Dying with dignity – Dignity-preserving care for older women living with incurable cancer at home

Katrine Staats

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Scientific environment

This thesis was conducted from June 2018 to August 2021 at the Centre for Elderly and Nursing Home Medicine (SEFAS), Department for Global Public Health and Primary Care (IGS) at the Faculty of Medicine, University of Bergen (UIB). The project was funded by Dam Foundation and the University of Bergen. The Norwegian Women's Public Health Association (NKS) collaborated in the funding process and served as a consultative body.

I have attended the Research School in Public Health and Primary Health Care courses at the University of Bergen and the Norwegian Research School for Research and Development of Municipal Health and Care (MUNI-HEALTH-CARE) at the University of Oslo. I have also participated in courses at Western Norway Graduate School of Educational Research II (WNGER II) and at the University of Stavanger; Hermeneutics: An Introduction.

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30.08.2021 Katrine Staats

Introduction

When I was a little girl, I was determined to be a nurse and to fulfil my education in The Netherlands – as did my parents. My plan was completed in 2006, following a steep professional and personal learning curve, as a result of which I became a more independent person. I graduated as a nurse, ready to meet challenges and conduct nursing care within the healthcare sector. I felt curious and eager for knowledge and was naturally also somewhat naive.

I started my carrier on an oncology ward in The Netherlands and broadened my knowledge of different cancer diseases. It amazed me how certain simple cells could expand and harm people in such an awful way. What overwhelmed me most was to observe how people coped, knowing that their lives would be shorter than expected. I witnessed and participated in several conversations on an interpersonal and existential level, and found it both scary and fascinating.

In Norway, I started working in the municipal healthcare service as a homecare nurse. During my 10 years in Enebakk municipality, I had the privilege of working with many skilful healthcare workers. I learned and also experienced failure, and my curiosity enabled me to meet people living with a life-threatening illness. After a few years, I undertook further training in oncology nursing and became a cancer coordinator. I also had the opportunity to lead a project, aimed at improving basic palliative care knowledge for all health workers in the municipality, and participated in several meetings and courses. This was partly because I had a fantastic leader, Hege Scott, who always believed in me and my somewhat impatient search for personal and professional growth.

After my master's thesis, I immediately embarked upon this project, within which Oscar Tranvåg had developed an excellent project plan. I was excited and humble, and was also rather apprehensive about entering this academic world. Now I am only glad for being where I am. Most of all, I am grateful for having had the opportunity to give a voice to older women suffering from incurable cancer, raising awareness of how healthcare professionals can meet their needs, by providing dignity-preserving care.

Abbreviations

HCP[1]	Healthcare professional
IC	Informal caregiver
GP	General practitioner
CC	Cancer coordinator
HCPN	Homecare palliative nurse

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[1] Being members of the healthcare services in the municipality, general practitioners (GPs), cancer coordinators (CCs) and homecare palliative nurses (HCPNs), will be defined as HCPs throughout this thesis when highlighting perspectives from all three professions.

Abstract

Background: the global population is ageing rapidly and most older people are women. They live longer than men, report more illnesses and have a poorer health status. When living with incurable cancer, gender perspectives and dignity should be emphasized within the care for older women, so as to fulfil their complex needs.

Aim: the aim of this project was to develop an empirical-theoretical model, based on the identification and documentation of experiences related to dignity and dignity loss among older women living with incurable cancer at home.

Methods: this thesis comprises individual in-depth interviews, focus group interviews and participant observations with home-dwelling women, living with incurable cancer, ICs and HCPs. A hermeneutical methodology was chosen for this research project, and Katie Eriksson's Theory of Caritative Caring was allocated as a theoretical foundation to interpret the findings.

Results: the women experienced dignity when feeling valued as individuals, having a sense of control in life and living in safe environments, where they were able to remain hopeful and find meaningfulness. A flexible, organizational culture of care contributes to a functional, professional collaboration, facilitating HCPs to provide dignity-preserving care for these older women. Dignity loss was identified when the women experienced a loss in terms of human value and the opportunity for self-determination. They experienced a sense of disconnection and alienation within their surroundings, when not being treated with gentleness and flexibility by others.

Conclusion: being confirmed and recognized as a worthy human being, when experiencing suffering, results in the older women experiencing dignity. Having a sense of physical and existential control in life, was crucial to shelter human dignity. When being invited into a caring communion by HCPs, the women felt a sense of at-homeness in safe and sheltered surroundings. Finally, when experiencing hope and dignity in their lives, they achieved optimal health and an inner peace when nearing end-of-life. On this basis, an empirical-theoretical *Model of dignity-preserving care for older home-dwelling women with incurable cancer*, has been developed.

List of Publications

Paper I	Staats, K., Grov, E. K., Husebø, B. S., & Tranvåg, O. (2020). Dignity and loss of dignity: Experiences of older women living with incurable cancer at home. *Health Care for Women International*, 1-23. doi:10.1080/07399332.2020.1797035
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A related publication not included in this thesis

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Contents

1. Background

Dignity-preserving care for older women living with incurable cancer at home is a complex matter, addressing several crucial perspectives that need to be explored. This chapter provides an overview of these perspectives. Firstly, we present women's health and ageing internationally and, secondly, consider the perspective of women living with cancer in Norway, particularly within the context of women born and raised in Norway. Subsequently, women's health and ageing are outlined in the historical and current Norwegian context, followed by a description of how end-of-life care is organized in Norway. Finally, the concept of dignity and the state of the art concerning care preserving dignity is presented.

This thesis focuses on older women with incurable cancer nearing end-of-life, and we have, therefore, used the term 'end-of-life care' throughout this research project. However, 'palliative care' is a corresponding and a widely used term and will be found on occasions in this thesis, due to a certain overlap with the concept of 'end-of-life care'. 'Palliative care' is also often used interchangeably with 'end-of-life' by HCPs. As palliative care is a broad term and may be assigned to a patient at the point of diagnosis until death, end-of-life care usually refers to the care provided during a patient's final months of life, who has been diagnosed with a progressive disease, impaired functioning and more severe symptoms (Hui et al., 2013; Hui et al., 2014). End-of-life care is an essential component of palliative care and can also be considered as the period preceding a patient's natural death from a process, upon which medical treatment is unlikely to have an effect. This often represents the last six months of a patient's life (Lamont, 2005), which complies with this thesis' target group, namely, older women living with incurable cancer at home and also outlines the challenges of determining when a patient is nearing end-of-life. A review from Huffmann and Harmer (2021) points out the challenges of defining the period of end-of-life. They state that improvements in healthcare, such as advances in medicine and the enhancement of the average length of life, have changed this trajectory. Thus, the end-of-life period varies significantly from person to person.

1.1 Women’s health and ageing

The rapid ageing of the population worldwide represents one of today’s most significant demographic changes, which has created major expectations within healthcare organizations. In particular, the group of people aged 65 years and older is considerable, due to an increase in life expectancy (World Health Organization, 2018). In this research project, we have defined ‘older women’ as females aged 65 years and above. However, there are challenges related to determining when a woman is older. There is a great difference worldwide in terms of the concepts of ‘age’ and ‘being older’. Firstly, on a biological level, ageing results in considerable molecular and cellular damage over time. For women, a reduction in bone mass and visual alertness are normal physiological changes and part of the ageing process. Moreover, with regard to all older people, a gradual decrease in physical and mental capacity, a growing risk of disease and, ultimately, death are all normal ageing processes. Secondly, socio-economic factors, such as living activities, income and access to healthcare greatly affect the way in which women experience ageing. Nevertheless, these changes are neither linear nor consistent and are only marginally related to a person’s age in number of years (World Health Organization, 2018). Therefore, we cannot make a clear distinction as to when an individual becomes an older person; however, we can lean upon well-known and reliable institutions, such as The United Nations (2020), who claim that 65 years and above may usually be considered as the age of older people.

Within this group of older people, most are women, who globally live longer than men. Older women report more illnesses, have a poorer health status and experience a lower, health-related quality of life in later years than men (Baum et al., 2021; Rochon et al., 2020; Tannenbaum & Mayo, 2003). The reason for this discrepancy is complex and, in many cases, even unclear. In a study examining social, behavioural, biological and sex differences in mortality, Rogers et al. (2010) found a 62 percent unexplained gap in life expectancy between men and women in countries with varying national income and development levels. However, the explanations probably lie in both biological and social determinants, including dominant gender roles and practices.

Women have often worked in the home and may have lower pensions and benefits than men, as well as reduced access to healthcare and social services. Worldwide, the risk of poverty, combined with other conditions of older age groups, like dementia or cancer, increases the likelihood that older women will experience poor health (Baum et al., 2021; World Health Organization, 2015). Naturally, this requires a focus on women's health and ageing and, optimistically, the perspective on women's health globally has changed over the past decades. There has been a shift from a focus on sexual and reproductive female health to non-communicative diseases (NCDs); these diseases are now the greatest cause of death among women. NCDs are most notably cardiovascular diseases, cancers, respiratory diseases, diabetes, dementia, depression and musculoskeletal disorders (Peters et al., 2016; World Health Organization, 2015).

Women have a different view on health and illness than men and seek healthcare-related help more often (Thompson et al., 2016). MacLean and colleagues (2017) highlight cultural and gender norms as factors explaining the differences in this help-seeking behaviour. Men are typically more reluctant and stoical, whereas women are more willing to consult their GP in relation to minor or trivial symptoms. Various studies highlight more gender differences in healthcare in relation to older women, such as having fewer interventions for secondary prevention of heart disease and stroke than men, and being more predisposed to anxiety, depression and physical symptoms that cannot be explained medically. Moreover, these studies indicate that women are seemingly more sensitive to pain (Racine et al., 2012; Saeed et al., 2017; World Health Organization, 2015). Thus far, the literature identifies a number of challenges relating to being an older woman with declining health. Before explaining these challenges further within the Norwegian context, it is necessary to present one of the NCDs, namely cancer, which represents the most significant cause of death globally and is one of the main issues within this project.

1.2 Women living with cancer

In 2020, an estimated 19.3 million people were diagnosed with cancer worldwide, of which 9.2 million were women (Sung et al., 2020). Immunity and genome distinctions in gender are crucial for cancer epidemiology, and the cellular and molecular differences between women and men need to be considered with regard to cancer treatment and cancer prevention (Clocchiatti et al., 2016; Dorak & Karpuzoglu, 2012). Globally, women's dominant types of cancers are breast, colorectal and lung cancers (Bray et al., 2018). More and more people survive cancer and are living longer with cancer-related challenges, as medical technology and cancer treatment improve (Foster et al., 2018; National Cancer Institute, 2021). However, cancer incidence and mortality are growing rapidly worldwide, and cancer is expected to rank as the leading cause of death in every country of the world in the 21st century (Bray et al., 2018). Worldwide, the estimated number of cancer-related deaths in 2020 was close to 6 million, within the age category of 65 years and older; regarding women in this age group, the number of deaths was 2.5 million (International Agency for Research on Cancer, 2019).

As for the situation in Norway, close to 35,000 patients were diagnosed with cancer in 2019, of whom 46.5% were women. The most frequent types of cancer affecting women in Norway in 2015-2019 were breast cancer, lung cancer, colon cancer and melanoma. Lung cancer is increasing considerably among women over 70 years, with an almost tenfold incidence increase since the early 1950s. In addition, the incidence of breast cancer has increased in the last 60 years, mainly as a result of the implementation of the Norwegian Breast Cancer Screening Programme, which started in 1996 and has facilitated the diagnosis of more women at an early stage. Furthermore, and of concern is the huge increase in melanoma and non-melanoma over the last two decades, especially among the oldest age group (Cancer Registry of Norway, 2020). A significant element of the sharp increase in cancers over the last 50 years is also related to the fact that we live longer, have become numerous and the proportion of the older population is increasing (Cancer Registry of Norway, 2019). Despite this, more people survive cancer diseases, yet it is still the case that a significant number die of cancer each year. In Norway, 11,049 died of cancer in 2018, of which 5,218 were women (Cancer Registry of Norway, 2019). However, advances in treatments prolong the lives of many women, who also require comprehensive, long-term support (Ministry of Health and Care Services, 2020). This means that many older women live longer and might experience physical, psychological and existential illness-related challenges, reducing their quality of life. Moreover, although the treatments of incurably ill women have intensified and have been improved significantly, approximately 25% will die within a period of five years following their diagnosis (Cancer Registry of Norway, 2020).

1.3 Women's health and ageing in Norway

The rapid ageing of the population worldwide is also represented in Norway (Christensen & Syltevik, 2018; World Health Organization, 2018). The rising numbers of older people in Norway may be explained by the post-World War II baby-boom generation, who are now reaching retirement age (Eurostat Statistics Explained, 2020). In 2019, women in Norway had an expected life span of 84.7 years compared to men, with a life expectancy of 81.2 years. However, this differential is decreasing; the gender gap will be reduced to approximately three years by 2040. Notably, at the age of 60, the number of women and men is almost the same, and at the age of 85, there is an overrepresentation of women, among which the older age group comprises approximately twice as many women as men (Statistics Norway, 2018).

Overall, women seem to live healthier lives than men in Norway (Statistics Norway, 2018). However, according to the Global Burden of Disease Study from 2015, figures from Norway show that women tend to live with illnesses for a longer period of time than men, with women reporting more often that they are suffering from long-term health problems (Norwegian Institute of Public Health, 2017). To improve these health-related challenges for women in the most efficient way, adequate resources and an increased focus on individualized treatment, should be employed. This complies with a relatively recent report, summing up gender research in Norway (Kilden Gender research, 2018), which highlighted an increased number of older women in need of healthcare-related services now and in the future. The report further documents that many women in Norway suffer from complex and compound conditions, with most medical knowledge related to these conditions having been adapted to men's health. As for medical treatment, this report shows that older people, in particular older women, are at risk from the potentially inappropriate interactions of medication (Nyborg, 2017). The report also reveals that the quality of life for older women is considered vital, when living in their own homes. In particular, managing their own routines in everyday life has increased their sense of joy and accomplishment (Narum & Bergland, 2009). Furthermore, despite women's vulnerability when getting older and living at home, there is a general expectation that they should still fulfil their caring role in their family and should spend time providing care for people within their surroundings (Breimo, 2014; Christensen & Syltevik, 2013; Holmås et al., 2016).

Gender and age have been found to have an impact on the different municipal healthcare services provided. Older patients are, in general, less frequently referred to end-of-life care in the municipality than younger patients, and older women living with poor social networks and a low income, are often left out of this essential healthcare service (Ternstedt, 2015). Although Norway is considered one of the most gender equal countries globally, a number of challenges to gender equality remain (Women in Global Health Norway, 2020). One of these challenges is that HCPs in Norway lack knowledge on gender and women's health, as these crucial themes are largely absent in the educational system (Kilden Gender research, 2020). To ensure quality in Norwegian healthcare services for older, home-dwelling women with incurable cancer, there is a need to increase the level of knowledge relating to the social and historical context of gender differences in the current context of women's health in Norway.

1.3.1 Historical context

During the last few centuries, there has been a prominent development in women's lives related to health, employment activity, education and marriage patterns. As a result of these changes and the period in which they were born, women in Norway today have different views and experience different conditions in life when getting older (Ministry of Health and Care Services, 1999). Throughout the 1800s, a woman's body was viewed as an underdeveloped version of a man's body (Johannisson, 1996), and being older was regarded as being in an inferior position in previous centuries. In the early 1800s, we identified the starting point of today's older ageing group increment, and 'ageing' was introduced in the medical literature (Christensen & Wærness, 2021). A Norwegian study examining the historical and cultural conditions of ageing from the 1800s and 1900s found that older people were viewed as weak and dependent, and were regarded as individuals without legal capacity (Bakken, 2014). Women, irrespective of age, were seen as primary caregivers for both older people and children, without gaining any recognition. Simultaneously, women reported poorer health and were, therefore, described as vulnerable and sickly. Remarkably, they seemed to need this role of being sick and vulnerable, as they did not occupy important positions in society otherwise (Ministry of Health and Care Services, 1999). This situation has partly retained its influence on today's welfare state. However, an increasingly intensive labour market for both men and women has essentially stigmatized today's role of a housewife (Christensen & Wærness, 2021).

A confrontation within the women's movement occurred in the 1970s. This was related to the way in which women were excluded from politics, the working environment, education and appropriate medical treatments, due to their biological history (Ryste, 2003; Kilden Gender research, 2020). In particular, typical women's diseases, such as fibromyalgia, chronic fatigue syndrome and irritable bowel syndrome were characterized as vague, low-status illnesses, with little research having been carried out on these illnesses (Bergstrøm, 2013). However, fortunately, over the last 25 years, significant improvements have taken place to include women's health in Norwegian epidemiology (Schei & Rostad, 2015).

1.3.2 Current context

At present, the position of older women in Norway in 2021 is dramatically different compared to earlier centuries. A Norwegian governmental strategy plan (Ministry of Health and Care Services, 2016) presents a more educated population among the older women age group and there has been a shift from the image of older women as weak and passive, to resourceful individuals (Christensen & Wærness, 2021).

A recent governmental reform entitled, *'Live Your Whole Life'* focuses on this active older age group, currently enjoying good health and participating in the social community (Ministry of Health and Care Services, 2017). This reform presents improved municipal healthcare measures, with the aim that all older persons should be able to continue enjoying their daily lives, even when health issues arise and healthcare services are needed.

As for older women's health, there is, however, still a need for increased knowledge related to biological and social differences in gender. Likewise, there is a need to spread and implement existing results from research into women's health (Kilden Gender research, 2018). Furthermore, women's roles within clinical research are more visible, as they participate to a greater degree by contributing to the development of more tailored treatment within healthcare services. However, this focus is on younger women, meaning that most older women are still omitted from research studies (Rochon et al., 2020). Concerning end-of-life care, a recent study, based on existing knowledge and research into women's health in the UK largely found that gender issues in terms of patient care, research and policy had been unconsciously neglected (Gott et al., 2020). Although the two latter references are not related to Norway, we believe there are similarities within the Norwegian healthcare system. Additionally, it is of significant importance that existing, research-based knowledge on women's health also reaches healthcare students. Despite the promises of governmental parties in 2019 to prioritize research on women's health and to implement this into educational programmes (The Norwegian Directorate of Health, 2019), it seems that gender perspectives have not been defined in learning outcomes and plans and are dependent upon the interests and knowledge of each teacher (Kilden Gender research, 2020). Against this background, there is a great need for knowledge concerning women's health and ageing, despite most older women today being resourceful individuals. When becoming incurably ill, gender perspectives should be emphasized within the care for older women to fulfil their complex needs. This presupposes an increased demand on the organization of end-of-life care in Norway, as well as a greater responsibility on the HCPs when providing such care.

1.4 Organization of end-of-life care in Norway

Norway is founded on the principles of universal access to healthcare. Municipalities are responsible for primary care and are required to offer healthcare services to all inhabitants, whereas the responsibility for specialist care and hospital services lies with the central government (The Commonwealth Fund, 2020). As for end-of-life care, we find a dualistic version in Norway. On the one hand, within primary care is the municipal homecare service, GPs, CCs and palliative units or 'palliative beds' in nursing homes. On the other hand, there are specialized hospital palliative care units, comprising both palliative care wards and palliative home teams (Johansen & Ervik, 2018; The Norwegian Directorate Health, 2019). These two versions of organizing end-of-life care in Norway have different funding mechanisms, administrative, political and professional cultures, as well as various collaboration systems (Romøren et al., 2011).

The Norwegian healthcare system is ranked highly internationally and is built on principles of equality for all citizens. The aim is to give all inhabitants, regardless of social or economic status, the same opportunities and access to healthcare services. Moreover, Norwegian municipalities have taken over the majority of the welfare state's tasks from the government over the last 20 years and have a great responsibility to provide adequate healthcare services (Ministry of Health and Care Services, 2018; Ringard et al., 2013). Efforts to ensure equal access to healthcare services are, however, challenged by geographical variations, such as local healthcare structures, economic aspects and healthcare resources (Fiva et al., 2014). Importantly, a new restructuring process began in the mid-1900s, called New Public Management (NPM). NPM was intended to make the Norwegian healthcare services more efficient by adopting organizational structures from the business sector. This development resulted in more competition and a variety of new organizational forms. Even if the intention has been to promote good services, a problematic outcome has been identified, related to the overarching focus on efficiency, as it is difficult to observe or verify the quality of a service (Boe & Kvalvik, 2015). In 2012, the Norwegian Ministry of Health and Care Services (2008-2009) introduced a Coordination Reform, aiming for a stronger multidisciplinary collaboration across different healthcare levels, in which patients should have a more explicit role. Norway appears to be hospital-centric among patients older than 65 years and has a high expenditure of patients dying with cancer (Bekelman et al., 2016). This may indicate that end-of-life care appears to be such a complex matter that most patients need specialized end-of-life care, when nearing death in Norway. However, it has also been identified that most oncologists at the hospital's outpatient clinic strive to refer cancer patients to palliative care early in the disease trajectory and include the municipality in this process to ensure the patient receives professional end-of-life care close to home (Brenne et al., 2020). This will facilitate a greater requirement for end-of-life care in the municipality.

1.4.1 Municipal end-of-life care

In Norway, the 356 municipalities are at the lowest governmental level and are responsible for providing primary health care, long term care services, homecare services and social care provision (Saunes et al., 2020). The Health and Welfare Offices in the municipalities are responsible for the way in which local healthcare services are organized, whereas the healthcare system distributes the resources to the different types of services (Norwegian Ministry of Health and Care Services, 2011).

Homecare services

One of these services, a fundamental source of care for older, home-dwelling women with incurable cancer, is homecare services. This service is an essential part of Norway's healthcare system and aims to ensure people remain at home for as long as possible. A key aim is also to reduce the number of unwanted and unnecessary hospitalizations. Moreover, among the group of older patients who require comprehensive homecare services, assisted living facilities or senior apartments, may be preferred and reasonable solutions (Munkejord et al., 2018). It appears, however, that it is rather challenging for the homecare organization to allocate fair services and to tailor these facilities to individual needs (Holm et al., 2017).

Within the homecare services, HCPs have a great responsibility when providing end-of-life care for patients and their families. The HCPs who see patients most often and are directly involved with daily end-of-life care are registered nurses, healthcare workers and care assistants. HCPNs and oncology nurses are also part of the homecare services in many municipalities, having a postgraduate diploma in either oncology nursing or palliative nursing – often holding an expert role (Lie, et al., 2018). To ensure the correct level of end-of-life care for home-dwelling patients, Danielsen et al. (2018) identified certain conditions that should be present in the homecare service team. There is a need for flexibility in shift plans and working lists, as well as a 'silent agreement' among HCPs to help and support one other when a patient's death is imminent. Without this flexibility, an increased possibility of the patient being admitted to the hospital was identified. To avoid such re-admissions and to strengthen and support the 24/7 care given, collaboration between HCPs in the homecare services, GPs and CCs is crucial. GPs and CCs are further described as key professionals within end-of-life care in the municipality and will be presented in the following sections.

General practitioner

GPs have a vital role in providing general end-of-life care to home-dwelling, older women and have the advantage of a long-term relationship with patients and their families (Almaawiy et al., 2014; Ko et al., 2014; Danielsen et al., 2018; Kjellstadli et al., 2020). Each GP is responsible for a number of patients in the municipality, which is regulated in the patient list system, introduced in Norway in 2001 (Regulations of the Regular GP's Scheme, 2012). In this system, the GP has an overall coordinating responsibility for care and treatment in the healthcare system (Romøren et al., 2011). For patients with cancer, the GP has an important role in understanding and exploring symptoms, treatments and side effects. The need for contact with the GP usually increases if the cancer progresses and the patient is nearing end-of-life. Psychosocial care and supporting patients and their families, as well as being a mediator between the patient and specialist care are crucial tasks (Holtedahl et al., 2018).

Cancer coordinator

In terms of key professionals within end-of-life care, Lie and colleagues (2018) present the role of the CC, also having specific responsibility for cancer patients and their families within the municipality. The CC is a nurse with a post graduate diploma.

He or she has a dependent function, assisting in coordinating and facilitating individual care for cancer patients, and fulfilling a collaborative and interdisciplinary role in the municipality (Lie et al., 2019). The overarching aim of the Norwegian Cancer Society (NCS) is to ensure that all Norwegian citizens have access to the service provided by a local CC, irrespective of whether they live in a big city or in outlying areas. In 2019, 70% of Norwegian inhabitants had this opportunity (Norwegian Cancer Society, 2020). The CC role is highly diversified across Norway, due to the NCS, who assigned the municipalities the responsibility of developing and implementing the CC position, in accordance with its context and needs (Syse & Moshina, 2015; Melby et al., 2017). Consequently, most CCs described the establishment of their role as ‘pioneering work’, which was surprisingly lonely and self-sufficient, while fulfilling a demanding position (Lie et al., 2019). Furthermore, several CCs experience a lack of understanding of their role from other HCPs, both in the municipal healthcare system as well as in specialized care. They also experience an enormous workload, not being defined in priority areas, with a broad range of potential tasks. However, despite the challenges, the uniqueness of the CCs lies in their autonomous work, determining how they can best help cancer patients and their families (Lie et al., 2019). In particular, when patients decide to die at home, the CC’s guidance and expertise are essential.

1.4.2 Dying at home

Among the general population worldwide, most people prefer a home death, and around 80% of patients do not change this preference despite the progression of an illness (Gomes et al., 2015). There is considerable country variation with regard to death, often explained by the way in which each country organizes end-of-life care and its healthcare resources (Cohen et al., 2015; Kjellstadli et al., 2018). The proportion of people dying at home ranges from 12% to 60% in Europe (Abel et al., 2013; Gomes et al., 2013; De Roo et al., 2014) and as for patients with incurable cancer in Norway, 12.4% died at home in 2019. This has been a gradually decreasing trend for many years (Norwegian Institute of Public Health, 2019). From the same source, statistics show that 33% of cancer patients died in hospital and 52% of all patients with incurable cancer died in other institutions, mainly in nursing homes.

Irrespective of the low number of patients dying in their homes in Norway, the concept of ‘home’ is crucial for older people. It is a place where many have lived for years, where they have their routines and feel safe. Despite worsening health, many older people strive to remain in their homes (Munkejord et al., 2018). Shepperd et al. (2016) have reported in a review that patients receiving end-of-life care at home felt more at peace during their last days of life than patients who died in hospital. Importantly, the level of grief among family members, was found to be less intense when the patient died in his/her home.

On the other hand, the home has become an unsafe place for some, when feeling anxious and lonely. This has been found in different studies revealing the complex reality of caring for older people in their home when nearing end-of-life (Aoun et al., 2016; Kjellstadli, 2020; Hov et al., 2021). To fulfil patients’ wishes and to create comfortable and safe conditions, there is a need for several elements to be optimized; an early discussion of the patients’ and ICs’ preferences, a pro-active GP making home visits, as well as policymakers implementing comprehensive end-of-life care at home (Gomes et al., 2015; Danielsen et al., 2018). Consequently, if the these elements are not enhanced, a crisis in the home of the patient and the caregiver may occur. A crisis could then result in re-submission or an undesired death in hospital (Gomes et al., 2015; Knighting et al., 2016). Therefore, it is essential to increase knowledge concerning end-of-life care at home, as experienced by patients, ICs and HCPs. In this project, we focus on dignity-preserving care as an important source for meeting the needs of older, home-dwelling women, living with incurable cancer at home.

1.5 Dignity

It is important for HCPs to address suffering extensively and to bolster the sense of dignity for older women who live in their own homes. To do so, this requires professional end-of-life care and an interest and desire to know the person you care for (Franklin et al., 2006; Aoun et al., 2016; Oosterveld-Vlug et al., 2014). However, what is dignity, and how can we incorporate this complex concept into healthcare services?

Despite the intricacy, the concept of dignity is a value philosophy and can be operationalized to articulate values, define goals, promote policies and defend services (Brennan, 2014). Pullmann (1999) also emphasizes the philosophical view of dignity, stating that basic human dignity is ascribed to all humankind, irrespective of colour, class or creed. Several international organizations acknowledge dignity as a crucial need, a fundamental right and an inherent quality of every human. As an important foundation for the Declaration of Human Rights, The United Nations (1948) emphasize that all human beings have an inherent dignity. In addition, the Declaration on the Promotion of Patients' Rights in Europe (World Health Organization, 1994) highlights the patients' right to be treated with dignity, while the Universal Declaration on Bioethics and Human Rights promotes human dignity and respect, related to bioethical principles (UNESCO, 2005). Furthermore, the ICN Code of Ethics for Nurses (ICN, 2012) underlines how the preservation of dignity is an essential part of caring. In Norway, the ethical guidelines for nurses (the Norwegian Nursing Association, 2019) accentuate similar crucial perspectives, aimed at preserving dignity, stating that the basis of all caring is founded upon the inherent dignity of all human beings. For GPs, the World Medical Association (2018a) declares that within 'The Physician's Pledge' the autonomy and dignity of each patient should be respected.

A political regulation entitled, *The Dignity Guarantee of Elderly Care* came into force in 2011 in Norway (Ministry of Health and Care Services, 2010). According to this regulation, the Norwegian health and care authorities should encourage all municipalities to guarantee their citizens a meaningful life and a dignified death, in line with their individual needs and preferences. Two more recent governmental reports in Norway (Ministry of Health and Care Services, 2017, 2020) underline the concept of dignity as being one of the leading, value-based principles in the future care of patients. The reports emphasize that each human being should be listened to and his or her wishes respected when nearing end-of-life.

Concerning dying with dignity, Chochinov et al. (2002; 2005; 2011) reveal that subjective dignity can be experienced within the end-of-life phase. They developed a psychological intervention, a ‘Dignity Therapy’, to assist people dealing with the imminent end of their lives, giving them opportunities to talk about complex issues. Several other perspectives of dignity have been identified when exploring the view of dignity-preserving care. Nordenfelt (2004) has developed a theory that describes four varieties of dignity; the first perspective concerns dignity linked to *human-dignity* (Menschenwürde) and the *inner* sense of dignity. Humans experience this type of dignity solely by being human. Secondly, *dignity of merit* deals with a person holding a special role or status. This type of dignity can come and go, for instance, when being recognized by others for something you have achieved. Thirdly, *dignity of moral stature* is attached to human beings earning value by good deeds. An example might be representing the resistance during the Second World War. The last perspective concerns *dignity of identity,* anchored in personal autonomy, integrity and self-respect. This is related to feelings of being valued or not valued, as disrespect of others can violate a person’s feelings and their sense of dignity. Clearly, Nordenfelt states that people who attain high office and demonstrate good morals, deserve respect. However, an appeal to *Menschenwürde* could be said to override particular respect for merit or moral stature, in so far as the nursing practice is concerned (Gallagher et al., 2008). Gallagher argues that *human dignity* does not only mean acknowledging someone or something worthy. We need to go further and say that we must preserve and engage with worth or dignity, which means that nurses need to understand the circumstances that promote or violate dignity (Gallagher, 2009). When dignity is applied to healthcare, Jacobsen’s (2007) awareness of the epistemological fundament is also important. Her review of ‘Dignity and Health’ has an interprofessional perspective. She describes two perspectives of dignity: *human dignity*, which belongs to every human being as a universal quality of value and cannot be destroyed, and *social dignity,* generating the interactions between and amongst individuals and societies. The last perspective may be divided into two types: *dignity-of-self;* the quality of self-respect and self-worth, and *dignity-in-relation*; the ways in which respect and worth are conveyed through individual and collective behaviour, respectively (Jacobson, 2009). Considering the fundamental view of dignity, the Finnish theorist, Katie Eriksson (1996), directed her research towards the ontological perspective of human nature. She argues that each individual has an inherent, absolute dignity. Absolute dignity is undeniable and is granted by virtue of being human, while the term relative dignity relates to concepts of self-worth and the experiences of human values in relation to others. Relative dignity is modifiable and can increase through the support and confirmation of others and can be torn down by violation (Eriksson, 1994, 1996, 2018; Lindström et al., 2018).

The previous section has shown a variety of national and international strategies, concerning the implementation of the concept of dignity. Despite this wide range of descriptions, there is a lack of consensus regarding the conception of dignity, as well as a critique arguing the vagueness of this concept (Billings, 2008; Gallagher, 2011). However, it seems to be generally accepted that dignity is a crucial element, defining 'being of value or worth because of the presence of some necessary characteristics' (Gallagher et al., 2008). Interesting are the arguments of Baillie et al., (2008) who claim that dignity is not just the responsibility of HCPs, it is also a governmental obligation. They state that a paradox exists in which, on the one hand, the government does not accept undignified care but on the other hand, allows targets that are inherently undignifying. Such governmental principles and guidelines cannot guarantee older, home-dwelling women dignity-preserving care, neither can researchers promise changes when identifying this topic broadly. However, we can send clear signals to prioritize the conditions for dignity as a basis for the future care of this patient group. Therefore, we argue that governmental plans, both national and international, should be supplemented by crucial sources from research, providing direction for dignity-preserving care for older, home-dwelling women living with incurable cancer.

1.5.1 Dignity-preserving care – a review of the literature

I conducted several systematic literature searches between June 2018 and August 2021. Combining the search terms 'dignity' and 'end-of-life care', published between January 2010 and August 2021, gave me a detailed insight into the research relating to care, which preserves dignity among people nearing end-of-life. Considering the aim of the study to a greater extent, I searched for studies that would help me explore the perceptions of dignity within end-of-life care, from the perspective of older women living with incurable cancer at home. Additional search terms used were ‘personhood, terminal care/ill, palliative care, death/dying, home, cancer/neoplasm’.

A growing body of literature reveals that there are many research studies concerning dignity in the context of palliative and end-of-life care. Appendix 1 presents an overview of articles, based on both qualitative and quantitative studies, although primarily qualitative studies, describing the perspective of patients living with an incurable illness. The context of municipality care is found in two reviews, in which dignity was explored from the view of community nurses (Johnston et al., 2015; McIlfatrick et al., 2017). The reviews emphasize the home of a patient as a complex setting, both to fulfil the needs of patients in need of palliative care and for nurses who may not feel equipped to address and ensure dignity in end-of-life care. When searching for ‘dignity’ in combination with ‘cancer’ we found an integrative review, highlighting how patients with cancer experience dignity. As this diagnosis and its treatment can be associated with a prominent issue of loss of dignity, we found that coping strategies should be fostered to control the physical and psychosocial factors threatening their sense of dignity (Xiao et al., 2021). To my knowledge, no studies explore the perspectives of older women, who have an incurable cancer diagnosis related to dignity and end-of-life care.

The literature further reveals a great degree of heterogeneity in the exploration of dignity, however, also some common components. First and foremost, several studies highlight that dignity is an ambiguous concept with many aspects relating to end-of-life care, as well as a subjective term comprising individual interpretations (Guo & Jacelon, 2014; Johnston et al., 2015; Choo et al., 2020). They suggest a more individual exploration of dignity-based care and stress that the promotion and maintenance of dignity are also important beyond palliative care. This means that dignity should be adapted within research for patients living with all types of diagnoses, and at all stages, from the moment of diagnosis until death. Another general outcome of the literature review, emphasizes the importance of a person’s sense of autonomy and control in life. This is linked to the patients being able to facilitate their daily living and make their own decisions in life, when experiencing loss of functionality (Guo & Jacelon, 2014; Johnston et al., 2015; Harstäde et al., 2018; Choo et al., 2020; Xiao et al., 2021). According to Rodriguez-Prat et al. (2016), dignity is understood as the desire for self-determination and the desire for control over the dying process. Related to this process, correct symptom control and the relieving of distress are described as crucial promotors for the patient to experience the meaning of dying with dignity (Östlund et al., 2011; Guo & Jacelon, 2014; Johnston et al., 2015; Harstäde et al., 2018; Östlund et al., 2019).

Several studies have utilized the Chochinov Model of dignity, also called Dignity Therapy (DT) or Dignity Care Intervention (DCI), a psychotherapeutic intervention for people facing serious illness (Fitchett et al., 2015). This intervention has also been adapted to a Swedish context, with the aim of encouraging nurses to provide quality palliative care and to strengthen a person-centred care that will conserve patients' dignity (Östlund et al., 2011; Harstäde et al., 2018; Östlund et al., 2019). These studies present 'care actions' or suggestions to preserve dignity in relation to certain issues, which is similar to themes and concrete findings from all studies in this literature review. Examples of care actions include listening to patients and taking them seriously, providing the correct information and advice, relieving symptom distress, facilitating daily living and including patients in decision-making processes (Östlund et al., 2011; Harstäde et al., 2018).

In general, the importance of existential concerns and the experience of a sense of meaning and hope was identified in several studies (Guo & Jacelon, 2014; Fitchett et al., 2015; Choo et al., 2020). For patients nearing end-of-life, spiritual support was regarded as crucial from HCPs and their family, related to both religious questions and planning for their future with a degree of hope (Xiao et al., 2021). The studies further state that dignity-preserving care should respect patients' human autonomy to strengthen their sense of hope, acceptance and self-worth. Another vital aspect of the experience of dignity is the patients' connectedness with their family and friends. A number of studies draw attention to the importance of the family in constructing the patients' sense of dignity (Guo & Jacelon, 2014; Fitchett et al., 2015; Xiao et al., 2021). Choo et al. (2020) illustrate how patients longed to develop emphatic bonds within their social networks for empowerment and support, and how this was found to safeguard their dignity. On the other hand, familial dimensions also result in a great responsibility for ICs, as well as distress for the patient, when worrying about being a burden to others in various ways (Johnston et al., 2015). Therefore, as found in Guo and Jacelon (2014), the closest family members should also be included when discussing physical, psychological and spiritual support for dying patients.

In summary, this review of the literature shows a repeated emphasis on the importance of being respected as a human being, including the maintenance of one’s autonomy, control, self-worth and acceptance in life. However, the literature also repeatedly reports that these values are often violated (Rodríguez-Prat et al., 2016; Harstäde et al., 2018; Choo et al., 2020; Xiao et al., 2021). Nonetheless, there should be an increased focus within healthcare policies to promote the provision of dignity in end-of-life care, as well as highlighting that dying with dignity is a human right (Guo & Jacelon, 2014).

2. Rationale of the thesis

With the rapid ageing of the population worldwide, most of these individuals are women. Women live longer than men, report more illnesses, have a poorer health status and experience a lower, health-related quality of life in later years. As for older women with cancer, 75% have a five-year relative survival rate and live longer with cancer-related challenges (Cancer Registry of Norway, 2020). Consequently, this may lead to older women having multiple and complex symptoms and experiencing suffering affected by their illness, which requires high-quality end-of-life care of an interdisciplinary nature. This warrants sufficient healthcare resources, recognizing gender differences, the correct alleviation of symptoms, as well as respectful and supportive care (Baum et al., 2021; Cain & Denny, 2018; Miller & Nevadunsky, 2018; National Cancer Institute, 2021; Torre et al., 2017).

As an important foundation for the *Declaration of Human Rights*, The United Nations (1948) emphasizes that all human beings have an inherent dignity. Other international organizations acknowledge this view by highlighting dignity and respect as qualities and crucial needs for every human being (UNESCO, 2005; World Health Organization, 1994). For both nurses and physicians, The International Council of Nurses ICN (2012) and World Medical Association (2018a) confirm that dignity-preservation is a core aspect of treatment and caring ethics. In the Norwegian context, ethical guidelines for nurses accentuate similar crucial perspectives to preserve dignity, stating that the basis for all caring is founded upon the inherent dignity of all human beings (Norwegian Nursing Association, 2019). This is in line with the Dignity Guarantee, a regulation aiming to encourage all Norwegian municipalities to ensure that their citizens have a meaningful life and a death with dignity, in accordance with their individual needs and preferences (Ministry of Health and Care Services, 2010). Moreover, the Norwegian legal system underlines that healthcare services should respect and safeguard the individual patient's integrity and human dignity (Norwegian Ministry of Health and Care Services, 2011; Patient and User Rights Act, 2001).

Despite an expanded knowledge and interest in women's health, little is known about older women living with incurable cancer in their home. There is still a disproportionate number of women included in medical research worldwide, showing that women's health and disease have long been ignored. Therefore, to improve women's health in Norway and worldwide, there is a need for adequate resources to be distributed as well as an increased focus on clinical research (Rochon et al., 2020). As previously mentioned, receiving dignity-preserving care is a human right and should be adapted to patients irrespective of their dwelling. However, organizational conditions, as well as HCPs attitudes and principles may influence experiences leading to dignity and dignity loss for older women. Therefore, both national and international policies should be supplemented with research-based knowledge and an increased understanding of sources, leading to a dignity-preserving care practice for older, home-dwelling women.

