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

Staats, Katrine; Christensen, Karen; Grov, Ellen Karine; Husebø, Bettina; Tranvåg, Oscar

Published in:
Journal of Women and Aging

DOI:
10.1080/08952841.2021.1946375

Publication date:
2022

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Staats, K., Christensen, K., Grov, E. K., Husebø, B., & Tranvåg, O. (2022). Healthcare professionals' perceptions of dignity-preserving care for older home-dwelling women with incurable cancer in Norway. *Journal of Women and Aging*, *34*(5), 567-581. https://doi.org/10.1080/08952841.2021.1946375

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain.
- You may freely distribute the URL identifying the publication in the public portal.

Take down policy
If you believe that this document breaches copyright please contact rucforsk@kb.dk providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 04. Dec. 2025

Journal of Women & Aging

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wjwa20

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

Katrine Staats, Karen Christensen, Ellen Karine Grov, Bettina S. Husebø & Oscar Tranvåg

To cite this article: Katrine Staats, Karen Christensen, Ellen Karine Grov, Bettina S. Husebø & Oscar Tranvåg (2021): Healthcare professionals' perceptions of dignity-preserving care for older home-dwelling women with incurable cancer in Norway, Journal of Women & Aging, DOI: 10.1080/08952841.2021.1946375

To link to this article: https://doi.org/10.1080/08952841.2021.1946375

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.

Published online: 19 Jul 2021.

Submit your article to this journal

Article views: 346

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=wjwa20

JOURNAL OF WOMEN & AGING
https://doi.org/10.1080/08952841.2021.1946375

Routledge
Taylor & Francis Group

OPEN ACCESS Check for updates

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

Katrine Staats[a], Karen Christensen[b,c], Ellen Karine Grov[d], Bettina S. Husebø[a], and Oscar Tranvåg[e,f]

[a]Centre for Elderly and Nursing Home Medicine, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway; [b]Department of People and Technology, Centre for Health Promotion Research, Roskilde, Denmark; [c]Department of Sociology, University of Bergen, Bergen, Norway; [d]Faculty of Health Sciences, Department of Nursing and Health Promotion, Oslo Metropolitan University, Oslo, Norway; [e]Faculty of Health and Social Sciences, Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway; [f]Norwegian Research Centre for Women's Health, Oslo University Hospital, Rikshospitalet, Norway

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

CONTACT Katrine Staats Katrine.staats@uib.no Centre for Elderly and Nursing Home Medicine, Department of Global Public Health and Primary Care, University of Bergen, Alrek Helseklynge, Årstadveien 17, Blokk D, Bergen 5018, Norway

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

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

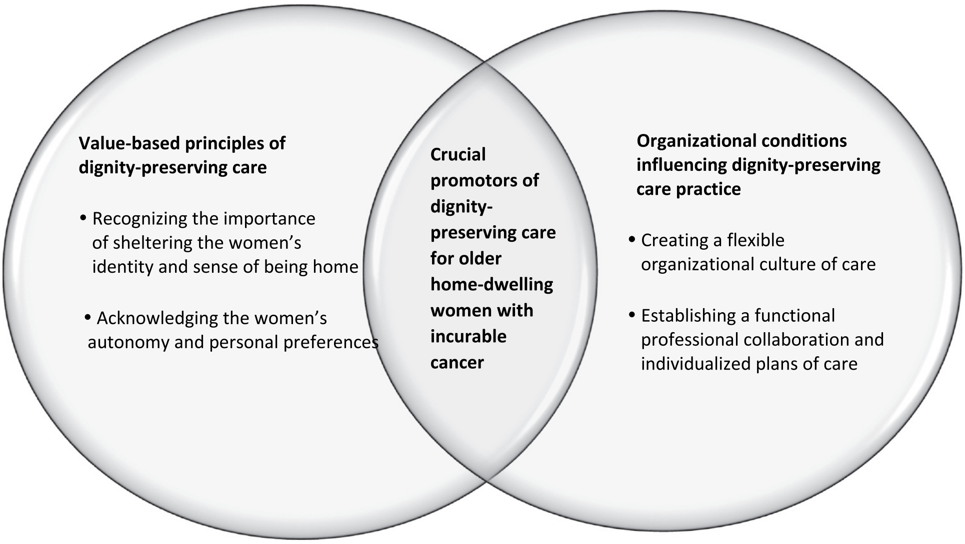

Figure 1. GPs', CCs' and HCPNs' value-based principles and organizational conditions promoting dignity-preserving care for older home-dwelling women with incurable cancer.

