about food and mealtimes in palliative care (study V). The first ten RNs who had expressed interest in interview participation were contacted via telephone. Nine of them still wanted to participate, whereas one was unreachable. Verbal information was provided, and written information was e-mailed, and an interview appointment was scheduled. Further recruitment was performed through purposive sampling, aiming for variation in age, education, years in nursing and work location in Sweden. Eleven RNs were contacted according to the procedure described above; however, one was unavailable, and ten more interviews were therefore conducted, comprising a total of 19 interviews. No new information of interest for the aim of the study was obtained after 16 interviews. However, three additional interviews were conducted and when no new information was detected data collection was closed after 19 interviews. The RNs worked at various locations in Sweden, divided into the north of Sweden (n=3), the middle (n=8) and the south (n=8). Their ages ranged from 31-71 years, and the majority were women, see Figure 1. Years since graduation varied from between five to 50 years. All except three of the RNs had post-graduate degrees in palliative care or other post-graduate nursing education. Two of the RNs had two post-graduate degrees. Three quarters worked in a palliative care setting and most had more than five years' experience as RNs. Three quarters had worked for more than five years in palliative care.

4.3. Data collection and procedures

4.3.1. Interview studies

Data collection for studies I, II and V was through interviews. An interview guide with open-ended questions was constructed for each study and interviews were conducted in a conversational format. The interview guides were constructed based on discussions within the research group and with experienced external researchers. Each interview guide was pilot tested on one or two persons with experience of the studied phenomenon. The PhD student

conducted all interviews in studies I, II and V. Similarities between the three interviews were the open approach and giving participants the opportunity to share their experiences of eating deficiencies in palliative care. Narratives of participants' experiences were sought and probing questions (Price, 2002), such as "Can you tell me more about that?", "How did you experience that?", were used, see Appendices 1, 2 and 3. The interviews were audio recorded with the participant's consent.

Patients who participated in study I decided on the place for their interviews and all but one chose their own homes. One invited the interviewer to accompany them to oncological treatments since this meant not losing any family time due to study participation. Multiple interviews were carried out with patients and the number of interviews was determined by their willingness and strength to participate. A total of 20 interviews were conducted with patients; one interview (n=5), two interviews (n=6) and three interviews (n=1). The time to death from the last interview varied between one week to more than 13 months (median 18 weeks, mean 9 weeks). The interviews were 20 to 112 minutes long). Open-ended questions were asked, such as "*Can you please tell me what it has been like for you to eat during your illness trajectory?*" "*What does food mean to you?*". No financial compensation was given to the participants.

Most of the partners in study II chose to be interviewed in their homes, the home they had shared with the deceased family member, whereas one chose to come to the clinic. Open-ended questions were asked, for example "*Can you tell me what it was like for you at home when your partner's food intake changed?*", "*Can you tell me about a situation you remember when your partner's changed food intake influenced your everyday life?*". The single interviews with partners of a deceased person lasted between 50 and 115 minutes. No financial compensation was given to the participants.

The telephone interviews with RNs (study V) were conducted at a time and place chosen by the participants. During the interviews, some were in their homes, others in their workplace, and one was walking home from work. Two participants had permission to be interviewed during their workdays, the others were interviewed in their spare time, for example weekends and evenings. The interviews started with an open-ended question: '*Can you tell me about a challenging*

situation concerning food and mealtimes in palliative care? Other questions asked were: *'How do you ask and talk about food and eating?'* *'What would you like to teach a new colleague about food and mealtimes?'* The interviews lasted from between 28 and 59 minutes. As a token of appreciation, the participants in study V were sent a gift certificate valued at approximately 47 Euros and valid in national shops.

4.3.2. Systematic review

First the PROSPERO protocol database at York University was searched for systematic reviews close to the aim and phenomenon of interest for study III. As none were found, a protocol for the present review with an integrated data-based convergent synthesis design was created and registered [CRD42020134290] in the PROSPERO database (National Institute for Health Research, 2019). The systematic review was designed together with experienced researchers and an experienced research librarian created search strings in collaboration with the PhD student. The Centre of Dissemination and Research Guidelines for Systematic Reviews in Healthcare (Centre for Reviews and Dissemination, 2009) was used and seven databases aimed at covering a broad area for suitable articles were selected. Initially, the systematic literature search resulted in 3151 identified articles.

The 3151 hits were imported from EndNote into Rayyan software (Ouzzani et al., 2016), a program for blind screening and evaluating articles. Duplicates were automatically removed by Rayyan and double checked by the PhD student. After duplicates were removed (n=374), 2777 hits remained for screening and evaluation of titles and abstracts. These were independently screened and evaluated by the PhD student and two researchers. Abstracts of articles with relevant titles were read and if found suitable, the full-length articles were assessed. After removing the blinding in the Rayyan software, disagreements were discussed in a meeting with all authors to reach consensus. There were articles presenting both patients' and family members' perspectives and these were included if the results were separable. Articles that were included for full-text screening and evaluation (n=61) were independently screened and evaluated by the PhD student and one researcher; the articles were then discussed in the research team. Thereafter, reference lists were hand searched and suitable

articles included. The process is presented in Figure 1. In total, 24 articles were included, 19 from database searches and 5 from hand searches.

4.3.3. Cross-sectional survey

The online survey was distributed during November and December 2020 in two groups for RNs interested in palliative care; one a closed Facebook group and the other group was members of a national association for RNs in palliative care.

A study specific questionnaire about RNs' perceptions of food and mealtimes in palliative care was constructed from findings in study III, i.e. a systematic review including 24 articles concerning patients' experiences of food and mealtimes in palliative care (study III). The main findings from the review were summarized to explore RNs perceptions of these findings, i.e. food and mealtimes perceived as distressing, affecting social life and interactions, and also improving health and well-being as well as prolonging life. Additionally, statements about RNs perceptions of their responsibilities regarding food and mealtimes in palliative care were included.

The development of the questionnaire started with the PhD student and the co-authors individually formulating factual statements which were then discussed and revised. This first draft of the questionnaire was evaluated individually in writing by a group (n=13) comprising RNs (n=6), dietitians (n=3), physicians (n=2) and patients in palliative care (n=2). Seven of the clinicians were active as researchers. The written evaluations were summarized by the PhD student and subsequently discussed in a workshop with all authors. Some revisions in the introduction were made and two of the statements clarified (items 16 and 19). The questionnaire was then tested to assess face validity (Taherdoost, 2016) in a RN population (n=5) and the items were found to be understandable and relevant, hence no revisions were made. See Table 2 for a presentation of statements (n=19) and the order of the statements in the final questionnaire.

Table 2. Statements (n=19) included in the questionnaire.

Item	Statement
1.	Many patients experience mealtimes as distressing at the end of life
2.	Difficulties eating remind patients that death is closing in
3.	Patients who manage to eat despite deficiencies experience increased well-being
4.	Difficulties eating make patients withdraw from family and friends
5.	Food and mealtimes entail community and promote relationships
6.	Patients show their will to live by eating
7.	Patients who manage to eat gain vitality and the energy to live longer
8.	For most patients, the illness and bodily changes make it impossible to eat at the end of life
9.	It is natural to stop eating when death is approaching
10.	Patients force themselves to eat for the sake of their families
11.	Conflicts over food and mealtimes between patients and families are common
12.	Family members experience a sense of responsibility for the patient's eating
13.	Family members who are women take greater responsibility for the patient's eating than family members who are men
14.	Family members organize food and mealtimes because they want to maintain everyday routines
15.	Family members focus on food because it is a way to keep death away
16.	Family members should accept that patients cannot manage to eat
17.	RNs should help patients accept that it is natural to stop eating at the end of life
18.	RNs should help family members accept that it is natural to stop eating at the end of life
19.	RNs should take an active part in the work with food and mealtimes at the end of life

In the final version of the questionnaire, four statements were linked to food and mealtimes being perceived as *distressing* (items 1, 2, 10, 11), five to *affecting social life and interactions* (4, 5, 12, 13, 14), three to *improving health and well-being* (3, 6, 7) and four to *food symbolizing life* (8, 9, 15, 16). Eleven of these items were statements from the patients' perspective (items 1-11) whereas five were statements from the family member's perspective (12-16). In addition, three statements concerned RNs' perceptions of their *responsibilities* regarding food and mealtimes in palliative care: helping patients and family members to accept that it is natural to stop eating at the end-of-life (items 17, 18), and taking an active part in the work with food and mealtimes in clinical practice (item 19). The RNs were asked to rate each item on a 4-point Likert scale: Strongly disagree (1 point), Disagree (2 points), Agree (3 points), and Strongly agree (4 points).

In addition, the RNs were asked an open-ended question: *'Based on your experience, what advice would you give a new colleague about food and mealtimes in palliative care?'*

Responding to the open-ended question was voluntary. There were no limits regarding number of letters or words used in the responses to the questions.

At survey start, study information, including the participants' rights, was described and contact information provided. The information also included anonymity, i.e. that the data could not be connected to any specific individual after submission. However, at the end of the survey RNs were asked if they were interested in participating in the upcoming interview study (study V) and if so to provide their contact details. Thirty-three (33%) RNs broke their anonymity and filled in contact information. Confidentiality was strictly observed for these RNs.