2.1 Aims of the thesis

The overall aim of this project is to identify and document experiences related to dignity and dignity loss of older women, living with incurable cancer at home. Against this background we will develop an empirical-theoretical model of dignity-preserving care for this female patient group. We explore this aim from the perspectives of three crucial sources, namely, from the perspective of 1) the older women themselves (study I); 2) the ICs of older women (study II) and 3) the HCPs who include GPs, CCs and HCPNs (study III). The following research questions were addressed:

Study I: How can dignity experiences of older women living with incurable cancer at home be preserved? How do older women, living with incurable cancer at home, describe their experiences leading to dignity loss?

Study II: How do ICs perceive sources related to dignity and dignity loss of home-dwelling, older women with incurable cancer nearing end-of-life?

Study III: How do GPs, CCs and HCPNs perceive value-based principles and organizational conditions of dignity-preserving care for older, home-dwelling women with incurable cancer?

3. Ontological perspective

An ontological perspective relates to the nature of reality and its characteristics. As researchers, it is crucial to document the ontological foundation on which the research is based, when searching for a deeper understanding of a phenomenon under investigation (Creswell & Poth, 2018, pp. 18, 20). My supervisors and I needed to position ourselves in relation to the subject of the enquiry, the research questions to be explored and the data collected for interpretation. According to Eriksson and Lindström (2009) caring is the core of nursing as a profession and the subject matter of caring science, which aims to promote health, alleviate suffering and protect patient's dignity. This corresponds to our interpretation of nursing care. Thus, to understand the empirical data collected throughout this research project, we found Katie Eriksson's Theory of Caritative Caring to be valuable as a theoretical foundation. This theoretical foundation consists of several crucial concepts, and some of these will be presented here.

3.1 Katie Eriksson's Theory of Caritative Caring

Katie Eriksson is a pioneer within nursing and caring science in the Nordic countries and started her scientific career in the 1970s (Lindström et al., 2018). Her Theory of Caritative Caring represents a non-medical paradigm, concerning the phenomena of nursing and the nursing care process. *Caritas*, means 'love and charity' and constitutes the motive for all true caring (Eriksson, 2002, 2006; Lindström et al., 2018; Fagerström et al., 2020). According to Eriksson, this is seen as a core foundation and endeavour of caregiving, aimed at preserving dignity among patients living with an incurable illness. Caring for these patients involves a will to utilize and mediate faith, hope and love (Lindström et al., 2018; Fagerström et al., 2020).

In Eriksson's later career, the nursing process became the *Caring* process which began a search for the wholeness and unity of caring (Näsman, 2020). Since Eriksson's perspectives of caring are general and do not view this science as profession-oriented, her theory has proved to be applicable in all caring contexts. Hence, she emphasizes the importance of medical doctors studying caring science to achieve a genuine interdisciplinary collaboration (Lindström et al., 2018), which also includes GPs as study participants within this research project.

Within Eriksson's perspective of caring, *ethos* is a core concept and a core value of all human beings. Ethos becomes ethics in practice through relational interactions with others (Eriksson, 1995); when considering ethics and health ontologically, ethos constitutes values that have been formed through culture and history. It refers to our habits and the way in which we do things, discussed in terms of moral norms and principles (Eriksson, 2003; Östman et al., 2019). Another central concept in the caritative caring theory is *caring communion*, which underlines the important context of caring and is determined as a form of intimate connection that characterizes caring. Being part of the caring communion means creating opportunities for one other, uniting and tying each other together, making caring significant (Lindström et al., 2018). To enter the caring communion, an *invitation* from another is required. Eriksson uses the concept of invitation as an act that occurs when the carer welcomes the patient to the caring communion, a place where the patient can rest, experience hospitality and where the patient's appeal for charity meets a response (Lindström et al., 2018). Importantly, the responsibility for this invitation lies with the carer. Eriksson claims that being present in a caring situation is an act of ethics, as one obliges oneself to see, hear and witness the needs of the suffering human being. As formulated in her mantra of caring ethics, "I was there, I saw, I witnessed, and became responsible" (Eriksson, 2013, pp. 70), Eriksson clearly portrays this ethical obligation and substantial responsibility within caring, promoting the good and resisting the evil (Eriksson, 2002; Nåden & Eriksson, 2000; Lindström et al., 2018).

3.1.1 The suffering human being

In this research project, *the suffering human being* is anchored in Eriksson's ontological foundation of caring science (Eriksson, 1992a, 2006; Lindholm & Eriksson, 1993). According to Eriksson (1987), health and suffering are inseparable parts of being human. The human being is seen as an entity of body, soul and spirit, and *health* applies to the concepts of wholeness and holiness (Lindström et al., 2018). We might think that health and illness are opponents, however Eriksson (2006) asserts that not illness, but *suffering* is the opposite of health. Suffering is the primary category of all caring, and if all suffering were removed from the world, nursing care would not be necessary (Fagerström et al., 2020). Eriksson emphasizes three different forms of suffering: *suffering related to illness*, *suffering related to care* and *suffering related to life*. Firstly, suffering related to illness concerns the experience of illness and treatment, where for example, physical pain captures a human's attention. According to Eriksson this form of suffering is a unique isolated experience and is not synonymous with pain (Eriksson, 1984, 1992b, 1994). Secondly, *suffering related to care* is the most usual source of dignity-violation in the patient-carer interaction. This is a form of suffering affected by uncaring attitudes and the behaviours of caregivers, having restricted awareness or lack of knowledge, preventing them from bringing the patient's wishes and needs to the forefront (Eriksson, 2006; Lindström et al., 2018). Thirdly, s*uffering related to life* concerns one's own unique life in which all aspects of being human are involved. This form of suffering is also related to circumstances disturbing the rhythm of life and situations threatening the safety in everyday living. Aspects associated with suffering related to life are feelings of loneliness, questions concerning the meaning of life and the living through various phases of life changes, due to developmental stages and life events (Näsman, 2020). Finally, when caring for suffering human beings, HCPs are presupposed to use their greatest sensitivity. As Eriksson (Lindström et al., 2018) emphasizes, a suffering person must receive confirmation of his or her dignity as a person.

3.1.2 Human dignity; serving with love for another

According to Eriksson (1996), dignity is a core concept describing the nature of human beings. She states that "human dignity means accepting the human obligation of serving with love" (Eriksson, 2001, p. 76). A person experiences dignity and a sense of mission in the purpose of serving or existing for another person, and the deepest motive in all caring involves respect for the absolute dignity of each human being (Eriksson, 2001; Naden & Eriksson, 2000). This brings me to present two forms of human dignity within the basic ethos concept of caritative caring (Eriksson, 1996;

Edlund, 2002): a*bsolute* and r*elative dignity.* Absolute dignity is an inherent and inviolable part of the human being, granted through creation and can neither be called into question nor be taken away. Relative dignity on the other hand, is a modifiable form of dignity that can both increase through the support and confirmation of others and can be torn down by violation, thus influenced by external contexts and cultures. Eriksson (1996, 2006) further divides relative dignity into inner and outer parts. *Inner dignity* refers to the internal freedom of human beings, enabling them to relate to themselves and their situation, while *outer dignity* characterizes a bodily and external dimension. Therefore, one might say that the source of personal worth is based upon its inner value and outer surroundings, surroundings being the place in which a person resides – one's living space – that has substantial meaning.

3.1.3 The search for health promotion within three living spaces

Eriksson (1987b, 2018) presents the theoretical concept of *living space* of the human being, constituting a foundation for movements in health processes while searching for health promotion. To ensure emotional safety and experience dignity in the place in which you reside, three different living spaces should be optimized. Firstly, in the *physical living space*, Eriksson (2018) highlights the primary functions in life to be enhanced, concrete situations found to be dignity-preserving in a safe and caring physical environment. Yet, Eriksson uses the term *caring culture* instead of environment and contexts, which characterizes the total caring reality founded upon cultural elements such as traditions, rituals and basic values (Lindström et al., 2018). Secondly, the *psychosocial living space* concerns relationship interactions between human beings. When experiencing the power of a caring relationship in this living space, human beings feel confirmed and recognized. Thirdly, within the last living space, known as the *existential living space,* Eriksson (2018) emphasizes experiences on a spiritual, cultural and aesthetic level. On this level, inner thoughts, wishes and hopes are given the necessary space to promote a meaningful life. In summary, human beings live their lives in a vast living space that is composed of three smaller living spaces, in which they reside during life. These living spaces reflect on and highlight contextual life circumstances that might obstruct the movement between the different human living spaces, leading to experiences of dignity loss. (Eriksson, 2010;

Rydenlund, 2012). Being incurably ill, and in need of support from a variety of healthcare services, is an example of such life circumstances affecting a patient's living space. In this context, it is also important to acknowledge that each person has individual boundaries and potential capacities to achieve optimal health (Eriksson, 2018). As for the ontological caring perspective, this achievement of optimal health is conceived as a developing movement towards a deeper wholeness – a forward-moving motion to fulfil one's potential in life (Rydenlund, 2012; Lindström et al., 2018).

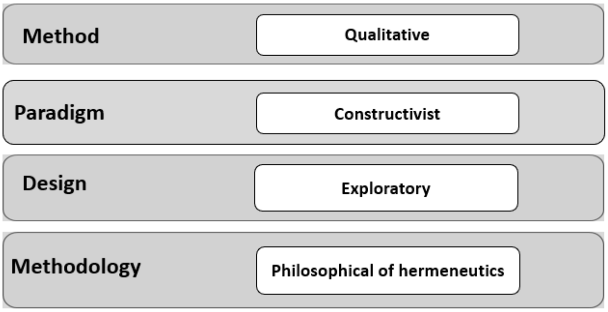
4. Methods

In this chapter, I will first introduce the epistemological foundation and study design within the constructivist paradigm. I will then describe Gadamer's philosophical hermeneutics (2010), determined to be a suitable methodology for this research project, as the main objective of this thesis is to explore people's experiences related to a phenomenon. Subsequently, in line with the philosophical hermeneutics, the researchers' pre-understanding will be thoroughly examined before the process of user involvement in the project is described. Finally, I present all three studies separately and give an account of the ethical considerations related to this project.

4.1 Epistemological foundation and study design

As Creswell and Poth (2018) maintain, epistemology is a philosophical assumption, referring to what counts as knowledge and how the researcher perceives reality, as well as how the researcher understands and learns about various phenomena. In this project, we turn the world into a series of representations by utilizing participant observations and interviews. Guiding us in this process, our study was grounded on the *constructivist paradigm*. This means that reality is not settled in advance, but rather exists within a context in which many constructions are possible (Polit & Beck, 2017). The constructivist paradigm is well suited to research concerning health-related questions and indicates that the enquiry process itself is important, focusing on people's lived experiences, understood as being located in a particular socio-historical context, rather than existing as a collection of external 'facts' (Guba, 1990; Labonte & Robertson, 1996). Moreover, within the constructivist paradigm, knowledge is maximized when the distance between the researcher and the participants is minimalized; subjective interactions are of crucial importance in accessing and understanding the phenomenon of interest (Polit & Beck, 2017). To increase a deeper level of understanding and nuances within dignity-preserving care for older home-dwelling women, we experienced flexibility and creativity as crucial approaches in this study. According to Maxwell (2013), the constructivist paradigm constitutes a creative approach, necessary when developing qualitative research design. He emphasizes the importance of the interaction between the persons involved and the need to continually assess how the design actually works, so as to accomplish the researchers' objective. An exploratory design was, therefore, found as an appropriate approach within the constructivist paradigm for this research. As the term *exploratory* implies, it is designed to reveal underlying processes and shed light on various ways in which a phenomenon is manifested (Polit & Beck, 2017). Such exploratory design is commonly used within qualitative research and is needed when exploring phenomena that cannot be easily identified and described. A typical example when utilizing this design, is to explore and hear the silenced voices (Creswell & Poth, 2018). In this research project, an exploratory design was found to be appropriate, as we wished to gain an in-depth understanding of the phenomenon of dignity-preserving care, as perceived by older women, ICs, and HCPs. As Creswell and Poth (2018) highlight, this in-depth understanding can only be established by talking directly to people, going to their homes, allowing them to tell stories and exploring their experiences and perceptions of the phenomenon of interest, in line with the exploratory design.

Figure 1 An overview of the project



Method	Qualitative
Paradigm	Constructivist
Design	Exploratory
Methodology	Philosophical of hermeneutics

4.2 Gadamer's philosophical hermeneutics

In this research project, I have focused on Hans-Georg Gadamer as one of the crucial founders of the hermeneutical philosophy. He was engaged in questions concerning how understanding of a phenomenon is possible and used this to outline his 'Philosophical Hermeneutic', which was the essence of his major work, 'Truth and Method' (Gadamer, 2010). Gadamer claims that new understanding emerges as a result of our interpretations within a circular process, in which we move towards exploring and documenting the relationships between parts of the texts and the text as a whole. He calls this the *Hermeneutic circle*. Gadamer also describes prejudice and preunderstanding as necessary conditions for our understanding (Gadamer, 2010), depending on the condition of each individual's horizon of understanding. 'To have a horizon' does not mean being limited to what is nearby, but being able to see beyond what is close at hand (Gadamer, 2010). Moules et al. (2015) explain the horizon as the coming together of two or more understandings of a topic, in addition to the curiosity of the researcher and the desire to understand the subject in a new way. Together, the Hermeneutic circle and the fusion of the horizon will bring forth meaningful interpretations from the empirical data, helping to further understand the subject under investigation.

4.2.1 A Gadamerian-based research method

Gadamer states that the ability of understanding does not need an awareness of rules. He argues that the ability to be prepared for and open to what can be found in the empirical data, leads the researcher to discover new understandings, creates possibilities and allows new horizons to come forth (Gadamer, 2010). Our research questions in studies I, II and III influenced the whole research process and guided us in gathering rich and purposeful data, which according to Gadamer (2010), leads to the opening up of possibilities for understanding. As a research team, we had a critical and curious approach during the whole project period, in line with Gadamer's view, asserting there is no understanding without the activity of questioning (Gadamer, 2010). Asking questions is also an appropriate approach when researchers need to provoke one's pre-understanding. By periodically reviewing our pre-understandings, we were able to enter the Hermeneutic circle (Gadamer, 2010) and remain orientated with the phenomenon under investigation. The researchers' pre-understanding is further described in part 4.3. Gadamer (2010) claims that a dialogue between the researcher and the participants is suitable for achieving an understanding of a phenomenon of interest. However, in this sense, the perception of dialogue not only means a conversation between two or more people, but also a dialogue between the reader and the text (Fleming et al., 2003; Gadamer, 2010). The interpretation is, in a sense, already underway during the data collecting phase, as well as during the transcription. This brings closeness to the participants and the read transcripts, listening not only to what was said or noted in the first place (Moules et al., 2015). Gadamer (2010) reiterates the power of the spoken words over the written, however, on the other hand, he argues – along with Eriksson (2010) – that spoken and written words are prerequisites for understanding the substance of a phenomenon. In our research project, text refers to taped words, transcribed interviews, written comments about the interview situation, as well as notes from participant observations, all to achieve common understanding (Fleming et al., 2003; Gadamer, 2010). Being inspired by Gadamerian hermeneutics in this research has helped us expand the horizon of understanding related to dignity-preserving care, and to further explore how new understanding could be further developed within a Hermeneutic circle (Gadamer, 2010). To do this, it was also crucial to examine our pre-understanding thoroughly.

4.3 The researchers' pre-understanding

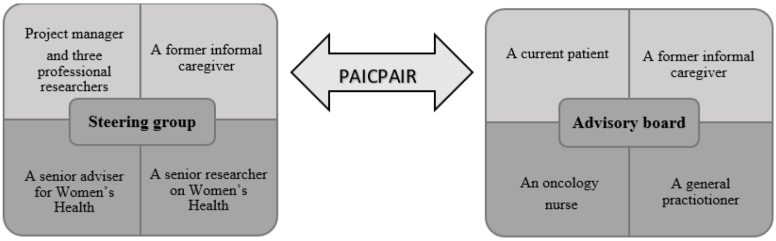
Pre-understanding is a necessary condition for understanding within a hermeneutic tradition (Gadamer, 2010). For me as researcher, pre-understanding is constantly changing, as I continuously gain new experiences, leading to a new understanding of the subject under investigation. This process needs to be transparent and is a prerequisite for the reader to achieve full clarity in relation to his own intentions, allowing him to position himself in relation to the text to be interpreted (Malpas & Gander, 2014).

My own pre-understanding is founded on my clinical experience as a nurse and an oncology nurse within the municipality healthcare services. Before commencing nursing studies in The Netherlands, I worked as an assistant in nursing homes, homecare services and within assisted living facilities for adults with mental disabilities. During my work period as a nurse within homecare services, I undertook further training in oncology and entered a CC position. My main task was to care for patients living with terminal cancer and to support their families. I was preoccupied with arranging for patients to fulfil their wish to die in their own homes, should this be preferred and be possible. During the PhD period, when collecting empirical data, I used my experience as an oncology nurse when communicating with incurably ill cancer patients and ICs concerning their present life situations. I also used my previous knowledge regarding multidisciplinary collaboration, which gave me a professional standing and ensured confidentiality during the interviews with the HCPs. Within the research team, our pre-understanding was not neutral and distanced, but influenced by a committed relationship to the subject under investigation, which we discussed throughout the research process. My supervisors and I have considerable clinical experience from psychiatric care, homecare nursing, palliative care and end-of-life care at home, intensive care and nursing home medicine. Within our research and academic interests, our experiences range from scholarship and research related to dignity as an ontological and ethical aspect of humanity and a person-centred approach, to large-scale randomized trials within nursing home medicine. Study III also included the view of a researcher, experienced within the fields of welfare sociology, care work and gender. We had different presumptions concerning the outcome of the study. For example, in study I, we believed that the older women appreciated having a sense of control in life and that they would perceive staying in familiar surroundings as a crucial dignity-preserving source. In study II we assumed that the ICs would be of the opinion that the dignity of these older women might also be affected by formal healthcare structures, leading to situations in which the older women received care from a large number of HCPs. We also anticipated that the women would be exposed to unstructured planning in transitions. In study III, our pre-understanding led us to expect that limited resources within healthcare services could potentially lead to a limited presence of HCPs and a reduced quality of care. We also expected HCPs to have a critical and uncertain attitude concerning the concept of dignity. These presumptions and expectations of the results were described in detail in the methodological sections of the papers.

4.4 Patient and IC participation in research

As qualitative researchers, we strive to understand both patients' and their caregivers' perspectives when providing information about their world, as well as their experiences of healthcare. Therefore, to be able to answer the relevant questions in research projects, we needed to listen to their valuable insights and opinions, and monitor their lived-life experiences, based on the power of their voices (Manera et al., 2018; Landstad et al., 2020). When planning for the recruitment of representatives undergoing similar life situations to the study participants, we identified a lack of ethical guidelines. Therefore, to achieve active participation among vulnerable people experiencing incurable, life-threatening illnesses, we had to think differently and innovatively, leading us to develop the framework, 'Patient and Informal Caregiver Participation in Research' (PAICPAIR) (Staats et al., 2020b). In line with previous research (Blackburn et al., 2018; Hoddinott et al., 2018), we acknowledge patient and IC representatives as experts in the subject under examination, contributing their unique experiences to all phases of this research project (Staats et al., 2020b). As suggested by Daveson et al. (2015), to ensure a real and meaningful impact on the research process, we emphasized the early and flexible recruitment of an advisory board and steering group members. One patient representative and one representative of the ICs were appointed to the advisory board, along with an oncology nurse and a GP from the municipal healthcare services. The steering group consisted of a former IC of an older woman with incurable cancer, a senior researcher and a senior advisor for women's health, as well as my supervisors and myself as research manager (see figure 2). The main tasks of the advisory board were to give their recommendations to the project plan, participating in formulating the study's aim, information letters, interview guides, as well as reviewing analyses and article drafts. The steering group discussed and approved substantial feedback from the advisory board and maintained an ongoing evaluation of the overall project process. The older women and former ICs, who contributed as co-researchers, were considered highly vulnerable in their present life situation. This required us as researchers to make ethical considerations. We humbly emphasized the exploration of their needs, provided emotional support and gave information concerning all sides of the research process, also stressing their right to exit the project at any time (Staats et al., 2020b). Despite the additional and time-consuming process of including patients and ICs as co-researchers, we found that their feedback during the whole research process strengthened the data quality. We gained valuable new insight, which lead the research process down fruitful pathways, resulting from the rich understanding of those experiencing disease and suffering.

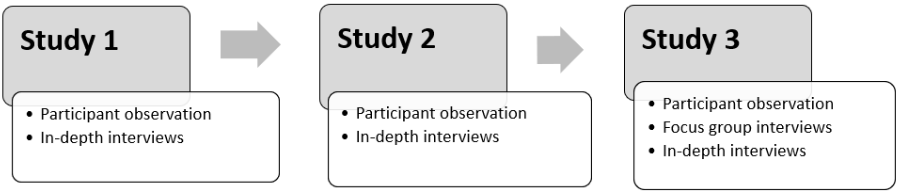
Figure 2: Patient and Informal Caregiver Participation in Research (PAICPAIR) (Staats et al., 2020b)



4.5 Sample, data collection and material

Combing different data collection tools strengthens the richness and understanding of data (Atkinson & Coffey, 2003), and was considered as a useful approach in this research project. We chose to combine participant observation, focus-group interviews and in-depth interviews as our data collection tools. All three approaches considered equal sources to produce empirical data for the same research questions.

Figure 3: Data collection approaches of the research project



Participant observations of the interactions of older women with incurable cancer living at home, their ICs and the HCPs were performed in the older women's own home. The data from these observations were used in all three studies. In study I and II individual in-depth interviews with home-dwelling women, living with incurable cancer and in-depth interviews with ICs were conducted, respectively. In study III, we performed focus group interviews with CCs and HCPNs, and in-depth interviews with GPs. This multi-method approach was chosen to allow a deeper insight into sources of dignity-preserving care, as a result of which I was able to explore the gathered data and its complementarity in more detail, when drawing on both interviews and participant observations. In the chapter that follows, I will present the sample, data collection and material of each study separately.

4.5.1 Study I

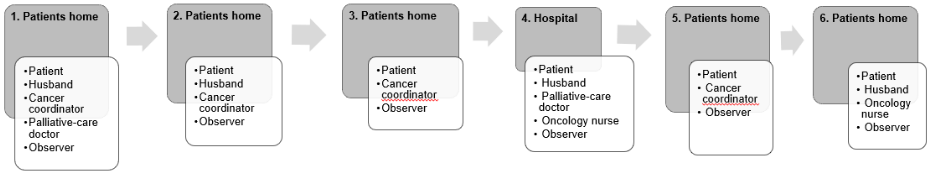
In study I, we used in-depth interviews and participant observations as data collection approaches, to explore how older women living with incurable cancer at home experienced dignity and dignity loss in their everyday lives. Considering the structure and order of the thesis, I will first describe participant observation as a data collection tool. This approach is also utilized in study II and III, and will, therefore, be briefly mentioned when introducing these studies.

Participant Observation

Participation observation was utilized as an approach in order to generate new knowledge by describing, interpreting and understanding the situation (Karlsson et al., 2012). We wanted to observe the interactions between the women, their ICs and the HCPs, as this would give us the opportunity to get closer to the women's everyday life and gain a deeper understanding of experiences related to dignity and loss of dignity in these important interactions in the patients' own homes. According to Spradley (2016), *engaging* and *observing* the activities when entering a social setting, are the two main objectives in terms of increasing the interpretation, as well as the understanding of a situation. In line with hermeneutic methodology, Gadamer (2010) implies that observations can be likened to watching a play, in which the audience (observer) experiences the play, discerns the meaning of it and describes what can be understood from it. This reveals what people think and shows us the cultural meanings they use daily. Nåden (2010) highlights the importance of conducting the participant observations without haste and in silence. The time taken to carry out the observations is of lesser importance than the inner time, which increases the possibilities for the researcher to wander the hermeneutic spiral and to be hermeneutically tuned.

The participants observed were recruited at an early stage in the research period, when recruiting older, home-dwelling women and their ICs to study I and II. Six older women and their ICs gave their consent to participate in the observations and allowed me to contact their CC to join a planned home-meeting. The participant observations were carried out between March 2019 and November 2019, and the home-meetings were arranged with a variety of HCPs (see figure 4). Five of these participant observations were carried out in the home of the women and their IC, whereas one observation was carried out in the hospital, due to a temporary admission. An effort was made to carry out follow-up observations, however, this was a challenging matter, due to the progress of the women's illness and difficulties in the arrangement of home-meetings with HCPs. Nevertheless, the six accomplished participant observations gave us a deeper understanding of the experiences and interactions, related to dignity-preserving care in the homes of older women.

Figure 4: Participant observation – setting and study participants



I performed all participant observations myself in which I also occasionally asked questions and carried out informal conversations with the women, the ICs and the HCPs. I utilized an observation-guide (appendix 2) that was developed to remind me of the key points. Some examples from the guide were:

- what characterizes the interaction between the woman, her IC and the HCPs?

- how do HCPs verbally and non-verbally express themselves to ensure dignity-preserving care?
- how are the women and ICs met by the HCPs when describing dignity-violating situations?

During the observations I was aiming to identify conditions that could potentially have an influence on the women's experience of dignity and loss of dignity, thus being relevant for developing a new understanding of crucial aspects, constituting dignity-preserving care. I strove to behave naturally within each setting, to ensure that the informants felt comfortable and could act normally in their surroundings, therefore, providing me with true observation data (Fangen, 2010). I believe that my presence did not affect the conversation and interaction between the parties, and I was prepared to end the observation at any point, if necessary. It is important that the observer documents not only what happens and what is contemplated, but also the thoughts and emotions that are evoked (Karlsson et al., 2012). I tried to write the observation-notes in a structured and detailed manner, generating 19 pages of empirical data for interpretation and creating an overall and contextual understanding of dignity-preserving care within study I, II and III.

In-depth interviews

Using in-depth interviews in qualitative research generate an insight into specific subjects and gives the researcher access to lived experiences (Brinkmann, 2015). Gadamer (2010) claims that a conversation between a researcher and participants is a suitable method of achieving understanding of a phenomenon of interest. Hermeneutic understanding is always an act of communication, by which we share something with another. In this act of 'sharing', the world becomes larger and the process of coming to a dialogical understanding is in play (Malpas & Gander, 2014). Within the hermeneutical dialogue, this play is driven by an interaction of questions and answers, seeking not the last word, but a means of keeping the conversation going (Moules et al., 2015).

Study I comprised a purposive sampling strategy. This means that we selected participants that would most benefit the study and would contribute well in relation to the study aim (Polit & Beck, 2017). These participants would present typical examples of the field and would inform me as researcher about the research problem under examination (Creswell & Poth, 2018). I contacted CCs in eight Norwegian municipalities, with the purpose of asking them to assist me with the recruitment procedure. In this context, I arranged meetings in which I presented the study purpose and aim, and distributed informal letters which the CCs could give to potential study participants. The CCs assisting with participant recruitment, regularly met older women with incurable cancer who lived at home. In total, 23 women were given verbal and written information about the study from their CC between November 2018 and February 2019. Inclusion criteria in this study were defined as follows: being female, aged 65 years or older, diagnosed with incurable cancer, living at home and receiving support from municipal healthcare services (figure 5). It was important to include women who had the strength, both mentally and physically, as well as the willingness to complete an interview of approximately one hour. Eventually, 13 of the 23 women gave their consent to participate in the study, whereas 10 women declined, due to tiredness, lack of interest, admission to hospital, disease advancement and death. The 13 women included in the study were aged 66 to 83 years, represented a variety of groups within the socio-demographic data, in terms of cancer diagnosis, marital status, housing, level of education and residence in urban or rural areas, as well as in relation to the level of municipal healthcare support (see paper I).

We developed a semi structured, modifiable interview guide (see appendix 3), based on open questions and key words to invite and encourage the participants to open up and talk (Creswell & Poth, 2018). The formulation of questions required an advanced preparation, underscoring the use of common vocabulary and phrasing the questions in such a way that the interviewees could understand their meaning (Polit & Beck, 2017). The PAICPAIR advisory board (Staats et al., 2020b) played a vital role in this development, bringing in crucial themes and keywords, as well as nuancing the wording, related to their own backgrounds. After interview number six, we adjusted the modifiable interview guide, due to certain questions being less relevant than expected and others having been omitted. The evaluation of our interview guide and the effort to make improvements in subsequent interviews, were also re-checked with the study advisory board. As an example, the opening-question before the evaluation was:

- Can you describe what you associate with the word, *dignity?* What appears in your mind?

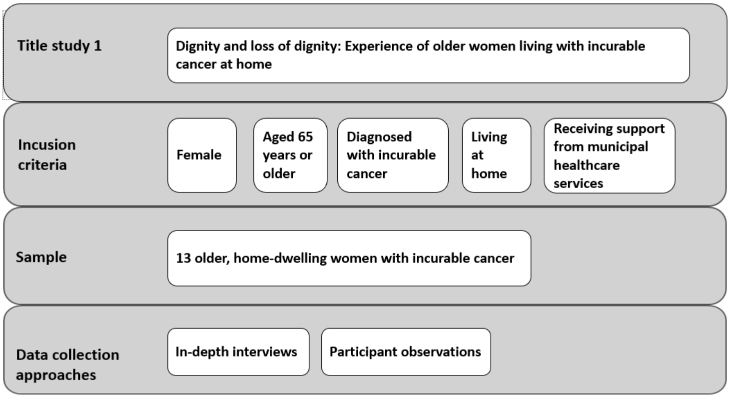
After the evaluation, the opening-question became more operationalized and was phrased as follows:

- Can you tell me about a situation, after becoming ill, that affected your experience of dignity? What happened?

This approach gave the women the opportunity to relate the concept of dignity to an experience which, subsequently, provided me with more detailed data. In the spirit of Gadamer's hermeneutical philosophy (2010), so as to develop a deeper layer of the meaning, I assumed a humble attitude and an openness towards the other perspectives related to dignity-preserving care. Nonetheless, during the interviews, the interview guide was not followed strictly, as it was important to be open to new themes that might emerge. I focused on listening carefully, giving the participant time to think of an incident before describing it, as recall can often take time. In turn, this helped me as researcher to understand the women's views more thoroughly.

In conclusion, our knowledge relating to these 13 women's views of dignity-preserving care is not exhaustive, however, contributes to increasing the knowledge surrounding this phenomenon under investigation. Therefore, concerning purposeful sampling, as stated by Lincoln and Guba (1985), the number of participants were determined when no new data emerged, and no new information was forthcoming from new sampled units, also known as the point of saturation. However, described in the chapter of study I, this is transmissible to study II and III.

Figure 5: Inclusion criteria, Sample and Data collection approaches of study I



Title study 1	Dignity and loss of dignity: Experience of older women living with incurable cancer at home
Incusion criteria	Female Aged 65 years or older Diagnosed with incurable cancer Living at home Receiving support from municipal healthcare services
Sample	13 older, home-dwelling women with incurable cancer
Data collection approaches	In-depth interviews Participant observations

4.5.2 Study II

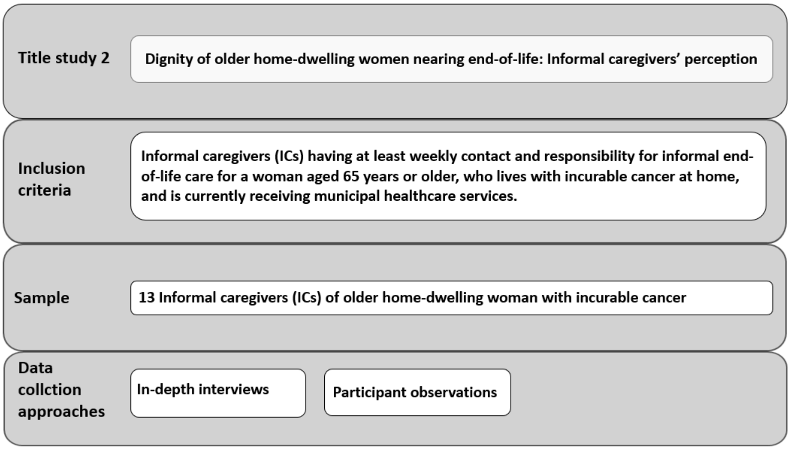
In study II, we used in-depth interviews (Brinkmann, 2015) to explore how ICs perceive sources related to dignity and dignity loss of home-dwelling, older women with incurable cancer. We also used participants' observations (Spradley, 2016), the data collection process of which is described above and is related to study I. We believe that the knowledge of ICs is highly relevant; ICs are important contributors when sharing their perceptions, as they deal with complex issues when living with an incurably ill wife, mother or sister. Denzin (1989) highlights the importance of person triangulation to help capture a more complete and contextualized portrait of the phenomenon under investigation. This involves collecting data from different types of people with the aim of validating the data through multiple perspectives (Polit & Beck, 2017). The data from the different sources (women, ICs and HCPs) constitute elements of a dialectical movement (Gadamer, 2010), as the overall aim of the study, is to gain a new understanding of research in the hermeneutic circle.

The purposive sampling strategy (Polit & Beck, 2017) carried out in study I, was also applied within study II. The CCs assisting with participant recruitment in study I also had regular contact with the ICs of the older women with incurable cancer, who lived at home. Their effort in finding ICs were, therefore, of crucial importance in the recruitment procedure. In this study, 23 participants from 11 Norwegian municipalities were given verbal and written information regarding the purpose and content of the study, with the following inclusion criteria: having at least weekly contact and responsibility for informal end-of-life care for a woman aged 65 years or older, who lives with incurable cancer at home, and is currently using municipal healthcare services (see figure 6). In the period between November 2018 and December 2019, 13 of the 23 ICs gave their consent to participate, whereas 10 ICs declined, due to fatigue, less involvement in daily care or having suddenly become bereaved. The 13 ICs included in the study were aged between 40 and 77, of which six were husbands, two were sisters and five were sons or daughters. The interviews took place in the homes of the ICs, with the exception of two; one was conducted at the participant's workplace and one in a café, the venues were requested by the participants themselves. All interviews were carried out with the IC alone, except for one, which was conducted in the presence of his wife, in accordance with their mutual wishes. Six of the 13 ICs were related to the older women participating in study I. The procedure of developing a semi structured, modifiable interview guide (Creswell & Poth, 2018) in study I was also implemented in study II (see appendix 4). Both the preparation and development of the interview guide was influenced by thorough cooperation with the PAICPAIR advisory board (Staats et al., 2020b). An example of a question guiding the ICs' in-depth interviews was:

- What is your wife's/mother's/sister's/friend's perception of dignity, as experienced by you in the capacity of an IC?

The participants demonstrated confidence in relation to their situations as ICs and most of them willingly invited me into their lives and shared their experiences. A few ICs were, however, not comfortable with the openness concerning end-of-life issues and were not familiar with reflecting on and talking about this. Yet, it appeared that certain ICs were in need of sharing their thoughts and emotions regarding this subject, as they opened up and were keen to express themselves, clearly having a lot on their mind. It was my responsibility to evaluate which questions to ask in which order, to understand when to end the interviews and to be gentle and sensitive in the interview setting. My flexible approach during the interviews enabled me to create a genuine conversation, leading to a more thorough understanding of the phenomenon under investigation (Gadamer, 2010).

Figure 6: Inclusion criteria, Sample and Data collection approaches of study II



Title study 2	**Dignity of older home-dwelling women nearing end-of-life: Informal caregivers' perception**	
Inclusion criteria	**Informal caregivers (ICs) having at least weekly contact and responsibility for informal end-of-life care for a woman aged 65 years or older, who lives with incurable cancer at home, and is currently receiving municipal healthcare services.**	
Sample	**13 Informal caregivers (ICs) of older home-dwelling woman with incurable cancer**	
Data collction approaches	**In-depth interviews**	**Participant observations**

4.5.3 Study III

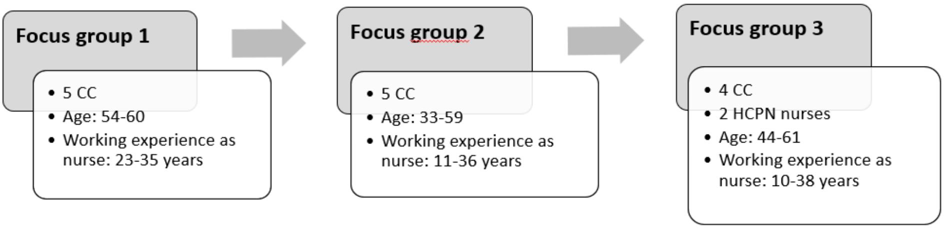
The last study of this research project involved the HCPs and included three focus group interviews with CCs and HCPNs, and seven in-depth interviews with GPs. We also utilized the data from the participant observations, similar to study I and II. In study III, we wished to explore how HCPs perceived the value-based principles and organizational conditions of dignity-preserving care for older, home-dwelling women with incurable cancer. Lambert and Loiselle (2008) argue that the integration of individual interview and focus group data is a productive strategy that leads to an enhanced description of the phenomenon's structure and its crucial characteristics. As Denzin points out, 'no single method ever adequately solves the problem of rival explanation' (1978, p. 28). He is of the opinion that multi methods must be employed when dealing with different sources of reality.

Focus group interviews

The purpose of focus group interviews is to obtain high quality data in a social context, in which people can consider their own original responses, as they hear the responses of others (Patton, 2015). Focus group interviews are essentially interviews and *not* a problem-solving session. Kreuger and Casey (2015) emphasize that focus group interviews should be carefully planned to create a ‘non-threatening environment’, in a setting that ‘encourages participants to share perceptions and points of view without pressuring participants to vote or reach consensus’ (p. 2). Gadamer concurs that such a conversation aims to gain an insight into a particular subject and attempts to unravel the truth, rather than gain agreement within a group (Moules et al., 2015).

When starting the recruitment of study III, I contacted CCs in seven Norwegian municipalities, consisting of 23 CCs and HCPNs. I considered these HCPs to be an information-rich data source for study III and assumed this would increase my understanding of the phenomenon. They were all informed by email of the purpose of the study and the implications of their involvement, and were asked to reply if they were interested in participating. They were also asked if they were involved in the care of older, home-dwelling women, living with incurable cancer. A total of 20 CCs and two HCPNs confirmed that they wanted to participate. Eventually, six CCs were prevented from attending, resulting in three focus group interviews as follows:

Figure 7: Focus group interviews – participant characteristics

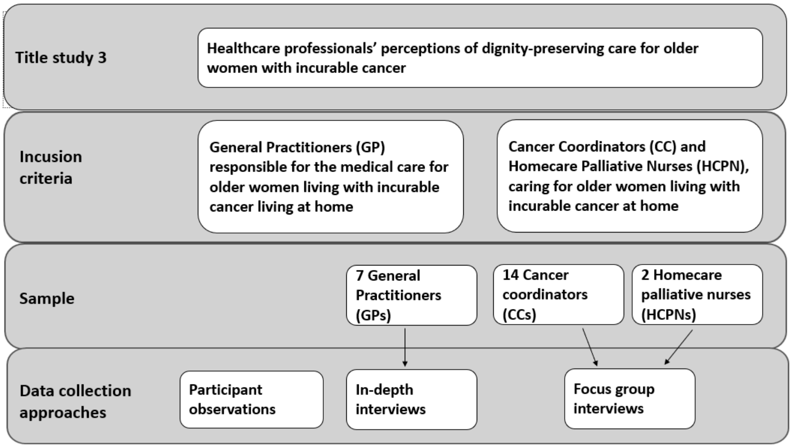


Fourteen participants worked as CCs, meaning that they had both a collaborative and interdisciplinary role in municipal cancer care, as well as individual care for patients. Two participants (HCPNs) were members of the regular homecare service team and were, to a large extent, more involved in the daily care of the patients. All participants were female and had a mean age of 54 years. Their average number of years of clinical practice as nurses was 27, mirroring their wealth of experience and adding diversity to their background. During the focus group interviews, I guided the discussions as the moderator and was assisted by my co-supervisor, EKG and two PhD candidates as co-moderators, respectively. I guided the focus group interviews according to a written set of questions and was inspired by Kreuger and Casey's (2015) guidelines to develop a good questioning route (appendix 5). However, when providing data through interactions in group discussions, I proceeded in a flexible manner, creating a permissive, non-threatening environment and using an open-ended approach. Kreuger and Casey (2015) argue that five to eight individuals constitute an ideal focus group. It should be mentioned, though, that hermeneutic research in not validated in terms of numbers, but in relation to the completeness of examining the phenomenon under investigation and the fullness and depth by which the interpretation extends understanding (Moules et al., 2015).

