

Contents lists available at [SciVerse ScienceDirect](http://www.sciencedirect.com)

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway

Siri Andreassen Devik^{a,b,*}, Ingela Enmarker^{a,c}, Guri Bitnes Wiik^c, Ove Hellzèn^{a,b,c}

^a Centre for Care Research Mid-Norway, Steinkjer, Norway

^b Department of Health Sciences, Mid-Sweden University, Sundsvall, Sweden

^c Nord Trøndelag University College, Namsos, Norway

A B S T R A C T

Keywords:

Incurable cancer
Older people
Rural palliative care
Suffering
Dignity
Phenomenological hermeneutics

Purpose: The aim of this study was to explore and understand the lived experience of older people living alone and suffering from incurable cancer in rural Norway.

Methods and sample: Narrative interviews were conducted with five older people with incurable cancer (three women and two men, aged 71–79), receiving outpatient and life-prolonging chemotherapy and living alone in their homes in rural areas. A phenomenological hermeneutical approach was used to interpret the meaning of the lived experience.

Key results: Four main themes were found: enduring by keeping hope alive, becoming aware that you are on your own, living up to expectations of being a good patient and being at risk of losing one's identity and value. Enduring this situation means struggling with terminal illness and facing death in a brave manner, and replacing former ways of living. The process of providing treatment may threaten dignity and cause additional distress.

Conclusions: These results show a complex and comprehensive situation where physical symptoms and emotions are interwoven. Further the results describe how the ways of suffering caused by the manner in which care is delivered, suffering related to the cancer disease and existential suffering, may increase each other's impact. The social and rural context calls for special attention as the patients may lack resources to gain sufficient care. Their comfort depends to a large extent on the health professionals' sensitivity.

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Introduction

Given the increases in cancer risk with age, and a growing population of older persons in most western societies, the cancer burden represents a major issue for the future (Boyle and Levin, 2008). Though there have been improvements in early detection and management of cancer, many patients still have to live with incurable illness for often long period of time (Higginson and Costantini, 2008). While younger patients receive extensive tumor-related palliative treatment, older patients are more commonly treated according to their symptoms (Sigurdsson et al., 2009).

Besides the suffering caused by living with advanced cancer, aging itself presents substantial changes: Decline in functionality and co-morbidity is common, and loss of spouses and friends along

with a shifting social role may influence both adjustment and quality of life (Boyle, 1994).

While most patients want to be cared for in their own homes, the health authority in Norway aims to organize and deliver high quality care independently of where people live (Ministry of Health and Care Services, 2008–2009). Still, services taken for granted in cosmopolitan areas may be limited in rural districts (Harris et al., 2004) and specialized palliative homecare exists in varying degrees throughout Norwegian municipalities (Haugen et al., 2006). Some municipalities have ambulatory palliative care in collaboration with the local hospital; others organize their palliative care as a part of regular homecare (Eklund, 2010). Robinson et al. (2009) emphasize that research literature on rural palliative care is sparse and eclectic. Likewise, they found little evidence to inform palliative policy and service development in rural settings.

The majority of the population in remote areas tends to be older (Rygh and Hjortdahl, 2007) and the number of people with terminal illnesses, living alone without a primary caregiver is increasing (Aoun et al., 2007). Although their health care needs may

* Corresponding author. Centre for Care Research Mid-Norway, Steinkjer, Norway. Tel.: +47 74 21 23 45; fax: +47 74212301.

E-mail address: siri.a.devik@hint.no (S.A. Devik).

be significant, studies show that people living alone are less likely to reach out for or receive services (Addington-Hall and Altmann, 2000). Recently, we found that old patients with advanced cancer living alone in rural areas were featured non-complainants who demanded little, though they bore significant stress (Wiik et al., 2011). Some suggest that a prevailing rural attitude may impact service utilization: “It’s the country where you expect less and we just look after our own when we can” (Ryan, 2007, p. 4). People living in rural areas have the same medical and palliative needs as those living in urban areas, but evidence shows that they are disadvantaged when it comes to accessing palliative care services (Ryan, 2007). A major gap in the body of research is caused by the lack of any in-depth examination of the influence of place and rural culture on a palliative patient’s experience (Robinson et al., 2009).