Responses were gathered via SurveyMonkey, a web-based tool used to collect data through online surveys. After the initial information, the survey started with questions concerning socio-demographic data, i.e. age, gender, number of years since graduation, post-graduate degree in palliative care and/or post-graduate degree not in palliative care, location of work place, work place, number of years working as RN and number of years working in palliative care. The survey then continued with the questionnaire items, i.e. the 19 statements with fixed answers and one open-ended question. Questions related to socio-demographic data and questionnaire items with fixed answers had to be completed to move on to the

next item, whereas the open-ended question could be left blank. On completion, the RNs were asked to choose a charity organization to be supported with €10 as a token of appreciation for their participation.

Most RNs (90%) answered the open-ended question about advice to give to a new colleague. The responses ranged from two to 330 words (mean 32 words). The total word count was 3197.

4.4. Analyses

In studies I, II and V, qualitative analyses of the data from interviews were performed. Articles included in the mixed-method systematic review, study III, were analysed thematically. In study IV, analytic statistics were conducted for the data and deductive content analysis for the free text answers.

4.4.1. Qualitative analyses

Qualitative analyses were used in studies I, II, III, IV and V; interpretive description (Thorne, 2008) in studies I and II, deductive content analysis (Elo & Kyngäs, 2008) in study IV, a thematic analysis in study III (Sandelowski & Leeman, 2012), and qualitative content analysis (Graneheim & Lundman, 2004) in study V.

In the initial phase of analysis for studies I and II, the transcribed interviews were read several times to gain a sense of the whole regarding the topic being studied. Units consisted of one or several sentences with descriptions related to the aim. The units were identified, coded broadly and then given labels based on their meanings, such as *'descriptions of eating for survival'*, *'eating for other'* or *'descriptions of losing familiarity with food'*. The process of broad coding was aimed at more contextual interpretations where the descriptions of experiences are interpreted in their context (Thorne 2008). Notes were made about ideas and preliminary interpretations; these were documented as questions or comments.

During the analysis, alternative interpretations were recurrently discussed and considered to avoid premature interpretations due to early closure. The last part of the interpretation was to identify patterns and their inherent variations, based

on differences and similarities of the descriptions. Relations within patterns were also sought (Thorne et al. 2004). During the whole research process, empiric and theoretical literature considering topics and concepts related to the area of the study were read. This included experiences of chronic life-limiting illness and eating deficiencies, and literature about the meaning of food and mealtimes for families and other social structures. See Table 3 for the analysis process.

Table 3. Example of the analysis process, study I.

Quotation	Broad coding	Analytical process	Interpretation	Pattern
“It’s also a feeling that like... I will, will die from this. The cancer is eating up my body but so far there are quite a few parts of my body that are not filled with cancer. The more weight I lose, the less of me that is healthy is left. So, it’s also a kind of resistance. Be able to keep like... that [Life]	Trying to influence with food	Theoretical and empirical texts were read to support interpretation During the interviews the participant and others described eating as aiming to try to remain healthy, preserve bodily functions and healthy parts of the body. The mood in the text is related to other statements of similar meaning	The text is related to other findings in this and other participants’ descriptions and interpreted as participants resisting death by eating. Food was giving the capacity to postpone death.	Resisting death by eating

In the survey in study IV, free text answers were analysed using deductive content analysis (Elo & Kyngäs, 2008) according to the palliative care dimensions: *physical, psychological, social* or *existential* (WHO, 2020). When coding data according to the four dimensions, the ten core competencies in palliative care described by Gamondi et al. (2013) were used as a complement to guide the sorting of data into the four palliative care dimensions. A structured matrix was used and relevant data not fitting into any of the categories were labelled *Other*. Next, based on the principles of content analysis the category labelled *Other*,

emerging categories with manifest content were created, and finally categorised as *palliative care approach*. NVivo 12 Windows (QRS International Pty. Ltd., Australia) was used for the analysis and the analysis was independently validated by the PhD student and co-authors.

For the interviews with RNs (study V) concerning their experiences pertaining to food and mealtimes in palliative care, an approach suitable for exploration was chosen (Lindgren et al., 2020). Transcripts were read multiple times to gain a sense of the whole. Thereafter, meaning units were extracted, condensed and inductively coded, for example *physical obstacles, challenges, doing, communication* and *a good death*. See Table 4 for example of the analysis process. Initial de-contextualization focused on illuminating the studied phenomenon, and data were condensed and separated from context (Lindgren et al., 2020), representing manifest content. These were descriptively coded, close to the text, with low levels of abstraction and interpretation.

Table 4. Example of the analysis process, study V.

Meaning units	Condensed meaning unit	Condensed meaning unit interpreted	Code	Sub-theme	Theme
“One is very eager to help in this profession... that’s how I feel sometimes anyways, that there is a lot one wants to do, and one is very active in finding solutions, and bending over backwards to help”	There is an eagerness to help and actively do things, find solutions and, the efforts have good intentions but are not always the best for the patient.	Eagerness and focus on doing	Doing	Easy to stick with doing	Supporting persons with eating deficiencies in-between palliative care and end-of-life care

In later analysis phases, the de-contextualized units were re-contextualized, i.e. meaning units were combined and returned to the context, forming sub-themes and an overarching theme, comprising interpretation of latent content. Differences and similarities in the data steered the analysis proceedings and alternating between closeness and distance to data resulted in increasing levels of abstraction (Lindgren et al., 2020). Findings were read and discussed in the research group until consensus and agreement regarding the final results were reached.

4.4.2. Systematic review

Quality appraisal was conducted for the 24 articles included in study III. Guidelines and transparency in line with the ENTREQ checklist (Tong et al., 2012) informed the review process throughout. Since ENTREQ is constructed for qualitative studies, PRISMA guidelines (Moher et al., 2009) were used to identify guideline items specific to quantitative studies. The Critical Appraisal Skills Programme Guidelines (CASP, 2018) were used to achieve comprehensive and explicit reporting of the study. Quality ranged from medium (3) to high (5). Methodological limitations were noted, for example if studies introduced selection bias or if questionnaires were not validated, making inferences difficult. Quality was not used to exclude studies, rather for focus and transparency regarding possible inferences and to allow assessment of the trustworthiness of review findings.

Data abstraction was performed, and the results were extracted according to the aim and coded by the PhD student and co-authors. This entailed including relevant parts of the article results, i.e. data or themes corresponding to the aim, into a data extraction template. Results of the extraction were discussed and confirmed in the research group and a matrix was constructed comprising an overview of included studies.

Data were synthesized using a data-based convergent design, i.e. extracted quantitative data were transformed and qualited; described in words. This was carried out in a parallel process by the PhD student and last author, transforming the quantitative results from descriptive and comparative analysis into plain text. This was then checked and validated by the co-authors. In the next step all data were compared, analysed, and synthesized using thematic

analysis, identifying similarities, differences and patterns (Sandelowski & Leeman, 2012). The extracted data were separated into text units and given labels to summarize the experiences described in the units, for example, 'physical impediments', 'distress', 'social', 'guilt', 'existential' and 'survival'. Similar labels were grouped together and discussed, and themes were created. The thematic analysis process entailed approaching and displaying data in different ways to allow shifting perspectives and ensuring robust analyses (Marshall & Rossman, 2016). The analysis process entailed independent reading, re-reading, written communications with reflections, and analysis meetings with all co-authors for verifying findings and drawing conclusions. This iterative process required moving from being close to the data in the individual articles to aiming for the emerging bigger picture by looking at the whole, i.e. combining results from articles.

4.4.3. Statistical analyses

Categorical data are presented as frequencies and percentages, n (%), while ordinal and continuous data are given as means and standard deviations (SDs). Unadjusted and adjusted linear regression analyses were used to estimate the magnitude of the association between the socio-demographic variables age, female gender, years since nursing exam, post-graduate degree, palliative care, post-graduate degree not in palliative care, working in larger urban area or suburb, working in specialist palliative care division, work experience as RN (0-5 years [reference] / 6-10 years / >10 years) and work experience in palliative care (0-5 years [reference] / 6-10 years / >10 years) (predictors) and RNs' perceptions of food and mealtimes in palliative care (outcome), separately for the five domains as well as the total group. The adjusted analyses included age, female gender and all statistically significant variables in the unadjusted analyses. The results are presented as slope coefficient β with accompanying 95% confidence intervals (CIs). All statistical analyses were performed in R 4.0.0 (R Foundation for Statistical Computing, Vienna, Austria) using two-sided statistical tests with P-values <0.05 considered statistically significant.

4.5. Ethical considerations

The research in this thesis was conducted in accordance with the Declaration of Helsinki (WMA, 2018) and with the recommendations of good research practice by the Swedish Research Council (2017). The four key principles of non-maleficence, autonomy, beneficence and justice (Beauchamp & Childress, 2019) have been considered.

Non-maleficence implies doing no harm (Beauchamp & Childress, 2019); researchers have an ethical and legal duty to avoid harming others. This was achieved by careful decision making. *Autonomy* has been safeguarded by providing sufficient and adequate information, time to understand and to make anonymous decisions regarding participation. Participants were provided with information about the purpose of the study and the procedure, and given the possibility to contact the researchers. *Beneficence* is directed at promoting the well-being of the participating individuals and society, and balancing risks against benefits. Study participation can be considered meaningful even in a vulnerable period of life. *Justice*, here through listening respectfully and acknowledging the other person's dignity, is fundamental. In addition, through presenting findings in a fair way and utilizing what participants had taken their time to share in interviews and the survey. In this thesis, the experiences and perceptions shared have been comprehensively analysed and presented, and thereby given justice.

