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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 health-care 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 municipalities 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	Urban	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 Practitioner, 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 *Patient and Informal Caregiver Participation in Research* (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 group 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.	Participants 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; Poulouse 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; Poulouse 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

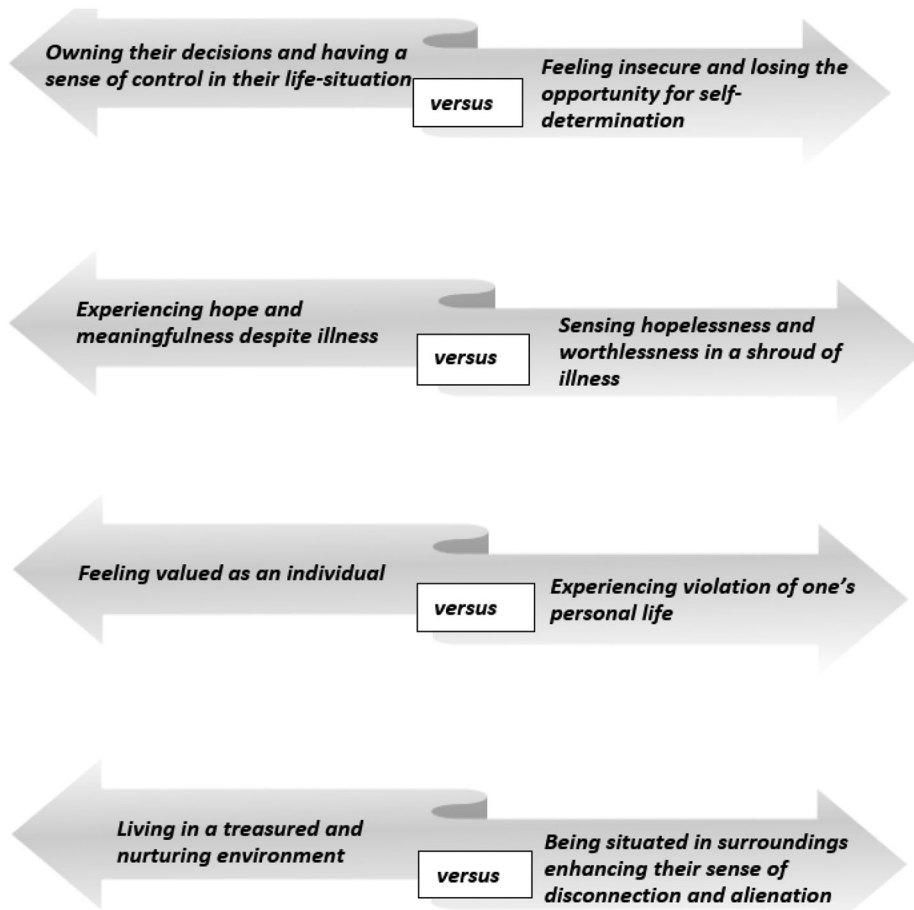


Figure 1. Dignity preservation and dignity loss—crucial dimensions as perceived by older women living with incurable cancer at home.

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

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