In-depth interviews

I started the recruitment of GPs by informing contact persons and participants from the focus group interviews of this element of the data collection process, and sent out information to networks of GPs nationally and chief medical offices in five municipalities. Only one GP responded to these announcements, however, several CCs and other HCPs gave me relevant contact information of GPs, responsible for the medical care of older women, living with incurable cancer at home. Due to challenges and uncertainties related to the COVID-19 pandemic outbreak in March 2020, our research was not a priority for GPs and other HCPs at that time. Nevertheless, using the snowball sampling method (Patton, 2015), I was able to carry out seven in-depth interviews with GPs between March and June 2020. Due to the challenges of reaching the target population, the snowball sampling method was helpful, as I could build on the sample of people with similar inclusion criteria, as recommended by Patton (2015). The in-depth interviews were carried out using digital methods, such as Skype and Teams, and by means of phone calls. Four male GPs and three female GPs participated, between 38 and 56 years old (mean 46). They had an average of 13 years' experience as a GP (variation from eight to 22 years) and had all been responsible for the medical care of older women, living with incurable cancer at home. However, despite being experienced doctors, there was a great variety in the way that the follow-up treatment of these women was carried out, as well as a certain unfamiliarity with the concept of dignity-preserving care. These challenges were thoroughly discussed within the research team as well as with the PAICPAR advisory board (Staats et al., 2020b), which assisted in both developing the informal letter and the interview guide. The patient on the advisory board, an older, incurably ill woman living at home, participated enthusiastically when preparing and developing questions for the interview guide (see appendix 6). She highlighted *time* and *presence*, *autonomy* and *personal preferences* as valuable themes to implement in the guide, which invited fruitful reflections and resulted in a richness of data collection. Reading and interpreting the preliminary results was also a crucial task for members of the advisory board, discussing the data from study I, II and III. The following section of this chapter describes, in greater detail, the process of interpretation of the data, collected from all three studies.

Figure 8: Inclusion criteria, Sample and Data collection approaches of study III



4.5.4 Data interpretation

Hermeneutic interpretation comprehends the recognition that occurs when something rings ‘true’, there is familiarity, kinship, resonance and likeness as well as difference. It involves carefully opening up associations that strengthen the understanding of a topic, rather than focusing on a single governing theme (Moules et al., 2015). Utilizing the Gadamerian-based circular process, we moved from interpretations of text parts to interpretations of the text-material as a whole (Gadamer, 2010). Data integration also involves moving back and forth between the data of the separate studies to uncover data convergence, divergence and complementarity (Lambert & Loiselle, 2008).

All interviews were audio recorded and transcribed successively, and field-notes from the participant observations were made shortly afterwards. I started the interpretation with a first reading of the interviews in their particularity and otherness, making preliminary notes and marks in the text and immersing myself in the material. As regards the first six interviews from study I, written reflections were made immediately after each interview, consisting of the interview techniques used, descriptions of the way in which the questions were asked and suggestions for improvements. My supervisor (OT) and I evaluated these reflections thoroughly, also discussing my pre-understanding and prior knowledge (Gadamer, 2010).

All transcripts were shared with my supervisors for individual interpretation, followed by planned meetings in which we shared our thoughts and our preliminary perceived patterns of meaning, as well as contradictory evidence. Moules (2015) argues that this teamwork raises the initial individual interpretation from each researcher to another level of interpretation, a level at which the research team develops an in-depth, rigorous, reflexive and communal focus on the data. When reading the transcribed material, we were constantly breaking apart our understanding, comparing it to another view or new experience and then putting it back together to create a new understanding of the horizon (Gadamer, 2010). The purpose of this persistent engagement with the text is to build a picture of emerging themes and sub-themes, presented as results (Brinkmann, 2015). However, within the hermeneutical interpretation, themes are more of a tool on the journey into the depths and richness of interpretation (Moules et al., 2015), demonstrating that we adjusted and re-evaluated the themes and sub-themes several times during the research process.

Gadamer (2010) states that new understanding emerges between new knowledge and previous knowledge in the hermeneutic circle. Therefore, the results from studies I, II and III were in a dialectical movement with one other, as well as with the overall aim, previous research, our pre-understanding and with the theoretical perspective. During the collaborative work with all three papers, our research team discussed various theoretical perspectives that might open up new horizons of understanding. This was affected by the diversity of our academic and clinical background related to dignity-preserving care and end-of-life care. Concurrent with these discussions, co-researchers from the PAICPAIR advisory board (Staats et al., 2020b) added nuances and diversity from their point of view, providing feedback on the preliminary results and sharing their thoughts on the way in which this experience corresponded with their own experiences.

In conclusion, the hermeneutic methodology seemed to be suitable as a means of conducting this research process, whereas our participants' perceptions challenged our initial pre-understanding, leading to a new understanding of dignity-preserving care for older women, living with incurable cancer at home. However, the interpretation within a hermeneutic philosophy is also deemed to be difficult and sophisticated, and it could be argued that the interpretation is sometimes hampered by its very openness (Moules et al., 2015). Therefore, we have paid careful attention to the use of language when presenting our results. We were open to suggestions and opportunities and were humble and understanding in relation to other perspectives and horizons of understanding. To pay attention to and to safeguard these latter perspectives, as well as to ensure cooperation with patients, ICs and HCPs throughout the research process, ethical concerns need to be highlighted. Therefore, the final section of this chapter describes, in greater detail, the research projects' ethical considerations.

4.6 Ethical considerations

This research project was conducted in line with the basic principles of the Declaration of Helsinki (World Medical Association, 2018b) and the Norwegian Health Research Act (The Health Research Act, 2008). The Norwegian Centre for Research Data approved the study (ref. no.138698) (see Appendix 7). An application was also sent to the Regional Committee for Medical and Health Research Ethics (REC), but their response was that the project was outside the scope of the health research legislation (Appendix 8). The participants in all three studies, received written information regarding the study in advance (appendix 9-14), as well as an oral presentation of the aim and purpose of the participant observations, in-depth interviews and focus group interviews prior to their commencement. Information was also provided concerning practical matters, such as the intention of recording the interviews and the storing of contact details, in the event of requiring further information or comment. Measures to ensure confidentiality and anonymity were presented, and the participants' right to withdraw from the study without providing any reasons, was repeatedly highlighted (Polit & Beck, 2017).

This project was founded on the acknowledgement of the inherent dignity of each participant, demonstrating sensitivity in relation to their individual integrity, autonomy and life-history (Nordenfelt, 2004). The target group of studies I and II, namely, older women living with incurable cancer at home and their ICs were highly vulnerable in their present life situations. We, therefore, decided to carry out one interview with each informant, due to ethical considerations and the potential burdensome consequences for the participants. We also introduced the option of taking part in a participant observation at a later stage, when finishing the interviews in their homes, thereby reducing the need to participate in both an interview and a participant observation. Thus, as a crucial supplement to traditional research ethics, moral sensibility was emphasized, to preserve participants' integrity and dignity (Heggestad et al., 2013). Consequently, I was emotionally touched by the stories that the participants shared during the interviews, however, this also enabled me to be sensitive and constantly aware of their actual situation, characterized by unpredictability and vulnerability.

Potential issues that may arise when collecting data during participant observations and interviews, such as an imbalance within a relationship, were toned down by avoiding leading questions and by maintaining an informal atmosphere in the conversations (Creswell & Poth, 2018). I was prepared to bring the in-depth interviews and observations to an end at any time. In some of the in-depth interviews it was necessary to take several breaks, due to the older women's health situation. I decided to end one interview prematurely, as the woman suffered from fatigue and showed signs of emotional discomfort. As researchers, we are obliged to prevent and/or minimize harm when conducting studies of human beings. Participants should not be subjected to unnecessary discomfort, and strategies should be employed to reduce all types of harm, albeit temporary (Polit & Beck, 2017). In this project, I attempted to spend sufficient time prior to and after the interviews and observations, so as to offer my support when necessary. In certain situations, the municipal CCs were contacted to provide further support for the participants. This only took place when the participant explicitly gave his/her permission.

One final ethical consideration concerns confidentiality. During the data interpretation phase, the research team focused on reporting multiple perspectives, not taking sides with the participants or only reporting positive results (Polit & Beck, 2017). Respecting the privacy of participants was also of crucial importance, therefore, extra precautions were taken to safeguard anonymity, when assigning numbers instead of names during the process of transcribing the interview texts. In addition, to use numbers and fictitious names on hospitals, HCPs and others, I had to distort the identifying information and avoid detailed descriptions when recording the results. These measures relate to anonymity, which is the most secure means of protecting confidentiality and is ideally achieved when the researcher cannot link the participants to their data (Polit & Beck, 2017). In this project, this was difficult, due to the close involvement of the participants. However, audio recordings, transcribed texts and written consents were kept in a safe and will be deleted after the project period (Brinkmann, 2015). Despite the COVID 19 pandemic during the last year of the project period, only minor methodological adjustments were required. A change from planned face-to-face, in-depth interviews with GPs to online interviews was deemed necessary. In terms of ethical approval in light of the COVID-19 pandemic, we were aware of the potential risks to confidentiality in shared online spaces and, therefore, took steps to reduce these risks (Chiumento et al., 2018), e.g., GPs were encouraged to use earphones and to remain in a private room to guarantee the discretion of the conversations. We also clarified whether there was any unfamiliarity or need for guidance in the use of the preferred online software.

5. Results

5.1 Paper I

In paper I, we identified four crucial dimensions leading to experiences of dignity versus loss of dignity in the everyday lives of these women:

Owning their decisions and having a sense of control in their life-situation versus feeling insecure and losing the opportunity for self-determination

A vital dimension leading to the experience of dignity for the older women was having a sense of control in life. This helped them maintain their self-respect and a level of autonomy. Having their voices heard and experiencing the respect of others was important for them in decision-making processes, promoting their sense of independence. For all women, respectful and compassionate treatment was crucial in enabling them to feel that their self-determination was recognized by others when facing end-of-life. Concerning experiences of dignity loss, we found that the women experienced this when sensing insecurity and an inability to make their own decisions. The women went through significant life changes when diagnosed with incurable cancer. Experiencing these changes also activated a sense of grief and a reduced sense of control over their life, primarily related to decreased bodily control and an increased need for psychological support. In our participant observations, we found that, on occasions, HCPs, seemingly unintentionally, appeared to overshadow and overrule the women, despite their need for self-determination. This caused the women to experience a loss of independence and dignity in situations created by HCPs.

Experiencing hope and meaningfulness despite illness versus sensing hopelessness and worthlessness in a shroud of illness

Most of the women maintained that hope was crucial when nearing end-of-life. Hope was related to their own decision to carry on with their treatment and was founded upon the perspectives and recommendations of HCPs. Several women accepted new treatments and continued with burdensome medication, despite suffering from side effects. As the disease became prolonged and women expressed a heightened level of vulnerability, their hope and a wish for inner strength also increased. Moreover, we found that certain participants had expressed wishes regarding their final days to die peacefully, without any pain or any difficulties. One woman expressed her wishes for her death with a metaphor, “like blowing out a candle”. We also found that some women felt their worthiness as a human being to be weakened, along with the progress of the illness. They experienced being a burden due to their age and illness, and felt more estranged from themselves as their illness took over their everyday life. They described feeling offended emotionally and existentially when peace and harmony were replaced with anguish and doubt.

Feeling valued as an individual versus experiencing violation of one’s personal life

Feeling the warmth and care of other people was crucial for the women. Such a level of care was experienced when family, friends and HCPs acknowledged them as human beings, not perceiving them solely as dying cancer patients and regarded as lost. The results also highlighted the importance of others showing their intention and willingness to help, which relieved the women's suffering in everyday life. The participant observations added nuances to the interview data, revealing that eye contact and visible relationships of trust between the women and HCPs were vital and meaningful. This relationship of trust was shown when the GPs highlighted the women’s right to be heard and took the time to listen to them closely. On the other hand, we also identified several women experiencing situations in which they felt neglected, invaded or offended by HCPs. These situations were encountered both in their own homes and during transportation between the hospital and the women’s home. In their state of vulnerability, these situations, consequently led to illness-related suffering and a sense of feeling insignificant.

Living in a treasured and nurturing environment versus being situated in surroundings enhancing their sense of disconnection and alienation

Most women described their homes as a secure base and a sheltered place to be. We found several sources that influenced their sense of living in a treasured and nurturing environment. However, only a few of the women stressed the importance of spending their final days at home. Most of them perceived quality of care as more important than the *physical place* when nearing end-of-life, even though their home was initially their preferred place to stay for as long as possible. It was important for them that their loved ones were taken care of, resulting in the women having more confidence in the complete situation. Several women highlighted the importance of being admitted to an institution if the caregiver burden should become too great for their family. Uncompassionate attitudes and limited support from HCPs also influenced their wishes concerning the preferred place to stay, when nearing end-of-life. This concerned both healthcare institutions and their own homes. Therefore, attitudes in general gave rise to the experience of being in a treasured and nurturing environment or being in an unfamiliar and/or uncaring environment.

5.2 Paper II

The aim of study II was to explore the ICs' perceptions of sources relating to dignity and dignity loss of home-dwelling older women with incurable cancer nearing end-of-life. The results elaborated upon three sources which preserved dignity, as well as three sources leading to dignity loss:

Sources related to dignity-preservation

Maintaining one's self-concept

We found that the ICs were preoccupied with the woman's importance of maintaining a sense of self-worth as a human being, when nearing end-of-life. They expressed the value of allowing the women to be the main person in their own life and to follow their lead. Several ICs expressed the need for the women to be recognized as independent individuals with their own names, not being reduced to a diagnosis. The ICs expressed the importance of being positive and participating in everyday occurrences, such as making a meal, reading a book and meeting up with friends and family, without discussing illness-related matters.

Remaining hopeful

The ICs determined hope as an essential aspect for the women in their challenging and uncertain life situations. They described how the women found new meaning that helped relieve their suffering and strengthened their hope, for example, hope for a new treatment, even when the disease had reached an advanced stage. The ICs also related hope to other people's presence and care, as well as people's interest in the women's life stories. This increased the women's feelings of security and were crucial sources which helped preserve their sense of dignity.

Sustaining freedom of choice

The ICs expressed the fact that the women enjoyed and cherished their quality of life when staying at home, maintaining their social lives and deciding how to plan their days. At the same time, the ICs underlined that many of the women experienced admissions to institutions as being seamless and safe. Irrespective of the dwelling place, most ICs emphasized the women's needs to tailor their own end-of-life care, despite having limited strength due to their illness.

Sources related to dignity loss

Sensing loss of human value

Living with a declining body provoked the women's feelings of meaninglessness and existential loneliness. The ICs described situations in which the women's decline in health affected their self-perception, making them feel less valued. The ICs reported situations in which the women lost their sense of self-efficacy, such as no longer being able to take a shower independently. Moreover, we found several other circumstances which the women could not participate in daily chores – finding that self-care had become too exhausting and being dependent upon the help of others. These situations often made the women feel insignificant, frustrated, and affected their experience of dignity.

Experiencing absence of gentleness

The ICs shared their experiences of how these ill women sometimes felt demeaned by HCPs, rather than being treated with compassion. It was important for the women to manage the 'little things' in their everyday lives, despite their reduced physical capacities. This need was strongly related to their requirement to be involved in decision-making processes, however, their voices did not seem to be heard at times. The ICs described how the women felt humiliated and invaded by HCPs in such situations. Sometimes they felt that their legal rights had been disregarded in what should have been a care intervention. In these settings, the women often had to mobilize all their strength to be seen, listened to and taken seriously.

Feelings of being treated as an object

The ICs described situations in which the women felt unsafe and were regarded as objects, for example, when efficiency strategies within the healthcare system made them feel overlooked. We revealed supplementary data from the participant observations, demonstrating that the GP in charge of the women's treatment was seemingly poorly prepared. Consequently, efficiency strategies led to the women feeling insignificant and frustrated. Long waiting times in the hospital were perceived as demanding and led to uncertainty and a feeling of insecurity in relation to the care given. In addition, the burdensome transportation between the hospital and their home was perceived as a violating aspect. The ICs explained how transportations were called ‘collective journeys’ and the women sometimes felt as though they were treated like objects while being in a state of dependency.

5.3 Paper III

The aim of study III was to explore and identify HCPs’ perceptions of dignity-preserving care for older, home-dwelling women with incurable cancer. We identified two categories reflecting their value-based principles and two categories portraying their perspective of organizational conditions, promoting dignity-preserving care:

Recognizing the importance of sheltering the women’s identity and sense of being home

All participants stated that safeguarding the women’s identity was of crucial importance and agreed on the value of women maintaining their independence and being recognized as worthy human beings. The GPs stressed the value of existential and relational aspects when being incurably ill and regarded the home as a treasured place for these women to stay. However, this created expectations of time-consuming home visits and conversations of an existential character, which tended to be avoided by several GPs. Many CCs talked about the importance of respecting and confirming the women’s identity *beyond* their illness, acknowledging their life as women, wives and mothers, and giving the women opportunities to share their life stories. Their home was seen as a source of identity, where they could uphold their cherished roles, stemming from a life in which these roles were central for many of these older women. We found that the two HCPNs reported situations in which the protection of the women's identity was complicated or even regarded as absent. They described several degrading care situations portraying, for example, how a woman was laid bare in her living room, exposed to a number of family members and her needs and wishes were neglected.

Acknowledging the women's autonomy and personal preferences

The HCPs in this study expressed disappointment with the Norwegian healthcare authorities, in which governmental plans promised to fulfil the wishes of patients to die in their own homes. We found that a lack of competency on the part of HCPs and a shortage of resources within healthcare services lead to uncertainty and sometimes unsafe situations for older women with incurable cancer, therefore, it proved difficult to honour the promise that patients should be allowed to die at home. This sometimes led to undesirable hospitalizations. Several GPs emphasized that insufficient knowledge of the gender-specific needs of older female patients could risk violating these needs. Acknowledging women's autonomy and personal preferences was, therefore, a challenging matter. CCs and HCPNs were also unanimously concerned with women's autonomy and self-worth, as well as with the risk of violating their personal preferences – in particularly when they were not able to communicate their wishes. They emphasized the importance of creating a purposeful environment, in which the older women could fulfil their cherished roles in life.

Creating a flexible organizational culture of care

We found that for all HCPs in this study, it was crucial to treat older, incurably ill women with awareness and gentleness. Therefore, generosity among HCPs and flexibility within the healthcare organization was required, including allocating sufficient time and knowledge to each patient's health status and life situation. According to the CCs and HCPNs, the importance of developing a culture of care was vital. A culture of care was described as an essential context in which to use the limited time positively. As for the GPs, we found that they experienced distance in their care for this group of older patients, attributing this to reasons such as disease complexity, lack of specialized competence and rarely caring for this patient group during their disease trajectory. Sometimes and perhaps interestingly, the GPs did not even know that they had an older, home-dwelling woman with incurable cancer on their patient list. However, the effort to find flexible solutions to meet the aforementioned challenges was made by one GP. She wrote a short letter to all her patients diagnosed with cancer, establishing contact early, enabling her to create a valuable foundation for collaboration and follow-up for her patients.

Establishing a functional professional collaboration and individualized plans of care

The GPs highlighted that proper collaboration and individualized plans of care were crucial in meeting the needs of older women living with incurable cancer and were required to help structure their everyday lives. The GPs further elaborated that a professional collaboration was the essence of care for dying women in their homes. Both GPs and CCs described how their relationship with these patients and their families made them feel responsible for the patients' treatment and care. This underscored the importance of establishing a functional, professional collaboration. Despite the functionality and importance of individualized plans of care, the CCs and HCPNs working closely with the patients, expressed discontentment in relation to the increasing number of plans and healthcare procedures. They experienced a decrease in individualized care and a declining quality in the communication with the older women and their families. As shown in one participant observation, plans of care were often given out routinely, without any sensitivity and explanation.

6. Discussion

In the first part of this chapter (6.1), I will discuss the main findings of the three studies in relation to previous research. Subsequently, in the second section of this discussion (6,2), I will engage in a dialogue with the empirical data, together with the perspectives of the Theory of Caritative Caring by Katie Eriksson, in order to develop a deeper understanding of the study results, creating an empirical-theoretical understanding – visualized in a *Model of dignity-preserving care for older home-dwelling women with incurable cancer.*

6.1 Results in relation to previous research

The overall results of this project concerning crucial aspects of dignity-preserving care for older home-dwelling women living with incurable cancer, were identified through hermeneutical reading of the results of the three studies separately, as well as the results as a whole. The overall results were formulated as follows: *being seen and acknowledged as an individual; having a sense of control in one's own life; living in a treasured and safe environment and experiencing an adjustable hope.*

6.1.1 Being seen and acknowledged as an individual

Our results show that respecting and confirming the women's identity, rather than being reduced to an incurably ill cancer patient, was crucial in preserving these women's self-worth and dignity. This enabled them to feel respected and valuable in their life situation (Staats et al., 2020). Many of the women had a limited physical capacity due to their illness, however, it was crucial for them to be recognized as worthy citizens and to still be contributors to society, despite their serious health condition. Being seen and acknowledged as women, wives and mothers, and feeling a sense of recognition regarding the way in which these roles influenced their lives, were therefore, essential to them (Staats et al., 2020a; Staats et al., 2021). Bylund-Grenklo et al. (2019) and Xiao et al. (2020) recognize the importance for patients, in general, to maintain their former roles to preserve their sense of self-worth. They further state that being valued as a person forms the basis of dignity, which is particularly important to uphold when a patient's illness progresses. Torre (2017) supports the latter view and highlights the importance of women's roles as societal participants and family caretakers, when living with cancer. As for *older* women, there are additional aspects to take into account concerning their wish to continue to be a contributor to society. Research has shown a general increase in loneliness with age (Dahlberg et al., 2015), which constitutes a challenging, emotional situation for the oldest women living at home in Norway, who often live in the intersection between embracing the present in solitude and fearing the future with additional declining health (Ness et al., 2014). Similar emotional circumstances were identified in our study, but also with a new insight into how the older women cherished the days when they could participate and contribute, to a larger degree, to the lives of others. In these circumstances, when the women lived their lives as close to normality as possible, their sense of self-worth and dignity increased (Staats et al., 2020a).

As for the HCPs in our study and their view on how best to acknowledge the older women as worthy individuals, they were unanimously concerned about violating the women's dignity. They related this to a lack of professional competencies and a shortage in resources within the municipal healthcare services, that could lead to uncertainty and unsafe situations for these older women, sometimes leading to undesirable hospitalizations (Staats et al., 2021). Viftrup et al. (2021) support these findings, underscoring HCPs' concerns regarding preserving patients' dignity. However, they found relational aspects to be more important than the time and resources available. The participants in their study, patients nearing end-of-life in a hospice, were more preoccupied with *how* the staff would provide care and whether they would be understood by HCPs, who sometimes focused more on frameworks and contextual factors, rather than being present in the care situation. Chochinov (2013) addressed the challenges related to limited resources and time within the healthcare system. He implied that HCPs must advance a culture of care by setting aside sufficient time, inevitably supported by their institutions. He also suggested that the HCPs should focus their attention on attitudes towards patients, and in so doing strengthen their ability to promote dignity in care. Aoun et al. (2016) suggested that HCPs should work with tailored plans of care that meet individual needs, thereby maintaining or restoring the patient's sense of self. They found that such plans promote a more holistic care and strengthen the relationships between the patient and HCPs at the end-of-life. In our study, a more dual view concerning such plans of care emerged. On the one hand, GPs highlighted individualized plans of care as being crucial for meeting the needs of older women living with incurable cancer. They found it helpful to structure the treatment and care. On the other hand, CCs and HCPNs expressed discontentment with an increasing number of plans and healthcare procedures. They reported that a regime of detailed plans and procedures could be a barrier to an individualized care practice and could, in certain circumstances, undermine individual care. Consequently, this could create obstacles in seeing the women and their needs, making it difficult for the women to be seen by others, which could lead to dignity loss (Staats et al., 2021). When reviewing the literature, several studies have noted the constructive use of different interventions, models and plans of dignity care, which has been proven to heighten cancer patients' sense of dignity, as well as bolster their sense of self-worth (Chochinov et al., 2008; Chochinov et al., 2012; Chochinov, 2013; Guo et al., 2018). However, there is evidence that formal conversations and planning do not increase the likelihood that end-of-life care is consistent with patients' preferences (Johnson et al., 2018). This outcome is somewhat contrary to the findings of Brattgjerd et al. (2020), a recent study exploring nurses' use of an integrated care pathway for dying patients in Norway. Their study shows that the nurses perceived the pathway procedure and checklists as a useful tool, making them feel safer and more confident in their care practice. On the other hand, this study also identified challenges when applying such pathways to the care for dying patients. Our findings support the fact that certain conflicting dimensions, both advantages and disadvantages, could affect the practical use of individual plans of care. To enhance the objective of such plans and to strengthen the HCPs' resolve to preserve the women's dignity, plans of care should be provided with a level of sensibility and a clear explanation. Therefore, individual preferences and needs in each unique care situation should be acknowledged (Staats et al., 2021).

An important dimension to include in this present discussion is related to the way in which the healthcare services have developed over time in Norway. Since the mid-1900s, municipal healthcare services have been restructured, in line with NPM ideas. Norway is a country with a wealth of geographic variety and the municipalities have been given responsibility for the use of economic resources within the healthcare services (Fiva et al., 2014). As stated by the HCPs in our study, this has created new challenges in the municipalities, when managing their work and ensuring dignity in care. These efficiency strategies can evoke feelings of insignificance and frustration among the older women (Staats et al., 2021). A study by Debesay et al. (2014) demonstrates the way in which efficiency requirements and time constrains affect HCPs and how they deal with changes in an organizational context. This study also highlights the feelings of insecurity experienced by patients when the HCPs close to the patients were given added work responsibilities. Hence, Den Herder-van Der Eerden et al. (2017; 2018) argue that a small number of key HCPs providing care is an important way of establishing a trusted relationship. They also argue that there is a need for integrated palliative care with professional teams and networks, rather than a standardization of care. The results from our study also call for the provision of care by a few but well qualified HCPs and add a new perspective on how insufficient HCP competence in certain situations can lead to conflicting values and principles in the care of older women. In particular, HCPNs reported that such conflicting values sometimes existed between themselves and their more target-driven managers, who prioritized plans of care influenced by efficiency, rather than individualized care based on collaboration. Additionally, GPs revealed a sense of distance between themselves and the older women, due to a lack of specialized competence, medical treatment and care for this patient group. Thus, our study provides a new insight into how dignity-preserving end-of-life care can be understood as a matter, influenced by bureaucratic-organizational dimensions. This is related to the way in which HCPs express disappointment concerning Norwegian healthcare authorities, which promise to fulfil the patients' wishes of dying with dignity in their homes, regulated in the 'Dignity Guarantee' (Ministry of Health and Care Services, 2010). Hence, the HCPs in our study experienced different challenges relating to the way in which the municipal healthcare services were organized in terms of the effort to promote dignified end-of-life care. These challenges were described as unsettling for the older women at their end-of-life, which sometimes resulted in undesirable hospitalizations (Staats et al., 2021). Nonetheless, and despite organizational factors hindering HCPs providing dignity-preserving care, we agree with Holmberg et al. (2019), who highlight the importance of lowering the tempo of care at the end-of-life, in spite of organizational restrictions. Importantly, they point out that personal respect and an engagement to acknowledge the patients is important when providing end-of-life care. Despite the fact that this is a complex matter for HCPs, we argue that this will enable the older women to experience control in life to feel that they are being seen, heard and treated with dignity.

6.1.2 Having a sense of control in one's own life

An overarching finding from all three studies and a vital dimension leading to the experience of dignity among the older women, was having a sense of control in life. Despite illness, uncertainty and unpredictability, they sought to establish a structure and a sense of control in their life situations. These findings are supported by a recent review in which autonomy and control are seen as two of the main drivers, enabling patients with cancer to preserve their dignity in life (Xiao et al., 2021). As for women's health, Cain and Denny (2018) claim that making one's own decisions is a crucial component of having a sense of control in life. They stress that HCPs should be responsible for making all options available to women living with cancer, regardless of context, since this strengthens women's autonomy and provides them with options to make choices in line with their personal preferences. This is consistent with the findings in our study, showing that women were not always included in decision-making processes that were important to them. They expressed, for example, a wish to be in charge and to have a certain control, when receiving health-related information. Our results highlight the importance of personal autonomy in relation to dignity preservation, as well as the need to balance the sense of being independent and being a receiver of assistance and help (Staats et al., 2020a).

In a recent governmental white paper in Norway, the Ministry of Health and Care Services (2020) conveyed a value-based message to the Norwegian citizens, in which ‘user involvement’ and ‘personal preferences’ were accentuated as two of the six main principles to be emphasized in healthcare. These principles highlight the importance of treating all patients holistically and independently, and in so doing increasing their self-determination and quality of life when being incurably ill. This is also supported by Probst (2017) and Sergev et al. (2017), who maintain that HCPs should set their goals of care in line with older women’s values and wishes. They suggest a personalized approach to be used by healthcare teams, to meet the women’s care needs. Our results confirm the importance of such professional cooperation, with an individualized approach, however, we would add that emphasizing the creation of a *flexible culture of care,* is an important dimension, when striving for the goal of individualized care. The core aspects of such a caring culture are described by GPs, CCs and HCPNs as follows: to use the limited time constructively, having knowledge of the women’s situations and ensuring flexibility and generosity among HCPs. In this way, when the HCPs express calmness and presence, irrespective of the time frame, the women’s sense of control in life seems to increase (Staats et al., 2021).

As for the ICs, Danielsen et al. (2018) point out that a high standard of end-of-life care should take into account the patient’s needs and preferences, in which the IC has a central role. If the patient prefers to stay at home, the support of the family seems to be fundamental and of utmost necessity. Our study supports these findings. Moreover, as Danielsen et al. (2018) do not have any gender perspective in their study, our findings add a new understanding of how the older women, despite their vulnerability, were preoccupied with caring for their ICs to prevent them from experiencing an exhausting caregiver burden. They, therefore, experienced a feeling of ‘self-care’ when their ICs were supported by others, nurturing their confidence and sense of control over their own situation. Another vital finding in our study was that the older, home-dwelling women experienced significant life changes when diagnosed with incurable cancer, leading to grief and a reduced sense of control in life, primarily due to decreased bodily control and a heightened need for support. This was experienced in certain care situations when the woman was laid bare, exposed to others and her personal integrity was sometimes neglected by the HCPs. These findings are in line with Bruun Lorentsen et al. (2019a; 2019b), who gave an insight into the meaning of the ambiguous body, while exploring advanced cancer patients' experiences of bodily changes in relation to dignity. They emphasize that the body is more than a physical, visible body and draw attention to the way in which the body can be unpredictable and disconnected with the self, when suffering from advanced cancer. They further highlight the importance for HCPs to understand what the body represents for the patients, when losing physical control. This understanding is crucial when aiming to provide dignified care that includes awareness and respect for the patients' autonomy. In line with these findings, our study adds to the knowledge of how reduced bodily functions and sense of control in life affect the experience of dignity for older, home-dwelling women living with incurable cancer. Moreover, our findings contribute to the understanding of several HCPs in their care practices, who are worried about violating the patients' autonomy and self-worth, when the women are unable to communicate their wishes. We found that HCPs sometimes overshadowed and overruled the way in which these women wanted to live their everyday lives, leading to experiences of a loss of dignity. These findings are supported by Gott et al. (2020) who report that older women do not have the same end-of-life choices as men, and how gender may affect the decisions made by HCPs. This stems from gendered assumptions that women should care for their husband and not vice versa. Gott et al. also state that the concept of gender in palliative care research, practice and policy has been largely and unconsciously neglected, despite the knowledge that gender influences almost all aspects of end-of-life preferences, experiences and care. This is rooted in both biological sex differences as social gender disparities (Gott et al., 2020). Therefore, our study adds to the sparse base of knowledge regarding gender-specific needs, identifying what constitute experiences of dignity and dignity loss for older women living with incurable cancer.

6.1.3 Living in a treasured and safe environment

When the older women were situated in surroundings which made them feel safe, their sense of dignity was preserved. Our study has provided a broader understanding of the meaning of home for older women, as well as the sources influencing their preferred place to stay. Since many studies have considered the number of home deaths and the underlying factors concerning the low number of people dying in their homes in Norway (Sorbye et al., 2015; Kjellstadli et al., 2018; Staats et al., 2018; Kjellstadli et al., 2020), we will focus on the concept of home and its value for these older women with incurable cancer. We found that most of them wanted to stay at home and described their home as a sheltered place to be. However, few of them wanted to stay in their home if their need for help from healthcare services became more advanced. They were more preoccupied with the quality of care than the physical place (Staats et al., 2020). These results reflect those of Hov et al. (2021) who found the value of quality care was of great importance to patients in the late palliative phase, living at home. Similar to our study, Hov et al. found that continuity of care, the correct symptom relief and the appropriate information from HCPs enabled patients to feel safe in their own home.

In the literature, the notion of home has been investigated to clarify the meaning of home and its significance for older persons experiencing illness. Munkejord et al. (2018) distinguish between the 'physical home' where most older people have lived for years and have their routines, and the 'feeling of being home', which is shaped by the view and interior of the living environment, both inside and outside. Moreover, the meaning of home has also been studied within the context of nursing home and hospice care, where patients used terms such as 'homelike', 'homelikeness' and 'at-homeness' in their description of the important aspects that increased their wellbeing and sense of being home. These terms include the vital dimensions of feeling safe, relaxed and protected in a personal way, within a social environment (Moore et al., 2013; Saarnio et al., 2017). Our study concerns *older women's* feelings of being in their *own home,* and we recognize the substance of these previous findings within an institutional context. From our 'own home perception' we will also add perspectives concerning the dignity-preserving experiences that these older female patients described: how they felt calmer and safer in their own home, a place in which showing their feelings openly was more natural to them (Staats et al., 2020). Our findings also add to the sparse knowledge base relating to the way in which an older women's preferred place to stay was affected by the level of compassionate care versus uncompassionate attitudes from HCPs, influencing the preservation of dignity (Staats et al., 2020a). Similar findings have been documented by Bigonnesse et al. (2014), who claim that feeling secure is largely influenced by physical and social aspects within a living environment. Freedom and choices of movement were identified as important elements related to the meaning of home in later life.

In our study, several women shared stories describing how they felt their freedom in certain surroundings had been curtailed, increasing their sense of disconnection and alienation. This was experienced both in their own home and when being admitted to an institution – influenced by uncompassionate attitudes and limited support from HCPs (Staats et al., 2020). Admittance to an institution was, however, the preferred choice of some older women, who felt they were becoming a burden to their closest family and were too great a responsibility for their relatives. Such hospitalizations increased their confidence in the situation, however, paradoxically, also induced a sense of dignity loss, as their personal wish was to be able to stay at home. Wye et al. (2014) highlight how HCPs can contribute to ensuring that patients and their family experience a sense of security and peace at home. HCPs should be highly skilled, experienced and have a wholeheartedly warm attitude to end-of-life care. A willingness to initiate existential conversations and to have access to sufficient resources to fulfil these requirements, were found to be vital. In line with these findings, our study also evidences how the attitudes of HCPs, as well as the organization of healthcare services can influence the sense of dignity loss and the experience of being in an uncaring environment, when these necessities are overlooked. We found that GPs often avoided conversations of an existential character, as they were uncertain as to how to conduct such dialogues. We also revealed that CCs and HCPNs reported a general lack of competencies, as well as resources, hampering their efforts to offer patients dignity-preserving, end-of-life care. In summary, this often causes older women to experience a lack of security in their home, negatively affecting their feelings of living in what was their most treasured environment. Almaawiy et al. (2014) and Danielsen et al. (2018) have previously identified similar findings in which they describe the collaborative meetings of HCPs in the patients' home as a good start for end-of-life care. Encouraging the continuity of care with GPs providing home visits was also essential. This was shown to reduce the chances of unwanted hospitalizations. Conclusively, we argue that the preferred place to be for older women, and how they experience the 'home' when nearing end-of-life, is a diverse and personal matter. There is, however, much more to be learned about the concept of home, as well as the planning of end-of-life care in patients' preferred places to stay.

6.1.4 Experiencing an adjustable hope

Remaining hope was documented as an essential source, enabling the older home-dwelling women within this study to experience dignity. This helped them find new meaning and strength in their life situations (Staats et al., 2020). Little was found in the literature documenting hope and end-of-life care from the perspectives of older women with incurable cancer. However, regarding cancer patients in general, hope was found to drive their search for meaning in life and was seen as a core need and an adaptable tool, helping them cope with their illness experiences (Bovero et al., 2021). These perspectives illuminate an important relationship between hope and meaning in life, found in our study, with older women viewing hope as an existential and adjustable experience (Staats et al., 2020). Our study supports previous research involving hope and nursing care; Lohne (2021) emphasizes hope as a transformational and indispensable concept. She describes how dimensions of hope and hoping are always present, but are also influenced by contextual suffering and losses. Herrestad et al. (2014) recommend a pragmatic approach and state that there are different ways of understanding hope. They claim that seeking any sort of consensus as to what constitutes hope, is in fact futile. Hence, hope is a challenging concept – an abstraction that opens different rooms for action in different contexts. This corresponds with our findings that hope for a new curable treatment is replaced with hope for a sustainable pain treatment, as the illness progresses (Staats et al., 2020).

Our findings also show that the older women's hope for quality of care seems to be more important to them than the actual place to stay (Staats et al., 2020; Staats et al., 2020a). Another perspective concerning hope and the place of residence has been found by Baczewska et al. (2019) who describe that the level of hope is similar, irrespective of whether patients live in small, medium or large communities. They found that hope is more dependent on its content and magnitude, regardless of dwelling. Similarly, with regard to the hopes and wishes of the women to be met with respect and consideration by HCPs, we found that communication with HCPs, who portrayed a sense of calmness and presence, was of crucial importance (Staats et al., 2021). Hawtorn (2015) and Mattes and Sloane (2015) identified that there is a need to improve such HCP skills within end-of-life care to protect the patients' experience of hope. In particular, the GPs' desire to convey a sense of hope while establishing early contact and a therapeutic communication, helping their patients prepare for the end-of-life, was regarded as vital.

We also identified how the older women struggled with feelings of hopelessness when they felt they were a burden to their ICs and even to their HCPs. They had to mobilize their strength to be seen and heard, and to be taken seriously (Staats et al., 2020; Staats et al., 2020a). Hammer et al. (2009) highlight this inner strength of the patients and emphasize the multidimensionality of hope. They visualize hope as a light on the horizon and encourage HCPs to be inspired and to reflect on the meaning of this metaphor. This is further based on the way in which Florence Nightingale walked with the lamp through the dark corridors and spread hope and light among the patients. Lohne (2021) also visualizes hope as an inner flame and relates this to a bright and shining 'lighthouse'. This means, metaphorically, a bright and shining centre where pushing limits and increasing feelings of hope are crucial for promoting health. We found a similar metaphor in our study, adding a new understanding of dignity preservation and hope for older women; hope was experienced when finding one's inner strength in the preparation for the last days and weeks of life. One woman expressed her hope for her death as follows: "like blowing out a candle", to die peacefully without any difficulties. This metaphor visualizes the way in which the light of hope shone until the end of the patient's life (Staats et al., 2020).