Benefits, risks, and burdens of participation need to be taken into special consideration when involving dying persons and families (studies I and II) since their time is limited. When conducting interviews concerning sensitive topics, the researchers must acknowledge that the interview may constitute distress for participants and researchers must, therefore, adhere to the ethical principles of beneficence and non-maleficence. A likely benefit to participants is the sense of sharing, influencing and contributing (Aoun et al., 2017; Bloomer et al., 2017; Dempsey et al., 2016). Based on this, it was estimated that the benefits of participating exceeded the risk of harm for the participants in this thesis. Furthermore, in studies I and II, the hospital chaplain and staff within the specialised palliative home care team were informed of the ongoing study, and the participants were invited to contact one of these professionals if feelings

arose that they felt they wanted to talk about. Several of the participants expressed that they valued the opportunity to participate in research.

Before each interview, informed consent procedures were observed (studies I, II, V). Participants were provided with written information about the study, including their rights, how confidentiality was guaranteed, data management and presentation of findings. The voluntary nature of participation and the right to withdraw from the study at any time were emphasised (Beauchamp & Childress, 2019; WMA, 2018). In studies I, II and V, before starting the interviews, the participants were given verbal and written information about the study and their rights, and informed consent was obtained. Confidentiality was guaranteed in relation to data management and the presentation of findings. Transcripts were kept on password protected databases without any personal data or details, and findings were presented in articles at group level to ensure there was no risk of revealing any participant's identity. To achieve representative trustworthiness (Thorne, 2008), variations were sought concerning age and diagnoses of patients in study I and partners in study II. The final sample is representative of the variation of diagnoses in palliative home care at the time (Palliativregistret, 2013).

Conducting study III did not require formal ethical approval, nevertheless ethical considerations were made; during the quality assessment, the included articles were screened concerning ethical approval and/or ethical considerations. When extracting data from the articles, which were then analysed and presented, this was conducted in such a way as wisely as possible can be stressed to include ethical considerations in every step.

In study IV, informed consent was obtained electronically during the first part of the survey. Data regarding age, gender and education were collected (social security number was not recorded) and the survey was accessible without the need for a password; due to the anonymous design, IP addresses were not collected. The persons who volunteered for interview gave their name, email address, and telephone number and these were deleted after contact. For studies IV and V, the sampling strategy was to reach RNs experienced both in palliative care and the phenomenon food and mealtimes.

The trustworthiness of studies always needs to be reflected on. According to WMA (2018), research is only justified if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research. In this thesis, an aim has been to include ethical considerations in the research process, to be transparent, and to do justice to the data, presenting findings in a fair and wise way and thereby contributing to the field of knowledge.

5. Findings

The findings of studies I-V are presented from the perspectives of patients (studies I and III), partners (II), and registered nurses (IV and V).

5.1. Perspectives of food and mealtimes in palliative care

5.1.1. Patients' perspectives

In studies I and III, patients' perspectives regarding food and mealtimes were explored and described, see Table 5 for an overview of patterns/themes and content in the respective studies and thereafter a synthesis of the results.

Table 5. An overview of patterns/themes and content – patients’ perspectives, studies I and III.

Study	Pattern/Theme	Content
I	Resisting death by eating	The significance of eating for well-being and survival were described. Increased awareness of bodily decline was described as an obvious marker of impending death. Enjoyment around food was lost. Eating to postpone death, not ready to die.
	Struggling with social gatherings around food	Social gatherings that included food and eating were troublesome and could lead to avoidance of sharing mealtimes with others. Although the withdrawal was self-imposed, it resulted in feelings of loneliness and feelings of being separated from the life they had lived.
	Eating to please and unburden others	Eating to please and acknowledge other people’s efforts and eating more to relieve family members and friend’s anxiety over the declining illness trajectory were described. In addition, eating was described as a way of expressing gratitude for all support around eating deficiencies.
III	Understanding their hampered eating - perhaps it is best to let nature run its course	Various physical impediments that hampered eating were described. Patients tried to understand their unpredictable bodily changes and one way of seeing this was as a natural part of progressing illness.
	Food and mealtimes evoke distress – reducing joy, testing interim ways	Eating deficiencies influenced everyday lives and was described as stressful. Former routines around food and eating were disrupted, and joy was reduced or lost. Patients tried to find interim ways to handle food and mealtimes along the disease trajectory.
	Struggling with food and mealtimes – eating to please others and postpone death	Forced eating was described as being to please others, to ease the stress of family and friends, and also to postpone death. Food was experienced as having the potential to improve well-being and to maintain life. Being able to eat promoted satisfaction and a sense of victory when resisting death.
	Food and mealtimes as caring and love – flanked by social disconnect	Preparing food and eating together, caring for each other and expressing love, were experienced as positive aspects of food and mealtimes. In social gatherings, the decreased ability to take part in meal preparation and eating comprised barriers to inclusion and partaking on the same terms as others. Social loss and being undeniably confronted with a looming social disconnect (death) was experienced.

The results from studies I and III are presented below in synthesized format, grouping similarities and shaping three new themes: *Struggling with food and mealtimes – distress in everyday life*, *Eating to resist death – adjusting to illness trajectory*, and *Eating together – becoming alone*.

Struggling with food and mealtimes – distress in everyday life

Eating deficiencies influenced patients' everyday lives and this was stressful, and the subsequent distress from eating deficiencies was profound. Former routines around food and eating could not be upheld, and joy was reduced or lost (studies I, III). Food and eating affected relationships and emotions were stirred in situations surrounding mealtimes (study III). Changes around mealtimes evoked feelings of being separated from the life they had lived earlier (study I). Patients experienced grief due to the loss of pleasure in food and tried to find new strategies to manage food and mealtimes. Feelings such as self-blame, being incapable, and being responsible for causing the disease, or feeling sad and weak due to the inability to eat like before, were described (study III). However, being able to eat could promote satisfaction and a sense of success (study I).

Eating to resist death –adjusting to illness trajectory

Bodily changes were obvious during the illness trajectory and the importance of eating became increasingly prominent (study I). Patients had physical impediments that hampered eating and they struggled to understand their unpredictable bodily changes; loss of appetite was rapid and unpredictable (study III). Losing weight was interpreted as a warning sign that death was approaching, and the eating deficiencies became an existentially loaded marker, hence food intake became a way of resisting death (studies I, III). The participants described eating even though they did not feel hungry. This was described as "turning on the autopilot" (study I). In their struggle to handle the eating deficiencies and to increase their food intake, different alternatives were explored, such as dietary supplements and recreational drugs that they hoped would help them regain their appetite. Food was attributed with the power to postpone death and also preserve bodily functions and increase well-being (studies I, III). Food had a symbolic value; managing to eat despite eating deficiencies, even if it was little, was associated with the hope of well-being and

potentially resisting or at least postponing death (studies I, III). Sometimes difficulties with eating were related to other symptoms. One way of seeing this was as a natural part of progressing illness and the illness trajectory. For some, not eating or just eating a little did not cause concern since food was anyway not perceived as influencing the illness trajectory (study III).

Eating together – becoming alone

Mealtimes were valued opportunities for social gatherings. Even though the illness trajectory disrupted situations around food and mealtimes, mealtimes were experienced as socially significant (studies I, III). However, living with eating deficiencies meant challenges that complicated and limited social interactions, since eating with others was troublesome with a diminished appetite or when food with modified texture was required (study I). Something was lost when they were unable to share the same dish as others and the situation itself resulted in a symbolic divide (study I). Social togetherness around food became instead an emotional struggle (studies I, III). Having eating deficiencies and difficulties around mealtimes could mean feeling different both in relation to others and to their own picture of how they wanted to be (study I). Hence, a self-imposed avoidance of social gatherings around mealtimes could be the least complicated solution (study I). When the ability to partake in food preparation, eating, and social gatherings was changed, this comprised barriers to inclusion and being part of social gatherings (study III). Although this withdrawal from social situations was their own choice, it nevertheless made them feel lonely (studies I, III). Social loss was experienced and, furthermore, comprised confrontation with the imminent social separation of death (study III).

Eating for others – food and mealtimes as caring and love

Patients perceived food and eating to have the potential to influence emotions and reactions (studies I, III). Patients tried to eat for others, to please others, and to acknowledge the efforts of meal preparation made by others (study I). Patients forced themselves to eat, food was regarded as fundamental, and eating was done to please others. Eating with others meant eating more and eating things that they did not want in order to ease the distress felt by others (study I,

III). Mealtimes made the potential of food visible and sometimes the goals of eating were to influence the emotions and reactions of others (Study I). Preparing food and eating together meant caring for each other and expressing love (study III). Their struggle to eat was aimed at easing the burden of awkwardness or anxiety felt by friends and family. Eating to please and to unburden others meant putting themselves aside for the benefit of others; however, this was described as somewhat satisfying and gave participants an opportunity to show their appreciation for others (study I).

5.1.2. Partners' perspectives

In study II, partners' experiences of everyday life while caring for a dying person with eating deficiencies at home were explored. The results indicated that partners' everyday lives were significantly impacted by the person's eating deficiencies. Two patterns, revealing dualities of distressing and rewarding experiences, were highlighted, firstly, *The challenge of doing the best*, and secondly *Striving to maintain ordinariness*. The first involves *Being significant around food and mealtimes* and *The distress of being unable to influence food and mealtimes*. The second involves *Losing familiarity with mealtimes and food habits*, and *Holding on to the social value of shared mealtimes*, see Table 6 for an overview of patterns, themes and content.

Table 6. An overview of content in patterns and themes – partners’ perspectives study II.

