


ORIGINAL ARTICLE

'I am still valuable' – A qualitative study of incurable cancer patients coping in hospice care

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Abstract

Background: Knowledge of the experiences of coping in patients with incurable cancer is essential for high-quality palliative and end-of-life care.

Aim and Objective: To describe the coping experiences of patients with incurable cancer in hospice care to better develop patient-centred care.

Methods: The data for this qualitative study were collected through semi structured interviews, with patients with incurable cancer in hospice care ($N = 20$) and analysed with inductive content analysis. Ethical and organisational approvals were obtained, and the participants received both verbal and written information before consenting to participate.

Results: The patients' coping was enhanced with their involvement in treatment-related decisions. Valuing day-to-day living and coping with emotional stressors helped them accept their own life situations. Accepting their increasing fragility was enhanced by their self-reappraisal. The patients found security in the possibility of receiving support when they needed it. Although the ordinariness of dying in hospice care settings was sometimes too much to bear, they understood dying to be a part of the natural cycle of life. They questioned the responsiveness of healthcare services because they felt that they were not always heard.

Study Limitations: Because this study was limited to a specific population of cancer patients in hospice care, the results might not be generalised to other patient groups with chronic diseases or other palliative care settings.

Conclusions: The experiences of patients in hospice care of coping with incurable cancer were reminiscent of the common coping process descriptions. Surprisingly, even though participants voiced that they had accepted their situation, dying itself was something they did not find crucial to discuss. The crucial aspects – without being in denial – dealt more with focusing on positive thinking and facing life.

KEYWORDS

coping, hospice care, incurable cancer, inductive content analysis, patient experience, qualitative, supportive care

INTRODUCTION

Patients with incurable cancer in hospice care often experience an increasing need for support in accepting uncertainty in their everyday lives [1]. To avoid overwhelming feelings of uncertainty and develop procedures that enable the management of and coping with the disease through the whole cancer trajectory, including hospice care, it is important to identify the challenging transitions implemented in palliative care [2–5]. In this context, uncertainty may be understood as one's unknown life expectancy which may provoke different psychological reactions [6]. In particular, anxiety may occur when incurable cancer patients face a situation where their disease is progressing despite oncologic therapies and there is no predictability regarding their lives [2, 7, 8].

The World Health Organization [9] defines palliative care (including hospice care) as the active and holistic treatment of patients facing incurable or life-threatening illness-related problems, and their loved ones, by relieving suffering. [9, 10]. Incurable cancer patients coping is enhanced in situations of healthcare professionals (HCPs) having a broader perspective of illness-related issues [5]. It is worth noting that during a cancer patient's care path, their life goals [1, 11] and knowledge expectations may vary [12, 13]. Patients prefer being given reliable information face to face [5, 12, 13] but they also search for information from the internet, or the eHealth tools offered to them [5, 13].

Incurable cancer also impacts social participation and contributions. It is crucial to remember that the care offered must be tailored to the individual and that the patient needs to be amenable to the care offered. [4, 14]. Patients with incurable diseases have complex care needs. Thus, care assessments should be done comprehensively, and all HCPs should share an understanding of the disease's impact on the patient [2, 14, 15].

There is no consensus regarding the term patient-centred care (PCC), even though it has become pervasive [16]. In the hospice phase, it is crucial to clarify the patient's individual needs because not all patients die within a few weeks. Common symptoms, fatigue, and pain affect patients' functional capacity [17–20] and the patients often suffer from psychological distress, death anxiety, the inability to cope and the fear of their condition worsening in the near future [21–24]. Cancer fatigue may be persistent and affect patient's social relationships and quality of life. The situations in which patients express symptoms should be assessed and evaluated [25]. In the present study, PCC is understood as respecting the patient's wishes and expressed needs. We present the findings related to hospice care patients' experiences of their coping when living with incurable

cancer. The results provide valuable information when developing patient-centred cancer nursing and in offering patient support.

MATERIALS AND METHODS

Design

The present study has a qualitative design. The qualitative method was chosen because of the nature of the studied phenomena and to explore the experiences of this group of patients entering the last phase of their lives [26].