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.

Acknowledgments

We are grateful for the HCP's trusting engagement in sharing their perceptions, and for the valuable collaboration with representatives in our advisory board and reference group.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This research was supported by the Dam Foundation and University of Bergen.

ORCID

Katrine Staats http://orcid.org/0000-0002-0529-3303
Ellen Karine Grov http://orcid.org/0000-0002-5347-8812

Oscar Tranvåg http://orcid.org/0000-0001-9529-7879

References

The Act on medical and health research (the Health Research Act). (2008). *[Lov om medisinsk og helsefaglig forskning (helseforskningsloven)]*. Retrieved February 7, 2021, from https://www.regjeringen.no/no/dokumenter/helseforskningsloven/id570542/

Atkinson, P., & Coffey, A. (2003). Revisiting the relationship between participant observation and interviewing. In *Postmodern interviewing* (pp. 109–122). Gubrium, J.F., & Holstein, J.A. (Eds.), SAGE Publications, Inc., https://doi.org/10.4135/9781412985437

Baillie, L., Gallagher, A., & Wainwright, P. (2008). *Defending dignity in care: Challenges and opportunities for nurses.* Royal College of Nursing.

Barclay, L. (2016). In sickness and in dignity: A philosophical account of the meaning of dignity in health care. *International Journal of Nursing Studies 2016*, *61*: 136–141. https://doi.org/10.1016/j.ijnurstu.2016.06.010

Bartz, D., Chitnis, T., Kaiser, U. B., Rich-Edwards, J. W., Rexrode, K. M., Pennell, P. B., . . . Manson, J. E. (2020). Clinical advances in sex- and gender-informed medicine to improve the health of all: A review. *JAMA Internal Medicine*, *180* (4), 574–583. https://doi.org/10.1001/jamainternmed.2019.7194

Berglund, H., Dunér, A., Blomberg, S., & Kjellgren, K. (2012). Care planning at home: A way to increase the influence of older people? *International Journal of Integrated Care*, *12*(5), e134. https://doi.org/10.5334/ijic.817

Bovero, A., Sedghi, N. A., Botto, R., Tosi, C., Ieraci, V., & Torta, R. (2018). Dignity in cancer patients with a life expectancy of a few weeks. Implementation of the factor structure of the patient dignity inventory and dignity assessment for a patient-centered clinical intervention: A cross-sectional study. *Palliative and Supportive Care*, *16*(6), 648–655. https://doi.org/10.1017/s147895151700102x

Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, *68*(6), 394–424. https://doi.org/10.3322/caac.21492

Brinkmann, S. (2015). *InterViews : Learning the craft of qualitative research interviewing* (3rd ed.). Sage.

Cain, J. M., & Denny, L. (2018). Palliative care in women's cancer care: Global challenges and advances. *International Journal of Gynecology & Obstetrics*, *143*(S2), 153–158. https://doi.org/10.1002/ijgo.12624

Christensen, K. (2018). The myth of the 'Elder boom'. In Christensen & Syltevik (Eds.), *The myth of the welfare state* (pp. 75–98). Cappelen Damm Akademisk.

Christensen, K., & Wærness, K. (2021). Alderdom og ulikhet [Age and inequality]. In S. Grønmo, A. Nilsen, & K. Christensen (Eds.), *Ulikhet: Sosiologiske perspektiver og analyser* (pp. 197–219). Fagbokforlaget.

Commission for Social Care Inspection [CSCI] and Audit Commission. (2006). *Living well in later life: A review of progress against the national service framework for older people*. Commission for Healthcare Audit and Inspection.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed.). Sage.

da Rocha Rodrigues, M. G., Pautex, S., & Zumstein-Shaha, M. (2019). Revie □: An intervention promoting the dignity of individuals with advanced cancer: A feasibility study. *European Journal of Oncology Nursing*, *39*, 81–89. https://doi.org/10.1016/j.ejon.2019.01.006

Dahlberg, L., Andersson, L., McKee, K. J., & Lennartsson, C. (2015). Predictors of loneliness among older women and men in Sweden: A national longitudinal study. *Aging & Mental Health*, *19*(5), 409–417. https://doi.org/10.1080/13607863.2014.944091

Danielsen, B. V., Sand, A. M., Rosland, J. H., & Førland, O. (2018). Experiences and challenges of home care nurses and general practitioners in home-based palliative care – A qualitative study. *BMC Palliative Care*, *17*(1), 95. https://doi.org/10.1186/s12904-018-0350-0

Danielsen, H. (2009). Husmorarbeid og yrkesarbeid. [Houswife-work and employments]. In K. Christensen & L. J. Syltevik (Eds.), *Kvinners arbeid* (pp. 65–81). Unipub.