6.2 Developing a Model of dignity-preserving care for older, home-dwelling women with incurable cancer

In this chapter, the empirical data will be further discussed in the dialogue with theoretical perspectives to develop a deeper understanding of the study results. The hermeneutical circle helped me achieve a dialogue with the texts of both the empirical data and the Theory of Caritative Caring by Katie Eriksson, in order to develop a new, empirical-theoretical understanding of our findings. Based on this understanding, four themes constitute the core foundation of dignity-preserving care for the older women participating in this study: *feeling recognized as a worthy human being when experiencing suffering*; *having a sense of control in life when being invited into a caring communion; experiencing at-homeness when staying in a safe and meaningful living space* and *achieving optimal health and an inner peace when experiencing hope.* The substance of this empirical-theoretical interpretation will finally be presented in the *Model of dignity-preserving care for older home-dwelling women with incurable cancer.*

6.2.1 Feeling recognized as a worthy human being when experiencing suffering

The empirical discussion highlights that when the older women live their lives as close to normality as possible, they uphold their sense of self-worth and dignity. To be able to fulfil their former cherished roles in life, being supported and met with consideration and gentleness by others, were of crucial importance. In this way, they felt safe and valued as individuals. According to Eriksson (1995, 1996; Lindström et al., 2018) and Nåden and Eriksson (2000), such relational interactions, being met with compassionate attitudes by HCPs, are vital value-based approaches within caritative caring. This involves respect and recognition, as well as the acknowledgement and confirmation of the absolute dignity of each human being – all important sources when developing a caring culture. An invitation to a caring culture confirms self-worth and equality for all human beings, regardless of their illness and what causes their suffering. Caring for older women living with incurable cancer in a caring culture, means caring for a person with absolute dignity, which is undeniable and granted by virtue of being human. A person experiences dignity when they are being treated with respect by others, and when being in the presence of caregivers who have the objective of serving with love (Eriksson, 1996, 2006, 2013). Edlund (2013) underlines that dignity for older persons is having value as a human being, being seen, listened to, taken seriously and believed in. Recognizing the absolute dignity of older home-dwelling women with incurable cancer has, therefore, been found to be a crucial source in dignity-preserving care.

Another important discovery from the empirical point of view is related to the way in which the women experienced a sense of worthlessness in a shroud of illness, as their body weakened along with the progress of their cancer. Several experiences had a considerable impact on their sense of relative dignity, and a great deal of suffering was revealed in the women's stories, as well as in the stories of the ICs and the HCPs. Eriksson (1994, 2006) claims that suffering, in its deepest meaning, is a form of dying from something, as suffering itself has no meaning. However, suffering makes human beings more sensitive and open to the purpose of life. In such a way, they are able to actualize their innermost being. In line with these perspectives, our observations and interviews gave us an insight into how the women grieved for their declining health, when they no longer felt whole and complete. Over time, this can lead to the experience of dignity loss among suffering human beings (Eriksson, 1994, 2006) – as found among the older women in our study. Exploring this topic helped me develop a further understanding of the suffering, in which I gained an insight into the lives of the older women, by observing their interaction with HCPs and their ICs. I identified that HCPs, seemingly unintentionally, sometimes overshadowed and overruled the women's need for psychological and existential care. In particular, poor communication on an existential level between the women and the GP was observed. In these cases, a more superficial collaboration and a lack of depth in their caring relationship, were identified. In the process of interpreting how the older women suffered in these relational interactions with HCPs, the theoretical view of Eriksson (1992, 1994, 2006) was helpful. She emphasizes the great responsibility of HCPs to care for suffering human beings and underlines the importance of avoiding *suffering* *related to care*. She accentuates that this is the most usual source of dignity violation in patient-HCP interactions, caused by caregivers with uncaring attitudes and behaviours, or by caregivers with limited awareness or knowledge failing to prioritize the patient's own wishes and needs. This form of suffering related to care disturbs the patient's rhythm of life and creates situations which threaten the patients' experience of safety in everyday living. In such circumstances, individuals often feel rejected and mistrusted, condemned, punished, neglected and placed in a non-caring situation (Eriksson, 1992, 2006; Lindström et al., 2018). Such a non-caring act or intervention amplifies the burden on those already *suffering due to illness* (Eriksson, 1994). As shown in our study, women's experiences of the side effects of their treatment, as well as their general symptom burden, can be considered as illness-related suffering. For these women, this led to a sense of dignity loss which negatively affected their physical and psychological condition. Finally, within the ontological perspective of suffering, s*uffering related to life* concerns one's own unique life, in which all aspects of being human are involved. Eriksson (1994, 2006) argues that a patient may experience suffering related to life just by being a patient, in which several circumstances disturb the rhythm of life. This form of suffering was experienced in our study when certain women felt being reduced to an incurably ill cancer patient – not being confirmed as a unique individual.

As visualized in the *Model of dignity-preserving care for older home-dwelling women with incurable cancer*, which ontologically is anchored in Eriksson's Theory of Caritative Caring (Eriksson, 1992, 2006; Lindholm & Eriksson, 1993), suffering and health are inseparable aspects of human existence and are understood as the opposite of one other. *The suffering human being* is seen as an entity of body, soul and spirit, while *health* applies to the concept of wholeness (Lindström et al., 2018). As such, we underscore the importance of a healthcare system, characterized by warmth and compassion – consisting of HCPs, who are able to see the wholeness of each of these older women and acknowledge them as worthy human beings. In addition, HCPs should be willing and sufficiently skilled to alleviate the older women's *suffering relating to illness*, *suffering related to care* and *suffering related to life* and as such, treat the women with dignity-preserving care. As I will discuss in more detail below, it is also crucial for HCPs to ensure that the older women have a sense of control over their lives, enabling them to be seen, heard and treated as human beings with freedom of choice.

6.2.2 Having a sense of control in life when being invited into a caring communion

The empirical discussion contributes a new level of understanding in relation to the way in which older, home-dwelling women experience reduced bodily functions that affect their control over their lives, when living with incurably cancer. In fact, their ill body was sometimes described as an obstacle to freedom. Edlund (2002) and Edlund et al. (2013) have previously described that freedom is a crucial dimension of human dignity. From the theoretical perspective chosen for this study, caritative caring aims to preserve the human dignity of suffering human beings, namely, older women with incurable cancer. As underlined by Eriksson (1994, 1996), absolute dignity is characterized by both responsibility and freedom. It is an inherent and inviolable part of the human being, granted through creation and can neither be called into question nor be taken away. In our study, several women were not able to carry out daily chores, due to their illness and were, therefore, dependent on others. They experienced a loss of their everyday, changeable sense of dignity, when their autonomy and self-determination was threatened. Experiencing a lack of support and confirmation in their present state of vulnerability, negatively affected their relative dignity. Consequently, this led to a loss of control for the women – as described by Eriksson (1994, 1996) – a loss of respect and tolerance, to confirm human dignity. This external violation was mostly described in the relational interaction with HCPs, in which the women did not feel welcome. When the women in our study, on the other hand, experienced the appreciation and acceptance of others in relation to choices made, this helped preserve their relative dignity. Therefore, a genuine respect for their autonomy and their desire to have a sense of control over their life helped them preserve their human dignity. This also alleviated suffering related to care, when establishing a vital caregiving relationship.

The empirical view also highlights limited capacity and rigid services within a bureaucratic-organizational healthcare. This could generate difficulties, as well as value-based conflicts that endanger dignity preservation. We found that this hindered HCPs from acting in a professional manner, preventing them from focusing on the women’s independence and sense of dignity. The importance of the presence of others in relation to older women was found to be crucial, as their intention and willingness to provide care helped relieve the suffering of these women in everyday life, and as such increased their sense of having control. Within caritative caring, we refer to the concept of *invitation,* which is related to the acknowledgement and *confirmation* of the inherent absolute dignity of each suffering human being. Eriksson uses the concept of invitation as an act that occurs when the carer welcomes the patient into a *caring communion* (Eriksson, 1995; Nåden & Eriksson, 2000; Lindström et al., 2018). Through this caritative invitation, older women experienced being welcomed by their family and HCPs into this caring communion, characterized by closeness, patience and respect. When the suffering women were invited into such a caring communion, they experienced an intimate connection, warmth and the understanding they needed – a room where they have control in life. This requires a conscious attention to the time and space for the act of caring – to be able to give caring its significance. It is important to recognize that this communion cannot be taken for granted, as this requires effort from each HCP (Eriksson, 1995; Lindström et al., 2018).

The caring communion between HCPs and the women, was found to be essential in upholding the women’s sense of control in life. However, frustration was found among the ICs when they experienced the opposite. They explained how the women had to mobilize all their strength to be seen, listened to and taken seriously, since many HCPs had a limited time to invest in forming relationships with these women. As such, the empirical discussion helped us understand that receiving HCP invitation and being met with gentleness was a vital source for relative dignity preservation in these older women. The experience of being seen, heard and treated as a human being, with freedom of choice was vital for maintaining a sustainable interrelationship. Importantly, the responsibility for this invitation lays in the hand of the HCP’s

(Eriksson, 1995; Lindström et al., 2018). Eriksson claims that by being present in a caring situation, which is an act of ethics – you oblige yourself to see, hear and witness the needs of the suffering human being. As formulated in her mantra of caring ethics, "I was there, I saw, I witnessed and I became responsible", Eriksson (2013, pp. 70) calls attention to the substantial responsibility of HCPs in caring for the suffering human being. Therefore, as visualized in the *Model of dignity-preserving care for older home-dwelling women with incurable cancer* and based on the respect for the *absolute dignity* of each human being, we argue that HCPs should prioritize the preservation of the suffering person's *relative dignity*, despite limited economic and organizational resources. For the women to have a sense of control in life, it was crucial to ensure that they felt understood and *confirmed* as individuals when being *invited* into a *caring communion.* To create such environments that shelter the women's sense of having control and being treated with respect, spaces where the women can sense a feeling of at-homeness should be created. This will be discussed further below.

6.2.3 Experiencing at-homeness when staying in a safe and meaningful living space

The empirical discussion illuminates several sources influencing the older women's sense of dignity, when living in a treasured and nurturing environment. Despite being incurably ill, the women enjoyed and cherished staying in their own home – a place where they felt confident and could more naturally verbalize their thoughts and feelings. The physical place to stay nearing end-of-life was of importance for the women, however, they did necessarily wish to remain in their own home. Admissions to an institution also enabled many women to feel secure and at peace. According to Eriksson (1987b, 2018) the *physical living space* is a concrete place to stay, consisting of primary functions in life. This is one of three living spaces described by Eriksson and vital for human health. Based on our findings, this place should be arranged according to what is treasured and nurturing for the women. It should also be a place where the women can feel safe, achieve proper treatment and care and be in charge of their own decisions. To promote such experiences in this physical living space, dignity-preserving care, provided by HCPs is of crucial importance. Within the second living space, known as the *psychosocial living space* (Eriksson, 1987b, 2018), such care is also essential for the women. Being met with gentleness and understanding by HCPs and being confirmed as a valued human being increases their sense of dignity within this living space. Irrespective of staying at home or in a healthcare institution, the women's wishes concerning the preferred place to stay when nearing end-of-life are affected by relational interactions. For the women to feel safe and experience meaningfulness, a third living space should be optimized. According to Eriksson (1987b, 2018) this is called the *existential living space*. In this living space, the women are able to live harmoniously embracing their values, inner thoughts and wishes, and as such preserving their identity, their hope and their needs. It is crucial that HCPs are aware of this existential living space and identify what is meaningful for each older woman. In fact, all three living spaces act as a foundation for movements in health processes, while searching for meaningfulness and experiences of dignity, irrespective of whether the women stay at home or in an institution.

Our empirical view further points out that the stagnation of health processes takes place when the women experienced a loss of relative dignity, for example when not being met with gentleness in their own home. Using the theoretical perspectives of Eriksson (2018) we argue that the living spaces in such cases were not optimized. The absence of care, which affects older women's relative dignity, is also described by Mann (1998). He argues that each culture defines an invisible personal space around the self, which may be violated if entered without permission. He also claims that this personal space can be entered by HCPs, if permission is given by the patients, potentially leading to dignity-preserving care experiences, when this relationship is based on trust and compassion. The findings from our study support these reflections, as such relational interactions within the psychosocial living space were found to be crucial for the women. We, therefore, argue that when this living space is optimized, together with the physical living space and the existential living space, the women's experiences of dignity and emotional safety in their living environment are strengthened.

As previously described, the quality of care was regarded as more crucial than the physical living space, and without the three living spaces being optimized – emotional security and the experience of dignity will not be preserved (Eriksson, 1987b, 2018). Therefore, it can be fruitful to focus attention on the older women's environment and explore the meaning of home from a theoretical perspective. When describing the physical living space of older, home-dwelling women with incurable cancer, there are several ways of determining the substance of the concept of 'home'. Eriksson uses the concept of a caring culture, as a substitute for the terms, environment and context of care. This characterizes the total caring reality, founded upon cultural elements such as traditions, rituals and basic values. Welcoming a suffering human being and meeting their needs, is essential for developing a compassionate caring culture (Eriksson, 1996, 2006; Lindstrøm et al., 2018; Nåden & Eriksson, 2000). Eriksson's theoretical viewpoints may help us understand how the HCPs in our study describe a flexible culture of care as a vital, valuable-based foundation for dignity-preserving care. Using the limited time given positively and expressing calmness and presence, are core aspects of such a culture of care. Within the caritative caring culture, Eriksson argues that this caring communion requires meeting in time and space, and is an absolute, lasting presence (Eriksson, 1992b). This study increases the understanding of how the women's family and the HCPs created such a caring communion, based on closeness, patience and respect. When the women were invited into the caring communion, they experienced a connection and warmth in their relational interaction with others and perceived a sense of understanding from their surroundings. We, therefore, argue that this is a crucial source of dignity preservation among suffering older women when living with incurable cancer.

Östman et al. (2019) present the concept of at-homeness in their study, the aim of which is to deepen the ontological understanding of ethics and health within a caring and nursing environment. They state that when a human being connects to his or her ethos, a sense of at-homeness occurs. This gives the human being courage, joy, warmth and an inner force. Moreover, a similar study, exploring the home as ethos of caring (Hilli & Eriksson, 2019) revealed that the home as ethos is an inner ethical dimension within the human being. Hilli and Eriksson emphasize that patients who feel a sense of at-homeness are in contact with their ethos, the self and dare to follow their inner voices. They also focus on the perspectives of HCPs and claim that nurses who understand the importance of at-homeness are able to invite patients into a caring relationship.

Based on the caritative theory of caring and visualized in the *Model of dignity-preserving care for older home-dwelling women with incurable cancer*, we argue that feelings of *at-homeness* and *dignity* are experienced in the place in which you reside, when the *physical living space, the psychosocial living space* and *the existential living space* are optimized. This theoretical view shows us how women search for *health* promotion within these living spaces and helps us understand how support, compassion and the presence of others are crucial sources in the dignity-preserving care of older, home-dwelling women. Thus, we believe that when HCPs recognize the older female patients as unique human beings and invite them into a *caring communion*, the older women feel safe and will experience being *confirmed* in their living environments. Further crucial dimensions leading to dignity-preserving care are the experiences of hope and an inner peace, which will be discussed below, in the last section of the discussion.

6.2.4 Achieving optimal health and an inner peace when experiencing hope

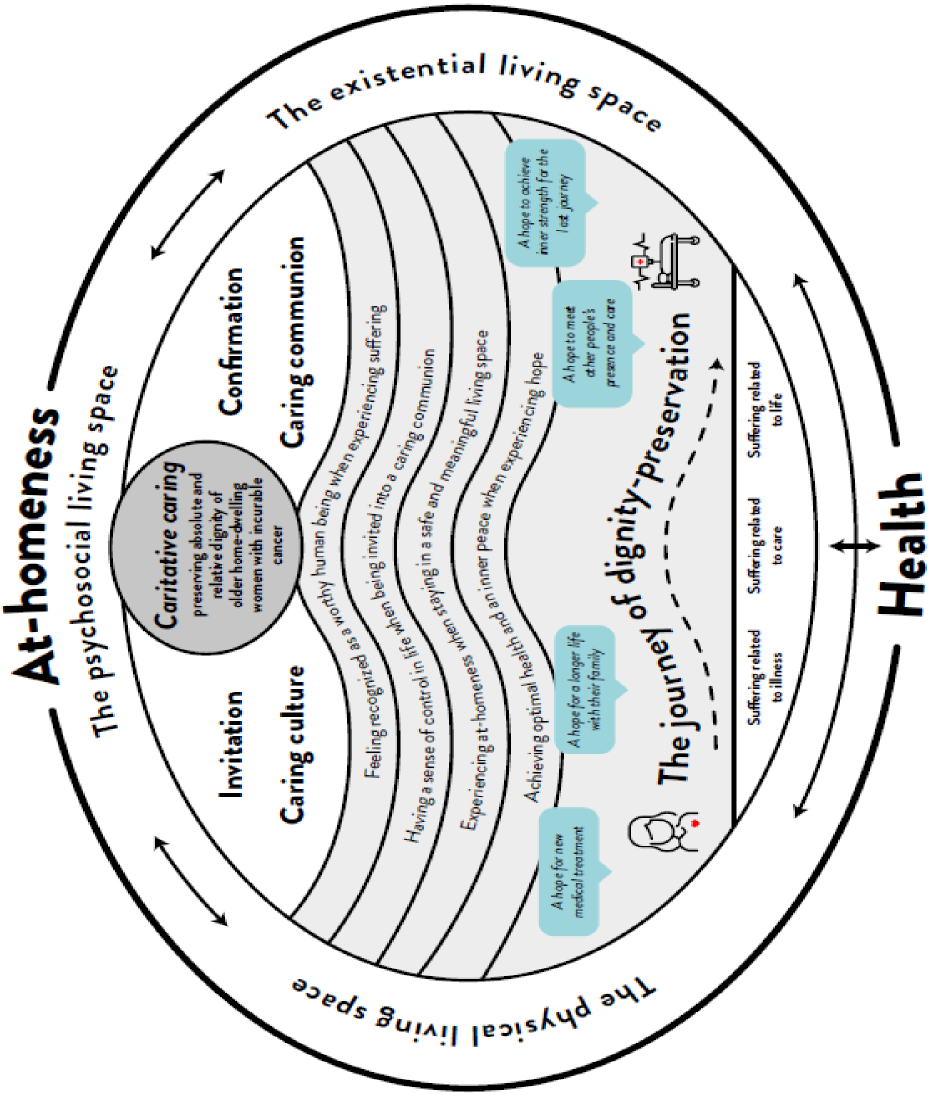
The empirical-based knowledge from this study shows that maintaining a sense of hope was crucial for the older women in terms of preserving their dignity experience when nearing end-of-life. Their hope was related to different aspects, such as hope that their current treatment would relieve burdensome symptoms or hope for a curable treatment in the near future. Importantly, the study shows that this hope was also an existential and adjustable experience and that the women's inner wishes, and what they hope for, is changed as their illness progressed. These findings can be related to the expression of hope and the will to live, as described in Eriksson's Theory of Caritative Caring. She states that when hoping for something, the human being has not given up; in fact, the person believes in the future (Eriksson, 2018). As the empirical discussion emphasizes, the women's hope was an essential aspect within their challenging and uncertain life situation. The presence of HCPs in care situations and the interest shown in the women's life-stories seemed to strengthen their hope. This adds to the theoretical viewpoint of Eriksson (1987b, 2018), which states that hope is closely related to other people's efforts to care. In these interactions, hope was a crucial element for human well-being and health. When HCPs were able to preserve care based on trust and comfort, they were able to support the suffering human foundation for experience hope as a meaningful dimension in life. All human beings have their own personal development and a capability for growth, as they can create new dimensions of health when suffering, and can as such, perceive dignity in care (Eriksson, 1992, 1994).

All human beings have a form of faith, and faith and hope belong together. A human being that can mediate faith, hope and love independently, is able to achieve a certain level of inner peace and freedom (Eriksson, 1987b, 2018). We found that to achieve such peace and freedom, the love and care of others were prerequisites for the women in our study. Eriksson claims that faith can have different dimensions. For many human beings, religious faith is fundamental, being an essential endorsement of hope when nearing end-of-life. For others, faith is related to what you hope for within the context in which you live, such as experiencing health as an integrated whole. As for the ontological perspective, the desire for optimal health is conceived as a development and movement towards a deeper wholeness – a forward-moving motion to fulfil one's potential in life (Eriksson, 1987a, 2018).

The empirical view outlines how a forward-moving motion could also stagnate and how certain women struggled with feelings of hopelessness, when they felt insignificant and subsidiary to others. An additional source leading to dignity loss when being in a vulnerable state was the feeling of being overridden by others, which consequently, led to suffering related to care, but also a search for hope. Eriksson states, 'Where there is suffering, there is also love and a possibility of growth' (Eriksson, 2018, p. 376). Moreover, *caritas,* meaning love and charity is required in a caring relationship among those who are suffering. Caring for a suffering human being, is always a struggle between the good and the evil, between hope and hopelessness, and between life and death (Eriksson, 1987a). Using the perspective of Eriksson (1994, 2002, 2018) finding meaning in these women's suffering involves a movement in which there is a will to live. We argue that HCPs can enhance this movement, by acknowledging what nurtures the sense of meaningfulness and hope in the lives of these women, and in so doing maintain the older women's dignified experience of living in a process of constantly becoming. However, people can always choose whether to channel their suffering into positive growth or allow their suffering to become an obstacle to such a development. For suffering to be a source of personal growth towards optimal health, human beings need confirmation from others in their suffering (Eriksson, 1994, 2006, 2018).

As visualized in the *Model of dignity-preserving care for older home-dwelling women with incurable cancer,* the quotes show how hope is an existential and adjustable experience. As expressed by certain women in this study and described as a crucial dimension of hope, staying in a place where one can experience human worthiness and achieve optimal *health* when nearing end-of-life, is vital. Thus, based on the findings of this study, we argue that this is a core foundation for promoting the experience of inner strength and freedom, as well as personal hope and peace, when nearing end-of-life. As described by Eriksson, "promoting what is good" lies in the ethos of caring. We believe that by following this lead, HCPs can meet the needs and wishes of older women living with incurable cancer at home – allowing them to die with dignity.

Figure 9: *Model of dignity-preserving care for older home-dwelling women with incurable cancer*



7. Methodological considerations and limitations

Qualitative researchers aim to provide interpretive material that makes the world visible, by attempting to make sense of or understand the meanings that people bring to them (Denzin & Lincoln, 2011, p. 3). In our project, we chose to use participant observations, in-depth interviews and focus group interviews as tools for data collection. These three approaches contributed to producing empirical data, considered as complementary sources, capable of answering the research questions addressed. As a researcher, I am responsible for making this process of data gathering and interpretation as transparent as possible, increasing the trustworthiness of the study. Therefore, being humble, honest and capable of emphasizing reflexivity have been my fundamental motives during the research process.

7.1 Reflexivity

Becker (2014) claims that being objective and avoiding taking sides is a very challenging task, requiring us to adopt an open approach and to be reflexive throughout the research process. Moreover, we must always be transparent, clarifying the boundary of our scope of study, as well as limiting our conclusions carefully. These crucial aspects will be discussed below.

Philosophical hermeneutics does not constitute finding a ‘technique’ of interpretation, but rather an event in which meaning is created and transformed, with the aim of understanding the phenomenon under investigation (Gadamer, 2010; Freeman, 2011). The purpose is not to present *the* truth, but to explore and bring to light potential interpretations and horizons of understanding. We are aware of how the hermeneutic circle of understanding is an infinite process in nature, and how it will always be possible to identify new ways of interpreting data (Gadamer, 2010). Moules et al. (2015) underline the importance of being humble in relation to these other interpretations, and as such, we have kept the doors open for other perspectives and have presented our findings in terms of suggestions and possibilities. It is vital to reveal the perceived strengths and limitations of the choices made during the research process. When carrying out participant observations in the home of incurably ill women, I strove to be a natural part of the setting, making use of my previous experiences as a CC, so as to establish a secure and positive atmosphere during the data collection phase. The six participant observations were not followed up by new observations, which potentially limited insights into the participants' everyday lives, as well as the interactions with HCPs in their homes. The decision to conduct just one observation of each participant was primarily taken so as not to inconvenience these older women, but also as a result of the challenges of organizing and attending such infrequent home-meetings with HCPs. Moreover, only one interview was conducted with each participant in all three studies. As a research team, these potential limitations were carefully discussed, and in studies I and II, the obligation of having sensibility towards the vulnerability of incurably ill women and ICs was a leading principle in protecting their integrity and dignity. There is a need for moral sensitivity as an important motivation to “do good” and “to care” (Heggestad et al., 2013).

Being both an oncology nurse and a researcher might have affected the interview situations in which I possibly made premature conclusions. However, my background as an oncology nurse was probably also a strength, due to my communication experiences with patients, ICs and HCPs. During the data collection phase, all participants willingly shared their experiences and personal histories, which provided us with rich descriptions and a thorough foundation of data. Nevertheless, it might be argued that the number of participants was rather small, and the experiences cannot be considered typical in the sense of being findings that can be generalized to older women living with incurable cancer, in general. However, we believe that all participants contributed to the rich data, making valuable contributions to the existing knowledge base of dignity-preserving care within the municipal healthcare services for older women, living with incurable cancer at home.

In study III, the proportion of CCs and HCPNs, respectively was imbalanced. We accept that this might have led to a stronger weighting of CCs' experiences and views concerning dignity-preserving care. However, as a researcher, I strove to focus attention on the valuable views of the two HCPNs, participating in the study.

Moreover, when using the snowball method to recruit GPs, the sample could have been restricted to a rather small network, increasing the likelihood of including participants who shared the same characteristics and interests in the research topic. Moreover, due to COVID-19 restrictions, the in-depth interviews with GPs were carried out digitally, which might have limited the interactional aspects of the data collection, such as thinking and feeling behaviours. However, irrespective of all the choices made, both intentional and unintentional, the researcher is responsible for establishing a trustworthiness, by describing the research process thoroughly (Fleming et al., 2003). This important aspect will be discussed further below.

7.2 Trustworthiness

Polit and Beck (2017) describe trustworthiness as the degree of confidence that qualitative researchers have in their data and analyses. I will present four criteria to assess the trustworthiness of qualitative research, formulated and recommended by Lincoln and Guba (1985); study *credibility, dependability, confirmability and transferability*, as well as a fifth criterion, *authenticity*, which was subsequently described by the same authors (Lincoln & Guba, 1994). These criteria have been used by many qualitative researchers over the years (Creswell & Miller, 2000; Watson, 2009; Elo et al., 2014; Polit & Beck, 2017; Creswell & Poth, 2018), as well as Fleming et al. (2003) who refer to them as being applicable for a Gadamerian research process, which is of great relevance in this study. I will now move on to discuss these in the same order as introduced above, starting with study, *credibility*.

7.2.1 Credibility

Credibility refers to the confidence and truth in relation to the interpreted data (Polit & Beck, 2017). We strove to establish credibility by means of a thorough reflection of our pre-understandings and to build study transparency throughout all phases of this research project. As Lincoln and Guba (1985) point out, the first step is to carry out the research process in a credible way. We initiated the project by establishing an advisory board to ensure ‘Patient and Informal Caregiver Participation in Research’ (PAICPAIR) as including the perspectives of these individuals when planning and carrying out the project strengthens the research credibility (Staats et al., 2020b). During the project period, I had a sound collaborate with patients and IC representatives as co-researchers, acknowledging them as experts in relation to the subject under investigation. Their competence and contributions were unique and of great value in all phases of the research process. They contributed to the formulation of the study's aim, participated in the development of information letters and interview guides, and read the analyses and article drafts. Enhancing study credibility was also sought by creating an open atmosphere during the interviews, summing up parts of the conversation and then asking the participants to determine and correct their statements. Moreover, as a research team we reflected upon our pre-understanding and various backgrounds, and continuously focused attention on the research questions throughout the research process. This made us aware of and curious about our varying expectations, so as to avoid making premature conclusions during the process of data interpretation.

7.2.2 Dependability

Dependability relates to whether the participants' stories are credible and consistent over time, when being repeated under different conditions (Lincoln & Guba, 1985; Elo et al., 2014). As Polit and Beck (2017, p. 559) point out, "Credibility cannot be attained in the absence of dependability". To obtain study dependability, transparent documentation of the research process was necessary. The recruitment procedure was distinguished by the characteristics of the sample, using a language that I believe was meaningful and understandable to the reader/study audience. In line with the perspectives of Creswell and Poth (2018), I strove to understand the phenomenon under investigation when meeting participants in person, spending time in their surroundings. However, I also asked myself the questions, "did I get it right?" and "could I have understood this experience differently?" It is of crucial importance to have a critical and cautious attitude and to reflect on such questions throughout the research process. To increase the study dependability ensuring thick descriptions of the phenomenon under investigation were stressed. In the process of data interpretation, we created transparent documentation to demonstrate the way in which certain themes and sub-themes were formulated from the transcripts and mind maps, with preliminary interpretations. We also repeatedly discussed the initial formulation of the study results within the research group, for example, when evidence contradicted our pre-understanding and there was a need to review alternative interpretations.

7.2.3 Confirmability

In qualitative research there is always the potential risk of incongruence in relation to the researchers' and the participants' voices (Lincoln & Guba, 1985; Polit & Beck, 2017). Confirmability concerns establishing data which represents the same information provided by the informants. For the study to achieve confirmability, data must not be invented by the enquirer (Polit & Beck, 2017). In line with Elo et al. (2014) and Polit and Beck's (2017) suggestions, we, as a research team, were responsible for the relevance and accuracy of the data and its interpretation. We held several meetings to discuss the adequacy of the interpretation process, when developing different themes and sub-themes. To strengthen the confirmability of the data, we also reflected upon our pre-understanding, so as to move away from our former pre-conceptions and to be open to new horizons of understanding (Gadamer, 2010). It was important for us to make the processes of decision making visible to the readers, enabling them to understand how the themes emerged from the data. This kind of transparency is part of a procedure called *triangulation* (Lincoln & Guba, 1985; Creswell & Miller, 2000). In this project, we chose to include in-depth interviews, focus group interviews and participant observations in the data collection process to increase the confirmability. Additionally, we searched for convergence among these different sources in the process of formulating the themes and sub-themes of this study.

7.2.4 Transferability

The purpose of writing thick descriptions of our research project was also to provide as many details as possible. This enabled the readers to make assessments on the applicability of the findings to similar contexts or settings (Lincoln & Guba, 1985; Creswell & Miller, 2000). As qualitative researchers, we were looking for the view of other people, the view of the study participants, collected during interviews and participant observations. We also acknowledged the view of our advisory board, as well as the feedback from the peer reviews of our papers. The co-researchers in our advisory board (Staats et al., 2020b) participated in discussing their perspectives on the transferability of the findings, whether they related to patients within other contexts, such as those suffering from a non-cancer-related incurable illness, yet also in need of palliative care. As researchers, the responsibility to provide sufficient descriptive data for the reader to evaluate the transferability in relation to other contexts, is of crucial importance (Polit & Beck, 2017). In our project, the number of participants were insufficient to allow for generalized conclusions. Moreover, in qualitative research, generalizability must be set aside in favour of an in-depth understanding of the phenomena under investigation (Creswell & Poth, 2018). A procedure used to ensure transferability in qualitative studies, is to systematically and accurately describe the connection between the results and the collected data (Elo et al., 2014). The findings of studies I, II and III are presented with quotes from incurably ill women, ICs and HCPs, respectively, to demonstrate the connection between the data and the results of each study. Additionally, in this present thesis, the collected data and the results of the three studies are interpreted and described as a whole.

7.2.5 Authenticity

A qualitative research paper has authenticity when it conveys the feelings and mode of participants’ lives as they are lived. Such a text also invites the reader to develop a heightened sensitivity to the issue, when the author portrays the feelings, experiences and the context of those lives (Lincoln & Guba, 1994; Polit & Beck, 2017). In this research project, our objectives were to identify and describe the feelings and experiences of the older women, ICs and HCPs. It was of crucial importance for us to formulate these as they were expressed by the participants themselves, to ensure authenticity and to bring to light dignity-related experiences. The purpose of this quality criterion, formulated by Lincoln and Guba (1994), is to convey the feeling or tone of the study participants in such a way that helps the readers develop an understanding of the participants’ experience. There is a tacit assumption that empathy between the researcher and the participants will increase the possibility of collecting richer and more detailed data – which in turn will produce more credible and trustworthy research findings and a stronger authenticity in the presentation of the participants' viewpoints (Lincoln & Guba, 1994; Watson, 2009).

Throughout the whole research process, we emphasized a reflexive approach, anchored in the hermeneutical circular process. Our understanding was developed through the movement of initial interpretation of each interview texts and observation notes. Subsequently, an interpretation across all individual texts aimed to better understand the text a whole, as such an understanding would also help us increase our understanding of parts of the text. Within this circular process, constructive interactions among the researchers are an essential part (Moules et al., 2015). We interpreted our findings through our chosen theoretical lens; other researchers may have developed an alternative understanding of the subject under investigation, utilizing alternative theoretical frameworks. Conclusively, employing other theoretical perspectives could have led to richer data material opening for other understandings (Brinkmann, 2015). Finally, although *our* understanding of the phenomenon of interest cannot be generalized across a broader population, this research project offers a deeper understanding of dignity-preserving care for older women living with incurable cancer at home – from the perspectives of the older women themselves, their ICs and HCPs.

8. Conclusion and future perspectives

Based on the perspectives of older women living with incurable cancer at home, their ICs and HCPs, we have developed an empirical-theoretical model of dignity-preserving care for older women living with cancer at home. A hermeneutical methodology was chosen for our exploration of the chosen research questions, to increase our understanding of this subject.

A vital dimension leading to the experience of dignity for older women was the feeling of being recognized as a worthy human being when experiencing suffering. Being able to participate in daily chores and maintain their cherished roles in lives, helped them uphold their sense of self-worth and dignity. Being respected and confirmed as human beings and not regarded solely as an incurably ill cancer patient, was found to be crucial for them. When HCPs treated them with consideration, warmth and gentleness, these older women felt safe and valued as individuals. However, we also found that organizational restrictions, efficiency strategies and a lack of competence on the part of HCPs, could negatively affect the women's perceptions of being worthy human beings – leading to dignity violations and suffering related to care.

Another vital aspect enabling these older women to experience dignity was having a sense of control in life. Being seen, heard and treated as human beings – by a caring communion, was vital in upholding their sense of dignity and self-determination in life. We also identified that they sometimes felt subsidiary to others and experienced a loss of relative dignity when their autonomy was threatened. For many, their ill body was described as a barrier to freedom, and we found that their level of bodily function had a crucial impact on their sense of control in life. This study also found that a bureaucratic-organizational healthcare system with limited capacity and rigid services, could generate organizational challenges and value-based conflicts, constituting an obstacle to dignity-preserving care practices.

Furthermore, we found that when the older women were situated in surroundings that made them feel safe, their sense of dignity were promoted. Most women wanted to stay at home in their present state of incurable illness. The home was described as a place where they could enjoy and cherish the quality of everyday life, express their feelings and maintain relational interactions with others. However, we found that when nearing end-of-life, they were more preoccupied with the quality of care than the physical living space. This was influenced by the compassionate versus uncompassionate attitudes of HCPs, as well as a general lack of competency and resources within homecare services. Experiences of disconnection and alienation were evident both in the women's homes and within institutions, if their freedom of choice was compromised. This was shown to bring about experiences of dignity loss, reducing their feelings of at-homeness.

Finally, maintaining hope was considered as a vital source to preserving the dignity of older women living with incurable cancer at home. We found hope to be an adjustable and existential experience, changing concurrently as the illness progressed. Sources leading to loss of dignity and a loss of hope were related to feelings of being overridden, not being able to communicate their preferences and struggling with inner existential thoughts. These situations, consequently, led to suffering and experiences of hopelessness. For the older women to perceive dignity in their lives, their innermost hopes and wishes for a meaningful and safe life must be taken into consideration. A crucial dimension of hope for these women was also related to residing in a place where they could find inner strength and freedom as worthy human beings, where they could be confirmed by others in their suffering and where they could die with dignity.

8.1 Implication for care practice

We consider dignity-preserving care to be a core dimension when meeting older women living at home with incurable cancer. We argue that there is need for increased knowledge concerning women's health and ageing in the municipal care practice, as health policies seem to lack the important perspective of dignity-preserving care. There is also a need for awareness concerning the social and historical context of gender differences, as well as an account of the current context of women's health in Norway. Therefore, governmental action plans regarding future, municipal end-of-life care for home-dwelling citizens should include perspectives of gender-specific care. This study contributes to the knowledge base relating to dignity-preserving care for older, incurably ill women.

Based on our findings, we suggest a stronger collaboration within the municipality healthcare services and advise GPs, CCs and HCPNs to create networks for mutual reflections and to focus on different measures and initiatives to improve the quality of end-of-life care for older women. It is also of crucial importance to implement knowledge from this study within educational programmes to define learning outcomes, and as such, to reach healthcare students responsible for the care of this target group in the future. Therefore, we recommend that emphasis be placed on the following to promote dignity-preserving care practices for older, home-dwelling women living with incurable cancer at home:

HCPs being able to see the wholeness of the older women, acknowledge them as worthy human beings – as women, wives and mothers, ensuring that these roles still influence their lives.

The older women should be invited into a caring and confirming communion, enabling them to feel loved and understood as a human being When establishing such a vital caregiving relationship, based on trust and care, human dignity will be sheltered and suffering related to care will be alleviated.

A genuine respect for the women's autonomy is crucial, acknowledging individual preferences and needs in each unique care situation. It is important to respect the older women's need to have a sense of control in life, in which they are being seen, heard and treated as human beings, with freedom of choice.

When these older women fear to lose their control in life and feel subsidiary to others, HCPs should utilize an approach based on sensitivity and generosity – creating an environment in which the women can experience a sense of control and at-homeness.

Professional cooperation with an individualized approach and an emphasis on the creation of a flexible culture of care should be promoted. This means using the limited time given constructively, having knowledge of the women's situations and ensuring flexibility and generosity among HCPs. When HCPs express calmness and presence, irrespective of the time frame, the women's sense of control in life could be strengthened.

A healthcare system should be established, characterized by warmth and compassion, consisting of HCPs willingness to prioritize the suffering patients' relative dignity, despite limited economic and organizational resources.

An acknowledgement of the hope expressed by these older women as an adjustable and existential experience means different things to different women. It should be noted that hope – and what is considered valuable in their life – seem to change as the illness progresses.

It is important to show an interest in the older women's life-stories and anchor caring in the core dimensions; trust and comfort. This seems to strengthen their hope and helps alleviate their suffering, when finding new meaningful dimensions in life.

It should be remembered that hope is also closely associated with finding one's inner strength – visualized as a light that is perceived as existing until the end-of-life. Therefore, the love of the caregiving other is a prerequisite for older women, facilitating their experience of hope and inner peace, when living with incurable cancer and dying with dignity.

8.2 Further research

This study encourages further research to increase the understanding of crucial aspects related to dignity-preserving care for older, home-dwelling women living with incurable cancer.

We found that there is an increased likelihood that older, home-dwelling women are treated with dignity during the final period of their lives, if dignity-preserving care and gender perspective are prioritized and implemented in the education programmes of HCPs. We, therefore, recommend further research to expand HCPs' knowledge on this important subject.

HCPs provide care for the study target group, and we have suggested a greater collaboration between the different professions in the municipal healthcare services. Therefore, future research should explore how research-based knowledge of dignity-preserving care can be implemented as an integrated part of end-of-life care within the municipal healthcare services. In addition, future research should focus on the networks of GPs, CCs and HCPNs, as well as other professionals involved in the care of older, incurably ill women living at home. This should, subsequently, be utilized to explore ways in which to improve the quality of end-of-life care.

This research project documents the crucial impact on ICs, involved in the care of their wife, mother or sister. In addition to their shared experiences concerning dignity-preserving care for incurably ill, older women, we identified how the ICs themselves struggle in their everyday lives. We, therefore, recommend further exploration of the way in which this impacts ICs on a personal level. Increased knowledge is also needed concerning HCP interventions directed towards ICs and the social network of older women in general, demonstrating how HCPs have a crucial influence on dignity-preserving care.

As this study focuses on the specific group of older women, living with incurable cancer at home, we believe there are similarities that are transferable to other groups of vulnerable patients. It might be possible to explore the meaning of dignity-preserving care in more depth, using the qualitative studies for other target groups and further developing this crucial dimension within healthcare. We, therefore, encourage other researchers to adopt our research findings, while identifying and documenting experiences leading to dignity and dignity loss among other groups of patients – and as such continue this conversation after us.