Settings and participants

The participants were recruited from the inpatient ward or home care of one hospice in Finland. The participants were taken care of at home or in hospice wards, per wishes. The nurses in the hospice approached patients who met the inclusion criteria to inquire about their willingness to participate. To be eligible, the patient had to be (1) diagnosed with incurable cancer, (2) over 18 years of age, (3) able to give informed consent to the study and participate in the interview, (4) referred to the hospice, (5) admitted to the hospice's ward or receiving home care by the hospice and (6) should not have been receiving oncologic therapies. A total of 20 patients were interviewed. Table 1 shows the participant characteristics.

TABLE 1 Participant characteristics.

Characteristic	Patients (n = 20)
Age: median (range)	77 (58–89)
Gender:	
Female	15 (75%)
Male	5 (25%)
Living arrangement:	
With spouse	7 (35%)
Alone with loved ones able to help	10 (50%)
Alone with no-one able to help	3 (15%)
Place of stay during interview:	
Hospice ward	9 (45%)
Hospice home care	11 (55%)
Primary tumour site:	
Breast	2 (10%)
Gastrointestinal	10 (50%)
Other	8 (40%)

Data collection

The data were collected via semi structured interviews conducted from November 2019 to March 2020 and from October 2020 to December 2020 by the first author (AV), who is an experienced cancer nurse with qualifications in palliative care and qualitative methods. The interviewer was not involved in the care of the study participants. There was a pause in the interviews because of the mandatory social distancing during the COVID-19 pandemic. The participants were interviewed once face to face at the participants' preferred location. The length of the interviews was set according to the participant's condition. They also had an opportunity to rest during the interviews. A literature-based thematic guide was followed when conducting the interviews. The topics included coping experiences during hospice care and the effects of incurable cancer on life. The interviews were audio-recorded and saved in the hospital password-protected database. The mean duration of the interview was 63 min (range 33–105 min).

Data analysis

The act of transcribing was partly analytic and enhanced the researchers' consciousness of the data [27]. The interpretation was enhanced with field notes and diary entries, which helped the interviewer re-live the interview moments. A gisted transcription was used [27, 28], in which only those contents related to the research question were transcribed. In the transcription process, all personal information was anonymised. The data underwent inductive content analysis, guided by the research objective and question. This method significantly contributed to a deeper understanding of the participants' perceptions and experiences [29, 30]. The participants' utterances deemed to describe the phenomenon were utilised as condensed meaning units of analysis and divided into subcategories and categories. Coding and categorising up to the subcategory level was carried out using the qualitative analysis software (QDAS) Atlas.ti tool [31, 32]. After this, abstraction of the data was done manually, with team review support. In examining the data, attention was paid to relevant phenomenon-related factors and similarities that emerged from the data [27]. An example of the analysis is shown in Table 2.

Ethical considerations

The current study was conducted in accordance with the Helsinki Declaration [33]. Ethical (58§ ETS R19110H) and organisational approvals were obtained. The participants

received both verbal and written information before consenting to participate, and they were informed of their right to ask questions regarding the study.

Protecting the participants was a principle that was carefully evaluated. To capture study-specific phenomena, the informants and their experiences were essential. The interviews proceeded on the terms of participants' feelings. The themes of the interview were modified by respecting the participants [33–36]. The patients' vulnerability may have been increased because of disease-related emotional issues that the participants might have had to face [37]. However, it has been shown that some participants may also benefit from interviews while being heard and getting the chance to reflect on their own stories with the interviewer [38].

RESULTS

The findings describe the coping of those patients with incurable cancer during palliative and end-of-life care, showing how the patients were being influenced by elements related to themselves and independent of them. The findings are presented in eight categories with 18 subcategories (Table 3). Quotes are referenced with 'f' for female and 'm' for male participant.

Intrinsic factors influencing individuals' coping mechanisms

Valuing day-to-day living

Cherishing life

Living everyday life according to one's own abilities and cherishing every moment enabled the participants to do what was important to them. Planning the future was possible on a minor scale regardless of their approaching death. The willingness to live in their own home was crucial, and they did everything possible within their capability to enable that. However, some participants were thinking of changing residence because of the disease situation, and some did 'death cleaning' to not leave to that chore for their loved ones. They tried to live life to the fullest and did not spend time mulling over the past. The participants were happy with the life they had lived, some even voicing that the incurable cancer may have given them more strength not to bend in the face of small adversities.