To understand the meaning of the patient’s illness is essential when fulfilling the intention of the palliative care philosophy, which is to deliver person-centered holistic care (WHO, 2002). Thus, it is necessary to listen to those experiencing terminal illness and hear what they emphasize as they reflect on their lives. The aim of this study was therefore to explore and interpret the meaning of the lived experience of older persons receiving palliative treatment, while living alone in a rural area.

Method

A qualitative approach was chosen for this study because when studying people’s experiences and understanding about their lives and world it seems important to talk to them, with the purpose of trying to understand the world from their point of view (Patton, 2002). This method applies an inductive style, focusing on individual meaning and the importance of rendering the complexity of a situation (Creswell, 2009). Therefore, the data interpreted in this study represent personal stories about personal experiences, which should be seen as unique and never generalized.

Research context and participants

To gain knowledge of the lived experience, our sampling-strategy was based on the following criteria: people suffering from incurable cancer, aged 70 years or above, receiving outpatient treatment – life-prolonging chemotherapy and living alone in their homes in rural areas. Contact with eligible candidates was mediated through an oncologic policlinic in a local hospital in Norway. Initially, ten candidates consented to participate. For three of the patients, chemotherapy turned out to be not advisable due to their declined health conditions. The remaining seven informants were all contacted in order to decide the time and place for the interview, but two of them had to end chemotherapy before the interview took place. Hence, the final sample consisted of five patients who met the aforementioned criteria. The recruiting procedure is described in detail elsewhere (Wiik et al., 2011). The participants resided in communities (both mountain- and coastal) with low population density. The number of inhabitants ranged from 920 to 7775, and the community area ranged from 318 to 2640 km²

(Statistics Norway, 2012). Characteristics of the participants are shown in Table 1.

Data collection

The data collection was performed (by third author GBW) through narrative interviews with broad open-ended questions (Patton, 2002). The interviewees were asked to choose and speak freely about their daily life situations and how they experience them. According to Kvaale (2007) there is a mutual dependence between human interaction and production of knowledge in an interview situation. The theme was introduced in a flexible order and adjusted to the situation so that the informants were able to express the thoughts they considered important. They were asked to narrate their stories about the following themes:

- What they think is important – what gives them the strength to manage their daily lives
- Their experience of living with cancer
- Their thoughts about and experience with chemotherapy and the journeys to their treatment site and returning home

The participants were encouraged to tell about specific situations and to reflect about their emotions, thoughts, and actions (Drew, 1993). Each interview lasted 55–125 min, and was tape-recorded and transcribed verbatim.

Analysis of data

We used a phenomenological–hermeneutic approach, inspired by the philosophy of Ricœur (1976), to shed light on the informants’ lived experiences of their daily lives, while undergoing palliative chemotherapy treatment. Ricœur (1991) states that when there is a language of symbols and metaphors, there is also hermeneutics. Single acts must be seen in a relationship, and the relationship must be seen in light of the single act. The text comes with a meaning (utterance meaning), and the reader then makes the reduction and seeks his or her meaning depending on the phenomenon that is to be illuminated (utterance meaning). The method combines phenomenological philosophy with hermeneutic interpretation in a dialectic process (cf. Ricœur, 1991). It was developed for use in nursing research (Lindseth and Norberg, 2004), and has been conducted in several qualitative studies (Elofsson and Öhlén, 2004; Jakobsen and Sørli, 2010; Tranvåg and Kristoffersen, 2008). In this analysis, we sought the utterance meaning, that is, what can be deduced from the text. The analytical process was performed in three steps:

1. In the first step, a naïve reading was performed in order to formulate a preliminary interpretation of the text, from this reading a naïve understanding of the meaning of living alone with incurable cancer was formulated as a starting point for further analysis of the text.

Table 1
Characteristics of participants.