Depaola, S. J., Griffin, M., Young, J. R., & Neimeyer, R. A. (2003). Death anxiety and attitudes toward the elderly among older adults: The role of gender and ethnicity. *Death Studies*, *27*(4), 335–354. https://doi.org/10.1080/07481180302904

Eriksson, K. (1987). *Vårdandets idé. [The idea of caring]*. Almqvist & Wiksell.

Eriksson, K. (1994). *Den lidande människan. [The suffering human being]*. Liber Utbildning.

Eriksson, K. (1996). Om människans värdighet. [on human dignity]. In J. M. I. T. Bjerkreim & R. Nord (Eds.), *Visjon, viten og virke* (pp. 76–86). Universitetsforlaget.

Fillingim, R. B. (2017). Individual differences in pain: Understanding the mosaic that makes pain personal. *Pain*, *158* (Suppl 1), S11–s18. https://doi.org/10.1097/j.pain.0000000000000775

Fiva, J. H., Sørensen, R. J., & Hagen, T. P. (2014). *Kommunal organisering : Effektivitet, styring og demokrati [Municipal organization: Efficiency, steering and democracy]* (7. utg ed.). Universitetsforl.

Fjose, M., Eilertsen, G., Kirkevold, M., & Grov, E. K. (2018). 'Non-palliative care' – A qualitative study of older cancer patients' and their family members' experiences with the health care system. *BMC Health Services Research*, *18*(1), 745. https://doi.org/10.1186/s12913-018-3548-1

Fleming, V., Gaidys, U., & Robb, Y. (2003). Hermeneutic research in nursing: Developing a Gadamerian-based research method. *Nursing Inquiry*, *10*(2), 113–120. https://doi.org/10.1046/j.1440-1800.2003.00163.x

Gadamer, H.-G. 1989. *Truth and method* (2nd, rev. ed. translation revised by Joel Weinsheimer and Donald G. Marshall. ed.). Sheed & Ward.

Gallagher, A., Li, S., Wainwright, P., Jones, I. R., & Lee, D. (2008). Dignity in the care of older people – A review of the theoretical and empirical literature. *BMC Nursing*, *7*(1), 11. https://doi.org/10.1186/1472-6955-7-11

Gemmati, D., Varani, K., Bramanti, B., Piva, R., Bonaccorsi, G., Trentini, A., . . . Bellini, T. (2019). 'Bridging the gap' everything that could have been avoided if we had applied gender medicine, pharmacogenetics and personalized medicine in the gender-omics and sex-omics era. *International Journal of Molecular Sciences*, *21*(1), 296. https://doi.org/10.3390/ijms21010296

Hiles, D., & Čermák, I. (2007,July). Qualitative research: Transparency and narrative oriented inquiry. *Paper presented at the 10th European congress of psychology*, Faculty of Health and Life Sciences, De Montfort University, Leicester, UK and Institute of Psychology, Academy of Science, Brno, CZ.

Holtslander, L., & Duggleby, W. (2010). The psychosocial context of bereavement for older women who were caregivers for a spouse with advanced cancer. *Journal of Women & Aging*, *22*(2), 109. https://doi.org/10.1080/08952841003716147

Jaworska, S., & Ryan, K. (2018). Gender and the language of pain in chronic and terminal illness: A corpus-based discourse analysis of patients' narratives. *Social Science & Medicine*, *215*, 107–114. https://doi.org/10.1016/j.socscimed.2018.09.002

Johansen, M.-L., & Ervik, B. (2018). Teamwork in primary palliative care: General practitioners' and specialised oncology nurses' complementary competencies. *BMC Health Services Research*, *18*(1), 159. https://doi.org/10.1186/s12913-018-2955-7

Johnson, S. B., Butow, P. N., Bell, M. L., Detering, K., Clayton, J. M., Silvester, W., . . . Tattersall, M. H. N. (2018). A randomised controlled trial of an advance care planning intervention for patients with incurable cancer. *British Journal of Cancer*, *119*(10), 1182–1190. https://doi.org/10.1038/s41416-018-0303-7