“In life, there are things for which you're able to do something, and then, there are

TABLE 2 Example of the analytical process.

Meaning units	Condensed meaning units	Subcategories	Categories
“I will die in near future even if I do not think about that all the time. I do not see life like that, that. well I should have just wait for death and be depressed. My moment is now and I will live the best out of it.”	The rest of the life is not waiting for the dying moment to happen.	Living without waiting to die	Valuing day-to-day living
“There has been a lot to think about and to handle in different phases of incurable cancer. I do not want to whinge to all the time to my spouse, it is not his fault that I have cancer.”	Own emotions are a lot to handle.	Observing own feelings	Managing emotional stressors
“Someone once said to me, that one has to understand that when it is time to die, you die. But when it is not one’s time to die, you’ll have to live your life. That is pretty much the way I think it. Dying belongs to life.”	You live when you are alive and die when you die.	Death as natural continuum of life	Accepting death as a part of life
“I voiced my thoughts that let’s stop the chemo. The doctor let me do the decision, or so I felt it. even though it was like well grounded first by doctor. Deep down I understood that this was correct decision to make. Good conversations, which helped me.”	The decision to end chemotherapy done together.	Being involved in decision-making during care	Active role in treatment decisions
“I am still the same, even though I am very sick. Cancer does not define me or what I am.”	Valuing self as sick person as much as being healthy.	Valuing self	Adapting with the deteriorating self
“I have a permission to go to hospice whenever I need to, if I cannot make it no longer at home.”	Permission to apply to hospice when needed.	Receiving help when needed	Relying on support facilities
“It is just that in hospice, when you could spend a moment in lobby, the personnel always transfer died roommates to the morgue. That is not only sad but also too much. like, you can not be without thinking that you might be next.”	The continuous presence of the death in hospice is distressing.	Facing overload of dying in hospice	Hospice-related feeling of discomfort
“I wish that they had time and they could really listen to me and my wishes. what I have to say. Like they do not hear, even they listen. They are thinking already their day forward, they do not stop.	The healthcare professionals do not see a individual behind the disease.	Lack of dialogue	Questioning the susceptibility of healthcare

this disease and dying ... You don't have the power over those. I've had a long life with my loved ones. Every day we've together is valuable.”

m17

that they were, most of the time, quite happy after all. They felt that at zest for life and trying to be humorous every now and then were supporting factors. They had small mercies because of their disease situation, such as not worrying about weight or slipping in a swearword every now and then. They felt that their waiting time was over.

Living without waiting to die

Death was not something the participants wanted to hasten, nor did they want to know the actual prognosis for the time they had left. Living day by day helped them understand

“I was thinking that because it seems that I'll after all have my 80th birthday, I'll organise a huge party, because why not. It is my money for me to spend.”

m20

Furthermore, doing enjoyable things, such as listening to books or going to the sauna, helped them not to think about their disease situation. Sleeping was also found to be enjoyable because it offered an opportunity to be free of their disease-controlled life. Discussions with others were preferred when handling issues other than the disease or dying because keeping up positive conversations and recollecting happy memories helped the participants get rid of melancholy.

Managing emotional stressors

Observing own feelings

The participants reported that their own emotions were a lot to handle sometimes. They occasionally chose the possibility of being alone with their own thoughts rather than sharing everything with others. There were situations in which it was not possible to get rid of feelings of depression. The feeling of an always present disease seemed to increase their hopelessness. However, the conflicting thoughts between lingering in sadness and then turning towards happiness finally led them to being quite satisfied with their days of reasonable well-being.

“I live now in such a phase that even if today might be a reasonable or a bad day, I underline that it is at least reasonable. And the silver lining in the cloud is that, tomorrow I might feel better.”

f7

The shock of the incurable cancer diagnosis disrupting their life was voiced. This led to the feeling of unfairness because the participants suddenly found themselves going from living a healthy life to a limited one with incurable cancer. The feeling of unbelievable shock was also related to the termination of disease-controlling therapy.

Bearing the fear of dying

The termination of disease-controlling therapy was perceived as a bridge to death. The approaching death caused fear, and it was not easy to accept or even think about it. They wished for dying itself to be as easy as possible. Reading the battle stories of celebrities was said to be annoying.