Gender	Age	Marital status	Distance from own home to hospital (km)	Travel time (one way) between home and hospital with car (min)	Mode of transportation
Female	79	Widow	120	120	Bus and train
Male	77	Unmarried	165	150	Car and boat
Female	78	Widow	170	150	Bus
Male	79	Unmarried	90	90	Car
Female	70	Widow	200	180	Bus and boat

2. The second step comprised an analysis of a number of “wild guesses” that had emerged in the naïve reading, in order to verify or deny them. This second step involved a thematic analysis. In order to expose the meaning, the text was sorted on the basis of different narrations of experiences, guided by questions such as “What situations are the informants talking about when narrating about their everyday lives as a home-living palliative patient? The text segments that expressed meaning were then condensed and arranged in themes.
3. In the third and final step, an interpreted whole was formulated based upon the naïve reading, the structural analysis (including the use of metaphors and the personal pronominal), and the authors’ pre-understanding.

The analysis was carried out by the first author (SAD). The second (IE) and fourth (OH) author read the interview transcripts, followed the path of the analysis, and discussed the validity and trustworthiness of the findings from the naïve reading to the structural analysis and finally to the interpreted whole, ensuring all the while that consensus was established. An overview of sub-themes and themes is presented in Table 2.

Ethical considerations

The regional research ethics committee of Northern-Norway approved the study (No. 4.2007.1149). The participants were informed about the purpose and procedure of the study both orally and by letter – and were assured confidential treatment. In addition, participants were informed that if telling their stories lead to any distress, they had the opportunity to talk to a psychiatrist. We received written consent from all participants.

Results

Naïve reading

Participants describe an exhaustive life, finding themselves in a conflicting state of hope and despair. Their stories reveal feelings of being on their own and having to rely on help from neighbors or relatives. The local health services are considered not useful or unavailable when needed. Experiences of being neglected and seen as a burden arise often. Some of the informants find meeting with health professionals humiliating – it gives them a sense of being of no value. It feels unfair having to fight for the right to be examined and receive treatment. The offer of chemotherapy treatment in spite of old age is considered very important. It holds hope for improvement and awakens a trust that doctors will do their best. Receiving the therapy appears to be a sign of acceptance that may restore their dignity. Nevertheless keeping this dignity demands a humble attitude and the patients do not want to complain. Organizing treatment – traveling, ordering tests and appointments –

Table 2
Overview of subthemes and themes.

Subtheme	Theme
Having confidence in the expertise at the policlinic	Enduring by keeping hope alive
Coping with conflicting feelings	
Dreaming and making plans	
Navigating alone	Becoming aware that you are on your own
Having limited control	
Avoiding becoming a burden	
Being in decline	
Losing identity	
Losing continuity	Living up to expectations of being a good patient
	Being at risk of losing identity and value

requires energy and exposes them to stress. Paradoxically, this empowerment to be in charge of their care may become a burden and even leave them with a sense of worthlessness. All the while, they have to face physical decline and a situation where end of life looms near. The preoccupation with staying alive and taking every day as it comes reduces their lives to a small world. Little energy is left for activities that earlier made life worth living.

Structural analysis

The analysis is presented in the following four themes:

- Enduring by keeping hope alive
- Becoming aware that you are on your own
- Living up to expectations of being a good patient
- Being at risk of losing identity and value

Theme: enduring by keeping hope alive

All interviewees demonstrate a strong will and hope for survival. None of them seem to have given up, and day after day is endured with impressive strength. Receiving chemotherapy appears to play the major role in keeping one’s spirit up. Although they seem to be aware that treatment cannot heal their illness, it is still perceived as an opportunity to delay death. Treatment implies an active problem-solving approach, that someone has faith and the will to help.

One of the men says:

The doctor said I could live another year if I took this poison...it’s like borrowing more time...//My mother got cancer in the stomach... she got very sick... You know, there wasn’t as much help in those days – she didn’t get any chemotherapy. It is better today...

Subtheme: having confidence in the expertise at the policlinic

Contact with health care professionals at the policlinic is highly appreciated. The informants have a common experience of being neglected and brushed aside when the first symptoms showed up. This is mainly related to the perception of general practitioners’ attitudes of indifference. Finally receiving the hospital’s competence and help inspires hope and reflects a relationship that is deeply dependent on the staff. The care provided is looked upon with gratitude and approval.