Johnston, B., Ostlund, U., & Brown, H. (2012). Evaluation of the dignity care pathway for community nurses caring for people at the end of life. *International Journal of Palliative Nursing*, *18*(10), 483–489. https://doi.org/10.12968/ijpn.2012.18.10.483

Karlsson, V., Forsberg, A., & Bergbom, I. (2012). Communication when patients are conscious during respirator treatment – A hermeneutic observation study. *Intensive and Critical Care Nursing*, *28*(4), 197–207. https://doi.org/10.1016/j.iccn.2011.12.007

Kim, H.-I., Lim, H., & Moon, A. (2018). Sex differences in cancer: Epidemiology, genetics and therapy. *Biomolecules & Therapeutics*, *26*(4), 335–342. https://doi.org/10.4062/biomolther.2018.103

Kirchhoff, R., Bøyum-Folkeseth, L., Gjerde, I., & Aarseth, T. (2016). Samhandlingsreformen og fastlegene – Et avstandsforhold? [The competence reform and GPs – A distance relationship?]. *Tidsskrift for Omsorgsforskning*, *2*(2), 95–106. https://doi.org/10.18261/.2387-5984-2016-02-04E

Kjellevold, A., & Skippervik, L. J. B. (2020). *Retten til individuell plan: Samt koordinator, kvalifiseringsprogram og andre planverktøy* [The right to an individual plan: A coordinator, qualifyprogram and other measurments] (5 ed.). Fagbokforlaget.

Kjellstadli, C., Allore, H., Husebo, B. S., Flo, E., Sandvik, H., & Hunskaar, S. (2020). General practitioners' provision of end-of-life care and associations with dying at home: A registry-based longitudinal study. *Family Practice*, *37*(3), 340–347. https://doi.org/10.1093/fampra/cmz059

Krueger, R. A., & Casey, M. A. (2015). *Focus groups: A practical guide for applied research* (5th ed.). Sage.

Lie, N. K., Hauken, M. A., & Solvang, P. K. (2018). Providing coordinated cancer care-a qualitative study of Norwegian cancer coordinators' experiences of their role. *Cancer Nursing*, *41*(6), 463–472. https://doi.org/10.1097/ncc.0000000000000504

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry. (75)*. SAGE.

Lindstrøm, U. Å., Lindholm, L., & Zetterlund, J. E. (2018). Theory of caritative caring. In M. R. Alligood (Ed.), *Nursing theorists and their work* (9th ed., pp. 140–164). Elsevier.

Lorentsen, V. B., Nåden, D., & Sæteren, B. (2019). Understanding the meaning of the ambiguous body – A hermeneutic concept analysis of flesh and fleshly. *International Journal* of *Caring*, *12*(2), 1–10. https://www.poquest-com.pva.uib.no/docview/2303669154?pq-origsite=primo

Mann, J. (1998). Dignity and health: The UDHR's revolutionary first article. *Health and Human Rights*, *3*(2), 30–38. https://doi.org/10.2307/4065297

Måseide, P. (2011). Morality and expert systems: Problem solving in medical team meetings. *Behaviour & Information Technology: Medical Team Meetings: Utilising Technology to Enhance Communication, Collaboration and Decision-Making*, *30*(4), 525–532. https://doi.org/10.1080/0144929X.2011.553748

Miller, D., & Nevadunsky, N. (2018). Palliative care and symptom management for women with advanced ovarian cancer. *Hematology/Oncology Clinics of North America*, *32*(6), 1087–1102. https://doi.org/10.1016/j.hoc.2018.07.012

Ministry of Health and Care Services. (2008-2009). *No. 47 (2008-2009) to the storting: The coordination reform. Proper treatment – At the right place and right time*. (Retrieved February 7, 2021, from https://www.regjeringen.no/en/dokumenter/report.no.-47-to-the-storting-2008-2009/id567201/

Ministry of Health and Care Services. (2010). *Verdighetsgarantiforskriften, Forskrift om en verdig eldreomsorg (verdighetsgarantien)* [Regulation concerning dignified care for older people (The dignity guarantee)]. Retrieved February 7, 2021, from https://lovdata.no/dokument/SF/forskrift/2010-11-12-1426

Ministry of Health and Care Services. (2019-2020). *No. 24 (2019-2020) to the storting: Palliative care and treatment - Some day we will all die. But on all the other days, we will not*. Retrieved February 7, 2021, from https://www.regjeringen.no/no/dokumenter/meld.-st.-24-20192020/id2700942/