Pattern: The challenge of doing the best	
<i>Theme</i>	<i>Theme content</i>
Being significant around food and mealtimes	In the challenge of doing their best, the participants felt that they had a significant role in matters around food. Being able to influence food intake made the participants feel as if they had contributed to their partners’ well-being.
The distress of being unable to influence food and mealtimes	Feelings of distress about not being able to handle the challenges and influence their partners’ decreased intake of food were experienced. Distress about failing and guilt were also prominent.
Pattern: Striving to maintain ordinariness	
<i>Theme</i>	<i>Theme content</i>
Losing familiarity with mealtimes and food habits	A gradual loss of familiarity with their partners’ food preferences and habits was experienced. Parts of the well-known person seemed to disappear and added to the feeling of a gradual separation from the partner who was dying.
Holding on to the social value of shared mealtimes	Partners strove to maintain ordinariness by upholding previously shared social values around mealtimes, such as eating together. When they managed to handle the challenges around food and mealtimes, they could occasionally rekindle the joy and good times around mealtimes.

The challenge of doing the best - Being significant around food and mealtimes

Partners found it challenging to do their best during the partner’s illness trajectory and the responsibility for food and mealtimes in everyday life was gradually changed. This meant assuming increased responsibility, both for the preparation of food and mealtimes and for the food intake of their partner. Partners felt that they had a significant role in matters around food. Preparing and organizing food remained one of the most important tasks, even during periods when enteral or parenteral nutrition was provided. Continuous efforts were made to prepare and modify meals to make them more attractive, for example by making particular dishes or modifying the food texture. Being able to influence food intake made the partners feel that they had contributed to well-being. In the emotionally challenging everyday life, the organization of food and mealtimes was something concrete to hold on to.

The challenge of doing the best- The distress of being unable to influence food and mealtimes

Feelings of being significant were sometimes replaced by, or experienced in parallel with, feelings of distress about not being able to handle the challenges and influence their partners' decreased intake of food. For partners, every bite or sip provided some hope of being able to postpone death a little longer. Linked to this, frustration and misdirected feelings of disappointment, as well as feelings of guilt brought about by the lack of control regarding food intake and the dying process, were prevalent. Partners experienced that they could not live up to their own norms of being a 'good partner'. These feelings were particularly prominent where they thought they had not actively tried to encourage or push their partners to eat or drink. Family members blamed themselves for not having been more observant and not having 'tried harder' to improve the situation when the dying person was still alive.

Striving to maintain ordinariness - Losing familiarity with mealtimes and food habits

Trying to encourage and sometimes putting pressure on their partner to eat profoundly changed the mealtime experience. A gradual loss of familiarity with their partners' food preferences and habits was experienced. They strove to maintain ordinariness by modifying and adjusting situations that involved food and mealtimes. Parts of the well-known person seemed to disappear, and this estrangement altered the ordinariness of everyday life. The loss of familiarity was described as adding to the feeling of a gradual separation from the partner who was dying.

Striving to maintain ordinariness - Holding on to the social value of shared mealtimes

Partners continuous efforts to maintain ordinariness, and to prepare and modify meals to make them more attractive, remained some of the most important tasks, even during periods when enteral or parenteral nutrition was provided. Managing to retain as many of their former shared habits as possible and continuing to share mealtimes was part of this. Despite the changes in everyday life, they could occasionally rekindle the joy and good times around mealtimes. There were social losses and limitations in what was possible but, when they managed to overcome these, this was something to be proud of.

5.1.3. Registered nurses' perspectives

In study IV, RNs' perceptions of mealtimes in palliative care were investigated, including their clinical perspectives of patients and families. An additional aim was to investigate associations between socio-demographic variables and RNs' perceptions of mealtimes. RNs' rated statements within five domains; see Table 7 for a presentation of RNs ratings (means and standard deviations (SD)) for each statement, for each of the five domains, as well as the total score for the 19 statements.

Table 7. RNs' (n=100) perceptions of food and mealtimes in palliative care.

Item	Domains and statements	mean	SD
	<i>Distressing</i>		
1.	Many patients experience mealtimes as distressing at the end of life	3.3	0.6
2.	Difficulties eating remind patients that death is closing in	3.1	0.6
10.	Patients force themselves to eat for the sake of their families	3.2	0.5
11.	Conflicts over food and mealtimes between patients and families are common	3.5	0.6
	Items 1-2, 10-11	3.3	0.3
	<i>Affecting social life and interactions</i>		
4.	Difficulties eating make patients withdraw from family and friends	2.8	0.6
5.	Food and mealtimes entail community and promote relationships	3.5	0.6
12.	Family members experience a sense of responsibility for the patient's eating	3.6	0.6
13.	Family members who are women take greater responsibility for the patient's eating than family members who are men	2.9	0.8
14.	Family members organize food and mealtimes because they want to maintain everyday routines	3.1	0.7
	Items 4-5, 12-14	3.2	0.4
	<i>Improves health and well-being</i>		
3.	Patients who manage to eat despite deficiencies experience increased well-being	2.9	0.7
6.	Patients show their will to live by eating	2.7	0.7
7.	Patients who manage to eat gain vitality and the energy to live longer	2.7	0.7
	Items 3, 6-7	2.8	0.5

	<i>Food symbolizing life</i>		
8.	For most patients, the illness and bodily changes make it impossible to eat at the end of life	3.4	0.8
9.	It is natural to stop eating when death is approaching	3.8	0.5
15.	Family members focus on food because it is a way to keep death away	3.3	0.6
16.	Family members should accept that patients cannot manage to eat	3.3	0.6
	Items 8-9, 15-16	3.5	0.4
	<i>RNs' responsibilities</i>		
17.	RNs should help patients accept that it is natural to stop eating at the end of life	3.6	0.5
18.	RNs should help family members accept that it is natural to stop eating at the end of life	3.8	0.4
19.	RNs should take an active part in the work with food and mealtimes at the end of life	3.6	0.6
	Items 17-19	3.7	0.4
	<i>Total</i>		
	Items 1-19	3.3	0.3

Note: RN, registered nurse; SD, standard deviation. There were no missing values for any of the variables.

Overall, the mean score on the 4-point scale was 3.3 points, indicating that RNs agreed with the statements. On average, RNs agreed to the largest extent with the given statements that concerned RNs' responsibilities (mean score 3.7 points), while they agreed to the least extent with statements concerning Improve health and well-being (mean score 2.8 points). The items with the highest scores were: *It is natural to stop eating when death is approaching* (3.8 points), and *RNs should help family members accept that it is natural to stop eating at the end of life* (3.8 points). The items with the lowest mean scores were: *Patients show their will to live by eating* (2.7 points), and *Patients who manage to eat gain vitality and the energy to live longer* (2.7 points).

Results of the linear regression analysis of the association between age (years), female gender, post-graduate degree, not palliative care, and work experience as RN (predictors) and RNs' perceptions of food and mealtimes in palliative care (outcome) are given in Table 8.

In the adjusted analyses, female gender was significantly associated with higher agreement with statements that food and mealtimes are perceived as distressing ($P = 0.049$) and was borderline significant ($P = 0.051$) with the statement that food and mealtimes affect social life and interactions ($P = 0.020$). Higher age was significantly associated with a lower degree of agreement with statements that food and mealtimes are perceived as distressing ($P = 0.004$). Moreover, having a post-graduate degree in an area other than palliative care was significantly associated with lower agreement with statements that food and mealtimes are perceived as distressing ($P = 0.007$), while having 6-10 years' working experience as a RN implied lower agreement with statements that food and mealtimes affect social life and interactions, compared to RNs with 0-5 years' working experience ($P = 0.042$).

On average, females had a 0.271 point higher agreement with the statement that food and mealtimes are perceived as distressing, and a 0.342 point higher agreement with the statement that they affect social life and interactions. RNs perceived that food and mealtimes were on average 0.012 point less distressing for each additional year older they were, while RNs with a post-graduate degree in an area other than palliative care had a 0.185 point lower agreement with the statement that food and mealtimes are perceived as distressing. Finally, RNs with a working experience as a RN of 6-10 years had on average a 0.392 point lower agreement with statements that food and mealtimes affect social life and interactions, compared with RNs having a working experience of 0-5 years.

Table 8. Results of linear regression analysis of the association between socio-demographic variables (predictors) and RNs' perceptions of food and mealtimes in palliative care (outcome).

		Unadjusted		Adjusted ^a	
Domain	Predictor	β (95% CI)	P-value	β (95% CI)	P-value
Distressing	Age (years)	-0.006 (-0.013; 0.001)	0.111	-0.012 (-0.020; -0.004)	0.004
	Female gender	0.287 (-0.0005; 0.575)	0.050	0.271 (0.002; 0.541)	0.049
	Post-graduate degree, not in palliative care	-0.181 (-0.320; -0.042)	0.011	-0.185 (-0.317; -0.053)	0.007
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	-0.311 (-0.630; 0.007)	0.055	-0.213 (-0.510; 0.083)	0.156
	> 10 years	-0.117 (-0.405; 0.172)	0.424	0.137 (-0.157; 0.431)	0.358
Affecting social life and interactions	Age (years)	-0.002 (-0.010; 0.006)	0.644	-0.008 (-0.018; 0.002)	0.109
	Female gender	0.389 (0.047; 0.732)	0.026	0.342 (-0.001; 0.685)	0.051
	Post-graduate degree, not in palliative care	0.072 (-0.099; 0.243)	0.407	0.072 (-0.096; 0.241)	0.395
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	-0.475 (-0.852; -0.098)	0.014	-0.392 (-0.770; -0.015)	0.042
	> 10 years	-0.236 (-0.578; 0.106)	0.173	-0.110 (-0.484; 0.265)	0.562

Note: None of the variables *Years since nursing exam*; *Post-graduate degree, in palliative care*; *working in larger urban area or suburb*; *Working in specialist palliative care division*; or *Working experience in palliative care* were statistically significant in any of the unadjusted analyses. CI, confidence interval; RN, registered nurse. Significant P-values are given in **bold**.