Subtheme: coping with conflicting feelings

Hope and despair pervade the patient’s experiences. They try to cope by suppressing doubts and anxiety and focus on the positive sides. There is no other way to get through it, but to carry on and take whatever comes. One woman describes it as living in a constant tension that leaves her in a position of feeling neither happy nor sad:

I really don’t know how I would react if someone told me that I had recovered. It sounds strange, but this is how it feels. All the time you go there and prepare for the worst...Yes, it is so stressful, and you become... (sighs) like that. I don’t ask so many questions, I can’t bear the negative answers, I leave that for later. Now I only want to hear positive things – it makes me stronger.

Subtheme: dreaming and making plans

Enduring also implies having dreams and planning for the future. They still engage in life, and by living as normally as possible, illusions of better days ahead are created. These illusions are grasped as opportunities and become catalysts for hope.

One man who has been fishing all his life says:

I have sold my boat, but I wish someone could take me out fishing again...It would be fun to sneak off...

Theme: becoming aware that you are on your own

The narratives reveal a lot about how older people are assumed to care for themselves. Though they are familiar with living and managing alone, their independence is potentially threatened by their illness. In some cases, maintaining autonomy encourages coping through mobilizing personal resources.

One man describes this ability with much pride:

I have been alone all my life so I'm used to taking care of myself. I travel alone to treatment of course – I'm not yet that poorly.

All informants find it difficult to ask for assistance, and the fear of causing someone inconveniences is strongly present. Even when their situation may be overwhelming, they seem reluctant to ask for help. One has temporarily moved into a neighbors' house and she is comfortable with the situation because she did not ask for it:

I presume he is fine with the arrangement. It was him that offered me to stay in his house for the winter...

Practical help is received when necessary from their families, but the informants tend to bother as less as possible. Contact with the family on the emotional level proves to be the most important.

When asked whether the polyclinic has followed up or guided their homecare they deny this or they cannot remember.

One woman says:

No they haven't asked me about that. But I have to say that I have been a bit lax...I guess, they take it for granted at the hospital, that we will manage.

Subtheme: navigating alone

Navigating through the health care system requires much energy and effort. They have to order tests and make appointments and this often takes hours to accomplish.

One woman says:

I have to order blood tests myself, it takes time when I call and only meet an answering machine...I feel that I don't have time for this...

One of the men describes his struggle with trying to solve his treatment schedule so he could manage to get back home at a reasonable time. Public-transport facilities are limited in this area. He says:

I had to go through a lot of trouble to get treatment early in the day so I can travel with the first ferry back home...Finally, they realized it from the lab and up through the system...

Theme: living up to expectations of being a good patient

Being a patient implies adjustment and entering a culture with certain expectations. Interviewees confirm a traditional power dynamic between themselves as patients and care-providers. Their thoughts reflect their obligation to be grateful and the feeling of being at the system's mercy.

Subtheme: having limited control

Lack of knowledge concerning the symptoms and progression of their disease is a common experience. They seem to know little about the effects of their chemotherapy treatment and they do not

recall much information about how to deal with it. Neither do they know how long the treatment will last or if it works. They wait and ask few questions. Additionally they have limited control over practical arrangements which often lead to long waits for a bed, a meal or a taxi home.

One woman talks about waiting and not knowing:

Sometimes I wait hours for the taxi. I can keep the bed until one o'clock. That's the worst. Not knowing. We aren't allowed to order a taxi by our self anymore. There is a person taking care of it – gathering patients to fill up the taxi...// usually I must call off the lunch because I don't know when I am to leave. So I buy a bun in the kiosk before I go home.

Subtheme: avoiding becoming a burden

Being a good patient also requires a humble and compliant behavior. Some of the informants struggle with figuring out how to please the system, as one woman states:

You can't easily reach a doctor up here. And if we call too often – it feels like we inconvenience them, and when we come to appointments they ask why we didn't come before...No it is not easy...

Community health care appears to be distant and not readily available. The system offers little help and the informants have few demands. Two of the women feel they cause inconvenience and feel guilty about receiving homecare (help with a wound and ostomy). One of them says:

Every time a new person would come, and they told me I did fine on my own. They have a long way to drive and I was told that I couldn't just call every time I needed help.