9. Source of data

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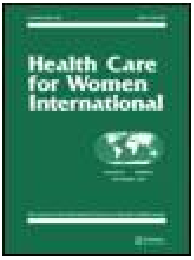

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Dignity and loss of dignity: Experiences of older women living with incurable cancer at home

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ABSTRACT

In this study, we explored and identified crucial experiences that constitute dignity and loss of dignity among older women living with incurable cancer at home. In-depth interviews with 13 women, and participant observations of five of these women, were performed. Hermeneutical interpretations of interview texts and field notes were conducted. Crucial experiences that preserved the women's dignity included having a sense of control, making one's own decisions, experiencing hope and meaningfulness, feeling valued as a human being and having the opportunity to be in a treasured and nurturing environment. Dignity loss was related to losing the opportunity for self-determination, sensing hopelessness and worthlessness in a shroud of illness, experiencing violation of their personal life and being situated in surroundings that enhanced their sense of disconnection and alienation. Quality of care was experienced as more important than the physical place in which to spend their final stage of life. The findings suggest that dignity preservation should be a core dimension in care for older women living with incurable cancer at home. Future research should investigate how dignity-preserving care can be organized and practiced within municipal palliative care services.

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Worldwide, cancer is the second leading cause of death. Breast cancer, stomach cancer, lung cancer and cervical cancer have the highest prevalence among female cancer patients (World Health Organization, 2017). The cancer incidence around the world was estimated at 8.5 million cases for women in 2018 (World Cancer Research Fund International, 2018) and approximately 1.7 million women, 65 years or older, died of cancer in 2018

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(International Agency for Research on Cancer, 2019). The world's population aged 60 years and older will nearly double between 2015 and 2050 (World Health Organization, 2018). This development will increase the number of people afflicted with cancer and create challenges within healthcare systems (Fjose et al., 2018).

Facing end-of-life, the majority of older people desire to live in the familiarity of their own homes and to die there (Gomes et al., 2013; Loh et al., 2016). Home speaks to the caring part of a person—caring about someone and being cared for (Swenson, 1998). Having solid cancers increases the chances of dying at home. However, being older and female decreases the chances of dying at home (Cohen et al., 2010). Worldwide, between 12% (South Korea) and 57% (Mexico) of patients with cancer die at home (Cohen et al., 2015). In Norway, 15% of people who died in 2012 and 2013 died at home, of whom only 6.3% had planned a home death (Kjellstadli et al., 2018). Over time, the numbers have remained stable and low worldwide (Cohen et al., 2015). As for other countries in Europe, the organization of municipal healthcare services in Norway varies depending on the local healthcare structure. Mainly, the municipals have either palliative units or a number of "palliative beds" in the nursing home, in addition to home-care services and the general practitioner's follow-up in the patients' home. In Norway, patients in need of palliative care services have limited access to institutional hospice care (The Commonwealth Fund, 2020). Nevertheless, the hospice philosophy is integrated in the municipal services and is prevalent during the whole disease trajectory. In other words, palliative care and the hospice philosophy are interrelated, and we need approaches to optimize quality of end-of-life care in home-based clinical practice.

The World Health Organization (2011) states that dignifying care is crucial for maintaining quality of life among patients with life-threatening diseases, while The Worldwide Hospice Palliative Care Alliance (2017) aims to preserve dignity of all citizens nearing end-of-life as a basic human right. Older women living with incurable cancer are at high risk of experiencing physical, emotional and existential suffering. When living in familiar surroundings, in most cases in their homes, they are often dependent upon family support in addition to formal care from municipal healthcare professionals (Willis et al., 2015). Baillie et al. (2008) state that *dignity* concerns how people act in relation to themselves and others. Treating people with dignity and respect highlights the feeling of being of worth and being valued as an individual.

Defining a *dignified death* is difficult and knowing how to give the dying patient *dignity-preserving care* is a challenging matter. The concept of *dignity-preserving care* has previously been described within dementia care

(Tranvåg, 2015), but will also be a central mission in future palliative care when arranging for care at home for older patients in their final stage of life (Aoun et al., 2016). We have to process a great deal of information on dignity-preserving care to understand how it affects patients and their families, and more specifically to comprehend what dignity means to women receiving care (Zirak et al., 2017).

Earlier research has highlighted factors leading to dignity and loss of dignity of dying patients in hospitals (da Rocha Rodrigues et al., 2019), in nursing homes (Oosterveld-Vlug et al., 2014) and in hospices (Bovero et al., 2018). However, knowledge concerning experiences that enhances the sense of dignity of older women living at home with incurable cancer, and their experiences leading to dignity loss, is currently insufficient. The Society for Women's Health Research (2018) and the Office of Research on Women's Health in the USA (2010) encourages increased research on gender-specific aspects related to women's health and disease. In accordance with healthcare for Woman International, aging females in particular (Davidson et al., 2011), bring about the increased requirement for an interdisciplinary approach adopting different measurements for female patients. It is vital that we share knowledge of the crucial experiences affecting women's health and suffering to better understand dignity and loss of dignity among women suffering from serious illness.

Study aim

The purpose of our study was to develop a new knowledge foundation for dignity-preserving palliative care practices within the municipal healthcare services. Our aim was to identify and document experiences crucial for dignity preservation, as well as experiences leading to dignity loss among older women living with incurable cancer at home. The following research questions were addressed: (a) How can dignity experiences of older women living with incurable cancer at home be preserved? (b) How do older women living with incurable cancer at home describe experiences leading to loss of dignity?

Methods

This study had a qualitative, explorative and descriptive design. Qualitative research tends to be holistic and flexible from which new understanding emerges during the course of data collection (Polit & Beck, 2017). Gadamer's philosophical hermeneutics (Gadamer, 1989) was selected as an appropriate methodology that highlights how interpretation and dialogue with the text may lead to new understanding of the phenomenon under investigation.

Table 1. Study participants – socio-demographic data.

Participant	Age	Diagnose	Merital Status	Housing	Level of education	Urban/ Rural	Community health care support*
1	78	Breast cancer	Married	With husband	Higher	Rural	CC, GP, PCT
2	83	Neuroendocrine carcinoma	Widow	Alone	Higher	Rural	GP, HCS
3	80	Lung cancer	Widow	At son's house	Primary	Urban	CC, GP
4	79	Gyn cancer	Widow	Alone	Primary	Urban	CC, GP
5	66	Gyn cancer	Married	With husband	Higher	Rural	CC, GP, HCS, PCT
6	73	Lung cancer	Married	With husband	Higher	Rural	CC, GP, HCS
7	75	Gyn cancer	Married	With husband	Primary	Rural	CC, GP, HCS
8	69	Myelomatosis	Married	With husband	Primary	Ruban	CC, GP
9	77	colon cancer	Divorced	Alone	Primary	Urbann	CC, GP, PCT
10	72	Gyn cancer	Married	With husband	Higher	Urban	CC, GP, PCT
11	75	Gyn cancer	Widow	At daughter's house	Primary	Urban	GP, HCS
12	75	Blooc cancer	Divorced	Alone	Higher	Urban	CC, GP, HCS
13	75	Gyn cancer	Single	Alone	Higher	Urban	CC, GP, HCS, PCT

*CC = Cancer Coordinator, GP = General Practiotioner, HCS = Home Care Services, PCT = Palliative Care Team

Participants

Participants were recruited from eight Norwegian municipalities. Municipal cancer coordinators supporting female cancer patients and their families in their home, assisted with participant recruitment. Utilizing a strategic sampling strategy, we formulated the following inclusion criteria for this study: being female, aged 65 years or older, diagnosed with cancer in the palliative care phase, living at home and receiving support from municipal healthcare services. From November 2018 to February 2019, 23 Norwegian women were given verbal and written information about the study by their cancer coordinator. Ten of the women declined to participate due to the following reasons: not interested, tiredness, admission to hospital, disease advancement and death. A total of 13 women aged 66 to 83, gave their consent to participate in the study (Table 1).

Patient and informal caregiver participation in research

User involvement improves the relevance and utility of research and gives insight into the user's unique experiences of everyday life (Morrow, 2012). A framework for ***Pa**tient and **I**nformal **C**aregiver **Pa**rticipation **in** **R**esearch* (PAICPAIR) suggests a stronger foundation for democracy, equality and research quality by promoting active participation among vulnerable people experiencing incurable, life-threatening illness, as co-researchers (Staats et al., 2019). This study implemented a thorough cooperation with the projects reference group, consisting of an older woman living with incurable cancer living at home, a former informal caregiver, who previously cared for a home-dwelling older woman with incurable cancer, a general practitioner and two oncology nurses employed in the municipal healthcare services. They all participated in decision-making concerning relevant research questions and developing the interview guide. They also participated in discussions of preliminary findings. Leading and evaluating the research process, our steering group continuously used the reference group as a vital source of information and feedback. The steering croup consisted of the authors of this article, a former informal caregiver to a home-dwelling older woman with incurable cancer, and two research advisors.

Pre-understanding and theoretical framework

Gadamer (1989) states that pre-understanding determines the validity of all fore-meanings directed at the text *via* the anticipated meaning. Thus, as researchers, our pre-understanding was not neutral and distanced, but characterized by a certain relationship to the subject. Researchers' pre-understanding should be available to ensure transparency (Hiles & Čermák, 2007) and trustworthiness (Lincoln & Guba, 1985). As members of the research team, each author brought her/his pre-understanding into the project and these perspectives were discussed and challenged throughout the research process. From her background as a municipal cancer coordinator, first author KS was experienced in communicative and ethical aspects concerning end-of-life care. OT had previously contributed to scholarship and research relating to dignity and care, and all four authors shared a commitment toward care that respects the dignity of the patient. Due to the authors' various professional backgrounds as cancer nurses (KS and EKG), mental health nurse (OT) and medical doctor with competence in palliative medicine (BH), the interprofessional perspective led to several fruitful discussions.

Dignity is a central concept when discussing the foundation for good end-of-life care. Several authors have contributed to the understanding of dignity in care (Chochinov et al., 2002; Eriksson, 2018; Gallagher, 2009; Jacobson, 2009; Nordenfelt, 2009; Tranvåg, 2015). The dignity concept has also been criticized as being vague and useless within the healthcare context (Billings, 2008; Macklin, 2003). However, as stated in *Universal Declaration of Human Rights*: "All human beings are born free and equal in dignity and rights," (United Nations, 1948, Article 1). Katie Eriksson is one of the pioneers developing caring science within the Nordic countries. In her Theory of Caritative Caring, dignity is one of the basic concepts, and Eriksson points out how people experience dignity and loss of dignity in everyday life and proposes that dignity can be perceived as partly absolute, partly relative (Eriksson, 1994). *Absolute dignity* is inherent in all people, inalienable and granted by virtue of being a human being. Absolute dignity thus involves both a right and a need for each individual to be recognized as a unique and worthy person. *Relative dignity* is, on the other hand, a modifiable form of dignity that is influenced by sociocultural factors of everyday life. Relative dignity concerns feelings of self-worth as well as worthiness in relation to other people. It can be strengthened through the support and confirmation of others, but can also be torn down and violated. Eriksson (2018) claims that caring does not deny the presence of *suffering*, on the contrary, it is the most important basic category of all caring. She describes three different forms of suffering; suffering related to *life*, suffering related to *illness* and suffering related to *care*. These are all related to the patient's experiences of dignity. Additionally, Eriksson (1994) divides relative dignity into an *inner* and *outer* part. Inner dignity refers to an internal freedom of the human being to relate to themselves and to their situation, while a bodily and external dimension characterizes outer dignity. Therefore, the source of personal worth is based upon its inner value and outer surrounding.

Data collection

We wanted to obtain detailed information about the women's perceptions regarding dignity and loss of dignity. Individual in-depth interviews were utilized as a data collection tool (Brinkmann, 2015). The interviews were carried out in the women's homes, except for two interviews conducted in a hospice ward where the participants were temporarily admitted. We used a modifiable interview guide to structure the interviews and to facilitate inclusions and explorations of new themes as they appeared throughout the data collection process (Brinkmann, 2015). Prior to the first interview and after interview number six, we used feedback from the reference group to develop and evaluate the interview guide. This approach is harmonious with hermeneutic methodology where new understanding of a phenomenon arises through continuous processes (Gadamer, 1989). Examples of questions guiding the interviews were: Can you tell me about your everyday life at home; how may your dignity be preserved? Can you describe a situation where loss of dignity was experienced when interacting with others? How does your living environment affect your experience of dignity? The first author (KS) conducted the interviews. The participants were encouraged to answer as freely as possible. Active listening and follow-up questions were used to gather rich descriptions from the participants (Brinkmann, 2015). All interviews were recorded and transcribed verbatim. One interview was conducted with each participant, lasting from 43 to 92 min (mean = 64.2 min) and produced 238 transcribed A4 pages.

Additionally, we collected data from participant observations (Knoblauch, 2005; Spradley, 2016) with five of the 13 interviewed women. The first author (KS) observed four home-meetings and one meeting at the hospital.

Table 2. Participant observation – study participants and setting.

Observation	Participant nr.	Participators in observation	Setting	Rural/Urban
1	1	Patient, husband, cancer coordinator, Palliative care doctor, observer	Patients home	Rural
2	7	Patient, husband, cancer coordinator, observer	Patients home	Rural
3	5	Patient, cancer coordinator, observer	Patients home	Rural
4	10	Patient, husband, palliative care doctor and oncology nurse, observer	Hospital	Urban
5	6	Patient, cancer coordinator, observer	Patients home	Rural

The next-of-kin and the healthcare professional (HCP) responsible for the palliative care were also present at these meetings (Table 2). By observing the interaction between patients, next-of-kin and HCPs, we gained a deeper understanding of their experiences related to dignity and loss of dignity. Based on the hermeneutical methodology, an observation guide was developed and utilized during the observations. Observation notes on aspects assumed to affect the women's experiences of dignity and loss of dignity were noted. This generated 19 pages of data available for analysis, making the total 257 pages of empirical data for interpretation.

Interpretation

All authors individually read each interview text and set of observation notes. Initially thoughts and ideas were noted in a log and further systematized to enable the construction of additional understanding (Brinkmann, 2015). When interpreting the transcribed texts, we moved from initial understanding of each interview and observation to preliminary ideas of all interviews and observations as a whole and then back to each single text. Every movement of this circular hermeneutic process of dialoguing with the text (Gadamer, 1989) elevated new understanding of dignity and loss of dignity. Close attention was given to our pre-understanding. Throughout the process of interpretation and before finally formulating our results, we looked for contradictory evidence, we critically assessed preliminary findings and discussions were held within the reference group.

Ethical considerations

When recruiting older women with cancer in the palliative care phase, sensibility toward preserving their integrity and dignity was emphasized. Moral sensitivity as a personal capacity is necessary to be able to distinguish between feelings, facts and values. This capacity is a moral motivation to "do good" and "to care" and links to our study concerning healthcare issues (Tymieniecka, 1971). The participants received written and oral information about the study before giving their consent to participate. These women were not in the terminal phase of their disease and had the motivation, strength and willingness to share their experiences and perspectives in an interview lasting for approximately one hour. The interviewer was aware of the sensitive topic and the possibility of activating emotional strains during the interviews. To reduce poignant experiences, all interviews started with a brief explanation about the study, mutual expectations and reassuring the right to withdraw from the interview at any time without any consequences. The need for pauses during each interview was accommodated and demanding topics were avoided at the end of the interviews. All participants were offered a telephone follow-up, as well as contact with an HCP after the interview if they wished. Due to their current health condition, participants were interviewed only once. The five participants who also participated in the observation sessions, gave their informed consent. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013), the Norwegian Health research act (The Health Research Act, 2008) and was approved by the Norwegian Center for Research Data (ref. no. 138698).

Results

We identified four crucial experiences leading to dignity *versus* loss of dignity in the everyday lives of these older women living with incurable cancer at home:

Owning their decisions and having a sense of control in their life-situation versus feeling insecure and losing the opportunity for self-determination

The women experienced a strong need to have a sense of control concerning important choices in their lives, as this helped them maintain self-respect and autonomy. Respect from others was important in decision-making processes. Having their voices heard was crucial for them. Their need for proper information concerning health issues, treatment and prognosis, was vital to enhance their senses of owning their decisions. One woman described this important aspect as follows: “It is much better to know (treatment and prognosis), even though it is uncomfortable.” Some of the women did however express the opposite, not wanting to know anything about the illness and prognosis, as this helped them endure challenges in their present situations. Feelings of control increased when other people promoted their senses of independence and autonomy. This was experienced as respectful, supportive and compassionate—a recognition of their self-determination when facing end-of-life:

> I have told my family that if I fall over, there will be “no heroics” … I want them to allow me dying. It is all written down in my journal. That is the essence of dignity, from my point of view; to be respected—to be asked what I want and what I do not want. (Participant 1)

As an opposition of owning one's decision and having a sense of control, the women experienced feelings of insecurity and loss of opportunity to make their own decisions. They reported major changes in life when being diagnosed with cancer, especially when it appeared to be incurable. Several women described feelings of grief when deprived of their sense of control in life. This was related to reduced control of their body and their psychological needs. In their current vulnerability, the women described situations created by HCPs, where they felt their autonomy was threatened, making them experience loss of power and independence. Also in our participant observations we identified that HCPs, seemingly unintentionally, sometimes appeared to overshadow and overrule the women despite their needs for self-determination:

> The problem is that the nurses are too kind … And too helpful. I feel that they seize my power… Make me completely passive. I just sit there and everything is being done for me… I can't stand it. Like someone took my life from me … just sitting there… (Participant 2)

Experiencing hope and meaningfulness despite illness versus sensing hopelessness and worthlessness in a shroud of illness

Maintaining hope was experienced as important for most of the women when nearing end-of-life. For some, hope was related to the decision to carry on with their treatment. For others, hope was founded upon perspectives and recommendations of HCPs, especially from the doctor. Several women kept on with their treatments despite their reduced physical conditions and the demanding side effects.

> Hope … Of course, I knew I was soon going to die. But we all are one day, right? You never know when it is going to happen … I got an offer… so I believed they had not given me up … just because I was old. I felt I had the right to … have a dignified life. That is how I felt it, and that's why I chose to accept the treatment they offered me. (Participant 5)

Wishes and expectations concerning end-of-life care were expressed by a sense of hope and strength when being vulnerable. Some of the participants had pronounced wishes concerning their final days, to die without pain and struggle and as calm as possible:

> When not knowing what is ahead of us … (crying) … I have a trust in gaining strength to get through with it… That is important for me… and for my nearest to feel the same strength—that it should be with dignity. That I can pass away peacefully … that would be a dignified death for me. Be spared from any great qualms. Like blowing out a candle. (Participant 10)

A number of women felt their worth as human beings was weakened along the progress of illness. They described violated feelings, particularly women who had not reconciled themselves to the fact that they were going to die. Some of them felt burdensome and lost due to their age and illness:

> I am about to lose my sight, and I see myself sitting there in a corner—blind—in the nursing home, chewing thick bread crusts … Because I always make my own bread. So it is like … what I am experiencing now … There is no use in me, is it? Old and sick … Who cares …? (Participant 2)

Several women felt more estranged to their personal self, occasionally responding in new, and for them unpleasant ways, as their illness captured their everyday life. They described being offended in an emotional and existential way when peace and harmony was replaced with anguish and doubt:

> Am I not acting with dignity when being upset, or showing my frustration and despair? I feel a lot of … not exactly anxiety, but something like that … I show all my feelings here in my home. The problem by showing it is me feeling guilty when I get angry and frustrated with someone … I cry a lot and have no problem with that … it is just that … feelings of doing something wrong … (Participant 5)

Feeling valued as an individual versus experiencing violation of one's personal life

The women described the importance of being met by other people's consideration and warmth. Such caring was experienced when family, friends and HCPs acknowledged them as human beings, not only perceiving them as dying cancer patients, showing their intentions and willingness to help relieve their suffering in everyday life:

> It is so important to be taken care of and to be seen. That you feel they can do something for you in your present situation … despite your illness … That you are not just discouraged. That has something to do with dignity. (Participant 4)

Several women experienced being in an emotionally challenging life situation and receiving respect and cautiousness from their family, friends and HCPs was of great importance to maintain their sense of integrity. When an HCP made an effort to get to know them and their specific personal needs, the women felt that they were being treated as unique individuals, not just "one in the crowd." Data from the participant observations added nuances to the interview data, revealing that eye contact and the visible relationship of trust between the women and their doctor in charge of treatment, was vital and meaningful:

> He looked me in the eyes and said: "You have the right to be understood. You have the right to be heard. You are here now, and we are here for you" … And … you know … I was so grateful to hear that. I felt that I was seen. Seen by him. And then I

> felt dignity. Dignity … and feeling valuable. I was both seen and heard. I really think that is of great importance to mention. The doctors cannot just be preoccupied with medicine. They must also see the individuals behind. No matter what. (Participant 5)

Through our participant observations, we also found that the quality of the relationship with their husband was crucial in their everyday life. However, being together with other family members was also of vital importance. Being able to have conversations with close family members, sharing their inner thoughts and feelings with them, were essential:

> I am privileged of having a husband who I can share my experiences with. He has been … you can say … more than good. He has pushed the situation forward and he makes sure that we get the most out of the remaining time. I do not think everyone can do that. He gives me dignity by saying: "You are in charge; we are walking your steps." Therefore, he and my family mean everything to me … (Participant 10)

Most women did receive or had previously received homecare services. To be seen as an individual in their own homely surroundings was important to them. However, several described situations where they felt neglected, invaded or offended by HCPs:

> … I was lying in my bed sleeping when she came into my bedroom and screamed: "You have to wake up now, you must get up!" …. Instead of being calm and easy … It is ok for me to wake up then, but it is not necessary to nag me awake. I do not like that very much. Yes … she even entered my bedroom and was about to shake my duvet to get me awake … (Participant 11)

Feelings of being offended were also experienced outside the women's homes. During transports and transfers between hospital and home, several of them, in their present states of vulnerability and illness-related suffering, had felt insignificant, like "one in the crowd":

> The feeling of just sitting there … and … each of us sitting there … no matter where we came from and who we were … we just had to sit there unconditionally and wait for a driver to show up. And when we came into the taxi, we drove through half the city … and I felt I was the last patient dropped off. It was … I think it was unworthy. It violated my dignity when sitting and waiting like this. And I felt so miserable … It all felt unworthy. (Participant 10)

Living in a treasured and nurturing environment versus being situated in surroundings enhancing their sense of disconnection and alienation

The majority of the women described their homes as a secure base and a safe place to be. However, several aspects influenced their feelings of living in a treasured and nurturing environment. Experiences concerning disease progression, as well as the next-of-kin's need for support, varied significantly. Only a few of the women stressed the importance of spending their final days at home. Most of them perceived quality of care more important than the *physical place* when nearing end-of-life, even though their homes was initially their preferred place to stay as long as possible:

> Living at home is fantastic …it is wonderful. But in the beginning when I got this (cancer), it was very important for me to stay in the hospital. It was crucial for my husband as well … because he wanted me to get proper help. He could not help me in our home … In the last instance, I might want to stay at home … but it all depends on the progress of my illness. Of course I want to be cared for to the last second … having someone around me understanding what I need and what this all means, both HCPs and my husband … (Participant 5)

When nearing end-of-life, it was important for the women that their next-of-kin and closest family were doing fine. To take care of the family was described as vital. This was also seen in our participant observations. They compared it to a type of self-care. Several of them attached importance to being admitted to an institution if the caregiver burden should become too heavy for their family. This was experienced as crucial, even though they had a strong wish to spend their final days in familiar surroundings together with their loved ones:

> I think I want to stay at home as long as I can manage. That will maintain my sense of dignity. But it is important for me not to overpass my children's potentials. I think that is very important. They have their lives as well. The burden is big enough, having a sick member of the family. I feel that when the burden gets too heavy for them, I won't stay at home—then I would resign… receive support from another place. I think this is all about being in a place where I can feel safe and getting what I need. One should all hope for that. (Participant 4)

Experiencing illness-related suffering due to incurable cancer and being situated in surroundings that enhanced their senses of disconnection and alienation brought about feelings of insecurity and integrity violation. In situations where the women felt that nobody was taking care of them, their decisions concerning preferred place to stay nearing end-of-life was affected:

> Well… you get admitted to the hospital and get this curtain around your bed. Then you just lay there until they figure out having room for you … and having time to talk to you. I must say this is not very much dignity-preserving. I did not have contact with anybody. Finally, I had to ask if somebody could look at my leg and redress my wound. Did they forget about me? The day after, I asked to go home. Because… I did not think this treatment was particularly dignified… just lying there… and not been taken care of. I felt this was very much degrading … It was just like not being there at all. (Participant 11)

Several other women in this study shared similar stories. They compared being met with compassionate care versus uncompassionate attitudes and limited support from HCPs, at home as well as in healthcare institutions.

Such attitudes were crucial contextual experiences of being in a treasured and nurturing environment or, on the contrary, in unfamiliar, uncaring surroundings.

Discussion

Four crucial experiences leading to dignity *versus* loss of dignity illuminate that knowledge of dignity-preserving care for older women living with incurable cancer at home is of high relevance for municipal healthcare services. First, the women described that having a sense of control in their lives and owning the decisions to be made in everyday life helped preserve their senses of dignity. Experiencing insecurity and losing the opportunity for self-determination led to dignity loss. Self-respect and self-esteem are important foundations for experiencing dignity when nearing end-of-life (Bovero et al., 2018). As their illness progressed, several of the women felt insecure and experienced loss of control when struggling with health-related challenges. They described a strong need to preserve their senses of control by being physically, emotionally and psychologically on their feet. Existing research supports our findings that when getting old and living with incurable cancer there is a risk of losing control and of no longer being valued as a human being (Devik et al., 2013; Morita et al., 2014). Those aspects of a patient's psychological and spiritual landscape that influence their senses of dignity is supported by the work of Chochinov et al., (2002) who proposed a model of dignity and dignity-conserving interventions for patients nearing death. Consistent with our results, one of the findings reflected in this model is the maintenance of autonomy and control over one's life. Contrary to this present study, Chochinov's dignity conservatory repertoire is neither gender-specific nor specifically based on experiences of older women with incurable cancer living at home (Chochinov et al., 2002). Previous studies have shown that gender and diagnosis may affect existential well-being as well as influence the number of physical and psychological problems when nearing end-of-life (Rohde et al., 2019; Vehling & Mehnert, 2014). Since these perspectives may be relevant to the experiences of dignity, we believe this present study adds to the body of knowledge through its gender perspective and the specific focus on older women with incurable cancer living at home .

According to care theorist Eriksson (1987), having a sense of control and being able to express independence are crucial aspects in preserving what she calls *relative dignity* of human beings. When living in harmony within the norms and demands defined by themselves, as well as their surroundings, a sense of dignity can be confirmed. However, when it is not possible to maintain these norms and demands, harmony is threatened. As shown in this study, several women experienced reduced opportunities to make their own decisions, a vital dimension of relative dignity according to Eriksson (1994) and Edlund (2002). Not being able to carry out daily chores due to illness becomes an impediment to achieve dignity in life. Eriksson (1994) describes relative dignity as something changeable, consisting of an inner and an outer part. We found that the women in this study experienced a loss of inner relative dignity when their autonomy and self-determination was threatened. According to Eriksson, upholding relative dignity is related to the experience of internal freedom and inner values of the human being. Occasionally, the loss of power and independence was experienced as external offenses, sometimes even initiated by HCPs, involving the outer part of relative dignity which is founded upon the relational interaction with people in the outer surroundings.

Second, the women experienced hope and meaningfulness versus feelings of hopelessness and worthlessness in a shroud of illness. A crucial experience leading to loss of dignity was related to the women's experiences of demanding side effects of their treatment. This affected their physical condition negatively and activated their senses of hopelessness. Eriksson (1994) states that this dimension can be seen considering *suffering caused by illness*, which is often connected with treatment. Eriksson (1984) claims that suffering is the most important basic category of all caring. It is a unique, isolated experience and is not synonymous with pain. This caring aspect revealed the importance for the women to be respected in their vulnerability. According to Devik et al. (2013), vulnerable patients may lack resources needed to gain proper healthcare services due to their varying life situations. They also describe how care practices can cause suffering. This is in line with the findings of our research. Women in our study, struggling on a daily basis with a variety of severe symptoms, reported episodes when they felt neglected and insignificant. This occurred in their own homes, in the hospitals, as well as during transports and transfers to and from hospitals. Fjose et al. (2018) and Hanratty et al. (2012) found that discomfort and exhaustion frequently was experienced by older cancer patients during "collective taxi journeys" and therefore often ended in re-admittances and dignity-violations. Ternstedt (2015) emphasizes how healthcare systems often fail to give attention to patients' needs because the organization of services is far too routine-based. Older patients, in particular women with a sparse social network, are in need of increased support from HCPs to maintain their senses of dignity (Ternstedt, 2015). This resonates with the findings of this present study documenting that being seen and recognized by HCPs increased these women's feeling of value and senses of dignity.

Third, the women's senses of dignity was preserved when they felt valued as individuals, while dignity loss was experienced when feeling violated in their personal lives. They described degrading experiences in situations when receiving care from HCPs, which underpinned the necessity to develop and implement knowledge-based dignity-preserving care. They described loss of dignity when feeling neglected, invaded in their personal lives and offended by HCPs. These findings are also supported by several studies of women sensing insecurity and experiencing violation in their everyday lives (Aabom et al., 2005; Cain & Denny, 2018; Poulose et al., 2013). The findings resonate with the theoretical perspective of *suffering related to care* as proposed by Eriksson (1994). She argues that patients are experiencing *suffering related to illness* and when being exposed to suffering related to care, which in practice can be perceived as absence of care—they are, in their vulnerability, experiencing dignity loss. Having a natural need to be treated as a unique person, being overlooked and having the feeling of being "one in the crowd" left the women in need of recognition and confirmation (Eriksson, 1992). Smith et al. (2019) requires HCPs to prioritize appropriate care for each patient. Simultaneously, they demonstrate how difficult and sensitive it can be to tailor care individually. Chochinov (2013) claims that the education of HCPs lacks a continued focus on achieving a culture of caring, which raises questions regarding the quality of dignity-preserving care to be given. We believe in developing a caring culture based on the ontological view of human nature that each individual has an inherent *absolute dignity* by virtue of being a human. As Eriksson (1994) claims, this can be the means to enable a deeper understanding among HCPs of human worth, equality and uniqueness as well as the need of each patient. As an ontological foundation for caring, recognizing the absolute dignity as inalienable and granted by virtue of being a human being, may lead to increased HCP awareness concerning the preservation of the patient's relative dignity in everyday care.

Fourth, living in a treasured and nurturing environment promoted a sense of dignity. When situated in surroundings making them feel disconnected and alienated they experienced dignity loss. They seemed to perceive the quality of dignity-preserving care as more important than the physical location of their final days. As shown in previous studies (Cohen et al., 2010; Kjellstadli et al., 2018; Poulose et al., 2013) the likelihood of dying at home is higher for males (especially young men), living in rural areas, being married and having early palliative care referrals. The majority of the women in our study wished to be admitted to a care institution when nearing end-of-life, even though they described their homes as the most secure and safe place to be. Aabom et al. (2005) found that older women were less likely to die at home due to unclear end-of-life care planning. This created feelings of insecurity and, in line with our study, led to the women seeking safety within institutional care. However, there is a great deal of uncertainty concerning preferred place of care and preferred place of death among patients and their relatives. Gerber et al. (2019) state that there are individual variations and difficulties in decision-making related to thoughts, emotions and actions. In our study the motives for wanting a transfer nearing end-of-life, were the women's feelings of being a burden to their families as well as experiencing insecurity as their diseases progressed. By trying to develop a deeper understanding of the women's living environment, we believe it should be possible to maintain the sense of dignity even when staying in unfamiliar surroundings. Being seen and being cared for by HCPs was crucial for the women regardless of place. We associate this perspective with Katie Eriksson's theoretical concept of *living space* of the human being, which constitutes a foundation for movements in health processes while searching for health promotion (Eriksson, 1987; 2018). For the women to feel safe and have emotional security at home, as well as in institutions, three different living spaces ought to be optimized. First, in the *physical living space* consisting of primary functions in life (Eriksson, 1987, 2018), concrete situations in the women's everyday life are experienced. Based on the findings of this study, emphasis should be put on arranging physical environments according to what is treasured and nurturing for each woman as this is found to be dignity-preserving. Second, in the *psychosocial living space*, relational interactions between the women and people in their surroundings take place (Eriksson, 1987, 2018). Experiencing the power of relationships happens in this space, as well as interactions with HCPs. We believe that relational interactions which confirm the women as valued human beings and enhance their senses of control and self-determination are crucial for preserving the dignity of these women living with incurable cancer. Third, the *existential living space* concerns the possibility of experiences at the spiritual, cultural and esthetic level (Eriksson, 1987; 2018). It is here that inner thoughts, wishes and hopes of each woman can be given the necessary space. Awareness of this dimension may enable HCPs to identify and preserve what is intrapersonal and meaningful for the individual patient. By highlighting these living spaces, Eriksson refers to an outer physical space as well as an inner space constituting the human living space as a whole, and we believe that the women participating in this study may experience a high quality of care when given a dignity-preserving living space in the end of their lives.

The four core dimensions related to dignity preservation and dignity loss (Figure 1) show that these women, living at home with incurable cancer, experienced that living in a treasured and nurturing environment promoted their dignity as this, to use Eriksson's term, helped optimize their physical living space. Opposite, dignity loss was experienced when the physical living space enhanced their senses of disconnection and alienation. Dignity was preserved when the women felt valued as individuals by others, while

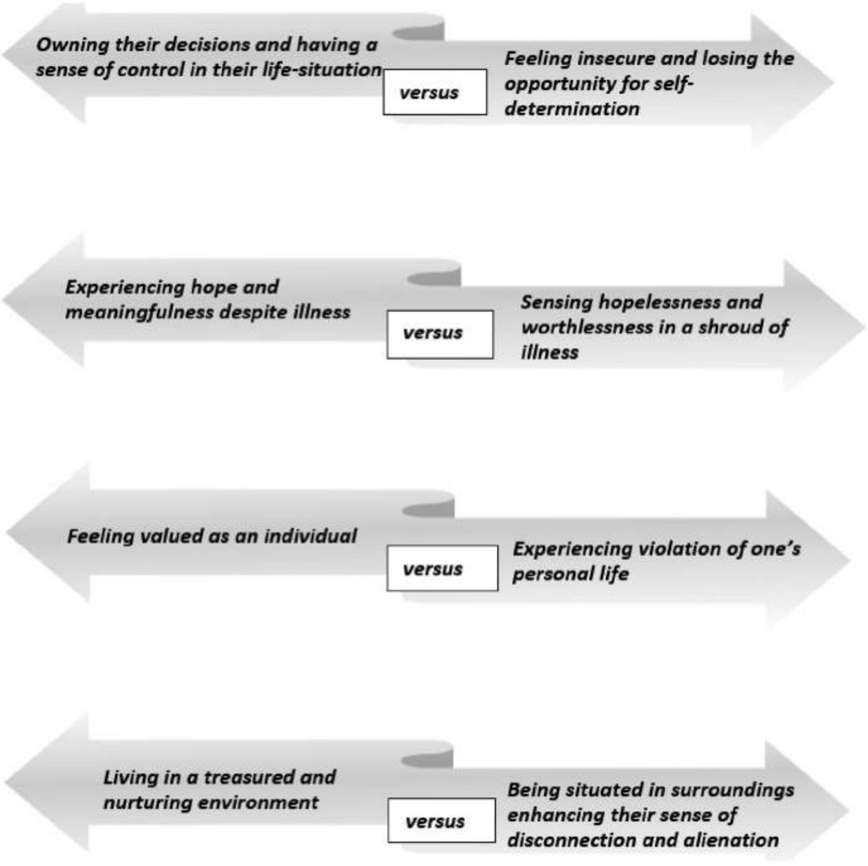

Figure 1. Dignity preservation and dignity loss—crucial dimensions as perceived by older women living with incurable cancer at home.

experiencing violation of one's personal life was leading to dignity loss—in what Eriksson describe as the psychosocial living space. Finally, dignity was experienced when the women felt that they own the decisions made, having a sense of control in life and when experiencing hope and meaningfulness despite of illness. In this same living space, by Erikson called the existential living space, insecurity, losing the opportunity for self-determination, as well as sensing hopelessness and worthlessness in a shroud of illness, led to loss of dignity among these women. Drawing upon Eriksson's theoretical perspectives, the experience of relative dignity and loss of relative dignity can be perceived as related to the physical, psychosocial and existential living space of each woman living with incurable cancer at home. Developing a caring culture recognizing the inherent absolute dignity of each woman, as well as optimizing her three living spaces, can prevent suffering related to care, relieve suffering related to illness and constitute an important foundation for dignity-preserving palliative care practices within the municipal healthcare services.

Methodological considerations and study limitations

All 13 women had rich life-experiences and a personal history, however, only one interview was conducted with each of them. Ethical considerations were taken due to the vulnerability of the women, as they were spared from the challenging implications of follow-up interviews. Consequently, we gained limited insight into their lives, which perhaps reduced the quality of the gathered data. Nevertheless, when utilizing qualitative research, the quality of data offers an in-depth understanding of the phenomenon of interest and cannot be generalized into a broader population (Brinkmann, 2015), of older women living at home with incurable cancer. We focused on women's experiences rather than the number of women and we believe that each woman contributed rich data. Recruitment of participants, data collection and interpretation continued until we reached a point of data saturation signaling that additional data would only serve to confirm our understanding (Polit & Beck, 2017). Participant observations were carried out with five of the 13 women, which we believe increased our understanding of the subject we were investigating. It is important to underline that, for a variety of reasons, 10 women declined participation in the study. These women might have had other experiences and perspectives, which may have enriched the data. In addition, the cancer-coordinators who were guided to recruit the participants may have left out vulnerable women because of their everyday struggle. These women could have added nuances to the data.

We included PAICPAIR as part of our methodological approach (Staats et al., 2019) and found this to be vital in strengthening the internal validity of the study. As members of the study reference group, the woman living with incurable cancer at home and the former informal caregiver strongly contributed in all phases of the research process (apart from the data collection).

To establish study trustworthiness, we focused on strengthening research credibility, dependability, confirmability, transferability, and authenticity (Guba & Lincoln, 1994; Lincoln & Guba, 1985). Credibility and dependability was sought through a thorough reflection of the pre-understanding as well as transparency of the study design process, data collection and analysis. Confirmability was empowered by emphasizing collecting the women's shared experiences while simultaneously reflecting on our pre-understanding as researchers. We carefully searched for disconfirming evidence within the data to avoid confirmation bias. To increase study transferability, focused attention was given on collecting sufficient descriptive data to ensure a thick description (Lincoln & Guba, 1985, Polit & Beck, 2017) of the women's experiences. To heighten study authenticity, portraying the women's experiences as expressed by themselves were highlighted (Guba & Lincoln, 1994).

The theoretical discussion (Brinkmann, 2015) was developed using an inductive-deductive hermeneutical process—in our opinion a sound approach in which the identification of empirical data helped us determine which theoretical concepts and perspectives to include in the empirical-theoretical discussion.

Conclusion and implication for practice

Dignity-preserving care was experienced when physical as well as emotional and existential needs were met. The women emphasized the value of having a sense of control and making their own decisions to experience dignity in their everyday lives. When retaining hope and meaningfulness, feeling valued as an individual and being situated in a treasured and nurturing environment, dignity was preserved. Experiences that led to dignity loss included the loss of opportunity for self-determination and control, experiencing HCPs invading and violating their personal lives, sensing hopelessness and worthlessness in a shroud of illness and when being situated in surroundings enhancing their senses of disconnections and alienations. The women experienced the quality of care as more important than the physical place in which they were to spend their final days. This seems to be caused by limitations in available HCP resources and competence, but also due to the women's fear of being a burden to their families. The findings strongly suggest a need for HCP training and education in dignity-preserving care within the municipal palliative care service. Future research should explore how dignity-preserving care can best be organized and practiced within the context of municipal palliative care service.