^aAdjusted for all other variables in the domain or total.

Table 8. Continued

		Unadjusted		Adjusted ^a	
Domain	Predictor	β (95% CI)	P-value	β (95% CI)	P-value
Improves health and well-being	Age (years)	0.004 (-0.007; 0.014)	0.506	-0.001 (-0.015; 0.012)	0.875
	Female gender	0.058 (-0.394; 0.510)	0.800	-0.027 (-0.493; 0.438)	0.908
	Post-graduate degree, not in palliative care	0.007 (-0.215; 0.228)	0.954	-0.029 (-0.257; 0.200)	0.805
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	-0.272 (-0.768; 0.224)	0.279	-0.271 (-0.783; 0.242)	0.297
	> 10 years	-0.007 (-0.456; 0.442)	0.977	0.018 (-0.491; 0.526)	0.945
Prolongs life	Age (years)	-0.003 (-0.010; 0.005)	0.489	-0.006 (-0.015; 0.003)	0.224
	Female gender	0.090 (-0.211; 0.392)	0.554	0.102 (-0.210; 0.414)	0.517
	Post-graduate degree, not in palliative care	-0.084 (-0.231; 0.063)	0.259	-0.087 (-0.240; 0.066)	0.263
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	0.004 (-0.333; 0.342)	0.979	0.047 (-0.296; 0.389)	0.788
	> 10 years	0.057 (-0.249; 0.362)	0.714	0.175 (0.165; 0.516)	0.308

Table 8. Continued

		Unadjusted		Adjusted ^a	
Domain	Predictor	β (95% CI)	P-value	β (95% CI)	P-value
RNs' responsibilities	Age (years)	-0.003 (-0.011; 0.004)	0.400	-0.001 (-0.011; 0.009)	0.823
	Female gender	0.025 (-0.294; 0.344)	0.878	0.043 (-0.289; 0.376)	0.797
	Post-graduate degree, not in palliative care	-0.038 (-0.194; 0.118)	0.633	-0.017 (-0.181; 0.146)	0.832
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	-0.096 (-0.451; 0.258)	0.590	-0.085 (-0.450; 0.281)	0.647
	> 10 years	-0.167 (-0.487; 0.154)	0.305	-0.142 (-0.505; 0.221)	0.438
Total	Age (years)	-0.002 (-0.007; 0.003)	0.407	-0.006 (-0.012; 0.00003)	0.051
	Female gender	0.195 (-0.018; 0.408)	0.072	0.171 (-0.041; 0.383)	0.113
	Post-graduate degree, not in palliative care	-0.042 (-0.147; 0.064)	0.434	-0.045 (-0.150; 0.059)	0.389
	Working experience as RN				
	0-5 years	Reference			
	6-10 years	-0.248 (-0.482; -0.014)	0.038	-0.194 (-0.428; 0.039)	0.102
	> 10 years	-0.102 (-0.314; 0.110)	0.342	0.017 (-0.214; 0.249)	0.884

Note: None of the variables *Years since nursing exam*; *Post-graduate degree, in palliative care*; *working in larger urban area or suburb*; *Working in specialist palliative care division*; or *Working experience in palliative care* were statistically significant in any of the unadjusted analyses. CI, confidence interval; RN, registered nurse. Significant P-values are given in **bold**.

^aAdjusted for all other variables in the domain or total.

Over half, 56 percent of the text in the responses to the open-ended question belonged to the physical dimension. In contrast, 14 and 9 percent of the text belonged to the social and psychological dimensions, respectively. Existential dimensions were described in percent, and palliative care approach in 17 percent of the text, see Table 9.

Table 9. Results of analysis showing RNs (n=90) advice to new colleagues sorted according to dimension, number of RNs giving answers belonging to each dimension, number of codes and percentage of text belonging to each dimension.

Dimension		RNs (n)	Codes (n)	Percentage of text (%)
Palliative care dimensions	Physical	61	69	56
	Social	25	29	14
	Psychological	20	21	9
	Existential	7	9	4
Other	Palliative care approach	10	20	17

The advice in the *physical dimension*, described by 61 RNs, included 69 codes that focused on aspects of eating and how to facilitate and maintain eating throughout the illness trajectory. Examples were practical advice such as adjusting size of meals and food options, and eliminating physical reasons for inability to eat (ulcers, mycosis, strictures etc.).

The *social dimension*, described in by 25 RNs, included 29 codes that pertained to advice that family members should be given space to eat together with patients. Responses were highlighting RNs' responsibilities to inform and educate families regarding the dying process and reduced food intake. Most common responses were about individual support to family members also, that RNs should help families find strategies to navigate food and eating towards the end-of-life. This could be achieved if families could understand physical deterioration during the dying process and that food no longer a necessary.

Advice in the *psychological dimension*, described by 20 RNs, included 21 codes that pertained to aspects of enjoyment around food. Several RNs underscored that eating should never be forced and that nagging was negative.

Advice regarding the *existential dimension*, described by seven RNs, included nine codes that focused on life experiences and meanings of eating, like keeping death at bay.

In the *other* category, advice was given concerning strategies for nursing and how to achieve a *palliative care approach*, advice from 10 RNs to new colleagues (20 codes). The most common advice was to focus on patients' needs and wishes to shape care interventions accordingly. Using attributes such as humility and respect were also encouraged.

To summarize the qualitative data in study IV, *physical* dimension was e.g. practical advice, as adjusting size of meals and food options, and eliminating physical reasons for inability to eat, *psychological* dimension e.g. reactions and emotions, *social dimension* e.g. not eating together or not eating the same food, or *existential* dimension e.g. food as upholding life, thoughts of starvation.

In study V, RNs (n=19) were interviewed regarding their experiences of caring for patients with eating deficiencies in palliative care. The analysis resulted in an overarching theme: *Supporting persons with eating deficiencies in-between palliative care and end-of-life care*, represented by three sub-themes: *Easy to stick with doing*, *Just being, without doing, is hard* and *Letting go*, see Table 10.

Table 10. Overview of theme, sub-themes and sub-theme content.

Supporting persons with eating deficiencies in between palliative care and end-of-life care	
<i>Sub-theme</i>	<i>Sub-theme content</i>
Easy to stick with doing	Patients' eating deficiencies were met with multiple caring interventions. The eagerness of doing something, versus the individual patient's will and preferences, was a challenge for experienced RNs in palliative care.
Just being, without doing, is hard	Stressors related to patients' eating deficiencies were part of the experienced RNs everyday work. RNs struggled with moving away from a nursing care model of "fixing" to one that is empowering and embraces shared responsibilities with patients and families.
Letting go	Although the experienced RNs stated that human beings stop eating when they are about to die, it was complicated to let nature run its course in palliative care.

Easy to stick with doing

RNs described that they easily got stuck with doing during patients' illness trajectories and end-of-life care. For RNs, eating was equated with quality of life, whereas for patients and families eating symbolized life. Analyzing physical signs and symptoms that influenced eating and could be solved or relieved was stressed by the RNs. Through education, both at general and specialist levels, RNs were prepared to tackle physical obstacles and provide support related to practical assistance or solutions, however, finding harmony between the eagerness of doing something, versus the individual patient's will and preferences, was a challenge for experienced RNs in palliative care.

Just being, without doing, is hard

RNs aimed to share the professional view on food, dying and death. Substantial energy was spent on how to share bad news without upsetting or frightening patients and families. RNs experienced lacking preparation to meet families' distress around mealtimes, and participating in challenging conversations about food, as this was not taught in their education. Existentially loaded questions were often met with silence from RNs. RNs struggled with moving away from a

nursing care model of “fixing” to more “being”. They realized the importance of capturing moments, when patients and families brought up concerns about food and mealtimes, and to be open, interested and truly present with patients, instead of focusing on practical solutions. RNs addressed patients’ and families’ distress and tried to ease the situation around food and mealtimes using multiple caring strategies. To alleviate family distress, practical solutions and information about physical processes in the human body related to the illness and dying were provided.

Letting go

RNs described eating as symbolizing social belonging for patients and their families. Favorite foods and snacks were offered to patients to postpone death, and the family sometimes nagged or pushed patients to eat. Patients often felt forced to eat or guilty when they could not eat. In these situations, when repeated information about the dying process and reduction in food intake had failed to change family members’ approach, RNs described that they insisted that family members were relieved of the responsibilities of food preparation and patients’ food intake. Taken together, the RNs, though educated and experienced in clinical practice, found that even though human beings stop eating when they are about to die, allowing nature to run its course in palliative care was complicated.

6. Discussion

For patients, partners and families, mealtimes and eating signified the potential to remain healthy, to improve well-being and to prolong life. Furthermore, eating deficiencies meant changes in everyday life that affected emotions, social life and interactions. RNs were less prepared to address existential, psychological and social issues in relation to mealtimes and eating, than tackle physical inconveniences and provide practical support or solutions. For patients, partners and families, food and eating were perceived as markers of impending death, whereas RNs found it natural for eating to stop when death was closing in.

In the following discussion, the main findings are reflected on in relation to awareness of dying and total pain/total suffering. Furthermore, they are also considered through the lens of dying in our welfare society and the need for palliative care providers to be sensitive to issues related to mealtimes and eating during palliative care.