Theme: being at risk of losing identity and value

The narratives expose a shrinking-life and world, wherein dealing with alterations and loss occupies most of their energy. Feelings of being on the decline are highly present and influence their self-esteem and quality of life.

Subtheme: being in decline

All informants have physical symptoms that complicate their daily living. Their nutritional situation is poor and weight loss is tangible. Bodily changes become visible signs that only emphasize their decline.

One woman says:

I used to weigh 80 kilos, now I'm 64...My clothes don't fit me anymore...//You see, I have something on my tongue..., they (at the hospital) said it was fungus...and I don't have any appetite...the food doesn't taste anything...it's a different taste...

Subtheme: losing dignity

Contact with some health professionals gives rise to feelings of inferiority. They are met with refusal and feel they are exposed to ageism. It awakens anger and sadness. One man bitterly says:

Yes, I feel like rubbish...It's like I haven't deserved it (the treatment)// I think the doctors ought to listen more to the patients... You can't judge everybody past their seventies to be senile...//I think it's odd that they won't treat older people (angry).

The journey back home from treatment appears to be marked by having to deal with side-effects like vomiting and abdominal pain. Privacy is also limited while sitting next to others in a car, and one of the men refuses to take the taxi when it is filled up. He says:

I don't like talking to strangers...people around here is so nosy. I won't let them see me this sick...

Subtheme: losing continuity

The narratives reveal patients' mourning for their past lives. The loss of energy accompanying illness and therapy prevent them from keeping up former activities. Additionally, age itself brings functional limitations which necessitates a change in lifestyle. It seems important to highlight the person one used to be and give credit to achievements from earlier days. One of the women says:

I used to work a lot in a nursing home and I must have assembled at least 500 national costumes.

Another man talks about a life of hard work and responsibility:

I grew up on an island before the war, at the age of 14 I was treated as an adult...// I have worked hard all my life, and now I benefit from that...I was in good physical shape...

Comprehensive understanding

Our interpretation suggests that quality of life as well as life itself is at risk, for the old palliative patients who live alone in rural areas. Enduring this situation means struggling with terminal illness and facing death by being brave and replacing former ways of living. The process of providing treatment causes increased distress as maintaining dignity becomes more difficult. This is seen as a paradoxical effect as the health care system "empowers" the patient to a position of less control and cooperation. Being at the mercy of the system's schedule, indebted with gratitude, patients feel that it is hard to complain or demand adjustments. There seems to be a disparity between patients' needs and the help that is offered, or perhaps *how* it is offered.

Discussion

The aim of this study was to explore and interpret the lived experience of older people suffering from incurable cancer and living alone in a rural area. We found four themes, further broken down in subthemes that shed light on interviewee's experiences; enduring by keeping hope alive, becoming aware that you are on your own, living up to expectations of being a good patient and being at risk of losing identity and value.

Enduring by keeping hope alive. The will to live and hold on to life is strongly present in the narratives, and hope appears to be the key to endure the distress. The most important source of hope exists in having the chemotherapy. The chemotherapy is not a cure, but it can, in this case, add more days to life. Having treatment means that someone cares and something is still to be done – they are not abandoned after all. This is a clear message in all the narratives: having chemotherapy is a good thing, but what it brings also raises more uncertainty. The chemotherapy symbolizes a two edged sword; on the one hand it provides hope and trust, on the other it represent uncertainty, physical side-effects and a stressful achievement. However, sticking to hope seems to be an intentional choice, as there is no other way to make it through. Hope is present in this theme as something tangible, i.e. the hope to stay alive. This hope is not understood as death-renouncing, but rather as life-affirming, also demonstrated by Elliott and Olver (2009).

Another dimension of keeping hope alive may originate from a need to be affirmed and recognized as an equal human being, and it defies prejudices saying that life in old age has nothing more to offer. Within this meaning, hope contradicts the negative power found in the latter themes that show devaluation and examples of care that diminishes patients' dignity.