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Dignity of older home-dwelling women nearing end-of-life: Informal caregivers' perception

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Abstract

Background: Most older people wish to live in the familiar surroundings of their own home until they die. Knowledge concerning dignity and dignity loss of home-dwelling older women living with incurable cancer should be a foundation for quality of care within municipal healthcare services. The informal caregivers of these women can help increase the understanding of sources related to dignity and dignity loss

Aim: The aim of this study was to explore informal caregivers' perceptions of sources related to dignity and dignity loss in end-of-life of older home-dwelling women with incurable cancer.

Research design and method: The study was founded upon Gadamer's philosophical hermeneutics. In-depth interviews with 13 informal caregivers were carried out, and four participant observations were performed during home meetings.

Ethical consideration: The study was based on voluntary participation, informed consent, confidentiality and the opportunity to withdraw at any time. The Norwegian Social Science Data Services approved the study.

Results: Three main sources important in preserving the older women's dignity were identified: maintaining one's self-concept, remaining hopeful and sustaining freedom of choice. We also identified three main sources that lead to dignity loss: Sensing loss of human value, experiencing absence of gentleness and feelings of being treated as an object.

Discussion and final considerations: On the individual level, the opportunity to maintain one's self-concept and control in life, preserved dignity, while feelings of existential loneliness led to dignity loss. On the relational level, being confirmed as worthy human beings promoted the women's dignity, whereas dignity loss was related to uncaring behaviours from healthcare professionals. On the societal level, individual decisions concerning travel situations and the place to stay when nearing end-of-life were of crucial importance. Constituting these women's living space, these perspectives should be emphasized in healthcare professionals' educational training and in the municipal end-of-life care of these patients.

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Keywords

Areas of practice, care of the older person, dignity in care, empirical approaches, end of life issues, home care, palliative care, qualitative research, topic areas

Introduction

The concept of dignity is important in the context of end-of-life care and has a major influence on the quality of care given by informal caregivers (ICs) and healthcare professionals (HCPs).[1] The United Nations has focused attention on human dignity and dignity-preservation stating that all human beings have an inherent dignity – thus having one's dignity preserved is a fundamental human right.[2] Furthermore, the World Health Organization claims that all people have the right to be treated with dignity and stresses that women are more likely to experience dignity-degrading treatments and practices due to the heritage of traditional and disadvantageous gender roles.[3] In Norway, regulations concerning dignified care for older people aims to guarantee older people a dignified, safe and meaningful life.[4] Internationally there seems to be an agreement that dignity and dignifying care are important within healthcare services.[5]

Being diagnosed with cancer is strongly related to age and a major cause of mortality among individuals 65 years and older.[6] Worldwide, the cancer incidence for women was estimated to be 8.5 million cases in 2018.[7] Women live longer than men and generally experience poorer health.[8] In addition, many older women outlive their spouses and live alone with an increased risk of social isolation.[9]

Informal caregivers provide most of the care and practical support for older people.[10] However, older women living with incurable cancer seem to have less support from family members compared to men[11] and make less use of municipal services.[12] Informal caregiving can be perceived as a meaningful and appreciated task, but can also be a highly stressful experience accompanied by a strong ethical commitment to not let their loved ones down.[13]

The opportunities to receive professional end-of-life care at home vary.[14] Most people wish to spend their last days of life in familiar surroundings – and to die there.[15] In Norway, the majority of these patients become nursing home residents in the last phase of life.[16] Only 15% of people who died in Norway in 2013 died at home, and of these only 6.3% had planned a home-death.[17] However, end-of-life care seemed to be of a higher quality and more dignifying when given at home compared to institutional care.[1,18]

In a previous study[19], we documented how older women with incurable cancer perceived having control, experiencing hope and meaningfulness and feeling valued as human beings, to be crucial sources for preserving dignity. We also described how losing self-determination, experiencing violation of their personal lives and feeling worthless, all led to dignity loss. However, we know little about what ICs close to these female patients perceive as crucial sources in preserving dignity, and which sources promote dignity loss. This proxy perspective would be a valuable contribution to the existing knowledge and increases the foundation for developing a dignity-preserving end-of-life care practice within the municipal healthcare services.

Aim

The aim of this study was to explore ICs perceptions of sources related to dignity and dignity loss of home-dwelling older women with incurable cancer nearing end-of-life.

Methodology

Gadamer's hermeneutical methodology was used in which interpretation of texts is fundamental in developing an understanding of their meanings.[20] We emphasized the process of hermeneutic circle movements

Table 1. Participants' age and relation to the older women with cancer.

Participant	Age	Relation
1	67	Husband
2	70	Husband
3	77	Husband
4	74	Husband
5	42	Daughter
6	45	Son
7	65	Sister
8	40	Daughter
9	74	Husband
10	45	Daughter
11	59	Daughter
12	73	Husband
13	66	Sister

to move beyond our pre-understanding, towards developing *new* understanding, while being oriented towards the project's aim.[20]

Participants and setting

Oncology coordinators in 11 Norwegian municipalities assisted with participant recruitment. The following inclusion criteria were used: ICs having at least weekly contact and responsibility for informal end-of-life care for a woman aged 65 years or older, who lives with incurable cancer at home, and is currently receiving municipal healthcare services. During the recruitment period, from November 2018 to December 2019, 23 ICs were asked to participate in the study. Of these, 10 participants declined due to tiredness, less involvement in daily care, or suddenly becoming bereaved. In all, 13 ICs, 7 men and 6 women aged 40–77, gave their consent to participate (Table 1). In addition, 4 of the 13 interviewed IC's gave their consent to take part in participant observations. The women with cancer and their HCP also consented to participate. The first author (K.S.) conducted participant observation of three home-meetings and one meeting at the hospital.

Informal caregiver representatives as co-researchers

We acknowledge both patients and IC representatives as experts with unique competence, valuable in all phases of the research process. Inspired by the Framework of patient and IC participation in research (PAICPAIR part 1)[21] we established contact with patient organizations in the planning phase of this research process to create a sound collaboration with ICs as co-researchers. Two ICs were recruited as co-researchers. They had previously been ICs in the end-of-life of a home-dwelling woman, aged 65 or older, with incurable cancer. They became IC representatives in the project steering group and advisory board, respectively. Other co-researchers included a home-dwelling woman (over 65 years old) with incurable cancer, a medical doctor, two oncology nurses and two research advisors – all with end-of-life care experiences. They provided us with constructive feedback on our initial project ideas, the research questions and interview guide. They brought nuances from their experiences into the study, which increased the quality of our data collection.[21] We maintained contact with the ICs by offering home visits and phone calls instead of expecting them to read several documents via email. We also kept in contact by digital newsletters describing the project's development. In addition, both ICs participated in discussions of

Table 2. Participant observation – study participants, HCPs and setting.

Observation	Participants observed	Setting
1	Patient, husband, cancer coordinator, palliative-care doctor, observer	Patient's home
2	Patient, husband, cancer coordinator, observer	Patient's home
3	Patient, husband, palliative-care doctor and oncology nurse, observer	Hospital
4	Patient, husband, oncology nurse, observer	Patient's home

preliminary findings, were engaged in the ongoing evaluation of the overall project process, and will be involved in disseminating the study results.[21]

Data collection

We used individual in-depth interviews[22] and participant observations[23] as data collection tools. A semi-structured, modifiable interview guide was developed to structure the data collection conversation. In line with the hermeneutical methodology,[20] exploration of new themes and reconstructions of the interview guide appeared throughout the data collection process. Examples of questions guiding the interviews were: *Can you describe a situation, after your wife/mother/sister got sick, as an example of dignity preserving care? Alternatively, a situation leading to dignity loss?* The first author (K.S.) conducted the interviews, all of them were recorded and transcribed verbatim. One interview lasting between 55 and 81 min (mean = 68.6 min) was performed with each participant, producing 220 transcribed A4 pages for data interpretation. Data collection also consisted of 16 pages of field notes from four participant observations (Table 2). The first author observed the interaction between ICs, the older women with cancer and HCP responsible for municipal end-of-life care at home. The participant observations lasted from 50 min to 2 h (mean = 82.5 min). Utilizing an observation guide, crucial care-related aspects that preserved dignity, and those leading to dignity loss, were observed and noted. Examples of themes guiding the observations were: *Which sources seem to contribute to the ill women's experiences of dignity, when observing the interaction between the women, IC's and HCPs? How do HCP communicate and interact with the ill women when she is sharing degrading experiences?* In this context, informal conversations were also carried out to get a better understanding of the observations. In addition, language, voice sound, important comments, key-phrases and passages were noted and guided the focus of the participant observations.

Interpretation

The empirical data were interpreted using Gadamer's hermeneutical methodology.[20] During the interpretation process, the authors met regularly to discuss preliminary emerging patterns of meaning. Understanding was achieved through a circular interpretive process that Gadamer called the hermeneutical circle, in which we moved from a preliminary interpretive understanding of each individual interview text, to an initial interpretation of the text as a whole. At this point, our preliminary new understanding helped us interpret and understand the various parts of the text as an interrelated, integrated whole, making it possible for us to formulate our final interpretive understanding. The intention of this hermeneutical process was to seek the truth according to Gadamer's outline, and see beyond what was close at hand.[20] Katie Eriksson's *Theory of Caritative Caring*,[24,25] in which safeguarding the dignity of the suffering human being is the ultimate goal, was chosen as the framework for the empirical-theoretical reflections performed in the discussion section, below.

Pre-understanding

As an oncology nurse and researcher, first author K.S. was experienced in communicating with ICs concerning their present life situations. O.T. is a mental health nurse, E.K.G. an oncology nurse and B.S.H. a medical doctor, all three experienced researchers. Our pre-understanding is not neutral and distanced, but influenced by a committed relationship to the subject under investigation. As a research team we believed that ICs would perceive staying in familiar surroundings as a crucial dignity-preserving source, as well as a way to protecting the older women from their most illness-related burdens. Simultaneously, we assumed that ICs would describe that dignity of these older women may be affected by formal healthcare structures leading to situations in which the women received care from a large number of HCPs, as well as being exposed to unstructured planning in transitions.

Ethical consideration

When recruiting IC's of older women living with incurable cancer at home, ethical demands for researchers sensitivity were raised to protect the IC's dignity throughout the research process. They were given the time they needed to determine whether to participate or not, and time and place for the interviews and observations were determined based on the participants' wishes. Most of the participants were familiar with the research project since their wife/mother/sister had participated in the first part of this project.[19] When carrying out participant observations in the home of the women with cancer, first author K.S. strived to be a natural part of the setting, safeguarded the need for privacy and made use of previous experiences as an oncology nurse. The ICs were assured anonymity and confidentiality regarding adaption and presentation and publication of the data. They were also informed that they could withdraw from the study without giving any reasons. All participants signed informed consent forms. They were also informed verbally by the oncology coordinator, as well as by the researcher before the interviews and the participant observations were performed. The study was conducted in accordance with the Declaration of Helsinki[26] and was approved by the Norwegian Centre for Research Data (ref. no. 138698).

Results

We identified three main sources preserving the older women's dignity: *maintaining one's self-concept, remaining hopeful* and *sustaining freedom of choice*. We also identified three main sources leading to dignity loss: *sensing loss of human value, experiencing absence of gentleness* and *feelings of being treated as an object*.

Sources related to dignity-preservation

Maintaining one's self-concept. The informal caregivers highlighted the importance for the woman to maintain a sense of self-worth as a human being when nearing end-of-life. They expressed the importance of letting the woman be the main person in her own life, and to follow her lead. It was of crucial importance for the woman to be recognized as an independent individual still carrying her name and not be reduced to a random carrier of a diagnosis:

> Don't look at her like someone who is reduced to 'an illness'. It is not only the disease defining her as the person she is. It's that . . . you exist while having an illness.(1)

When living close to normality and searching for the bright spots in life, they were more able to uphold their senses of self-worth and personal integrity. Several IC's expressed the importance of being positive and grabbing hold of everyday occurrences, such as making a meal, reading a book and meeting up with friends and family, without discussing illness-related matters.

Remaining hopeful. The informal caregivers found that remaining hope was essential to these women in their challenging and uncertain life situations. They described how the women found new meaning that helped relieve their suffering and strengthen their hope – for example, hope for new medications and treatments, even though the disease had reached an advanced stage:

> She has already accepted that her life is going to an end. However, at the same time, she has not. She has a constantly need of being oriented concerning new medications. Therefore, she has a little hope for a dramatic turn. Not yet. Maybe later . . . because there is hope on . . . keep going on for several years to come . . . (12)

Other people's presence and care were crucial sources to enhance the women's senses of being secure and safeguarded. Being seen as the women they are, and *experiencing other people's interest* in their life stories, were valuable dignity-preserving sources. Data from the participant observations added nuances to the interview data; when a HCPs took the time to become acquainted with the woman, they could show compassion and gentleness based on their knowledge of her preferences and wishes:

> There was this nurse working the nights . . . she was visiting my mother every early morning. She wrote some words on a napkin: «Have a great day». Every morning she did that. I remember she did that the first morning, and my mother woke up and expressed «How nice!» Little things like that are so valuable: «They see me», she said. (8)

Sustaining freedom of choice. Several ICs pointed out the women's need and willingness to tailor their own end-of -life care, despite having limited strength due to their illness. It was therefore crucial for them to know that other people respected them and their wishes. They were enjoying and cherishing the quality of life when staying at home, deciding how to arrange their days and maintaining social contacts. At the same time, many of the women had experienced admissions to institutions and found it peaceful. The IC expressed the importance of respecting the women's wishes concerning preferred place to stay nearing end-of-life:

> I know she wants to stay at home, and she feels much better there. I think that means a lot to her, deciding where to be. Even though it feels unsafe for me . . . who am I to tell her not to be at home? (5)

Sources related to dignity loss

Sensing loss of human value. The informal caregivers described situations where the women's decline in health affected their self-perception, making them feel of less value. Living with a deteriorating body evoked the women's feelings of meaninglessness and existential loneliness. A sister of an old woman nearing end-of-life expressed it like this:

> I can see her body weakening. She wants to have control in her life and be part of everything happening around her. It's her sense of dignity in life. However, I sense her vulnerability when she cries between the sheets during nighttime. Then she tells me she has these dark and painful thoughts . . . difficult taking about . . . (13)

The informal caregivers also described situations where the women felt insignificant, frustrated, often related to situations in which they felt unable to participate in daily chores, for example, when finding that self-care had become too exhausting, and they were dependent on others:

> It is about her dignity. Not being able to take a shower herself anymore. That she must be hosed down with water in another room . . . I think she is very sorry, losing her sense of self-efficacy. I believe this is affecting her experience of dignity. She is after all an independent type of woman . . . (9)

Experiencing absence of gentleness. In certain situations, the women felt degraded rather than being met with consideration by HCPs. As perceived by ICs, the women had a need to manage 'little things' in their everyday lives, despite their reduced physical capacities. This need was strongly related to their requirement to be involved in decision-making processes, where at times their voices seemed to be unheard. ICs described how the women sometimes felt humiliated and invaded by HCPs. In fact, sometimes they felt their legal rights had been disregarded:

> This nurse went into my mother's room with the intention to give her the evening care, but my mother said: «No, I can do it myself». Then the nurse answered: «No, come over here, I am going to do it for you . . . It says here that I am going to give you the evening care». She was already on her way to drag my mum into the bathroom . . . My mother got furious and sad, and eventually she asked the nurse to leave. She felt violated and unsafe. (8)

In such circumstances, absence of HCPs gentleness prevailed in physical care settings. Feelings of humiliation and uncertainty emerged due to the women's senses of being a burden to the HCPs, in addition to carrying many other unspoken worries. In these situations, the women had to mobilize all their strength to be seen, listened to and be taken seriously. The ICs felt that the life of the ill woman laid in the hands of others; being cases of little value, made her feel insignificant and subsidiary to others:

> There was this young nurse, even so with strong opinions . . . obviously not very experienced. She meant that she had to use a certain big size of a needle when she inserted the cannula in my wife's hand. The nurse wouldn't listen to my wife when she argued for using a smaller one. She said it was not our business; needles were expensive and so on . . . She was pretty revolting and brutal: «You just have to bear with this» – so that was quite . . . shocking for her. (1)

Feelings of being treated as an object. HCPs willingness and effort to devote sufficient resources and spend sufficient time with the women were perceived as vital. The ICs described situations where the women felt unsafe and that they were regarded as objects more than people, for example, when changes and efficiency strategies within the healthcare system made them feel overlooked as individuals. This was also identified in our participant observations, where some of the women felt insignificant as the doctor in charge of their treatment seemed poorly prepared to follow up her specific treatment plan:

> The doctor hadn't even looked at the X-rays, he didn't have the time . . . we did not get any information at all. Why should we come there at all then? It was quite a strain for my mother to get there. A lot of suffering when walking all the corridors as well as hours of nodding off in the waiting room because there is a lot of waiting . . . (5)

Different events seemed to have a negative impact on the lives of the women. This included, for example, unworthy and burdensome transportations between hospitals and their homes, where the women sometimes felt they were treated like objects while being in states of dependency. Several ICs referred to such negative experiences, where the women felt that they were not being acknowledged as individuals:

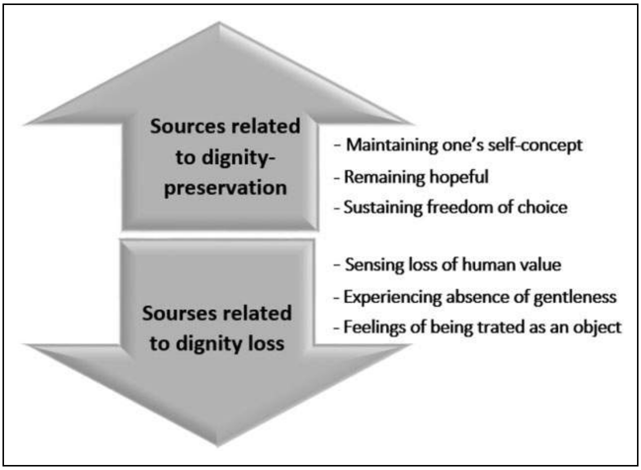

Figure 1. The results divided into categories.

> Most of the transportations are 'collective journeys'. That is not very satisfying or dignifying when you are feeling ill. My wife had to sit four hours waiting for a taxi to be full enough before leaving . . . although 30 taxis were standing ready. It is not well paid, so they do not bother with these trips . . . (6)

Discussion

Although interrelated, the results presented in Figure 1 are discussed here on three different levels (Figure 2). First, the results highlight sources related to dignity-preservation and dignity loss on the individual level: *maintaining one's self-concept* and *sensing loss of human value*. Second, the results show that dignity-related experiences of *remaining hopeful* and *experiencing absence of gentleness* are affected by human interactions, and will thus be discussed on the relation level. Finally, we will discuss what we identify as core dignity-related sources on the societal level: *sustaining freedom of choice* and *feelings of being treated as an object.*

On the individual level, being treated with respect and having the opportunity to maintaining one's self-concept and control in life seemed essential for preserving older women's dignity experiences. As found in previous studies,[1,27,28] it was important for the women to feel significant and valuable while living with incurable cancer. Being involved as the person one is and strives to become, is related to dignity.[27] In work by Benson et al.[28] ICs highlighted older women's experiences of dignity as central sources in generating power to help them making their own decisions. Our results support these findings, while adding new nuances; the ICs emphasized the women's vital need to maintain their individual self in everyday-life situations, whereas common self-care, independently having a shower and preparing meals were examples of coping and finding joy in daily activities. Aiming to continue their lives, treasuring these habits and searching for the bright spots in life, were perceived as vital for upholding their senses of self-worth and personal integrity. Barclay[29] points out that the patient is maintaining her dignity when she is able to live in accordance with her standards and values. Values and standards can however deteriorate, particularly when vulnerable and living with a life-threatening illness.[29] These perspectives support the findings of our study, where the ICs reported how the women described unworthy experiences related to getting old and being incurable ill. Becoming weaker both physical and mentally, evoked feelings of meaninglessness and existential loneliness. Despite these degrading experiences, care theorist Katie Eriksson[30] highlights human equality, describing each human being as *unique* – an entity of body, soul and spirit – even in times of vulnerability. For the women to experience security and meaningfulness, Eriksson[31] highlights three different living spaces to be optimized: *the physical living space, the psychosocial living space* and *the existential living space.* Eriksson associates the perspective of the concrete place to stay with what she terms the *physical living space*.[31] The ICs related this to the physical environment, a place where the women could feel safe, valuable and in charge of decisions. In the *psychosocial living space*, all relational interactions between the women and people in their surroundings take place – affecting their everyday experiences. Referring to the *existential living space* Eriksson[31] describes this as a place where each human being find and nurture the inner thoughts, wishes and hopes that promote a meaningful life. When nearing end-of-life, different circumstances can obstruct these women's *living spaces*, leading to experiences of dignity loss. It is therefore of vital importance for HCPs to gain knowledge and awareness of these dimensions in order to increase the women's individual intrapersonal dignity experiences.

On the relational level, dignity-preserving care was experienced when the women felt recognized and confirmed as worthy human beings by the HCPs, being able to take part in conversations and being treated with equality. Previous research reports that the attitude of HCPs and their unwillingness to preserve the patient's autonomy deprived the women of their standards and values.[29] These findings also relate to Eriksson's *Caring culture*[32] in which she states that all caring is formed in the relationship between the human being and the caregiver. However, the findings indicate that the attitude of HCPs could negatively affect the women's experiences of dignity. As observed during participation observations and described by ICs, there were situations where the women felt humiliated due to what they experienced as uncaring behaviours, in particular in situations where the women felt dependent upon HCPs. These findings are similar to the patients' stories described in Chochinov's research[33] where he highlights HCPs' duty to provide the most comprehensive empathic end-of-life care to relieve suffering and distress. Laursen et al.[34] support this view and emphasize that patients nearing end-of-life, who experience existential loneliness, have a particular need for HCPs who are dedicated to identifying their patients' individual needs. They highlight that every human being should be seen and supported in their everyday lives, as this strengthens their senses of dignity.[34] The findings of our study contribute to this area of research by calling for HCPs to pay attention to the core values of genuine presence and gentleness. Closeness and having a kind and agreeable manner may increase the women's senses of worthiness, help uphold their experiences of personal integrity and strengthen their *relative dignity* – a modifiable form of dignity described by Eriksson.[24,31] *Relative dignity* can be preserved when the *suffering human being* receives *caring recognition and confirmation* from others, to use Eriksson's terms.[31] Being modifiable, the relative dignity can also be torn down through external humiliation, leading to dignity loss.[31] Therefore, the caring attitude and behaviour of each HCP is vital to preserve the relative dignity of these women nearing end-of-life.

Importantly, Eriksson[31] also describes another inalienable form of dignity termed *absolute dignity.* Founded upon this view of human nature, absolute dignity is inherent in all people, granted by virtue of being human. Consequently, recognizing the absolute dignity of each human being is a fundamental view of humanity with implications for caring since this constitutes HCPs core understanding of themselves, the patient, the ethics of caring, and how they themselves affect the relative dignity of their patients. These crucial, relational sources can be seen as vital dimensions and parts of the women's *psychosocial living space*.[31] Experiencing the power of relationships happens in this living space, which may confirm the women's value and relative dignity as well as enhance their senses of control and self-determination.

Finally, on the societal level, the results suggest that the women have a fundamental need to be treated with compassionate understanding in travel situations. In some situations, the women felt regarded as an

Figure 2. Interpretive understanding of the results on three dignity-related.

object, with no significance. According to Fjose et al.,[35] transportations characterized by discomfort and overfull taxis are exhausting and may even lead to re-admissions. ICs in this present study reported that these old and frail women sometimes considered cancelling treatment appointments at the hospital to avoid dignity-depriving transportation experiences. The ICs description of the older women's lack of influence on the transportation routines, contrasts the women's need of sustaining their freedom of choices. With respect to choices, the ICs expressed the importance of giving the women the option to tailor their own end-of-life care, and make decisions concerning the preferable place to stay when nearing end-of-life – even with limited strengths. Autonomy and personal integrity have previously been found to be essential aspects inherent in dignity-preserving care,[36] and are at stake in situations like these.

The results of this present study also show that the women's preferences regarding the place to stay when nearing end-of-life were characterized by doubts, insecurities and lack of coherences. The ICs described how the women wanted to stay in familiar surroundings and live their final days in their own, treasured homes. However, when feeling insecure, some women wanted to be admitted to an institution to receive continuity of care and reduce IC burden – in both cases their preferred *physical living space* according to Eriksson.[31] Importantly, the reciprocal interaction of the individual, relational and societal sources affecting dignity should be recognized. These sources serve to illustrate that dignity can be affected on different levels. In addition, since being interrelated the dignity experience on one level may influence the sense of dignity also on the other levels, or to use Eriksson's words; *the physical living space, the psychosocial living space* and *the existential living space* are parts of the human living space as a whole.[31] As reported by ICs and discussed in this study, dignity-preserving care for older, home-dwelling women living with incurable cancer can be promoted when focused attention is given to uphold their living spaces according to their wishes and needs. This knowledge should therefore be emphasized in HCPs' educational training and in the municipal end-of life care for these patients.

Methodological considerations

We found in-depth interviews and participant observations to be suitable data-collection tools. The first author's long practice as a municipal oncology nurse helped her establish a safe and good atmosphere during data collection. Ten ICs declined to participate in the study, and we acknowledge that a greater number of participants would have strengthened the data collection. While collecting data on the ICs' experiences, reflecting upon our pre-understanding and focusing on collecting detailed descriptions, afforded study transferability.[37] As part of the methodological approach, we used the framework PAIC-PAIR part 1[21]to strengthen study trustworthiness[38] regarding the credibility and internal validity of the study;[38] two ICs contributed in all phases of the research process, as members of the steering group and advisory board. Dependability[38] was sought through a transparent documentation of the research process. A procedure to empower confirmability[38] was emphasized, in which checking and rechecking all the collected data was performed thoroughly. To strengthen study authenticity,[38] portraying the IC's perceptions as formulated by themselves, was highlighted.

Conclusion and recommendation

According to ICs, older women experience dignity on the individual level when maintaining one's self-concept and self-worth. The value of remaining hopeful, experiencing joy and being seen as an independent individual, were crucial dignity-preserving sources on the relational level. On the societal level, the ICs highlighted the women's need for sustaining freedom of choice concerning the place to be when nearing end-of-life.

Sources leading to dignity loss on the individual level were related to the women's sense of losing their human value. On the relational level, lack of HCP presence and gentleness, led to a sense of humiliation and worthlessness. On the societal level, feelings of being treated as an object were experienced as a dignity-depriving source. The findings strongly suggest a practical value for emphasizing HCPs ethical training and reflections upon dignity-preserving end-of-life care provided by municipal healthcare services. Regardless of the woman's preferred place to stay when nearing end-of life, the attitude and behaviour of HCPs should consist of gentleness and consideration, as well as compassion and awareness of the women's condition and subjective needs. Further research should explore dignity and dignity loss as perceived by HCPs responsible for the care and treatment of older women living with incurable cancer at home. Further studies are needed to see how changes in municipal end-of-life care services affect experiences of dignity for this group of patients.

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Healthcare professionals' perceptions of dignity-preserving care for older home-dwelling women with incurable cancer in Norway

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ABSTRACT
Municipal end-of-life care for older home-dwelling patients with cancer is a complex matter requiring healthcare professionals (HCPs) to recognize gender differences in a social, historical and organizational context. A qualitative approach was chosen to explore and identify HCPs value-based principles and organizational conditions promoting dignity-preserving care practice for these women. HCPs recognized the importance of sheltering the women's identity, their sense of being home and acknowledged their personal preferences as value-based principles, whereas creating a flexible culture of care, establishing a functional professional collaboration and developing individualized plans of care, were crucial organizational conditions influencing the practice of dignity-preserving care.

KEYWORDS
Women's health; end-of-life care; dignity

Introduction

Due to an aging population and cancer expanding worldwide, the number of older women with cancer is increasing (Torre et al., 2017). Breast, colorectal and lung cancers accounted for the top three of women's cancers, with breast cancer representing the leading cause of death (Bray et al., 2018). Providing palliative care for women with cancer seems to be hampered by lack of both human and physical resources as well as policy absence or barriers (Cain & Denny, 2018). *Palliative care* is a widely used term within cancer care, and may be provided to the patient at any point from diagnosis to end-of-life. This article has its focus on older women nearing end-of-life, and we have therefore used the term *end-of-life care* throughout this article. Against this background, high quality end-of-life care for the rising number of older women with incurable cancer is now of great importance and should warrant sufficient healthcare resources, proper alleviation of symptoms, and respectful and supportive care (Cain & Denny, 2018; Rochon et al., 2020). This presupposes increasing demands on healthcare services and a multidisciplinary collaboration among healthcare professionals (HCPs) with complementary competencies to fulfil the complex needs of patients with incurable cancer (Johansen & Ervik, 2018).Figure 1

Despite the diversity in the term "older age" due to genetic inheritance and the environments in which older people live, we here define "old" from the age of 65 years in this study (WHO, 2020). Older people are often considered as a single group without taking account of gender differences, whereas care for older women requires an approach on aging, disease morbidity and treatment that is different

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from care for men (Gemmati et al., 2019; Rochon et al., 2020). The biological, hormonal and social differences between men and women should be incorporated when developing personalized therapeutic cancer treatment as well as palliative symptomatic treatment (Bartz et al., 2020; Kim et al., 2018). Cain and Denny (2018) suggest that this would contribute to more efficient symptom alleviation and better quality of life for women with incurable cancer. A number of studies have reported that women experience pain, anxiety, depression and loneliness more frequently than men (Dahlberg et al., 2015; Fillingim, 2017; Jaworska & Ryan, 2018; Wright et al., 2019). Depaola et al. (2003) found that older women score higher than men on a subscale measuring fear of death, indicating the importance of approaching women differently to men.

In Norway, women live longer than men, and in 2019, women had an expected life span of 84.7 years compared to men's 81.2 years (SSB, 2020). Public narratives and policies often describe the aging population as a societal challenge and a burden due to increasing dependency upon the welfare state (Christensen, 2018). With modern societies making independency a central concept, aging people are easily presented as unwanted in society (Christensen & Wærness, 2021; Staats et al., 2020a). In the 1950s, the main role for a woman was to be a housewife. This first changed during the 1970s when women's employment and education activity radically increased (Danielsen, 2009). Sociological studies in Norway have paid much attention to this history of women's unpaid house and care work (Christensen & Wærness, 2021), which is central to the understanding of their life stories. During their lives, many women have experienced challenges related to being both a spouse and a caregiver; when being older women, there is a perception that they are still occupying the caregiver role (Holtslander & Duggleby, 2010). When nearing end-of-life, older women themselves prefer a treasured and nurturing environment, with quality of care being more important than the physical place (Staats et al., 2020a). It is therefore crucial to learn more about current healthcare services for older, home-dwelling women nearing end-of-life.

For older women with incurable cancer, important municipal healthcare services are cancer coordinator (CC) and general practitioner (GP) follow-ups, short or long-term care in nursing homes and homecare services, consisting of registered nurses, healthcare workers and care assistants. Homecare palliative nurses (HCPNs) are also members of the homecare services and are directly involved with the daily end-of-life care. GPs have the medical responsibility and a key role in securing appropriate end-of-life care for patients in the municipality (Svedahl et al., 2019) and collaborating with the hospital and different specialists. CCs also have a specific responsibility of coordinating and facilitating individual care for cancer patients and their families. Their task is to fulfil an interdisciplinary role and have an overview of services available within and outside the municipality (Lie et al., 2018). Both GPs and CCs experience the ideal collaboration as a "meeting of experts" with complementary competencies (Johansen & Ervik, 2018). Using an individual plan of care can improve the HCP collaboration as well as strengthen their cooperation with the patients' relatives (Kjellevold & Skippervik, 2020). Nevertheless, for HCPs to meet potential challenges within the municipal healthcare services for older women in Norway, interventions of dignity-preserving care should be emphasized.

The Norwegian health and care authorities encourage all municipalities to ensure their citizens a meaningful life and a death with dignity in accordance with their individual needs and preferences (Ministry of Health and Care Services, 2010). Dignity is a complex concept; however, it is a value philosophy at the very heart of good nursing care (Gallagher et al., 2008). According to the Commission for Social Care Inspection (CSCI) and Audit Commission (2006), HCPs should treat patients with dignity at all times and in all situations. The Declaration of Human Rights (United Nations, 1948) states that being human presupposes an *inherent dignity*. Likewise, in her theory of caring, Katie Eriksson (1996) stresses the ontological view of human nature as one where each individual has an inherent *absolute dignity*. This absolute dignity is undeniable and granted by virtue of being human, while the term *relative dignity* relates to each individual's personal experiences of self-worth and human value in relation to others. The latter is therefore a form of dignity that is changeable; it can be both violated and preserved (Eriksson, 1994, 1996; Lindstrøm et al., 2018).

Previous research documented that experiencing love and confirmation, social inclusion and fellowship, humane warmth and understanding within a caring culture are crucial aspects of dignity-preserving care for home-dwelling patients with dementia (Tranvåg et al., 2015). Studies have also described that a patient-centered positive approach and a focus on spirituality are factors leading to dignity within institutional care (Bovero et al., 2018; Da Rocha Rodrigues et al., 2019). As gender influences health throughout people's lifespan, we have documented crucial sources enhancing dignity-preserving care seen from the perspective of older women and their informal caregivers (Staats, Grov, Husebø, Tranvåg, 2020a; 2020bblinded). We found that having control, experiencing hope and meaningfulness, and maintaining one's self-concept were crucial sources to preserve dignity for older women, while losing self-determination, feeling treated as an object, experiencing violation or an absence of gentleness, all led to dignity loss.

In spite of increasing acceptance of women's health and roles within healthcare, we know little about how GPs, CCs and HCPNs perceive dignity-preserving care for older home-dwelling women with incurable cancer. The aim of the present study was to explore and identify these HCPs' perceptions of value-based principles and organizational conditions promoting dignity-preserving care for older home-dwelling women with incurable cancer. The term *value* is understood to mean qualities and standards of each HCP, whereas *principles* refer to beliefs and rules that govern their actions – as grounded on their values. Being members of the healthcare services in the municipality, GPs, CCs and, HCPNs will be defined as HCPs throughout this article when highlighting perspectives from all three professions.Being members of the healthcare services in the municipality, general practitioners (GPs), cancer coordinators (CCs) and homecare palliative nurses (HCPNs), will be defined as HCPs throughout this article when highlighting perspectives from all three professions.

Methods

This article draws on a study using a qualitative approach combining participant observations, focus group interviews and in-depth interviews. We apply Gadamer's philosophical hermeneutics (Gadamer, 1989) as a methodology emphasizing interpretative dialogs with transcribed interview text and notes from participant observations, leading to new understanding of the phenomenon under investigation. Combing different data collection tools strengthens the richness and understanding of data (Atkinson & Coffey, 2003; Creswell & Poth, 2018). The participant observations in this study, carried out between March and November 2019, are part of background material from an overarching project (Staats et al. 2020a), creating an overall and contextual understanding of the phenomenon under investigation. In addition to the data from six participant observations, the data in the present article comprise three focus group interviews with CCs and HCPNs, conducted in March 2020, and seven in-depth interviews with GPs conducted between March and June 2020 (Table 1).

Participant observations

We used participant observations to get insight into the everyday lives of older women living with incurable cancer and developed themes for further exploration in the interviews. The participants observed were recruited previously, when interviewing older home-dwelling women with incurable cancer and their informal caregivers (Staats et al. 2020a). New knowledge was generated by describing and developing an interpretive understanding (Karlsson et al., 2012; Spradley, 2016) of the interactions between the older women, their informal caregivers and the HCPs, as these acts unfolded within the context of the patients' homes. All observations were carried out by the first author and one of the six observations was performed within the hospital context because of the patient's hospital admission. Two of the participant observations included a palliative care doctor (PCD), a specialist within treatment and care for patients living with serious illnesses. In the context of older incurable ill women, these two PCDs have similar sporadic contact as the GPs in this study. Following hermeneutical methodology (Nåden, 2010), an observation guide was developed, including questions such as:

What characterizes the interaction between the woman, informal caregiver, PCDs and CCs? How do PCDs and CCs verbally/non-verbally suggest promoting dignity-preserving care? A total of 23 pages (10,705 words) of observation data were made available for analysis.

Focus group interviews

The first author contacted CC networks in seven municipalities in the south-east area of Norway, covering urban and rural areas. Sixteen members gave their consent to participate and were allocated into focus groups varying in size from five to six CCs and HCPNs in each group (Table 1). Eligibility criteria required the participants to be involved in the care of older home-dwelling women living with incurable cancer. The focus group interviews yielded a rich data material (Krueger & Casey, 2015) deriving from the interactions and dialogs between participants. The duration of clinical practice mirrored their wealth of experiences and added diversity to their background. During the focus group interviews the first author, as moderator, was assisted by the third author (E.K. Grov) and two PhD candidates as co-moderators. We used a semi-structured interview guide, including questions such as: As CCs and HCPNs, how do you recognize dignity-preserving care for older home-dwelling women? Which organizational conditions are crucial to ensure these women die with dignity? All three focus group interviews were recorded and transcribed verbatim, lasting from 65 to 70 minutes, resulting in 48 transcribed interview pages (30,156 words).

Table 1. Overview of the study participants.

	Participant observed*	Setting	Gender	Age	Profession*	Years of working experience as HCP
Participant Observation 1:	Patient, husband, CC, PCD	Patients home				
Participant Observation 2:	Patient, husband, CC	Patients home				
Participant Observation 3:	Patient, CC	Patients home				
Participant Observation 4:	Patient, husband, PCD, CC	Hospital				
Participant Observation 5:	Patient, CC	Patients home				
Participant Observation 6:	Patient, husband, CC	Patients home				
Focus group interview 1:			F (5)	Range, 54–60 Y (mean, 57)	CC (5)	Range, 23–35 (mean, 29)
Focus group interview 2:			F (5)	Range, 33–59 y (mean, 52)	CC (5)	Range, 11–36 (mean, 28)
Focus group interview 3:			F (6)	Range 44–61 y (mean, 53)	CC (4) HCPN (2)	Range, 10–38 (mean, 24)
In-depth interview 1:			F	56	GP	10
In-depth interview 2:			F	51	GP	22
In-depth interview 3:			M	41	GP	8
In-depth interview 4:			M	44	GP	18
In-depth interview 5:			M	38	GP	9
In-depth interview 6:			M	51	GP	13
In-depth interview 7:			F	43	GP	10

*CC = Cancer Coordinator, PCD = Palliative Care Doctor, HCPN = Homecare Palliative Nurse
GP = General Practitioner

In-depth interviews

In order to gain insight into GPs' views, we used in-depth interviews (Brinkmann, 2015). Following medical sociology traditions (Måseide, 2011), we focused both on GPs' interactions with older women and GPs' inter-relationships with other professionals. Recruitment involved strategic sampling, using the snowball method to help identify GPs responsible for older women's medical treatment (Creswell & Poth, 2018). The participants were recruited from four municipalities, both urban and rural. Due to COVID-19 pandemic circumstances, the interviews took place over digital platforms and telephone. We used a semi-structured modifiable interview guide, giving us the opportunity to take a flexible approach during the interviews, including questions such as: What do you experience as fundamental to safeguard older home-dwelling women's dignity? In your role as a GP, can you explain which conditions you perceive as vital for dignity-preserving care practice? All seven in-depth interviews were recorded and transcribed verbatim, lasting from 43 to 60 minutes and resulting in 74 transcribed pages (47,515 words).

Interpretation

All authors individually read the interview texts and observation notes, and regularly met to discuss preliminary patterns of meaning and contradictory evidence. Through a circular interpretive process; Gadamer's hermeneutical circle, we moved from interpretations of text parts to interpretations of the text-material as a whole (Fleming et al., 2003; Gadamer, 1989). Keywords and phrases were noted, then formulated into themes and sub-themes (Brinkmann, 2015). In addition, we implemented a thorough cooperation with HCPs as experts, inspired by the framework of patient and informal caregiver participation in research (PAICPAIR) (Staats et al., 2020b). As members of the project reference group, one GP and two CCs provided us with constructive responses on initial ideas and interview guides, and participated in discussions concerning preliminary findings.