6.1. Food and eating - loaded markers of impending death

From patients', partners' and RNs' perspectives, mealtimes and eating were found to be loaded markers of impending death. Partners and RNs struggled to organize and adapt food and mealtimes and encourage the dying person to eat. For patients and partners, the amount of food eaten by the patient was interpreted as a marker of the time left to live. Patients pushed themselves to eat as a way of enhancing well-being and even avoiding death. The findings showed that food and eating had a profound existential loading, and that food and eating can be a powerful mediator for patients' and partners' sense of being able to resist death. In studies I and II, patients and partners were well informed about the illness prognosis, and knew that death was inevitable, yet patients struggled to keep eating and partners took on the role of providing food as a strategy to manage the situation. The distress related to food and mealtimes can be looked at through the lens of hope. Hope and hopelessness can occur simultaneously and should not be seen as opposites, but rather as two poles on a

continuum (Robinson, 2012). The awareness of dying has been pertinent for decades and research indicates that an open awareness enables patients to prepare for their dying (Andrews & Nathaniel, 2009). Patients talk about death and more often die in their homes when they are aware of their upcoming death, and this has associations with a peaceful death (Anderson et al., 2013). Full awareness of dying has also been shown to reduce stress and prolong grief, but not everybody reaches that stage, or wants full information, since humans have their own individual ways of meeting challenges. It is vital to use patients' perceptions about mealtimes and eating as the starting point for care planning. This seems, however, to present a challenge for RNs, whose knowledge and presumptions recognize a total awareness of dying as being a 'good death', yet who acknowledge that this is not every individual's chosen way of dying.

As demonstrated by the findings in this thesis, patients and partners used several strategies to manage their everyday lives in the vicinity of death. Their experiences were complex and parallel, and contradicting perceptions of the current situation were prominent. It seems that being aware of dying and simultaneously trying to postpone death with food was conceivable, although perhaps not surprising considering the inherent complexity of human beings and humanity. Partners of deceased patients experienced guilt, both about having pushed the dying person to eat, and at the same time questioning whether they had done enough. Experiences of survival guilt after having lost a family member are well-known (Li et al., 2014) and families often assumed responsibility for food and mealtimes. Food and mealtimes may be 'controllable' in situations where most things are out of control, i.e. the illness was incurable, and the future uncertain. As demonstrated in the results, maintaining ordinariness by upholding the family's former shared habits was vital. Mealtimes could be seen as the continuous creation of meaningful events in everyday life (Scott, 2009). The gradual social separation, even if sometimes presented as a self-imposed withdrawal by patients, comprised a loss for both patients and partners. In palliative care, the concept 'social death' is recognized as withdrawal from activities and relationships following bodily decline and illness (Lawton, 2000), and may be considered a natural event in preparation for death. In this thesis, the findings indicate that social loss remains a reminder of the impending finite separation through death.

Communication about food and eating was challenging. Higher age of the RNs was significantly associated with a lower degree of agreement concerning statements that food and mealtimes are perceived by patients as distressing ($P = 0.048$). One could suggest that having lived longer means having a wide variety of life experiences and reflecting on these may result in a heightened awareness about dying and death that impacts assumptions. Self-awareness, and being reflective as an RN, facilitates distress reduction and also provides space for more open conversations and interactions (Rasheed et al., 2019). This could be an explanation for these findings. Food-related discussions in palliative care are challenging; the results indicate that mealtimes and eating have many underlying meanings for patients, families and RNs. If RNs have predetermined perceptions of an ideal death, they may lack some of the openness and flexibility required to adapt to patients' needs. International policy documents and guidelines stress that palliative care should pay special attention to the specific needs and preferences of individuals (IAHPC, 2018; WHO, 2021). Core constituents of palliative care comprise enhancing physical comfort throughout patients' disease trajectories, but also meeting patients' psychological, social, and existential needs, to contribute to providing palliative care where dignity and autonomy are prominent (Gamondi et al., 2013). Failing to address concerns regarding mealtimes at the end of life means overlooking actual care needs that may potentially have improved patients' well-being. Awareness and knowledge about how mealtimes and eating relate to social, psychological, and existential dimensions may guide RNs in shaping interventions to promote well-being for patients with chronic life-limiting disease in palliative care.

6.2. Postponing death with food – or acceptance of discontinued eating

The findings emphasize that distress about food and eating were related to far more than the physical dimension. Food and eating are obviously linked to life, and in our society, the general perception is that food choices and eating are linked to health (Bouwman et al., 2009). Based on the results, RNs wanted to inform patients and families about changed nutritional needs and eating habits during the disease trajectory, hoping to reduce distress, hence care interventions

often focused on the physical dimensions. This may be considered in relation to the concept of “total pain”. Total pain was formulated by Dame Cicely Saunders (Clark, 1999) to include physical, psychological, social, and existential elements of care needs and this framework may assist with further contextual understanding of the findings. Information about bodily changes has its place but, based on the results, RNs also need to keep in mind that mealtimes and eating in palliative care can cause multidimensional pain. More specifically, psychological pain (e.g. reactions and emotions on loss of function), social pain (e.g. not eating together, not eating the same food), or existential pain (e.g. food as upholding life, thoughts of starving to death). Since pain is still mainly associated with physical pain, the use of the wording and mindset ‘total suffering’ instead of total pain might be a possible alternative. Suffering, as it is defined in the Nordic caring sciences, might broaden perspectives, highlighting that suffering is a condition of human existence (Arman et al., 2015).

Suffering has been presented as subjective and complex, and also an inevitable aspect of life to be endured, minimized, relieved and explored for meaning (Cutcliffe et al., 2015), and that authenticity can be experienced by being open and accepting of suffering, rather than avoiding it. Based on this reasoning and to address the experiences of patients in this thesis, RNs need to expand their perceptions of suffering and re-think how they respond to suffering, since this influences care provision; they should keep in mind that the results highlighted that mealtimes and eating caused distress as a loaded marker of impending death. Furthermore, one may argue that RNs need to embrace their role as a holistic presence with suffering patients and accompany patients on their journeys. Patients’ experiences of suffering can be exacerbated as a result of their healthcare experiences if their perspective was overlooked; not embracing a patient’s dimensions of suffering can result in them experiencing challenges with having their healthcare needs and autonomy respected, or can result in them feeling abandoned (Berglund et al., 2012). Neither of these are desirable outcomes for patients nor in harmony with the ethical standards of nursing (ICN, 2012).

A strategy to address suffering entails sharing stories, talking and reflecting, since suffering needs to be articulated and restated in order to transform suffering for patients (Råholm, 2008). In the context of mealtimes in palliative

care, communication about patients' needs and distress related to food and eating would be highly appropriate in order to address patients' care needs. Furthermore, open questions about the patient's mealtimes and eating earlier in their life may open up for conversations leading to deeper understanding. When caring for patients with palliative care needs, RNs can be instrumental in leading care processes and healthcare interventions focusing on well-being and care satisfaction, by embracing holistic perspectives comprising physical, psychological, social and existential dimensions of human existence. From a strict perspective of caring sciences, it may be inconsistent to speak about dimensions of a human being, since humans comprise indivisible entities (Arman, 2020); however, keeping the various dimensions in mind may be helpful if we RNs are able to encounter them as a whole. Wholeness is not about adding and subtracting parts, rather about how the parts relate to each other and form an entity grounded in patients' perceptions and experiences. As the findings showed, experiences of mealtimes and eating in palliative care revealed physical, psychological, social and existential aspects that formed the foundation for patients' experiences of suffering as well as their health and well-being. In caring practices within palliative care, RNs must reflect on and design care interventions keeping both the separate parts of human existence and the wholeness in mind, since mealtime challenges were found to involve all dimensions. This is the only way to ensure that palliative care standards (WHO, 2020) and ideals are respected and strived for, ultimately promoting respectful and dignified end-of-life care.

6.3. Paying attention to needs in relation to mealtimes and eating near death

During the illness trajectory, patients' needs for care interventions related to mealtimes and eating evolve. It is a reasonable assumption that in the early stages of illness, e.g. during surgery or other treatments with curative intent, there would be an active approach aiming at optimizing nutrition intake. Often these interventions pertain to artificial nutrition, supplements, and energy rich foods and snacks. The findings of this thesis showed that symptoms and practical obstacles affected mealtimes and eating for patients and families in

diverse ways, and this aligned with the RNs' experiences and narratives. For patients and partners, food and eating were perceived as imperative even close to death, whereas for the RNs, closeness to death meant that it was natural to stop eating and instead focus on improving health and well-being. These facts present a potential divide in care priorities and subsequent care interventions, since the wishes of care recipients potentially divert from the care provider's priorities.

In our society there is still a trust in advanced medical treatment, and, from this perspective, death can be seen as a failure; the normalization of death is therefore warranted (Abel & Kellehear, 2016). The idea of refusing to accept death as a failure marked the starting point for hospice development and the ensuing palliative care movements (Clark, 1999). Dame Cicely Saunders concurrently promoted rigorous testing of medical treatments to alleviate symptoms for patients in palliative care, and stressed that the four dimensions, physical, psychological, social and existential, should be included in care planning and provision. There are still challenges with implementing palliative care throughout the healthcare sector, since the medical paradigm and treat to cure remains prominent in healthcare (Graven & Timm, 2021; Noonan et al., 2016). RNs are also trained to treat and provide treatments with curative intentions; however, palliative medical care interventions may be considered in parallel with aspects of compassionate care. Ultimately, RNs' behaviors and attitudes need to align with patients' values and wishes (Wiechula et al., 2016).