As indicated by our comprehensive understanding of the narratives, quality of life may be at risk and is contextualized in the themes: becoming aware that you are on your own, living up to expectations of being a good patient and being at risk of losing identity and value.

Health care providers possess the powerful means to either empower or discourage the patients in their care (Halldorsdottir and Hamrin, 1997) and lack of care or non-care is found to be the most frequent reason for undesirable care (Attree, 2001; Sundin, 2000). Absence of care may be demonstrated in the *awareness of being alone*. The fear of causing other people inconvenience is strongly present in our analysis. These concerns are addressed to both formal and informal helpers. Formal health care is mainly delivered by the policlinic at the hospital. Contact with general practitioners and community health care services seem to be minor. Health professionals' guidance or consultation about choices and future perspectives is hardly mentioned by our informants. Neither do they receive practical help nor advice concerning symptom control or daily-living. Their statements indicate an implied acceptance of the situation as they are told that they manage just fine on their own; moreover, it is pointed out to them that services are not available every time because they reside off the beaten track. Lack of resources (both staff and equipment) and long travels between clients are well known barriers to optimal palliative care in rural areas (Robinson et al., 2009). Research shows that cancer patients living with a caregiver receive far more health services than those living alone (Aoun et al., 2007). The assumption is that caregivers are more proactive in requesting services. In this case, our informants may be both geographically and socially disadvantaged. It is obvious that when in contact with their family and social network they wish to make a good impression and be a pleasant company. As other findings (Thomé et al. 2003), thoughts about family relationship are concerned with feelings of closeness and worry about being regarded as troublesome. They sense that giving the disease too much attention can affect social interaction along with their own self-esteem. This was also found by Kralik et al. (2004) explained as a behavior to avoid placing strain on others and to protect one's self. In most cases, the family members reside far from the informants, so the most appreciated care is just having their love and thoughtfulness. On the other hand, realizing that they are alone may have also catalyzed patient's coping abilities. Our informants show an impressive mobilization of personal strength and willpower to carry out self-care.

Patients' effort to be independent and less troublesome becomes visible in the theme of: *living up to expectations of being a good patient*. Pleasing the system and trying to fulfill what they think is expected of them can also serve as a means to maintain their dignity. According to Eriksson et al. (2006) suffering could be caused by illness, care, and life situations all of which shape meaning of being a patient. Suffering caused by care is strongly connected to the risk of violating the dignity of patients' (exemplified by Eriksson et al., 2006) as condemnation or punishment, misuse of power and absence of care. Dignity as a concept can be explained to be connected to the "human office" dealing with equality and trustworthiness (Eriksson et al., 2006). From this follows that dignity is an absolute value demonstrated through the ability to be responsible and independent. In one way, the older persons are left to control and arrange for themselves (ordering tests, appointments etc.). Although, they seem to be empowered patients, this may be only illusory. The conditions of the system are looked upon as vague and unverifiable. One example is the hospital's handling of transportation. The patients are not trusted to organize transportation by themselves, and having to sit in a taxi filled with strangers feels awful. Another issue is the long

period of waiting and not knowing what will happen next. Furthermore they do not have sufficient information about the progression of their disease or their treatment, or how to deal with side-effects. Lack of knowledge about how to handle symptoms and to understand the implications of physical complications is also found in other studies (Melin-Johansson et al., 2008; Sægrov and Halding, 2004). Even if there are acceptable reasons complicating an optimal care scenario, such messages can silence patients and lead to relinquishing of rights. Research gives reason to believe that cancer patients in general, and particularly those who are socially disadvantaged, have considerable unmet needs for both information and help with navigating their care (Carroll et al., 2010). Those researchers showed that having a trained lay-person helping the patient to facilitate care throughout the treatment period was valued as a bridge between a fragmented, poorly coordinated health care-system and the complex needs of the patients.