“I don't like following in the media, celebrities or actors' battle stories. I didn't have the opportunity to fight my own battle with

cancer or to choose a healthy life. I'm afraid of dying. Does that make me a loser?”

f2

Fear of dying also entailed worrying about loved ones, and it was understood as an emotional stressor. The participants understood that their loved ones did not necessarily have the strength to discuss the incurable nature of the cancer and that they were also frightened about the impending loss of their loved one.

Vanishing meaning of life

Time felt long and thoughts were heavy when their health conditions worsened. The participants lost their interest in activities, which led to the feeling of being incapable with no interest in focusing on anything new in life or investing in themselves. Life with an incurable cancer signified a new era described by a few participants as involving scheduled waiting for help from others as a bedridden patient as well as a feeling of not being as valuable as patients who were more independent. They had to accept being dependent on the help offered.

“You must be waiting for help and for heaven's sake, don't call for help when it is the nurses' report-time. They also have many other patients. They say, that I'll come as soon as I can. It feels to me that the other patient is more important than me.”

f23

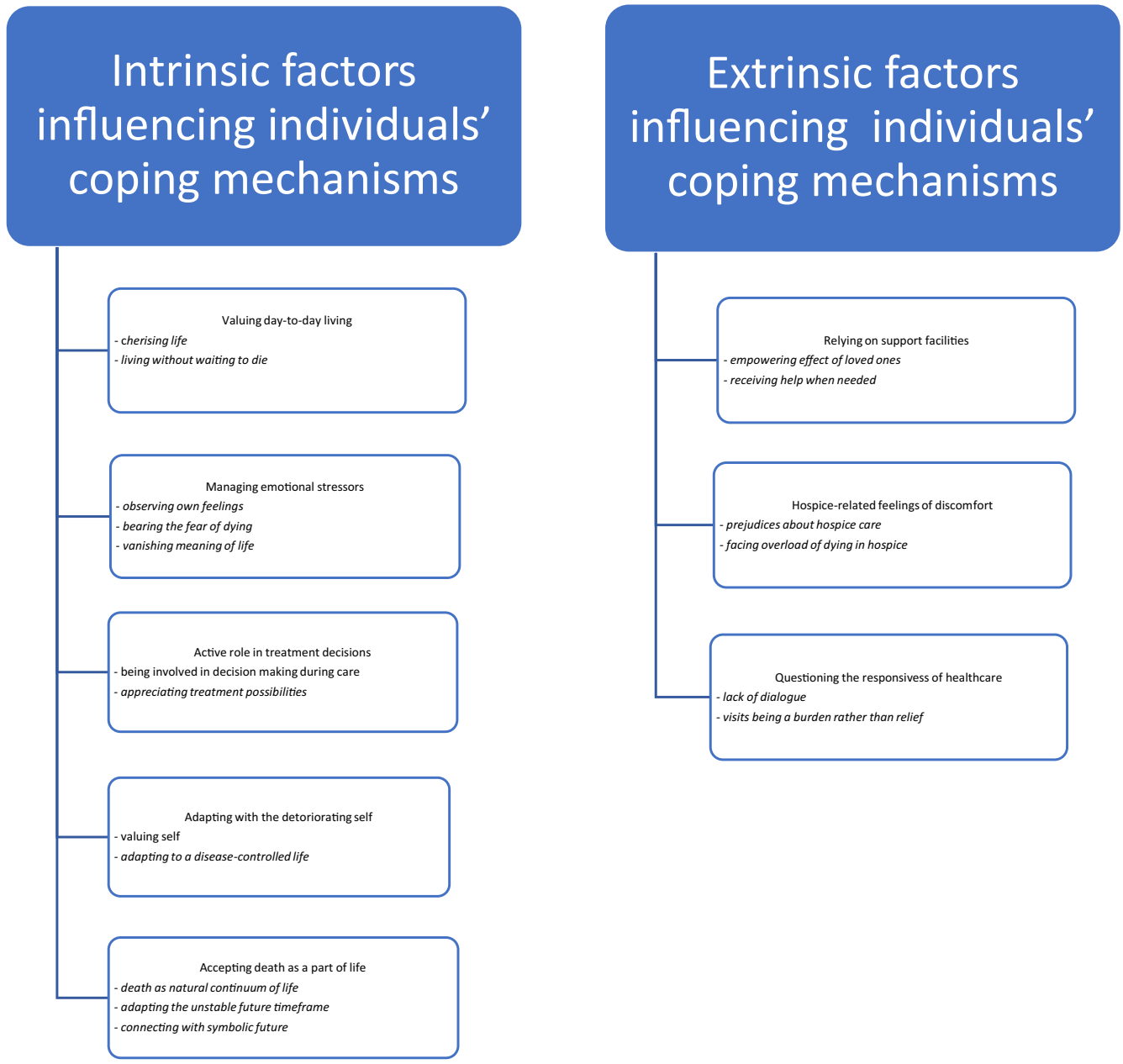
This part of their lives was characterised as being eternally tired, with sleep never taking away the tiredness or brightening them up. This inevitably led to a narrowed social sphere, which occasionally also implied, as the patients described, the unfortunate result of being lonely and feeling that life had no meaning.