As a result, both aspects of care can and should be provided in parallel; RNs need to practice *doing* and *being* when caring for patients in palliative care. This is vital if palliative care ideals, such as promoting health and reducing suffering, are to be accomplished. Providing palliative care that aligns with patients' 'true' care needs, and not RNs' well-meaning expedition of the process of moving on to the acceptance of death, requires doing more than focusing on and solving physical problems. RNs need to more consciously listen to patients' narratives and to make space for conversations embracing all four dimensions in palliative care: physical, psychological, social and existential. Communication is most likely the key, and communication is not only about what or how things are said. Hence, being present and offering silent space to 'hear' what patients and families cannot articulate (Dettmore & Gabriele, 2011) comprises a starting

point. This would mean not only *doing* caring, but also *being* caring (Sitzman & Watson, 2019), in the context of palliative care nursing. Taken together, to better understand the breadth of experiences related to mealtimes and eating in palliative care, RNs are urged and encouraged to practice being without necessarily doing. Only this way can palliative nursing interventions contribute to reducing suffering and enhancing well-being in palliative care.

6.4. Methodological considerations

This thesis aimed to explore mealtimes in palliative care from patients', partners' and RNs perspectives. To broaden and deepen the understanding of the studied phenomenon, qualitative and quantitative methods, as well as a mixed-method systematic literature review, were used. When interpreting the results, it is important to bear in mind that the included studies were performed over a 10-year period. Thus, perspectives as well as clinical practice regarding mealtimes in palliative care may have changed over time, and guidelines and checklists to promote explicit and comprehensive reporting of research have been developed. There are also methodological considerations that have to be considered. Aspects related to trustworthiness of qualitative findings and validity/reliability of quantitative findings are discussed further below.

6.4.1. Qualitative methodological considerations

The pre-understanding of being a PhD student with experience as a RN specialised in nutrition may have influenced the interviews and other parts of the research process. According to Thorne (Thorne, 2008), pre-understanding consisting of theoretical, empirical and clinical knowledge constitutes an important knowledge base for designing clinically relevant research questions. Reflecting with experienced researchers was helpful after the interviews and during the analyses, both for learning as a PhD student and for the results of the study. Research that is conducted is closely linked to the researcher's credibility, which Patton (2015) described as "intellectual rigor", i.e. it is essential to reflect and ask questions about who you are and what can impact the findings taking shape as they do.

In studies I, II and V, purposive sampling was used that aimed at capturing a variety of experiences from patients, partners and RNs. However, in studies I and II, RNs selected and recruited potential participants. It is possible that recruitment was biased, potentially making the aimed purposive sampling void. Study V was conducted during the COVID-19 pandemic in 2020, with heavily increased workloads among healthcare professionals. This may have skewed our sample towards RNs with extensive interest in palliative care, with long experience of palliative care, and RNs who were highly educated (post-graduate degree in Nursing), thus the purposive sample was carried out by a relatively homogenous group.

Face-to-face interviews were performed in studies I and II, whereas telephone interviews were conducted in study V. The literature indicates that the quality of data collected through telephone interviews is comparable to face-to-face interviews (Carr & Worth, 2001). In addition, other positive aspects related to telephone interviews are flexibility, reduced disruption of the day and cost-effectiveness. The weaknesses may be that persons with language or hearing problems may be excluded from participation, potentially contributing to inequalities in health by excluding underrepresented and underserved populations from research. Body language cannot be seen when performing telephone interviews and it may be more difficult to capture nuances. Further, in study I, repeated interviews were performed whereas single interviews were conducted in studies II and V. The literature suggests that participants may speak more freely when a relationship with the interviewer has been established (Denzin & Lincoln, 2018). Furthermore, repeated interviews were found positive from several perspectives; patients with limited strength were able to participate, and there was time to reflect between interviews, with inherent chances of 'verbal validity' (Kvale et al., 2014; Patton, 2015). People not speaking Swedish were excluded in studies I and II, which is a limitation as this may have excluded potential participants with diverging experiences. Furthermore, the sample is not representative of dying people, since specialised palliative care is far from standard care in all care settings.

Last, but not least, there is always an interviewing effect to consider when collecting data through interviews (Kühne, 2020). The interviewer as a person, that is their gender, age and interview approach, influences the interview and the

collected data. The participant may try to 'give the right answers' and the interviewer can be eager to positively confirm statements and implicitly guide the participants to describe more. When conducting the first interviews as a PhD student, this meant abandoning the well-known communication patterns utilized as a RN, and interviewing was therefore a new way of communicating. Education, reflection and feedback from experienced researchers was crucial for the development of interview technique. Furthermore, experience gained gradually over the years as a PhD student most likely honed this interview technique. The interviews in this thesis were not checked by participant validation and this may be a weakness. However, verbal summaries were made during the interviews to verify interpretations.

In study IV, an open-ended question was used to explore the advice given by RNs to new colleagues about mealtimes in palliative care; 90 percent of the RNs answered. The results are in line with findings from study V, i.e. that experienced RNs in palliative care focus on tackling physical inconveniences and provide support related to practical assistance or solutions around mealtimes. This is a strength to have both collected anonymous data and in-depth interviews, possibly providing variations of experiences and perceptions.

As described by Elo and Kyngäs (2008), both inductive and deductive methods can be used with qualitative data. In study IV, the open-ended question was analysed through the deductive sorting of data according to the four dimensions of palliative care (WHO, 2020). However, the study was not designed to test existing data in a new context or to test a model as a commonly described purpose of deductive analysis (Elo & Kyngäs, 2008). The structure chosen for analysis was to give complementing information about the balance of palliative care dimensions in study IV, indicating topics that RNs focused on. In study IV, the findings are presented as the extent in terms of percentage of text, and also number of codes and RNs, respectively, so that quantitising can be seen as contributing to the transparency of the data (Sandelowski et al., 2009). When using existing concepts as a matrix of analysis, such as the four dimensions of palliative care (WHO, 2020), the data or text that does not fit into the framework needs to be handled (Elo & Kyngäs, 2008). Therefore, the remaining data were analysed and a complementing category was created, again aligning

them with the palliative care framework and RNs responsibilities, rather than excluding data.

The systematic mixed-method review was carefully planned, and established guidelines for systematic reviews and checklist were used (CASP, 2021; Flemming, 2018; Noyes et al., 2019) throughout. The quality of the included articles varied, and two separate guidelines for reporting qualitative (ENTREC) (Tong et al., 2012) and quantitative data (PRISMA) (Moher et al., 2009) research were used. The limitations of individual studies are assessed and reported in a transparent way to allow readers to judge and evaluate findings as well as possible transferability. Proceedings were conducted in a systematic and transparent manner to allow readers to assess study credibility and trustworthiness (Hopia et al., 2016). This was a strength since the structured process reduced the risk for bias.

Gathering findings, both qualitative and quantitative, is never free from subjectivity and interpretation. The PhD student and at least one co-author conducted each step independently in the review. In the inclusion and extraction processes, there was movement between blinding and transparency to ensure quality, every step comprised at least two researchers, and conflicts were discussed for negotiated consensus. The articles included were from developed countries and, consequently, the results may not be transferable to other regions.

Finding articles focusing on the perspectives of mealtimes when living with chronic life-limiting disease was challenging. Articles were gathered from fields beyond palliative care and cancer. Nevertheless, most of the articles included cancer diagnoses and palliative care contexts. This is a result in itself; this is where the vast majority of research in the area of mealtimes is conducted.

6.4.2. Quantitative methodological considerations

There were several limitations in this cross-sectional study, e.g. internal validity non-response bias, sampling bias, and desirability bias. Firstly, a study specific questionnaire was constructed. Using a non-validated questionnaire presents a limitation with regards to internal validity (Creswell & Creswell, 2018) since we do not know if it measures what it was intended to measure. However,

statements originated from the existing literature regarding how patients in palliative care experience eating (study III), and the questionnaire was also discussed, tested and reflected on by a multi-professional group before use. Steps such as these are important when constructing a questionnaire (Kumar, 2015; Waltz et al., 2010). Moving forward with the questionnaire, collecting further observations, and performing psychometric testing is called for.

Secondly, given the low response rate (approximately 21%), no claims of generalization can be made. Nevertheless, 100 persons responded and of those, 33 volunteered for interview during an ongoing pandemic. The survey was distributed during the intense period of COVID 19, which might have contributed to a sample of RNs with genuine interest in palliative care and in mealtimes. Our sample consisted of RNs who had extensive clinical experience, were highly educated and were experienced in palliative care, thus further limiting the generalization of the finding. However, the sample potentially indicates how RNs with specialist education view circumstances around food and mealtimes at the end of life. Initial exploration implies that RNs perceptions align with patients' and families', indicating awareness of the challenges that patients and families face.

Another risk with questionnaires such as this is the introduction of desirability bias (Ferrari & Cowman, 2004), i.e. when distributing a questionnaire indicating there are challenges, participants may give answers in line with that. On the other hand, this might have been avoided since RNs answered anonymously and could utilize the free text answers for elaboration without any direct influence by the researchers. The open-ended question was included to provide RNs with the opportunity to add experiences that were not highlighted in the questionnaire. A shortcoming with free text is that the answers may be influenced by the statements given in the survey (Waltz et al., 2010). The RNs were keen to express their views, since 90% responded to the free text item. Having an open free text question may act as a safety net, opening up for possibilities to identify issues not covered by the closed questions (Biemer et al., 2013).