The last theme; *being at risk of losing identity and value* represents a further dimension of their suffering and can be discussed in the light of suffering caused by the illness which refers to experiencing bodily decline (Eriksson et al., 2006). Fatigue is the most pronounced symptom. The informants appear worn out and unable to recover between treatments. Despite problems with coping, for example problems, such as weight loss and difficulty eating, they do not call for attention or help. This result is concurrent with other studies (Kenefick, 2006; Lundh Hagelin et al., 2009) finding that patients living with their partners report significantly more symptom distress than those living alone. When sharing a household, symptoms become more obvious to others and therefore more legitimate to express? Fatigue is demonstrated to have negative influence on quality of life (Benzein and Berg, 2005; Lundh Hagelin et al., 2009) and is described as a subjective experience of physical or mental exhaustion (Ryan et al., 2007). According to Eriksson et al. (2006), physical deterioration may also give rise to feelings of guilt and shame, and these narratives shows examples of such attempts to hide one's misery. Some state their dislike of being watched and judged by other people. This may not only be a matter of escaping other peoples nosiness, it can also lead to neglecting needs for help.

Our informants' life situations are highly affected by the strain and frailty experienced due to both aging and illness. They are prevented from continuing familiar ways of living and have to reorganize activities to make their goals achievable. In many ways, this process involves putting life "on hold" – whilst waiting to see if opportunities can be revived. Some statements during the interviews give rise to doubts about whether or not the informants actually understand how sick they are. Their statements come out in contradictory meanings; on the one hand dreaming and planning as if they will recover the next day, and on the other hand, showing acceptance that death is imminent. A possible interpretation could be that surviving this conflict of feelings mirrors an individual's psychological capacity to transform reality (Baltes and Smith, 2003). Earlier studies have shed light on the remarkable ability people have to regulate the subjective impact of health-related losses (Baltes and Smith, 2003). This reaction also fits the theory of Eriksson et al. (2006) which states that the threat of destruction (also in a non-literal meaning – as not being recognized) interferes with the will to live and fight. What is conspicuous is the patient's strong need to display his/her personality acknowledging the person he/she used to be, and show that this person is still here.

Many sources of distress may not be readily visible or easily articulated by patients (Chochinov et al., 2009). The present study confirms this impression which stresses the importance of making their voices heard.

Limitations

One limitation of this study was the small number of informants. Problems with recruitment are well known in palliative research, and the population density in this context and the strict recruitment criteria may explain some of the challenges. Moreover, suffering from serious illness will affect patients both physical and physiological, which in turn could have impacted the patients' motivation to participate. Attitudes among health professionals who helped with recruiting may represent another barrier (Kleiderman et al., 2012). The ethical obligation to be cautious about causing additional distress may have led to a less persistent recruitment. Even though the informants were few, they provided information-rich narratives. The researchers still find the importance of communicating these findings justified both scientifically and ethically. Qualitative inquiry seeks to widen understanding and generalization was never the goal. The goal of this research was to gain knowledge about a lived experience of which little is known.

Our findings through this research method must be seen as a unique synthesis of what the text taught us, of what theoretical stand we took and how we integrated all of this within our own personal experience. It is also important to note that interpretations of the findings were based on the unique experiences of those who shared their personal stories.

Conclusion

The narratives in our study show a complex and comprehensive situation where physical symptoms and emotions are interwoven and how the three ways of suffering interfere with and may increase each other's impact. We found the impact of physical symptoms being overshadowed by the suffering caused by loneliness, feelings of worthlessness, and fear of becoming a burden. This lived experience imbued the need to be affirmed, appreciated and treated with respect; moreover reconciliation to life and one's own integrity, seems more important than accepting the end of life.

This analysis revealed unmet needs that are poorly flagged. The informants may have varying awareness of the needs, or difficulties expressing them, and it may even be hard to see what help there is to ask for. The results of the study highlight areas of crucial importance to the affected older patients in maintaining credible sense of self, and those charged with providing treatment and care should make attempts to learn from these individuals in this process.

What these cancer patients have shed light on through their stories may not differ in general from other patients suffering from life-threatening illnesses, but their social and rural context calls for special attention because they seem to lack resources to gain sufficient care. The patients' comfort depends to a large extent upon health professionals' sensitivities.

Conflict of interest

The authors declare that there is no conflict of interest.

Acknowledgment

We extend our thanks to the patients who shared their thoughts and reflections with us.

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