Pre-understanding

The authors had various professional backgrounds – two cancer nurses, a sociologist, a medical doctor and a mental health nurse – covering various experiences within end-of-life care and research related to dignity and women's health. This pre-understanding is made available so the reader can learn about the researchers' preconceptions, as well as ensuring study transparency (Hiles & Čermák, 2007) and trustworthiness (Lincoln & Guba, 1985). As a cancer nurse and researcher, the first author (K.S) is experienced in collaboration with HCPs concerning the care for older home-dwelling women with incurable cancer and their informal caregivers. The other authors are experienced researchers within the fields of welfare sociology, care work and gender (K.C), have experience from end-of-life care and research into person-centered care (E.K.G), have clinical specialist expertise in anesthesiology, intensive care, palliative care and nursing home medicine (B.S.H), and research expertise in dignity and care as an ontological and ethical aspect of humanity (O.T). As a research team, our pre-understanding was characterized by our professional backgrounds and affected by the knowledge of limited resources within healthcare services, potentially leading to the limited presence of HCPs and reduced quality of care. We also experienced a critical and uncertain attitude concerning the concept of dignity. However, we assumed that dignity-preserving interactions were possible within the group of HCPs caring for older women in their home – when based on a supportive and caring context.

Ethical considerations

This study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013), the Norwegian Health Research Act (The Act on medical and health research (the Health

Research Act), 2008) and approved by the Norwegian Center for Research Data (ref. no. 138.698). The participants received written information on all aspects of the study and were informed of the principles of voluntariness of participation, the duty of confidentiality and deidentification, along with their rights to withdraw. All participants signed informed consent forms.

Results

In our study, GPs, CCs and HCPNs indicated that the term dignity was not a common word in their vocabulary about professional everyday work. However, it was meaningful to them as a value-based principle; they were able to reflect on it in a daily setting with care for older home-dwelling women. Their reflections comprised of two value-based principles: *Recognizing the importance of sheltering the women's identity and sense of being home* and *Acknowledging the women's autonomy and personal preferences*. Additionally, the results depict their perspectives of two organizational conditions influencing the practice of dignity-preserving care: *Creating a flexible organizational culture of care* and *Establishing a functional professional collaboration and individualized plans of care* (*Figure 1*).

Recognizing the importance of sheltering the women's identity and sense of being home

The informants overall reported that safeguarding the women's identity was crucial to maintaining a level of independence and to being recognized as worthy human beings – in particular, at times when the women experienced reduced bodily and psychological control. The GPs experienced the home as a treasured place to be for the women and stressed the importance of existential and relational aspects when being incurable ill. However, consequently, from their position, this also created expectations of home visits, which were described as time-consuming. Our observations revealed that GPs seemed to avoid conversations of an existential nature, as one stated: "It is hard talking about death and dying with my patients, so perhaps, if I don't bring up these difficult themes, they wouldn't do it either" (GP 4). We found situations where both GPs and CCs violated the women's sense of identity due to poor communication and neglecting their wishes and needs. CCs, however, were more preoccupied and comfortable with asking existential questions, underlining the importance of respecting and confirming the women's identity *beyond* their illness, acknowledging their lived life as wives and

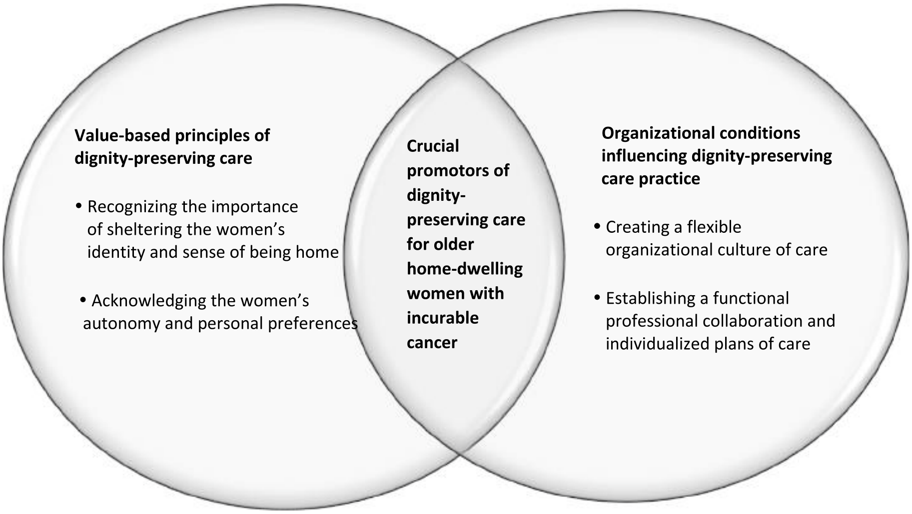

Figure 1. GPs', CCs' and HCPNs' value-based principles and organizational conditions promoting dignity-preserving care for older home-dwelling women with incurable cancer.

mothers. The CCs found it crucial to focus less on the future and more on the past, giving the women opportunities to share their life stories and thereby shelter their identity:

CC: She was an older woman with a limited social network, in her 90s, completely dependent upon nursing care. However, entirely clearheaded . . . she shared her life story . . . it was definitely a dignified moment, and it made an overwhelming impression on me. From being a tiny, hunched, old woman – suddenly becoming an upright, confident woman. It was her story. She was content with the situation and her life, which was important for her to talk about before moving on to the last phase. (FG 2)

HCPNs described situations where sheltering the women's identity was complicated or even experienced as being absent. When the CCs and HCPNs discussed this topic in the focus groups, an HCPN working close to older women giving bodily care described a degrading care situation:

HCPN: When giving nursing care to a woman lying in a hospital bed in her own living room, her family wouldn't leave the room. It was like . . . husband, daughter, cousin and other family members. We tried to make a provisional folding screen to protect her from everyone's sight . . . because it was excrement and urine . . . you know . . . The woman had difficulties in expressing herself due to a brain tumor, and I will never forget that look, telling me: "Please cover me up." We tried the best we could, but it was awful . . . and absolutely a degrading situation. (FG 3)

All CCs and HCPNs expressed difficulties and inner conflicts when being part of such violating actions. Limited capacity hindered them in acting as professionals giving adequate attention to shelter the woman's identity. Despite these challenges, the CCs and HCPNs described the home of the women as a source of identity and a place to uphold their role as a housewife with cherished duties, stemming from a life in which this role was central for many of these older women.

Acknowledging the women's autonomy and personal preferences

To maintain the women's autonomy and self-worth as they were nearing end-of-life, CCs emphasized the importance of creating a purposeful environment, meeting their preferences. When asked about opinions concerning women's preferred place to stay when nearing end-of-life, CCs and HCPNs were unanimously dissatisfied with the Norwegian healthcare authorities' promise to people to fulfil their wishes of dying in their homes, when the reality shows that a lack of competences and resources leads to uncertainty and unsafe situations for these female patients, and sometimes to undesirable hospitalizations. However, whilst the HCPNs showed effort and willingness to meet the women's needs and preferences despite a lack of resources, several CCs stated that there were situations where the women felt overridden, not able to communicate their wishes:

CC: She felt pressured to give up her house key to the homecare service. They wanted to be able to let themselves in her house during the night to make sure she was doing well. She made it perfectly clear to me that she felt it as an infringement, having strangers in her house when she was sleeping. The HCPs kept asking her about this key . . . I understand her frustration. Why should they override her preferences? (FG 1)

Most older women were described as having multiple roles and prominent responsibility within their household, which were regarded as integral parts of their lives. Therefore, this situation was experienced as a severe infringement of identity. For several GPs, acknowledging the women's autonomy and personal preferences was a challenging matter due to unsettled values and principles. They expressed disappointments of not being able to prevent violations of older home-dwelling women because of a lack of resources and poor knowledge of the patient.

Creating a flexible organizational culture of care

The GPs, CCs and HCPNs all stated that it was crucial for them to meet older, incurable ill women with awareness and gentleness. To do so, generosity among HCPs and flexibility within the healthcare organization were required, including sufficient time and knowledge about the patients' situations. The importance of developing a culture of care was more prominent in the focus groups with CCs and HCPNs than in the interviews with GPs. A culture of care was described as an essential context for using the limited time given positively, in particular by the HCPNs. The GPs rather experienced a distance in their care for the older women, attaching this to factors such as disease complexity, lack of specialized competence and infrequently caring for this patient group during their sickness trajectory. Sometimes the GPs did not even know they had an older, home-dwelling women with incurable cancer on their list. One GP found a way to meet these challenges, creating a flexible solution:

GP: They get their cancer diagnosis, it reaches an advanced stage, and they get their follow ups from the hospital without us knowing about their situation. Then, in the end we are suddenly visible, using a lot of effort to get updated. We must establish some contact at an early stage, yet without being persistent. My way of doing so is to write a short letter letting the women know that I know . . . and hopefully she will contact me. . . . it gives me more time, takes less effort, and the opportunity to give much better care. (GP 7)

Such creativity enabled the GP to create a proper collaboration and follow-up for this patient. CCs and HCPNs highlighted the importance of expressing calmness and presence, independent of the time frame, and prioritized only a few HCPs visiting each patient. However, depending on possibilities given by the healthcare management and overarching organizational policies, they stated that there might be a risk of a hectic time toward end-of-life, characterized by poor quality of care. According to one CC, the purchaser authority in the municipality seemed to have the power to influence what specific services they considered available, sometimes resulting in the women feeling neglected:

CC: She was severely influenced by fatigue. I asked her: "What do you need? What is important for you?" She told me she did not want the homecare service to come to her daily, it was too exhausting. She only asked for a phone call two or three times during Christmas . . . Unfortunately, we did not manage this . . . the case officer said *no*, we do not have a resolution to give phone calls . . . we did not succeed in giving her what she needed. Her family was away, and this was the little help she asked for to feel safe. (FG 1)

The CCs highlighted the need of an organization with a flexible culture of care, contrasting rigid services focusing on bureaucratic-organizational care. Several CCs and HCPNs experienced conflicting values when caring for these older women, especially HCPNs who described offensive situations caused by "target-driven" managers and insufficient HCP competence.

Establishing a functional professional collaboration and individualized plans of care

GPs emphasized that proper collaboration and individualized plans of care were crucial for meeting the needs of older women living with incurable cancer. One GP argued that professional collaboration was the essence of care for dying women in their homes – where HCPs were all depending on each other. Some GPs and CCs described their feelings of being responsible for the whole care trajectory of these patients and their families because of their general knowledge and acquaintance. They therefore stressed the importance of establishing a functional collaboration. Concerning the medical treatment, we found some GPs desiring to give a proper follow-up by ensuring an individualized plan of care for all involved HCPs, even when not being on duty themselves:

GP: We must create a proper cooperation with the outpatients, being accessible and making update lists of end-of-life medications with clear instructions. It is important for everyone to know how to get hold of the medications, exactly what to give and being confident in providing it. The ambulance service should also know about these plans, to avoid an unwanted admittance in the emergency ward, or sending an ambulance helicopter. All doctors on duty should know this strategy, or at least know how to find such a plan concerning the patients' needs and wishes. (GP 1)

A shared view amongst the participants was that caring for these older home-dwelling women was a complex matter, from a physical, psychological and existential perspective. According to GPs, various individualized plans of care were useful when structuring the women's everyday lives. CCs and HCPNs working closer to the patients, however, expressed a discontentment with an expanding number of plans and healthcare procedures. They experienced a reduced level of individualized care and a decreasing quality in the communication with the older women and their families, as expressed in this observation extract from the hospital setting:

Participant observation: An older woman with advanced cancer shares her thoughts about her death and explains openly how she will arrange her final days in her home. When her husband starts sharing *his* thoughts about his wife's last phase of life, the CC interrupts him, puts a piece of paper in his hand … and asks him to look at this questionnaire at home and contact her if he has any questions related to *his* situation. He quickly folds it and puts it in his pocket, not further participating in the conversation. (Participant observation 4)

This observation shows that the husband's attempt to share his thoughts was interrupted by the presentation of a questionnaire, given mechanically and without sensitivity and explanation, hindering him in supporting his wife in her end-of-life phase. As suggested in the focus groups by the CCs, these plans of care should be applied appropriately and adapted to the individual.

Discussion

The discussion is anchored in a social, historical and an organizational context. We will first present our findings illuminating HCPs' value-based principles leading to dignity for older home-dwelling women with incurable cancer, followed by organizational conditions influencing the practice of dignity-preserving care. The whole text will follow the order of GPs' perspectives and the perspectives of CCs and HCPNs.

First, we found that recognizing the importance of sheltering the women's identity and sense of being home was crucial for preserving their dignity. The results also revealed that acknowledging the women's autonomy and personal preferences maintained their level of independence. These findings support recent studies highlighting the importance for older home-dwelling people to uphold the ability to make choices in line with one's value (Persson et al., 2020; Segev et al., 2017). Previous research from Norway and Scotland has revealed that healthcare services do not meet the demands of care of older home-dwelling cancer patients, implying a risk of hindering older people's access to proper end-of-life care (Fjose et al., 2018; Miller & Nevadunsky, 2018). Another risk relates to older people being considered as one group without appreciation of gender differences related to life-threatening illnesses (Cain & Denny, 2018; Rochon et al., 2020). Whereas dignity in care has been discussed from the perspective of HCPs in general (Baillie et al., 2008; Barclay, 2016; Johnston et al., 2012), we found that GPs, CCs and HCPNs emphasized sources of dignity differently. For GPs, experiencing an overwhelming responsibility for older home-dwelling women living with incurable cancer, they are often absent in complex, multidisciplinary care situations. However, despite these challenges, we argue that GPs may maintain dignity when being wholly present during the care interaction, recognizing these older women as unique human beings. Based on Eriksson's theory of caring (Eriksson, 1996), we interpret that it is essential that HCPs, including GPs, perceive that each older woman living with incurable cancer has an inherent *absolute dignity*, undeniable and granted by virtue of being human. It is also vital to perceive *relative dignity*, that is modifiable, being influenced by relational interactions. These may include recognition of each patient's uniqueness and gendered role history (Christensen, 2018). The understanding of absence of care, as affecting the older women's relative dignity, was supported by Mann (1998). He proposed four types of dignity violation: *Not being seen, being subsumed into a group identity, invasion of personal space* and *humiliation*. We see the first type of violation, *not being seen*, as mirroring the absence of GPs, thereby making the women feel unrecognized or that their preferences and values were not sufficiently acknowledged. Our study highlights that several GPs had poor knowledge concerning the older women's lived lives and end-of-life preferences. This raises the possibility of loss of relative dignity for the women in inadequate interactions with GPs. We found that GPs were eager to recognize the older women as worthy human beings, but seemed to have reduced opportunities to do so, as well as less willingness to accomplish situations increasing the relative dignity – despite their duty to carry out home visits to patients incapable of traveling to the GP office (Regulations of the regular GP's scheme, 2012). Gallagher et al. (2008) related GPs' limited awareness of the concept of dignity to staff attitudes and culture of care, whereas Johansen and Ervik (2018) drew attention to GPs' missing out of collective networks, learning primarily from individual-professional experiences.

As different from GPs, the CCs and HCPNs enhanced their competence through belonging to a nursing network. Findings also indicated that they developed stronger relationships with the older women nearing end-of-life, being familiar with their needs and preferences. This supports the findings of Lie et al. (2018), who found that patients living with incurable illnesses had more frequent contact with CCs than with GPs. However, in our study, CCs were more distant from the patients as they carried out their work more at a managing level, making the HCPNs more involved in the daily care for the patients. This seems to be consistent with Fiva et al. (2014), emphasizing a diversity of CCs' work descriptions arising from geographic variations between Norwegian municipalities. However, both CCs and HCPNs in our study reported the importance for older women to maintain their autonomy and sense of identity *beyond* their illness when being at home, which was described as a place to uphold their roles and desires. According to Eriksson (1987), the desire for life drives human beings in the direction of a meaningful context influenced by fundamental values resting on love and care for the other. Despite changes in older women's life situations due to incurable illness, it is important to participate in daily chores, being confirmed as the person one used to be, sharing one's life-story with others (Staats et al., 2020a). Nåden and Eriksson (2000) also highlighted the significance of *confirmation*, an anchor during a difficult period in life. Confirmation implies being seen and understood, while not being confirmed implies being ignored (Lindstrøm et al., 2018), leading to dignity violation (Mann, 1998). To achieve confirmation, we argue that the invitation to existential conversations for older women were of crucial importance. We also argue that in situations where the caring *invitation* (Eriksson, 1994) was absent, the women's voices were silenced. In our study, CCs performed most existential dialogs with the participants. Notably, all HCPs in the present study, including GPs, highlighted this as one of the most crucial conditions promoting dignity-preserving care. In particular, the CCs and HCPNs reported dissatisfactions with a lack of healthcare recourses providing a scant foundation for sheltering the women's identity. Moreover, the HCPNs expressed how they felt hindered in being professionals giving high attention to the women, which could strengthen the relative dignity experience. Mann (1998) would call this *humiliation*. Being exposed to bodily violations when, for instance, not being covered up during intimate care, could have a severe impact on the older woman, even when living in a dignity-affirming environment. Being aware of older women's wordlessness and invisibility of their body is crucial in order to treat them as unique individuals and help them regain experience of dignity and health (Lorentsen et al., 2019).

Second, we found that a flexible organizational culture of care was crucial for GPs, CCs and HCPNs to meet older, incurable ill women with the necessary awareness and generosity. Functional professional collaboration and individualized plans of care were crucial to daily practice to meet the needs of these older women. GPs experienced a distance in the care of older women living with incurable cancer at home, which affected their dignity-preserving care practice. This is a well-known challenge, documented in recent studies, underscoring GPs' limited specialized competence and their infrequent provision of care for this patient group (Danielsen et al., 2018; Kjellstadli et al., 2020). In 2012, the Norwegian Ministry of Health and Care Services (2008–2009) introduced a Coordination Reform, aiming at a stronger integration of GPs into the joint collaboration between HCPs within the various municipal healthcare services. Kirchhoff et al. (2016), who evaluated the Coordination Reform and the role of GPs, found an unintentional lack of engagement of GPs and that this distant GP role seemed largely to be accepted by central municipal managers. A new Norwegian reform concerning end-of-life care (Ministry of Health and Care Services, 2019–2020) requires GPs to collaborate and arrange care for home deaths in the municipalities, and particularly emphasizes that the patient's own preferences and values should be prioritized. However, the reform also acknowledges GPs' challenges of availability, capacity and recruitment. Simultaneously, a legal regulation (Ministry of Health and Care Services, 2010) is supposed to ensure all older people a dignified death. While these governmental reforms and regulations cannot guarantee citizens dignity-preserving care, they send a clear signal of giving priority to the conditions for dignity, including at the organizational level. Several GPs in the present study stressed professional collaboration to be an essential condition influencing the practice of dignity-preserving care. To create such collaboration, GPs suggested individualized plans of care for each older woman with incurable cancer, living at home. This suggestion, however, contrasts findings from previous studies, documenting that too much focus on planning the care in advance for older people may decrease the level of individualized care (Berglund et al., 2012; Johnson et al., 2018) and result in dignity violations, when *being subsumed into a group identity* (Mann, 1998). However, as nursing researchers, Gallagher et al. (2008) highlighted individualized planning of care as constructive for operationalizing dignity in everyday practice. A recent study showed GPs being excluded from the opportunity to implement individual care plans (Kjellevold & Skippervik, 2020), which is a legal right and sets out required services, goals and resources. We argue that older home-dwelling women living with incurable cancer will benefit from supportive formal, individualized plans. This will help them and their relatives cope better in their own treatment and care, as well as enabling HCPs to establish functional professional collaborations.

According to Gallagher et al. (2008), organizational conditions set the context for staff attitudes and the practice of dignity preservation of older people. Moreover, dignity-preserving care for older vulnerable, home-dwelling people is dependent upon HCPs' kindness and gentleness, developing a caring culture in which patients can experience themselves as equal human beings (Tranvåg et al., 2015). These findings also harmonize with Eriksson's concept of a *caring culture* (Eriksson, 1994) where care is formed in the relationship between the human being and the caregiver. Eriksson (1987) used the concept of caring culture instead of environment, which in the present study can be interpreted to include both standardized (Fiva et al., 2014) and flexible (Lindstrøm et al., 2018) conditions helping female patients preserve their gendered roles developed through their lives (Bartz et al., 2020; Christensen & Wærness, 2021).

Methodological considerations

This study used a combination of data collection tools (Creswell & Poth, 2018) and included PAICPAIR (Staats et al., 2020b) as part of the methodological approach, which strengthens its trustworthiness and transferability (Lincoln & Guba, 1985; Polit & Beck, 2017). However, there are limitations to consider. First, the six participant observations were not followed up by new observations. This may have limited insights into the participants' everyday life interactions with professionals in their homes. Second, the proportions of CCs and HCPNs within the focus group interviews were imbalanced and possibly led to a stronger weighting of CCs' values and principles of dignity-preserving care. However, the two HCPNs contributed with rich data by sharing valuable experiences, which generated an in-depth understanding of the phenomenon of interest (Krueger & Casey, 2015). Third, using the snowball method to recruit GPs might have increased the likelihood of participants sharing the same characteristics and interests in the research topic. Also, due to COVID-19 pandemic circumstances, the in-depth interviews were carried out digitally. This might have limited interactional interview aspects, such as feelings and thinking behaviors, but was countered by the first author's long experience as a CC, being able to establish a safe and trustful atmosphere during the interviews (Brinkmann, 2015).

Conclusion

According to GPs, CCs and HCPNs, value-based principles of dignity-preserving care for older home-dwelling women were experienced when HCPs recognized the importance of sheltering the women's identity and sense of being home. The CCs and HCPNs described the home as a source of identity for the older women and a crucial place for them to uphold their roles, developed through a gendered, female life. This study reveals that acknowledging the women's autonomy and gendered preferences is a core value-based principle for promoting professional dignity-preserving care. However, GPs, CCs and HCPNs experienced different challenges concerning older home-dwelling people's ability to make choices in line with their own values developed through their gendered roles in life. GPs acknowledged a lack of awareness of the women's preferences arising from a level of disconnection with their treatment. CCs and HCPNs were more involved in the daily care, but experienced barriers to sheltering the women's identity. This study also identified organizational conditions influencing dignity-preserving care. GPs underscored the importance of functional collaboration with CCs and other HCPs, and individualized plans of care. In contrast, HCPNs pointed out decreasing quality of care when focusing too much on plans, emphasizing that dignity-preserving care is more depending on HCPs' kindness and gentleness within the culture of care. CCs, adapting such plans of care to individual lives, had a strong focus on explanations and follow-ups, safeguarding the women's autonomy and personal preferences. Finally, our findings illuminate a too-often neglected perspective in health policies; dignity of women living with incurable cancer at home. Governmental action plans for future care should therefore include the gender perspective and be founded upon knowledge of dignity-preserving care for this vulnerable group of women. We suggest a stronger collaboration within the municipality healthcare services and recommend GPs, CCs and HCPNs to create networks aiming for reflections and quality improvements concerning end-of-life care. There is an increased likelihood that older home-dwelling women are treated with dignity during the final period of their lives if dignity-preserving care and the gender perspective are emphasized in HCP education. We therefore recommend these perspectives to be clearly integrated. Future research should explore how research-based knowledge of dignity-preserving care can be implemented as an integrated part of end-of-life care within the municipal healthcare services.

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Appendix 1: Dignity-preserving end-of-life care; a review of the literature

Author/Year/ Country	*Theme*	*Inclusion/exclusion criteria*	*No. of studies (review)*	*Main findings*
Xiao et al. 2021. China	*Patients with cancer and their experience of dignity*	Incl: Cancer patients ≥18 years and their perception of dignity Excl: View of HCPs or mixed sample, and perception without addressing dignity	22	The ways that patients with cancer perceived dignity include autonomy and control, respect and self-worth, family connectedness, acceptance, hope and future perspectives, as well as religious aspects. This was perceived as important aspects fostering coping strategies to control the physical, psychosocial factors and experience of sufferings that threaten their sense of dignity.
Choo et al. 2020. Singapore	*Dignity in End-of-Life Care*	Incl: Dignity from the perspectives of patients, family caregivers, and health-care professionals	48	The Dynamic Reciprocity of Dignity model highlights the importance of adopting a systemic lens to address dignity-related needs and concerns at the end of life, while providing insights on how compassionate care and self-compassion can serve as the foundation of dignified care, which in turn serve as a buffer against patients' existential suffering as well as caregivers' burnout and fatigue.
Östlund et al. 2019. Sweden	*Dignity in palliative care from the view of older patients, significant others (SO), and HCP in Sweden*	Incl: Patients having palliative care needs, SO being close to the patient, and HCP working regularly with palliative care Excl: Inability to understand Swedish and/or cognitive impairments.	1	The Dignity Care Intervention (DCI), developed in Scotland, is now being adapted to a Swedish context (DCI-SWE). This study added relevant care actions for collaborative planning of individualized care in mutual dialogues between nurses and those they care for. Care actions were also found to be linked to each other, showing the importance of a holistic perspective in conserving dignity. The adapted intervention, DCI-SWE, has the potential to help the nurses in providing palliative care of evidence-based quality.
Werkander Harstäde et al. 2018. Sweden	*Care actions preserving dignity in palliative care*	Incl: patients ≥ 18 years and in need of palliative care. Containing themes in Chochinov's model of dignity Excl: Euthanasia. Patients with dementia and/or mental illness	33	Suggested care actions in the dignity model included listening, communication, information, symptom control, facilitating daily living and including patients in decision-making. The adapted DCI will be a way for Swedish nurses to provide person-centered palliative care that will conserve patients' dignity.
McIlfatrick et al. 2017. Ireland	*Dignity care intervention in the community setting*	Incl: Community nurses attended DCI education session and participated in the implementation of DCI tool in practice.	1	The community nurses found the DCI useful. It helped the nurses to provide holistic end-of-life care and assisted in the overall assessment of palliative care patients, identifying areas that might not otherwise have been noted. Whilst it was a useful tool for communication, they noted that it stimulated some emotionally sensitive conversations for which they felt unprepared.
Rodríguez-Prat et al. 2016. Spain	*Dignity, Autonomy and Control at the end-of-life*	Incl: Dignity, autonomy, and control in patients/older people	21	Dignity and autonomy are intertwined and can be perceived as a multidimensional concept, one that is close to the notion of personal identity. The ability to regard dignity as an intrinsic quality has a positive impact on patients, and the design of care

		with an advanced disease, relatives and/or HCP Excl: Paediatric samples		strategies should take this into account. Autonomy was understood as the desire for control over the dying process and the desire for self-determination. Dignity mediated by the loss of functionality and was linked to the loss of control.
Fitchett et al. 2015. USA	*Human spirit and dignity therapy*	Incl: Feasibility, acceptability, and effects of Dignity Therapy (DT) for patients Excl: Dignity therapy model. DT and the family	25	DT report high satisfaction and benefits for themselves and their families, including increased sense of meaning and purpose. The effects of DT on physical or emotional symptoms, however, were inconsistent.
Johnston et al. 2015. The UK and Sweden	*Dignity-conserving care in palliative care settings*	Incl: Dignity conserving care, palliative care/life-limiting conditions/frail older, nursing interventions. Excl: Dementia and/or mental illness. Euthanasia	31	Nine Dignity Model themes were used to classify care actions: Level of Independence; Symptom Distress; Dignity-Conserving Perspectives; Dignity-Conserving Practices; Privacy Boundaries; Social Support; Care Tenor; Burden to Others; and Aftermath Concerns. Reported care actions included listening, conveying empathy, communication and involving patients in care.
Guo & Jacelon 2014. USA	*Dignity in end-of-life care*	Incl: Dying with dignity, model development, instruments or interventions for dignity at the end of life Excl: Legal aspects of death with dignity. Patients' dignity other than at the end of life	52	Themes of dying with dignity are as follows: a human right, autonomy and independence, relieved symptom distress, respect, being human and being self, meaningful relationships, dignified treatment and care, existential satisfaction, privacy, and calm environment. Interventions to support dignity stressed physical, psychological, and spiritual supports not only to dying patients but also to family members.
Östlund et al. 2012. Sweden and the UK	*Dignity conserving care at end-of-life*	Incl: dignity/terminal illness/elderly people. Dignity/distress/self-esteem and self-worth related to palliative or end of life care. Dignity interventions and its implementation Excl: dementia and/or mental illness. Euthanasia and physician assisted suicide	39	Several care actions were identified related to all themes contained within the Dignity Model. Examples include controlling symptoms; listening to the patient and taking them seriously; providing advice concerning how to cope on a daily basis; treating patients as equals and with respect and encouraging the family members' presence. The suggested care actions will be used to develop a dignity care pathway for end-of-life care. The intention is to provide more valid evidence for the effectiveness of the care actions suggested.

Appendix 2: Observation guide

Observasjonsguide

- Hva kjennetegner samhandlingen mellom pasient/pårørende og helsepersonell når pasienten ble møtt med verdighet?
    - Hvordan kommer verdighetsbevarende omsorg til uttrykk i deres møte?
        - Verbalt?
        - Non – verbalt?
        - Hvordan anvender helsepersonell språket i møtet med pasienten og den pårørende?

    - Hvordan beskriver pasient, pårørende og helsepersonell sin opplevelse av en slik (observert) situasjon?

- På hvilken måte uttrykker helsepersonell seg overfor pasienten når det gjelder ivaretakelse av åndelige og eksistensielle aspekter?

- På hvilken måte ordlegger helsepersonell seg for å ivareta en verdighetsbevarende omsorg for kvinnen?
    - Dagligdags språk? / fagspråk?
    - Formidles budskap på en tydelig måte?
    - Stemmebruk? rolig? / blikk?
    - Annet?

- Hvilken atferd og hvilke holdninger er tilstede i situasjoner hvor pasientens (og pårørendes) verdighet fremmes?

- Pasienten tilbys hjelp fra den kommunale helsetjenesten (i varierende grad). Hvordan blir pasienten møtt av helsepersonell ved ytring av behov/forventninger/ønsker om hjelp?

- Hva kjennetegner samhandlingen mellom pasient/pårørende og helsepersonell når pasienten forteller om en opplevelse hvor hun opplevde at hennes verdighet ble krenket?
    - Respekt/høflighet?
    - Støtte/forståelse?
    - Anerkjennelse av lidelse?
    - Annet?

- Hvilke atferd og hvilke holdninger er tilstede i situasjoner hvor pasientens (og pårørendes) verdighet krenkes?

- Hvordan blir pasienten møtt av helsepersonell når hun forteller om en situasjon hvor hennes verdighet ble krenket?

- Hvordan blir pårørende møtt av helsepersonell når hun/han forteller om en situasjon hvor hans/hennes verdighet ble krenket?

Appendix 3: Interview guide for study I

Semistrukturert modifiserbar intervjuguide: Pasient (delstudie 1)

Åpningsspørsmål:

- Jeg vil gjerne høre hva du forbinder med ordet verdighet? Hva tenker du på når du hører ordet verdighet?

- Hva handler verdighet om for deg?

- Kan du fortelle meg om en situasjon, etter at du ble syk, som handlet om opplevelsen av verdighet – for deg?

    - Hva handlet denne erfaringen om?
    - Kan du utdype dine erfaringer/perspektiver?
    -

Din situasjon – din hverdag

- Kan du si litt om hvordan det er å leve med sykdom – og om dette får følger for din opplevelse av verdighet i hverdagen din?

- Hva bidrar til å bevare din verdighet i hverdagen?

- Når opplever du at du blir behandlet med verdighet?

- Kan du fortelle om en situasjon hvor du opplevde dette?

    - Hvordan opplevde du denne situasjonen?
    - Hva var det ved situasjonen som gjorde at du fikk denne opplevelse av å bli behandlet med verdighet?

- Hva kan bidra til å krenke din verdighet i hverdagen?

    - Når opplever du at din verdighet blir krenket?

- Kan du fortelle om en situasjon hvor din verdighet ble krenket?

    - Hvordan opplevde du denne situasjonen?

- Hva (evt. Hvem) kan bidra til å fremme din opplevelse av verdighet i din hverdag?

- Har stedet du bor og oppholder deg noen betydning for din opplevelse av verdighet?

    - Hjemme? / Opphold i institusjon?

Hjelp fra kommunehelsetjenesten

- Er ordet «verdighet» noe som naturlig brukes når du snakker med hjemmesykepleien/Fastlegen?

- Hvilke tanker gjør du deg om å ha en verdig hverdag her hjemme og samtidig motta hjelp fra kommunal helsetjeneste?

- Kan du fortelle om en situasjon hvor du opplevde verdighet når du var i kontakt med hjemmesykepleien/fastlegen?

  - Hva var det pleieren gjorde (evt. sa)?
  - Hva var det fastlegen gjorde (evt. sa)?

- Har du opplevd situasjoner der du opplevde det motsatte? – At du ikke ble møtt med verdighet?

  - Hva var det pleieren gjorde (evt. sa)?
  - Hva var det fastlegen gjorde (evt. sa)?

- Har du opplevd situasjoner som er «nedverdigende»?
  - Hva gjør disse situasjonene nedverdigende?
  - Hvordan kan en bevare verdighet i nedverdigende situasjoner?
  - Hvordan ville du ønske å bli «forberedt» på slike situasjoner?

- Hvordan mener du at den kommunale helsetjenesten kan bidra til en verdig avslutning på ditt liv? (Spørsmålet stilles hvis samtalen og situasjonen tilsier at det er riktig. Sløyfes hvis det ikke passer inn i samtalen.)

  - Behov?
  - Ønsker?
  - Forutsetninger?
  - Utfordringer?

- Hvilke tanker gjør du deg om det å eventuelt bli pleietrengende og samtidig ha en verdig tid hjemme?

  - Hva er viktig for deg i en slik situasjon?
  - Hva vil bidra til å bevare din verdighet i denne situasjonen, slik du tenker om det nå?

Avslutning

- Er det noe vi ikke har snakket om, som du mener er viktig å få frem om dette vi nå snakker om – hva som bidrar til å bevare din verdighet, og hva som kan krenke den?

Avslutningsvis takker jeg for denne intervjusamtalen.

Appendix 4: Interview guide for study II

Semistrukturert modifiserbar intervjuguide: Pårørende (delstudie 2)

Åpningsspørsmål:

- Du er nær pårørende til din kone/mor/søster/venninne som har kreftsykdom, og jeg lurer på: kunne du fortelle meg litt om hva du forbinder med ordet «verdighet» når det gjelder din kone/mor/søster/venninne? Hva tenker du på når du hører ordet «verdighet» i denne sammenhengen?

- Kan du fortelle meg om en situasjon etter at din kone/mor/søster/venninne ble syk, som handlet om opplevelsen av verdighet for deg som pårørende?
  - Hva handlet denne erfaringen om?
  - Kan du utdype dine erfaringer/perspektiver?
  - Kan du fortelle om en situasjon hvor din verdighet som pårørende evt ble krenket?
  -

Din kones/mors/søster/venninnes hverdag

- Kan du si noe om hvordan det er å være pårørende – og om dette får følger for din opplevelse av verdighet i hverdagen din?

- Hva bidrar til å bevare din kones/mors/søsters/venninnes verdighet, slik du erfarer dette som pårørende?

- Når opplever du at hun blir behandlet med verdighet?

- Kan du fortelle om en situasjon hvor du opplevde dette?

- Kan hennes verdighet krenkes?

- Kan du fortelle om en situasjon hvor hennes verdighet ble krenket?

- Hva (evt.hvem) kan bidra til å fremme din kones/mors/søster/venninnes opplevelse av verdighet i hennes hverdag?

- Har stedet hvor hun bor og oppholder seg noen betydning for HENNES opplevelse av verdighet?
  - noen betydning for DIN opplevelse av verdighet?
  -

Hjelp fra kommunehelsetjenesten

- Er ordet «verdighet» noe som naturlig brukes når din kone/mor/søster/venninne snakker med hjemmesykepleien/Fastlegen?

- Hvilke tanker gjør du deg om at din kone/mor/søster/venninne har en verdig hverdag her hjemme og samtidig mottar hjelp fra kommunal helsetjeneste?

- Kan du fortelle om en situasjon hvor du opplevde verdighet overfor din kone/mor/søster/venninne når hun var i kontakt med hjemmesykepleien/fastlegen?

  - Hva var det pleieren gjorde (evt. sa)?
  - Hva var det fastlegen gjorde (evt. sa)?

- Har du opplevd situasjoner der hun opplevde det motsatte? – At hun ikke ble møtt med verdighet?

  - Hva var det pleieren gjorde (evt. sa)?
  - Hva var det fastlegen gjorde (evt. sa)?

- Har du opplevd situasjoner som er «nedverdigende» for din kone/mor/søster/venninne?
  - Hva gjør disse situasjonene nedverdigende?
  - Hvordan kan en bevare verdighet i nedverdigende situasjoner?
  - Hvordan ville du som pårørende at helsepersonell «forberedte» din kone/mor/søster/venninne på slike situasjoner?

- Hvordan mener du at den kommunale helsetjenesten kan bidra til en verdig avslutning på livet for din kone/mor/søster/venninne?

  - Behov?
  - Ønsker?
  - Forutsetninger?
  - Utfordringer?

- Hvilke tanker gjør du deg om at din kone/mor/søster/venninne eventuelt blir pleietrengende og samtidig har en verdig tid hjemme?

  - Hva er viktig for henne i en slik situasjon?
  - Hva vil bidra til å bevare hennes verdighet i denne situasjonen, slik du tenker om det nå?

- Kan du fortelle noe om din opplevelse av verdighet som pårørende hjemme, samtidig som dere mottar hjelp fra kommunale helsetjenester?

  - Hva er viktig for deg som pårørende i en slik situasjon?

Avslutning

- Er det noe vi ikke har snakket om, som du mener er viktig å få frem om dette vi nå snakker om – hva som bidrar til å bevare din kones/mors/søsters/venninnes verdighet, og hva som kan krenke den?

Avslutningsvis takker jeg for denne intervjusamtalen.

Appendix 5: Interview guide for study III (Focus group)

Semistrukturert modifiserbar intervjuguide: Kreftsykepleiere (delstudie 3)

Åpningsspørsmål:

- Jeg vil gjerne høre hva dere forbinder med begrepet verdighet når det gjelder behandling av kreftsyke, eldre kvinner som ønsker å være hjemme ved livets slutt?

- Hva handler verdighet om for dere som kreftsykepleiere?

- Kan dere fortelle meg om en situasjon, i kontakt med en eldre, kreftsyk kvinne i hjemmet, som handlet om verdighet?

    - Hva handlet denne erfaringen om?
    - Kan du utdype dine erfaringer/perspektiver?

Kreftsyke, eldre kvinners verdighet

- Hva ville dere som kreftsykepleier si kjennetegner verdighetsbevarende behandling, pleie og omsorg for kreftsyke kvinnelige pasienter som ønsker å være hjemme i den palliative fasen?

- Hva tenker dere kan bidra til å bevare verdigheten til kreftsyke eldre hjemmeboende menn versus kreftsyke, eldre hjemmeboende kvinner?

    - Hva er deres tanker rundt kjønnsforskjeller til eldre palliative kreftpasienter som ønsker å bo hjemme?
    - Kan dere fortelle om en situasjon hvor dere opplevde kjønnsforskjeller i behandling av eldre kreftsyke hjemmeboende pasienter?

- Kan dere fortelle om en situasjon der dere erfarte å fremme verdigheten til en eldre kvinne i palliativ fase?

- Hva er de viktigste faktorene knyttet til det å fremme denne pasientgruppens verdighet?

- Hva kan vanskeliggjøre en slik omsorgspraksis?

    - Individuelt? (målrettede handlinger, gode overveielser, konsekvenser)
    - Relasjonelt? (interaksjon mellom pasient og fastlege)
    - Organisatorisk? (i et større samfunnssammenheng? Til beste for befolkningens helse?)
    - Etiske utfordringer? (helhetlig tilnærming? verdier?)

- Kan det oppstår situasjoner hvor hennes verdighet krenkes når kvinnen har kort forventet levetid?
    - Optimal smertelindring /symptomlindring?
    - Sår? / lukt?
    - Munnstell?
    - Angst? Delir?

    - Annet?

- Kan dere fortelle om en situasjon hvor dere opplevde at den eldre kvinnens verdighet ble krenket?

    - Hvordan opplevde dere denne situasjonen?

- Hva (evt. Hvem) kan bidra til å fremme kvinnens opplevelse av verdighet i hennes hverdag?