Nåden, D. (2010). Hermeneutics and observation – A discussion. *Nursing Inquiry*, *17*(1), 75–81. https://doi.org/10.1111/j.1440-1800.2009.00472.x

Nåden, D., & Eriksson, K. (2000). The phenomenon of confirmation: An aspect of nursing as an art. *International Journal of Human Caring*, *4*(3), 23–28. https://doi.org/10.20467/1091-5710.4.3.23

Persson, C., Benzein, E., & Morberg Jämterud, S. (2020). Dignity as an intersubjective phenomenon: experiences of dyads living with serious illness. *Qualitative Health Research*, *30*(13), 1989–2000. https://doi.org/10.1177/1049732320938343

Polit, D., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10 ed.). United States of America: Wolters Kluwer.

Regulations of the regular GP's scheme. (2012). *Regulations of the regular GP's scheme*. Retrieved February 7, 2021, from https://lovdata.no/dokument/SF/forskrift/2012-08-29-842-KAPITTEL_3

Rochon, P. A., Mason, R., & Gurwitz, J. H. (2020). Increasing the visibility of older women in clinical research. *Lancet*, *395*(10236), 1530–1532. 10.1016/s0140-6736(20)30849-7. https://doi.org/10.1016/S0140-6736(20)30849-7

Segev, Y., Segev, L., Schmidt, M., Auslender, R., & Lavie, O. (2017). Palliative care in ovarian carcinoma patients-a personalized approach of a team work: A review. *Archives of Gynecology and Obstetrics*, *296*(4), 691–700. https://doi.org/10.1007/s00404-017-4484-8

Spradley, J. P. (2016). *Participant observation*. Waveland Press, INC.

SSB. (2020). *Befolkningsframskrivingene [National population projections], 2020-2060. Tabell 3: Forventet levealder*. Retrieved February 7, 2021, from https://www.ssb.no/folkfram

Staats, K., Grov, E. K., Husebø, B., & Tranvåg, O. (2020a). Dignity and loss of dignity: Experiences of older women living with incurable cancer at home. *Health Care Women International 41*, 1–23. https://doi.org/10.1080/07399332.2020.1797035

Staats, K., Grov, E. K., Husebø, B., & Tranvåg, O. (2020b). Framework for patient and informal caregiver participation in research (PAICPAIR): Part 1. *Advances in Nursing Science*, *43*(2), E58–E70. https://doi.org/10.1097/ANS.0000000000000289

Svedahl, E. R., Pape, K., Toch-Marquardt, M., Skarshaug, L. J., Kaspersen, S.-L., Bjørngaard, J. H., & Austad, B. (2019). Increasing workload in Norwegian general practice – A qualitative study. *BMC Family Practice*, *20*(1), 68. https://doi.org/10.1186/s12875-019-0952-5

Torre, L. A., Islami, F., Siegel, R. L., Ward, E. M., & Jemal, A. (2017). Global cancer in women: Burden and trends. *Cancer Epidemiology Biomarkers & Prevention*, *26*(4), 444. https://doi.org/10.1158/1055-9965.EPI-16-0858

Tranvåg, O., Petersen, K. A., & Nåden, D. (2015). Relational interactions preserving dignity experience: Perceptions of persons living with dementia. *Nursing Ethics*, *22*(5), 577–593. https://doi.org/10.1177/0969733014549882

United Nations. (1948). *United nations universal declaration of human rights*. Retrieved February 7, 2021, from http://www.un.org/en/documents/udhr/

WHO. (2020). *World health organization. We are not all 'old' at the same age: Life expectancy is a policy matter*. Retrieved April 27, 2021, from https://extranet.who.int/agefriendlyworld/we-are-not-all-old-at-the-same-age-life-expectancy-is-a-policy-matter/

World Medical Association. (2013). World medical association declaration of Helsinki. *JAMA*, *310*(20)), 2191–2194. https://doi.org/10.1001/jama.2013.281053

Wright, E. M., El-Jawahri, A., Temel, J. S., Carr, A., Safren, S. A., Park, E. R., . . . Traeger, L. (2019). Patient patterns and perspectives on using opioid regimens for chronic cancer pain. *Journal of Pain and Symptom Management*, *57*(6), 1062–1070. https://doi.org/10.1016/j.jpainsymman.2019.02.023