Recruiting participants via a Facebook group and an association for RNs in palliative care means that reasons for declining participation were unknown. The two groups might have some overlap, i.e. the exact response rate is unknown.

Sample bias is possible due to the convenience sampling; however, some significant results were found.

Another aspect to consider is the gender imbalance with six participating men and 94 women. This is somewhat lower than the proportion of male RNs in Sweden (National Board of Health and Welfare, 2019). Despite this gender imbalance, statistically significant differences were found between male and female RNs regarding their perspectives on food and mealtimes being perceived as distressing in palliative care; female RNs had a significantly higher agreement. Based on our study, no conclusions can be drawn regarding the clinical importance of these findings; however, it does indicate that exploring these differences further may provide gendered nuances of caring practices. A larger sample could also have detected potential differences between general and specialised palliative care, and also concerning education.

7. Conclusions

Based on the findings in this thesis the following conclusions can be drawn:

- Eating symbolised social belonging and quality of life for RNs, whereas for patients in palliative care and their families it also symbolised life.
- For patients, eating deficiencies were experienced as fundamentally affecting social life and interactions in a way that hampered their possibilities of sharing valuable moments with friends and family members during the final period of life.
- For partners, living close to a person who has eating deficiencies at the end of life was challenging, both from a caring perspective, i.e. stressors related to not eating enough and how to hold on to social values around food when eating habits were changed, as well as for their own personal well-being.
- RNs experienced in palliative care were well prepared to tackle physical inconveniences and provide support related to practical assistance or solutions, however, findings indicate that RNs might be less prepared to address existential, psychological and social issues in relation to eating and mealtimes.
- RNs need to give attention to the individual wishes of patients at the end of their lives. Thus, involving and empowering patients in the decision-making process regarding mealtimes and eating is imperative.

8. Clinical implications

Nursing interventions aimed to minimize distress related to that people experience in relation to challenges with eating in palliative care are important due to the, since this is imperative for patients' and partners' well-being at the end-of-life. The findings of this thesis can also be used to initiate and inspire discussions in clinical settings concerning core palliative care values, and further highlight that RNs perform a balancing act between medical considerations and care in parallel with psychological, social and existential considerations in nursing practice.

Awareness and knowledge about how mealtimes and eating relate to social, psychological and existential dimensions, as highlighted in this thesis, may guide RNs in shaping interventions to promote well-being and reduce suffering for patients with chronic life-limiting disease. The findings also underscore the importance for RNs to be aware of the somewhat conflicting dualities of doing and being. Structured reflection in relation to clinical practice may support and encourage RNs to hone their practice in caring for patients with eating deficiencies, by embracing both *doing* nursing and *being* a nurse. Findings may also enable palliative home care teams and other healthcare providers to implement palliative care in a way that goes beyond giving practical advice about food. Initiating discussions about the situation in general, utilizing open questions about food and mealtimes, for example: "What is it like for you when you/your partner has challenges eating?", "What does food mean to you?" could open up conversations related to food and mealtimes, while embracing the scope and the dimensions of palliative care, potentially better meeting the multifaceted care needs of patients, partners and families at the end of life.

9. Future research

This thesis contributes to the evidence base concerning patients' and partners' needs in relation to food and mealtimes at the end of life, and furthermore, elucidates the inherent challenges for RNs' in palliative care contexts. This knowledge can contribute to healthcare professionals' understanding of needs and highlight foci for intervention studies regarding the challenges of patients, partners and families in relation to food and mealtimes. In addition, research specifically exploring the liminal experiences perceived by RNs would be helpful in identifying foci for studies regarding RNs' practice in relation to food and mealtimes at the end of life.

Future research should also target areas outside of oncology care, including aged care settings and acute care hospitals. Last, but not least, in line with clinical guidelines and evidence-based care, the development of clinical practice guidelines regarding the management of challenges surrounding food and mealtimes at the end of life is called for.

Sammanfattning

Mat och måltider är centrala för människors välbefinnande, både avseende fysiologiska aspekter av mänskligt liv och sociala samvaro. Svårigheter att äta är vanligt när man lever med livsbegränsande sjukdomar. Givet den centrala roll mat och ätande har i vardagen kan frågor relaterade till måltider orsaka betydande oro. Att stödja matintaget är en viktig aspekt av omvårdnad. Men det förekommer att sjuksköterskor upplever utmanande situationer och etiska dilemman när det gäller mat och näringsintag inom palliativ vård, samt att det inte är givet vilka råd som ska ges och hur samtal ska föras. Ett ökat behov av palliativ vård är att vänta och förståelse och medvetenhet om aspekter kring mat och måltider är nödvändigt. Det finns behov av studier med fokus på olika perspektiv på mat och måltider för att bredda och fördjupa kunskapen och för att förbättra klinisk praxis.

Det övergripande syftet med avhandlingen var att utforska mat och måltider inom palliativ vård ur patienters, partners respektive sjuksköterskors perspektiv. Avhandlingen innehåller fem delstudier. Kvalitativ (studie I, II och V) och kvantitativ (studie IV) studiedesign användes. Tre intervjustudier (studier I, II, V), en systematisk litteraturöversikt (studie III) och en tvärsnittsstudie (studie IV), genomfördes.

Resultaten visade att patienterna kämpade med mat och måltider och upplevde stress. Mat var förknippat med potential att bibehålla hälsa, förbättra välbefinnande och förlänga livet. Ättsvårigheter hade inverkan på det sociala livet och samvaro med andra blev förändrat. Andra människors försök till stöd kunde öka stress och patienter uppskattade stöd som var följsamt till deras sätt att hantera utmaningar vid måltider. För patienter i palliativ vård och deras familjer symboliserar ätande liv. Partners till en döende person beskrev hur de försökte stödja genom att sträva efter att upprätthålla det vardagliga välbekanta kring mat och måltider, samt hitta nya sätt att stödja ätandet. Mat och måltider i palliativ vård i symboliserar social tillhörighet och livskvalitet erfar sjuksköterskor. Stöd runt mat och måltider, när patienten närmar sig livets slut är utmanande. Sjuksköterskor är väl förbereda för att möta fysiska besvär och ge

praktisk assistans, men mindre förberedda för existentiella, psykologiska och sociala frågor i relation till ätsvårigheter som upplevdes.

Sammanfattningsvis behövs insatser för att minska den oro och stress som patienter och familjer upplever relaterat till måltider inom palliativ vård. Ett område som skulle kunna vidareutvecklas är hur man kan stödja sjuksköterskor i att kommunicera om mat och måltider inom palliativ vård för att främja patienters, partners och familjers välbefinnande i slutet av patienters liv.

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Appendices

Intervjuguide studie I

Under intervjusamtalet kommer stor vikt läggas vid att skapa en ömsesidig och trygg relation med informanten som bygger på hans eller hennes ork och vilja att dela med sig av sina erfarenheter. Intervjuerna kommer ha en öppen karaktär. Beroende på vad och hur informanten väljer att berätta ställs uppföljande frågor för att förtydliga och fördjupa informantens berättelse.

Kan du berätta om hur det har varit att äta sedan du blev sjuk?

Kan du berätta lite om hur det var när det började bli svårt för dig att äta?

Kan du berätta om någon situation där dina svårigheter att äta haft betydelse i vardagen?

Hur var det för dig under den här tiden?

Vad betyder mat för dig?

Hur påverkas din tillvaro av att inte kunna äta så som tidigare?

Hur påverkas er gemensamma tillvaro av ätsvårigheterna?

Exempel på uppföljande frågor:

Kan du berätta mer om...

Hur upplevde du det?

Hur kände du inför...

Vad fick du för tankar?

Intervjuguide studie II

Skulle du kunna berätta lite för mig om hur livet var under de sista månaderna i din make/maka/sambos liv?

Kan du berätta hur det var för dig när din maka/make/sambos matintag förändrades?

Kan du berätta om någon situation där din maka/make/sambos svårigheter att äta hade betydelse i vardagen?

Hur var det för dig under den här tiden?

Hur påverkades er gemensamma tillvaro av att din maka/make/sambo inte kunde äta som tidigare?

Vad betyder mat för dig?

Om du skulle ge råd till en annan person som befann sig i samma situation som du gjorde då, vad skulle du säga?

Exempel på uppföljande frågor:

Kan du berätta mer om...

Hur upplevde du det?

Hur kände du inför...

Vad fick du för tankar?

Intervjuguide studie IV

Kan du berätta om någon situation som varit utmanande där en patient har haft svårt att äta? (och hur du hanterat det?)

Hur brukar du lyfta frågor om ättsvårigheter, mat, och måltider med patient och närstående?

Utiifrån dina erfarenheter, vilka råd skulle du ge en ny kollega kring mat och måltider?

Vad anser du kan vara stödjande i relation till ättsvårigheter? Berätta!

Finns det stöd eller hjälp som du tror att patienter kan sakna i relation till sina svårigheter att äta/det som hade med matsituationen att göra? Berätta

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Mealtimes in palliative care contexts

Perspectives of patients, partners, and registered nurses

This thesis explored patients, partners and registered nurses' experiences and perceptions of mealtimes in palliative care contexts. The findings highlight perspectives aiming to better meet care needs and support patients and their families in palliative care. Health care professionals are required to provide care in line with individual wishes of patients at the end of their lives. Thus, involving and empowering patients in the decision-making process regarding mealtimes and eating is imperative.



Viktoria Wallin is registered nurse, specialised in nutrition and has worked at Ersta Hospital for many years. Currently she is employed as a lecturer at Marie Cederschiöld University teaching nursing students in 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 accommodated.



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