Hjelp fra kommunehelsetjenesten

- Er ordet «verdighet» noe som naturlig brukes når vi snakker om hjemmesykepleien/fastlegen?

- Hvilke tanker gjør dere dere om at kvinner har en verdig avslutning på livet hjemme og samtidig mottar hjelp fra kommunal helsetjeneste?

- Kan dere fortelle om en situasjon hvor dere erfarte at kvinnen opplevde verdighet når hun var i kontakt med hjemmesykepleien/fastlegen?

    - Hva var det pleieren gjorde (evt. sa)?
    - Hva var det fastlegen gjorde (evt. sa)?

- Har dere erfart situasjoner der dere opplevde det motsatte? – At kvinnen ikke ble møtt med verdighet?

    - Hva var det pleieren gjorde (evt. sa)?
    - Hva var det fastlegen gjorde (evt. sa)?

- Har dere opplevd situasjoner som er «nedverdigende» for kvinnen?

    - Hva gjør disse situasjonene nedverdigende?
    - Hvordan kan en bevare verdighet i nedverdigende situasjoner?
    - Hvordan ville dere som kreftsykepleiere kunne «forberede» kvinnen på slike situasjoner?

- Hvordan mener dere at den kommunale helsetjenesten kan bidra til en verdig avslutning på livet for eldre, kreftsyke kvinner?

    - Behov?
    - Ønsker?
    - Forutsetninger?
    - Utfordringer?

- Hvilke tanker gjør dere dere når en eldre kvinne blir pleietrengende og samtidig ønsker å ha en verdig tid hjemme?

    - Hva tenker dere er viktig for henne i en slik situasjon?

    - Hva vil bidra til å bevare hennes verdighet i denne situasjonen, slik dere tenker om det?

- Vi vet at i enkelte situasjoner blir ikke kvinner møtt med verdighet. Har dere noen tanker om hva som hindrer helsepersonell i å møte disse kvinnene med verdighet?

    - Hvilke følger har dette for kvinnene, ifølge dere?
    - Hva skjer med dere når dere opplever dette?
    - Hva kan dere som kreftsykepleiere gjøre for å endre dette?

Avslutning

- Hva er viktig for dere å vektlegge – i deres gjerning som kreftsykepleiere – for å verne om verdigheten til kreftsyke eldre kvinner som ønsker å tilbringe sin siste levetid hjemme?

    - Opplever dere i deres arbeidshverdag at dere i tilstrekkelig grad har anledning til å rette oppmerksomheten mot disse pasientenes verdighet?
    - Har sykepleiefaget i sin grunnlagstenkning teorier, retningslinjer eller annen form for tekst nedfelt at sykepleiefaget skal bevare pasientens verdighet?

- Er det noe vi ikke har snakket om, som dere mener er viktig å få frem om dette vi nå snakker om – hva som bidrar til å bevare eldre, kreftsyke kvinners verdighet, og hva som kan krenke den?

Appendix 6: Interview guide for study III (In-depth interviews)

Semistrukturert modifiserbar intervjuguide: Fastleger (delstudie 3)

Åpningsspørsmål:

- Jeg vil gjerne høre hva du forbinder med begrepet verdighet når det gjelder behandling av kreftsyke, eldre kvinner som ønsker å være hjemme ved livets slutt?

- Hva handler verdighet om for deg som fastlege?

- Kan du fortelle meg om en situasjon, i kontakt med en eldre, kreftsyk kvinne i hjemmet, som handlet om verdighet?

    - Hva handlet denne erfaringen om?
    - Kan du utdype dine erfaringer/perspektiver?

Kreftsyke, eldre kvinners verdighet

- Hva ville du som fastlege si kjennetegner verdighetsbevarende behandling, pleie og omsorg for kreftsyke kvinnelige pasienter som ønsker å være hjemme i den palliative fasen?

- Hva tenker du kan bidra til å bevare verdigheten til kreftsyke eldre hjemmeboende menn versus kreftsyke, eldre hjemmeboende kvinner?

    - Hva er dine tanker rundt kjønnsforskjeller til eldre palliative kreftpasienter som ønsker å bo hjemme?
    - Kan du fortelle om en situasjon hvor du opplevde kjønnsforskjeller i behandling av eldre kreftsyke hjemmeboende pasienter?

- Kan du fortelle om en situasjon der du erfarte å fremme verdigheten til en eldre kvinne i palliativ fase?

- Hva er de viktigste faktorene knyttet til det å fremme denne pasientgruppens verdighet?

- Hva kan vanskeliggjøre en slik omsorgspraksis?

    - Individuelt? (målrettede handlinger, gode overveielser, konsekvenser)
    - Relasjonelt? (interaksjon mellom pasient og fastlege)
    - Organisatorisk? (i et større samfunnssammenheng? Til beste for befolkningens helse?)
    - Etiske utfordringer? (helhetlig tilnærming? verdier?)

- Kan det oppstår situasjoner hvor hennes verdighet krenkes når kvinnen har kort forventet levetid?
    - Optimal smertelindring /symptomlindring?
    - Sår? / lukt?
    - Munnstell?
    - Angst? Delir?

    - Annet?

- Kan du fortelle om en situasjon hvor du opplevde at den eldre kvinnens verdighet ble krenket?

    - Hvordan opplevde du denne situasjonen?

- Hva (evt. Hvem) kan bidra til å fremme kvinnens opplevelse av verdighet i hennes hverdag?

Hjelp fra kommunehelsetjenesten

- Er ordet «verdighet» noe som naturlig brukes når vi snakker om hjemmesykepleien/fastlegen?

- Hvilke tanker gjør du deg om at kvinner har en verdig avslutning på livet hjemme og samtidig mottar hjelp fra kommunal helsetjeneste?

- Kan du fortelle om en situasjon hvor du erfarte at kvinnen opplevde verdighet når hun var i kontakt med hjemmesykepleien/fastlegen?

    - Hva var det pleieren gjorde (evt. sa)?
    - Hva var det du som fastlege gjorde (evt. sa)?

- Har du erfart situasjoner der du opplevde det motsatte? – At kvinnen ikke ble møtt med verdighet?

    - Hva var det pleieren gjorde (evt. sa)?
    - Hva var det du som fastlege gjorde (evt. sa)?

- Har du opplevd situasjoner som er «nedverdigende» for kvinnen?

    - Hva gjør disse situasjonene nedverdigende?
    - Hvordan kan en bevare verdighet i nedverdigende situasjoner?
    - Hvordan ville du som fastlege kunne «forberede» kvinnen på slike situasjoner?

- Hvordan mener du at den kommunale helsetjenesten kan bidra til en verdig avslutning på livet for eldre, kreftsyke kvinner?

    - Behov?
    - Ønsker?
    - Forutsetninger?
    - Utfordringer?

- Hvilke tanker gjør du deg når en eldre kvinne blir pleietrengende og samtidig ønsker å ha en verdig tid hjemme?

    - Hva tenker du er viktig for henne i en slik situasjon?
    - Hva vil bidra til å bevare hennes verdighet i denne situasjonen, slik du tenker om det?

- Vi vet at i enkelte situasjoner blir ikke kvinner møtt med verdighet. Har du noen tanker om hva som hindrer helsepersonell i å møte disse kvinnene med verdighet?

    - Hvilke følger har dette for kvinnene, ifølge deg?
    - Hva skjer med deg når du opplever dette?
    - Hva kan fastleger gjøre for å endre dette?

Avslutning

- Hva er viktig for deg å vektlegge – i din gjerning som fastlege – for å verne om verdigheten til kreftsyke eldre kvinner som ønsker å tilbringe sin siste levetid hjemme?

    - Opplever du i din arbeidshverdag at du i tilstrekkelig grad har anledning til å rette oppmerksomheten mot disse pasientenes verdighet?
    - Har medisinen i sin grunnlagstenkning teorier, retningslinjer eller annen form for tekst nedfelt at medisinen skal bevare pasientens verdighet?

- Er det noe vi ikke har snakket om, som du mener er viktig å få frem om dette vi nå snakker om – hva som bidrar til å bevare eldre, kreftsyke kvinners verdighet, og hva som kan krenke den?

Avslutningsvis takker jeg for denne intervjusamtalen.

Appendix 7: Ethical approval from the Norwegian Social Science Data Service (NSD)

NSD Personvern

30.10.2018 14:52

Det innsendte meldeskjemaet med referansekode 138698 er nå vurdert av NSD. Følgende vurdering er gitt: Det er vår vurdering at behandlingen vil være i samsvar med personvernlovgivningen, så fremt den gjennomføres i tråd med det som er dokumentert i meldeskjemaet 30.10.2018 med vedlegg, samt i meldingsdialogen mellom innmelder og NSD. Behandlingen kan starte.

MELD ENDRINGER Dersom behandlingen av personopplysninger endrer seg, kan det være nødvendig å melde dette til NSD ved å oppdatere meldeskjemaet. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

TYPE OPPLYSNINGER OG VARIGHET Prosjektet vil behandle særlige kategorier om helseforhold og alminnelige personopplysninger frem til 12.06.2021.

LOVLIG GRUNNLAG Prosjektet vil innhente samtykke fra de registrerte (de kreftsyke, pårørende, fastleger og sykepleiere) til behandlingen av personopplysninger. Vår vurdering er at prosjektet legger opp til et samtykke i samsvar med kravene i art. 4 nr. 11 og art. 7, ved at det er en frivillig, spesifikk, informert og utvetydig bekreftelse, som kan dokumenteres, og som den registrerte kan trekke tilbake. Lovlig grunnlag for behandlingen vil dermed være den registrertes uttrykkelige samtykke, jf. personvernforordningen art. 6 nr. 1 a), jf. art. 9 nr. 2 bokstav a, jf. personopplysningsloven § 10, jf. § 9 (2).

FASTLEGENES OG SYKEPLEIERNES TAUSHETSPLIKT Vi minner om at fastleger og sykepleiere har taushetsplikt. Intervjuene med disse må derfor gjennomføres på en slik måte at det ikke fremkommer identifiserende opplysninger om enkeltpasienter eller som avslører taushetsbelagt informasjon. Vi minner om at det ikke bare er navn, men også bakgrunnsopplysinger som kan være identifiserende. Vi anbefaler at forsker minner legene om taushetsplikten før intervjuene starter.

PERSONVERNPRINSIPPER NSD finner at den planlagte behandlingen av personopplysninger vil følge prinsippene i personvernforordningen: - om lovlighet, rettferdighet og åpenhet (art. 5.1 a), ved at de registrerte får tilfredsstillende informasjon om og samtykker til behandlingen - formålsbegrensning (art. 5.1 b), ved at personopplysninger samles inn for spesifikke, uttrykkelig angitte og berettigede formål, og ikke viderebehandles til nye uforenlige formål - dataminimering (art. 5.1 c), ved at det kun behandles opplysninger som er adekvate, relevante og nødvendige for formålet med prosjektet - lagringsbegrensning (art. 5.1 e), ved at personopplysningene ikke lagres lengre enn nødvendig for å oppfylle formålet DE

REGISTRERTES RETTIGHETER Så lenge de registrerte kan identifiseres i datamaterialet vil de ha følgende rettigheter: åpenhet (art. 12), informasjon (art. 13), innsyn (art. 15), retting (art. 16), sletting (art. 17), begrensning (art. 18), underretning (art. 19), dataportabilitet (art. 20). NSD vurderer at informasjonen som de registrerte vil motta oppfyller lovens krav til form og innhold, jf. art. 12.1 og art. 13. Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har behandlingsansvarlig institusjon plikt til å svare innen en måned.

FØLG DIN INSTITUSJONS RETNINGSLINJER NSD legger til grunn at behandlingen oppfyller kravene i personvernforordningen om riktighet (art. 5.1 d), integritet og konfidensialitet (art. 5.1. f) og sikkerhet (art. 32). For å forsikre dere om at kravene oppfylles, må prosjektansvarlig følge interne retningslinjer/rådføre dere med behandlingsansvarlig institusjon.

OPPFØLGING AV PROSJEKTET NSD vil følge opp underveis (hvert annet år) og ved planlagt avslutning for å avklare om behandlingen av personopplysningene er avsluttet/pågår i tråd med den behandlingen som er dokumentert.

Lykke til med prosjektet! Kontaktperson hos NSD: Belinda Gloppen Helle Tlf. Personverntjenester: 55 58 21 17 (tast 1)

Appendix 8: Response letter from Regional Committees for Medical and Health Research Ethics (REK)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			07.09.2018	2018/1354/REK nord
			Deres dato:	**Deres referanse:**
			12.06.2018	

Vår referanse må oppgis ved alle henvendelser

Oscar Tranvåg

Institutt for global helse og samfunnsmedisin

2018/1354 Den verdige døden

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 23.08.2018. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

Forskningsansvarlig institusjon: Universitetet i Bergen

Prosjektleder: Oscar Tranvåg

Prosjektleders prosjektomtale (original):
Norske helse- og omsorgsmyndigheter vil sikre alle eldre en verdig død. Forskning viser at de fleste eldre ønsker å tilbringe sin siste levetid hjemme, og å dø i eget hjem. Kunnskap om hvilke faktorer som fremmer en verdig avslutning på livet er sparsom. Kunnskap som krenker denne pasientgruppens verdighet, er også mangelfull. Studien vil undersøke og dokumentere hvilke faktorer som fremmer en verdig avslutning på livet for hjemmeboende kreftsyke kvinner over 65 år. Hensikten med prosjektet er å utvikle ny kunnskap som kan anvendes av den palliative omsorgstjenesten i kommunene. Vi vil undersøke og dokumentere erfaringer og perspektiv hos pasienter (delstudie 1), pårørende (delstudie 2), samt hos fastleger og kreftsykepleiere i kommunehelsetjenesten (delstudie 3). Studien vil ha et kvalitativt, beskrivende og eksplorativt design, forankret i hermeneutisk metodologi. Vi vil anvende dybdeintervju og fokusgruppeintervju, samt deltagende observasjoner.

Data
Data innhentes gjennom individuelle dybdeintervju med pasienter, pårørende og fastleger, samt fokusgruppeintervju med kreftsykepleier i kommunehelsetjenesten.
Data omhandler deltakernes opplevelser og erfaringer omkring hva som fremmer versus krenker hjemmeboende eldre kvinners verdighet ved alvorlig kreftsykdom.

Framleggingsplikt
De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke. I dette prosjektet er formålet å få innsyn i deltakernes opplevelser og erfaringer omkring hva som fremmer versus krenker hjemmeboende eldre kvinners verdighet ved alvorlig kreftsykdom. Selv om dette er en helsefaglig studie og funnene i studien indirekte vil kunne gi en helsemessig gevinst faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Godkjenning fra andre instanser
Det påhviler prosjektleder å undersøke hvilke eventuelle godkjenninger som er nødvendige fra eksempelvis personvernombudet ved den aktuelle institusjon eller Norsk senter for forskningsdata (NSD).

Vedtak
Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke framleggingspliktig, jf. hfl § 2.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til: Guri.Rortveit@uib.no

Appendix 9: Information letter and informed consent – study I

Forespørsel om deltakelse i forskningsprosjektet

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til eldre kvinner med kreftsykdom som bor hjemme

Mitt navn er Katrine Staats. Jeg er kreftsykepleier og ansatt som doktorgradsstipendiat ved Universitetet i Bergen. Vi skal gjennomføre et forskningsprosjekt som skal undersøke hva som bidrar til å fremme opplevelse av verdighet hos eldre hjemmeboende kvinner med kreftsykdom. Studien vil også undersøke hva som kan bidra til å redusere opplevelsen av verdighet.

Vi henvender oss derfor til kvinner, 65 år eller eldre, som lever hjemme med kreftsykdom med en forespørsel om å delta i forskningsprosjektet. Vi vil utforske hva verdighet handler om, og hva som kjennetegner en verdig hverdag. Formålet er å oppnå kunnskap om dette som kan anvendes av helse- og omsorgstjenesten i kommunene.

Universitetet i Bergen ved Senter for alders- og sykehjemsmedisin er ansvarlig for forskningsprosjektet. Prosjektet støttes av Norske Kvinners Sanitetsforening, og finansieres av ExtraStiftelsen og Universitetet i Bergen. Resultatene vil bli formidlet i internasjonale tidsskrifter, gjennom foredrag og i media – for på denne måten å gjøre det kjent for politikere, ledere, helsepersonell og helsefagstudenter.

Hva innebærer det å delta i prosjektet?

Dersom du ønsker å delta i prosjektet innebærer dette en samtale i ditt hjem, eller et annet sted du ønsker. Samtalen er beregnet å vare i cirka halvannen time. Det er ønskelig å ta samtalen opp på lydbånd slik at den kan skrives ordrett ned som tekst. Her er noen eksempler på spørsmål jeg ønsker å stille deg:

- *Hva forbinder du med begrepet verdighet? Når opplever du at du blir behandlet med verdighet?*
- *Kan du fortelle om en slik situasjon?*
- *Er det situasjoner hvor du føler at din verdighet blir krenket?*

Etter samtalen vil jeg gi deg et skriv som omhandler en forespørsel om muligheten til å komme tilbake ved en senere anledning. Formålet vil da være å observere samhandlingen mellom din(e) pårørende, deg og helsepersonellet, for å forstå mer om hvordan verdighet og verdighetsbevarende omsorg viser seg i samhandlingen. Dersom dette ikke er ønskelig, kan du likevel delta i denne samtalen.

Mulige fordeler og ulemper

Å være deltaker i studien kan oppleves som positivt og meningsfullt. Å kunne snakke med en som er interessert i ens erfaringer, kan være en god erfaring. Opplevelsen av å bidra i utviklingen av ny viktig kunnskap, som kan komme andre til gode, kan også være givende. Noen vil imidlertid kunne oppleve samtalen som krevende – ved at en kommer inn på tema som oppleves som følsomme. Som forsker vil jeg derfor opptre med varhet overfor dette.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er selvsagt frivillig å delta i prosjektet. Dersom du ønsker å delta, ber jeg deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke tilbake ditt samtykke. Dette vil selvsagt ikke ha noen negative konsekvenser for deg. Du vil da kunne be om å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte Katrine Staats på telefon 970 19 717 eller email: katrine.staats@uib.no

Hva skjer med informasjonen om deg?

Jeg har som doktorgradsstipendiat ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Personopplysninger og innsamlede data vil bli behandlet konfidensielt. Innsamlede data vil bli lagret for seg i et låst skap, kun tilgjengelig for doktorgradsstipendiaten. Dette vil bli slettet ved prosjektslutt. Alle opplysninger som kommer frem under intervjusamtalen vil bli avidentifisert. Dette innebærer at alle direkte gjenkjennende opplysninger blir fjernet slik at det ikke er mulig å forstå at utsagn kommer fra deg. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Godkjenning

Prosjektet er godkjent av Norsk Senter for Forskningsdata (saksnummer: 138698). Dersom du har spørsmål som du ønsker å avklare før du bestemmer deg for å delta i prosjektet, vennligst ta kontakt med meg eller prosjektleder. Hvis du samtykker til å delta i studien ber jeg deg undertegne «samtykkeerklæringen» nedenfor og returnere den i vedlagte ferdig adresserte og frankerte konvolutt. Når jeg mottar samtykkeerklæringen vil jeg ta kontakt for å avtale tid og sted for intervjusamtalen.

Med vennlig hilsen

Katrine Staats

Doktorgradsstipendiat
Senter for Alders- og sykehjemsmedisin
Institutt for global helse og samfunnsmedisin
Det medisinske fakultet
Universitet i Bergen
Email: katrine.staats@uib.no
Telefon: 97019717

Oscar Tranvåg

Postdoktor og prosjektleder
Senter for alders- og sykehjemsmedisin
Institutt for global helse og samfunnsmedisin
Det medisinske fakultet
Universitetet i Bergen
Email: oscar.tranvag@uib.no
Telefon: 55 58 61 19 / 92 23 00 18

Samtykke til deltakelse i prosjektet

Jeg samtykker til å delta i samtale med doktorgradsstipendiat Katrine Staats i forbindelse med prosjektet «Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner». Jeg er kjent med hva prosjektet går ut på og at jeg kan trekke meg fra prosjektet når som helst.

Sted og dato	Deltakers signatur
Telefon	Deltagers navn med blokkbokstaver

Appendix 10: Information letter and informed consent – study II

Forespørsel om deltakelse i forskningsprosjektet

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til pårørende til eldre kvinner med kreftsykdom som bor hjemme

Mitt navn er Katrine Staats. Jeg er kreftsykepleier og ansatt som doktorgradsstipendiat ved Universitetet i Bergen. Vi skal gjennomføre et forskningsprosjekt som skal undersøke hva som bidrar til å fremme opplevelse av verdighet hos eldre hjemmeboende kvinner med kreftsykdom. Studien vil også undersøke hva som kan bidra til å redusere opplevelsen av verdighet.

Vi henvender oss derfor til pårørende til en kvinnelig kreftpasient med en forespørsel om å delta i dette forskningsprosjektet. Kvinnen er 65 år eller eldre, har en kreftsykdom og er hjemmeboende. Vi vil utforske hva verdighet innebærer for din kone/mor/søster/venninne, og hva som kjennetegner en verdig hverdag for deg som pårørende. Formålet er å bidra til økt kunnskap om verdighetsbevarende omsorg som senere kan anvendes av helse- og omsorgstjenesten i kommunene.

Universitetet i Bergen ved Senter for alders- og sykehjemsmedisin er ansvarlig for forskningsprosjektet. Prosjektet støttes av Norske Kvinners Sanitetsforening, og finansieres av ExtraStiftelsen og Universitetet i Bergen. Resultatene vil bli formidlet i internasjonale tidsskrifter, gjennom foredrag og i media – for på denne måten å gjøre det kjent for politikere, ledere, helsepersonell og helsefagstudenter.

Hva innebærer det å delta i prosjektet?

Dersom du ønsker å delta i prosjektet innebærer dette en samtale i ditt hjem, eller et annet sted som du ønsker. Samtalen er beregnet å vare i cirka halvannen time. Det er ønskelig å ta samtalen opp på lydbånd slik at den kan skrives ordrett ned som tekst. Her er noen eksempler på spørsmål jeg ønsker å stille deg:

- *Hva forbinder du med begrepet verdighet?*
- *Når opplever du at din kone/mor/søster/venninne blir behandlet med verdighet?*
- *Kan du fortelle om en slik situasjon?*
- *Er det situasjoner hvor du føler at hennes verdighet blir krenket?*

Etter samtalen vil jeg gi deg et skriv som omhandler en forespørsel om muligheten til å komme tilbake ved en senere anledning. Formålet vil da være å observere samhandlingen mellom din(e) pårørende, deg og helsepersonellet, for å forstå mer om hvordan verdighet og verdighetsbevarende omsorg viser seg i samhandlingen. Dersom dette ikke er ønskelig, kan du likevel delta i denne samtalen.

Mulige fordeler og ulemper

Å være deltaker i studien kan oppleves som positivt og meningsfullt. Å kunne snakke med en som er interessert i ens erfaringer, kan være en god erfaring. Opplevelsen av å bidra i utviklingen av ny viktig kunnskap, som kan komme andre til gode, kan også være givende. Noen vil imidlertid kunne oppleve samtalen som krevende – ved at en kommer inn på tema som oppleves som følsomme. Som forsker vil jeg derfor opptre med varhet overfor dette.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er selvsagt frivillig å delta i prosjektet. Dersom du ønsker å delta, ber jeg deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke tilbake ditt samtykke. Dette vil selvsagt ikke ha noen negative konsekvenser for deg. Så lenge du kan identifiseres i datamaterialet, har du rett til:

- Innsyn i hvilke personopplysninger som er registrert om deg
- Å få rettet personopplysninger om deg
- Få slettet personopplysninger om deg
- Få utlevert en kopi av dine personopplysninger (dataportabilitet)
- Å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger

Godkjenning

Vi behandler opplysninger om deg basert på ditt samtykke. På oppdrag fra UiB har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket. (saksnummer: 138698). Hvis du samtykker til å delta i studien ber jeg deg undertegne «samtykkeerklæringen» nedenfor og melde ifra til din kontaktperson eller direkte til meg. Når jeg mottar samtykkeerklæringen vil jeg ta kontakt for å avtale tid og sted for intervjusamtalen.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Oscar Tranvåg, Postdoktor og prosjektleder ved Senter for alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitetet i Bergen. Email: oscar.tranvag@uib.no Telefon: 55 58 61 19 / 92 23 00 18
- Doktorgradsstipendiat, Katrine Staats. Senter for Alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitet i Bergen. Email: katrine.staats@uib.no Telefon: 97019717
- Vårt personvernombud: Janecke Helene Veim, Seniorrådgiver, Personvernombud NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17

Med vennlig hilsen

Katrine Staats

Samtykke til deltakelse i prosjektet

Jeg samtykker til å delta i samtale med doktorgradsstipendiat Katrine Staats i forbindelse med prosjektet «Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner.» Jeg er kjent med hva prosjektet går ut på og at jeg kan trekke meg fra prosjektet når som helst.

Sted og dato	Deltakers signatur
Telefon	Deltagers navn med blokkbokstaver

Appendix 11: Information letter and informed consent – study III (CC and HCPN)

Forespørsel om deltakelse i forskningsprosjektet

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til kreftsykepleiere/palliative sykepleiere med omsorgsansvar for eldre kvinner med kreftsykdom som bor hjemme

Mitt navn er Katrine Staats. Jeg er kreftsykepleier og ansatt som doktorgradsstipendiat ved Universitetet i Bergen. Vi skal gjennomføre et forskningsprosjekt som skal undersøke hva som bidrar til å fremme opplevelse av verdighet hos eldre hjemmeboende kvinner med kreftsykdom. Studien vil også undersøke hva som kan bidra til å redusere opplevelsen av verdighet.

Vi henvender oss derfor til kreftsykepleiere som vil dele sine erfaringer rundt tema verdighet og oppfølging/behandling av hjemmeboende kvinner, 65 år eller eldre med kreftsykdom i palliativ fase. Formålet er å oppnå kunnskap om dette som kan anvendes av helse- og omsorgstjenesten i kommunene.

Universitetet i Bergen ved Senter for alders- og sykehjemsmedisin er ansvarlig for forskningsprosjektet. Prosjektet støttes av Norske Kvinners Sanitetsforening, og finansieres av ExtraStiftelsen og Universitetet i Bergen. Resultatene vil bli formidlet i internasjonale tidsskrifter, gjennom foredrag og i media – for på denne måten å gjøre det kjent for politikere, ledere, helsepersonell og helsefagstudenter.

Hva innebærer det å delta i prosjektet?

Dersom du ønsker å delta prosjektet innebærer det deltagelse i et fokusgruppeintervju med anslagsvis seks til åtte kreftsykepleiere/palliative sykepleiere. Dialogen innad i gruppen vektlegges, og temaene er knyttet til verdighet- hva som fremmer eldre kvinners opplevelse av verdighet, og hva som eventuelt krenker deres verdighet i hverdagen, slik dere erfarer det. Fokusgruppeintervjuet vil ha en tidsramme på 60-90 min. For at jeg skal kunne konsentrere meg fullt om fokusgruppeintervjuet, ønsker jeg å ta dialogen opp på lydbånd, for deretter å kunne foreta en ordrett transkribering av intervjuet. Her er noen eksempler på spørsmål jeg ønsker å stille i fokusgruppeintervjuet:

- *Hva bidrar til å bevare kreftsyke, eldre kvinners verdighet i palliativ fase slik dere erfarer dette?*
- *Kan dere fortelle om en slik situasjon?*
- *Er det situasjoner hvor dere føler at kvinnens verdighet blir krenket?*

Vi ønsker også å observere samhandlingen mellom deg, fastlege, pasient og pårørende i en hjemmesituasjon for å undersøke hva som bidrar til å fremme kvinnens verdighet i disse relasjonene. Observasjonen vil vare inntil 2 timer, ved 1 – 2 hjemmebesøk hos pasienter og deres pårørende som samtykker til dette. I vedlagte samtykkeerklæring kan du krysse av for deltagelse i intervjustudien, observasjonsstudien, eller begge.

Mulige fordeler og ulemper

Å være deltaker i studien kan oppleves som positivt og meningsfullt. Å kunne snakke med en som er interessert i ens erfaringer, kan være en god erfaring. Opplevelsen av å bidra i utviklingen av ny viktig kunnskap, som kan komme andre til gode, kan også være givende. Noen vil imidlertid kunne oppleve samtalen som krevende – ved at en kommer inn på tema som oppleves som følsomme. Som forsker vil jeg derfor opptre med varhet overfor dette.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er selvsagt frivillig å delta i prosjektet. Dersom du ønsker å delta, ber jeg deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke tilbake ditt samtykke. Dette vil selvsagt ikke ha noen negative konsekvenser for deg. Så lenge du kan identifiseres i datamaterialet, har du rett til:

- Innsyn i hvilke personopplysninger som er registrert om deg
- Å få rettet personopplysninger om deg
- Få slettet personopplysninger om deg
- Få utlevert en kopi av dine personopplysninger (dataportabilitet)
- Å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger

Godkjenning

Vi behandler opplysninger om deg basert på ditt samtykke. På oppdrag fra UiB har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket. (saksnummer: 138698). Hvis du samtykker til å delta i studien ber jeg deg undertegne «samtykkeerklæringen» nedenfor og ta den med til intervjusamtalen.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Oscar Tranvåg, Postdoktor og prosjektleder ved Senter for alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitetet i Bergen. Email: oscar.tranvag@uib.no Telefon: 55 58 61 19 / 92 23 00 18
- Doktorgradsstipendiat, Katrine Staats. Senter for Alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitet i Bergen. Email: katrine.staats@uib.no Telefon: 97019717
- Vårt personvernombud: Janecke Helene Veim, Seniorrådgiver, Personvernombud NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17

Med vennlig hilsen

Katrine Staats

Samtykke til deltakelse i prosjektet

Jeg samtykker til å delta i samtale med doktorgradsstipendiat Katrine Staats i forbindelse med prosjektet «Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner». Jeg er kjent med hva prosjektet går ut på og at jeg kan trekke meg fra prosjektet når som helst.

Sted og dato Deltakers signatur

Telefon Deltagers navn med blokkbokstaver

Jeg ønsker å delta i:

A) intervjustudien ☐

b) observasjonsstudien ☐

c) intervjustudien og observasjonsstudien ☐

1. Kjønn: ☐ Kvinne ☐ Mann

2. Alder: ________

3. Tittel: ________________________

4. Antall års erfaring: _________________

Appendix 12: Information letter and informed consent – study III (GP)

Forespørsel om deltakelse i forskningsprosjektet

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til fastleger som er ansvarlige for behandling av eldre hjemmeboende kvinner med kreftsykdom

Mitt navn er Katrine Staats. Jeg er kreftsykepleier og ansatt som doktorgradsstipendiat ved Universitetet i Bergen. Vi skal gjennomføre et forskningsprosjekt som skal undersøke hva som bidrar til å fremme opplevelse av verdighet hos eldre hjemmeboende kvinner med kreftsykdom. Studien vil også undersøke hva som kan bidra til å redusere opplevelsen av verdighet.

Vi henvender oss derfor til fastleger som vil dele sine erfaringer rundt tema verdighet og oppfølging/behandling av hjemmeboende kvinner, 65 år eller eldre med kreftsykdom i palliativ fase. Formålet er å oppnå kunnskap om dette som kan anvendes av helse- og omsorgstjenesten i kommunene.

Universitetet i Bergen ved Senter for alders- og sykehjemsmedisin er ansvarlig for forskningsprosjektet. Prosjektet støttes av Norske Kvinners Sanitetsforening, og finansieres av ExtraStiftelsen og Universitetet i Bergen. Resultatene vil bli formidlet i internasjonale tidsskrifter, gjennom foredrag og i media – for på denne måten å gjøre disse kjent for politikere, ledere, helsepersonell og helsefagstudenter.

Hva innebærer det å delta i prosjektet?

Dersom du ønsker å delta i prosjektet vil jeg komme til ditt fastlegekontor, eller annet avtalt sted, for en intervjusamtale (honorar avtales). Intervjusamtalen er beregnet å vare i cirka halvannen time. For at jeg skal kunne konsentrere meg fullt om samtalen med deg, ønsker jeg å ta intervjusamtalen opp på lydbånd, for deretter å kunne foreta en ordrett transkribering av intervjuet. Her er noen eksempler på spørsmål jeg ønsker å stille i intervjusamtalen:

- *Hva bidrar til å bevare kreftsyke, eldre kvinners verdighet i palliativ fase slik du erfarer dette som ansvarlig for den palliative omsorgen?*
- *Kan du fortelle om en slik situasjon?*
- *Er det situasjoner hvor du føler at kvinnens verdighet blir krenket?*

Vi ønsker også å observere samhandlingen mellom deg, kreftsykepleier, pasient og pårørende i en hjemmesituasjon for å undersøke hva som bidrar til å fremme kvinnens verdighet i disse relasjonene. Observasjonen vil vare inntil 2 timer, ved 1 – 2 hjemmebesøk hos pasienter og deres pårørende som samtykker til dette. I vedlagte samtykkeerklæring kan du krysse av for deltagelse i intervjustudien, observasjonsstudien, eller begge.

Mulige fordeler og ulemper

Å være deltaker i studien kan oppleves som positivt og meningsfullt. Opplevelsen av å bidra i utviklingen av ny viktig kunnskap, som kan komme andre til gode, kan også være givende. Som forsker vil jeg like fullt være oppmerksom på mitt forskningsetiske ansvar for å forebygge negative erfaringer, da noen vil kunne oppleve samtalen som krevende. Jeg vil derfor opptre med varhet overfor dette.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er selvsagt frivillig å delta i prosjektet. Dersom du ønsker å delta, ber jeg deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke tilbake ditt samtykke. Dette vil selvsagt ikke ha noen negative konsekvenser for deg. Så lenge du kan identifiseres i datamaterialet, har du rett til:

- Innsyn i hvilke personopplysninger som er registrert om deg
- Å få rettet personopplysninger om deg
- Få slettet personopplysninger om deg
- Få utlevert en kopi av dine personopplysninger (dataportabilitet)
- Å sende klage til personvernombudet eller Datatilsynet om behandlingen av dine personopplysninger

Godkjenning

Vi behandler opplysninger om deg basert på ditt samtykke. På oppdrag fra UiB har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket. (saksnummer: 138698). Hvis du samtykker til å delta i studien ber jeg deg ta kontakt med meg på mail (katrine.staats@uib.no eller tlf 97019717) så vil jeg følge opp for å avtale tid og sted for intervjusamtalen.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- Oscar Tranvåg, Postdoktor og prosjektleder ved Senter for alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitetet i Bergen. Email: oscar.tranvag@uib.no Telefon: 55 58 61 19 / 92 23 00 18
- Doktorgradsstipendiat, Katrine Staats. Senter for Alders- og sykehjemsmedisin. Institutt for global helse og samfunnsmedisin. Det medisinske fakultet. Universitet i Bergen. Email: katrine.staats@uib.no Telefon: 97019717
- Vårt personvernombud: Janecke Helene Veim, Seniorrådgiver, Personvernombud NSD – Norsk senter for forskningsdata AS, på epost (personverntjenester@nsd.no) eller telefon: 55 58 21 17

Med vennlig hilsen

Katrine Staats

Samtykke til deltakelse i prosjektet

Jeg samtykker til å delta i samtale med doktorgradsstipendiat Katrine Staats i forbindelse med prosjektet «Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner». Jeg er kjent med hva prosjektet går ut på og at jeg kan trekke meg fra prosjektet når som helst.

Jeg ønsker å delta i:

A) intervjustudien ☐

b) observasjonsstudien ☐

c) intervjustudien og observasjonsstudien ☐

Sted og dato Deltakers signatur

Telefon Deltagers navn med blokkbokstaver

Appendix 13: Information letter and informed consent – Participant observation for patients

Forespørsel om deltakelse i observasjonsstudie i forskningsprosjektet:

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til eldre kvinner med kreftsykdom som bor hjemme

Mitt navn er Katrine Staats. Jeg er kreftsykepleier og ansatt som doktorgradsstipendiat ved Universitetet i Bergen. Vi skal gjennomføre et forskningsprosjekt som skal undersøke hva som bidrar til å fremme opplevelse av verdighet hos eldre hjemmeboende kvinner med kreftsykdom. Studien vil også undersøke hva som kan bidra til å redusere opplevelsen av verdighet.

Vi henvender oss derfor til kvinner, 65 år eller eldre, som lever hjemme med kreftsykdom, med en forespørsel om å delta i forskningsprosjektet. Vi ønsker å observere samhandlingen mellom deg, dine pårørende og helsepersonellet som kommer hjem til deg, for å undersøke hva som bidrar til å fremme din verdighet i disse relasjonene. Observasjonen vil vare ca. 2 timer, og vil bli forlenget 1 – 2 ganger etter avtale med deg. Formålet er å bidra til økt kunnskap om verdighetsbevarende omsorg som senere kan anvendes av helse- og omsorgstjenesten i kommunene.

Universitetet i Bergen ved Senter for alders- og sykehjemsmedisin er ansvarlig for forskningsprosjektet. Prosjektet støttes av Norske Kvinners Sanitetsforening, og finansieres av ExtraStiftelsen og Universitetet i Bergen. Resultatene vil bli formidlet i internasjonale tidsskrifter, gjennom foredrag og i media – for på denne måten å gjøre det kjent for politikere, ledere, helsepersonell og helsefagstudenter.

Hva innebærer det å delta i prosjektet?

Dersom du ønsker å delta i prosjektet vil jeg komme hjem til deg for å være deltager i en samtale som utføres av kreftsykepleier og fastlege som har ansvar for din oppfølging. Jeg vil være en deltagende observatør under samtalen, noe som innebærer at jeg observerer samtalen og samhandlingen mellom dere, samtidig som jeg deltar ved å stille enkelte spørsmål. Her er noen eksempler på aspekter jeg ønsker å observere:

- *Hvilken atferd og hvilke holdninger er tilstede i situasjoner hvor pasientens (og pårørendes) verdighet fremmes?*
- *Hvilke atferd og hvilke holdninger er tilstede i situasjoner hvor pasientens (og pårørendes) verdighet krenkes?*
- *Hvordan kan språket skape opplevelse av verdighet hos pasienten, og hvordan kan verdighet krenkes i språket?*
-

Mulige fordeler og ulemper

Å være deltaker i studien kan oppleves som positivt og meningsfullt. Opplevelsen av å bidra i utviklingen av ny viktig kunnskap, som kan komme andre til gode, kan også være givende. Noen vil imidlertid kunne oppleve observasjonen som krevende – ved at en kommer inn på tema som oppleves som følsomme. Som forsker vil jeg derfor opptre med varhet overfor dette.

Frivillig deltakelse og mulighet for å trekke sitt samtykke

Det er selvsagt frivillig å delta i prosjektet. Dersom du ønsker å delta, ber jeg deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke tilbake ditt samtykke. Dette vil selvsagt ikke ha noen negative konsekvenser for deg. Så lenge du kan identifiseres i datamaterialet, har du rett til:

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Godkjenning

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Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

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Med vennlig hilsen

Katrine Staats

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Sted og dato	Deltakers signatur

Telefon	Deltagers navn med blokkbokstaver

Appendix 14: Information letter and informed consent – Participant observation for IC

Forespørsel om deltakelse i observasjonsstudie i forskningsprosjektet:

«Verdighetsbevarende omsorg for hjemmeboende kreftsyke eldre kvinner»

Til pårørende til eldre kvinner med kreftsykdom som bor hjemme

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Vi henvender oss derfor til pårørende til en kvinnelig kreftpasient med en forespørsel om å delta i dette forskningsprosjektet. Kvinnen er 65 år eller eldre, har en kreftsykdom og er hjemmeboende. Vi ønsker å observere hvordan samhandlingen mellom deg, din kone/mor/søster/venninne og helsepersonellet arter seg i hverdagen deres Vi vil utforske hva verdighet betyr for henne, og hva som kjennetegner en verdig hverdag for deg. Observasjonen vil vare ca. 2 timer, og vil bli forlenget 1 – 2 ganger etter avtale med deg. Formålet er å bidra til økt kunnskap om verdighetsbevarende omsorg som senere kan anvendes av helse- og omsorgstjenesten i kommunene.

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