Active role in treatment decisions

Involvement in decision-making during care

When involved in decision making, the participants felt that they were being heard, and they reported a good relationship with the HCPs, which also gave them a sense of security and helped them accept the distress caused by the diagnosis. The clinic visits entailed an open, transparent conversation about their disease situation, and the participants felt they were supported in facing the limited lives.

TABLE 3 Factors influencing the coping of patients with incurable cancer in hospice care settings.



“The doctor said that he'd recommend for me not to start disease-controlling chemo because of my poor physical condition. I'd feel even worse. We decided my care would be continued in hospice.”

f1

Appreciating treatment possibilities

Some of the participants experienced that their lives were longer thanks to chemotherapy. The participants trusted the HCPs. This satisfaction extended to the healthcare sector as a whole, as well as to the possibility of being accepted

as a participant in clinical studies. In independent symptom treatment, the participants valued the knowledge and guidance they had received during clinic visits, which helped them be active in their own care. Chemotherapy was described as quite demanding because of occasionally heavy side effects. After the ending of chemotherapies, the participants tended to feel better and valued the time that was now free of schedules caused by clinic visits.

“Now I've time to do what I wish without having to think of chemo-schedules. It was good that there was a chemo-option for me, but now it's used and that's it.”

f21

Adapting to the deteriorating self

Valuing self

Even while entering the last phase of their lives, the participants felt that the disease did not define them and that they still had all their dignity left. The symptom-free days helped them better cope, and they were doing everything in their power to enhance their well-being. Being seriously ill, however, did not help them grow as human beings.

“I’m not at all wiser now, nor more forgiving. Actually, quite the opposite. I mean, I didn’t grow up being a better person. Having an incurable cancer doesn’t make me a hero.”

f7

Adapting to a disease-controlled life

Resilience to adapt to a disease-controlled life was enhanced when one’s financial situation was stable. However, many participants stated that the uncertainty of life because of incurable cancer was present every day, and a few said that the life of being incurably ill felt unfair.

“I’ve had rich a life and seen a lot. However, I feel like I have not seen anything. Like, being here and thinking about my life with ups and downs and all the people in it. It motivates me to be, instead of former me of being ambitious, proud ... I’m an ordinary person and a result of my life. Here and now. Take it or leave it.”

f1

Their worsening health condition was annoying, and the limitations of endurance were difficult to acknowledge. The majority of the participants discussed the limited possibility of being independent leading to their own existence seeming to be more fragile. Some said that the symptoms decrease their own possibilities to cope with the incurable cancer, leading to less night-time sleep, a loss of appetite and being labelled a sick person.

Accepting death as a part of life

Death as a natural continuum of life

The older participants believed that it was only natural to leave life behind when they were old. The younger

participants experienced incurable cancer as something to live through as part of life. There was no possibility of choosing their diagnosis outcomes, and they experienced that thinking about it was useless. This was understood as having a realistic understanding of life as a whole, as defined by destiny.

“When you’re aged, it might help you cope with the disease. Like you’re ready for changes in life. You also understand it better that dying is not something you’re able to bargain with.”

f10

The participants tried to solve discrepancies in their social relations. Succeeding in this aim helped them to find peace with themselves, allowing for even the possibility to make plans for their own funerals, such as voicing their wishes to loved ones. For some participants religion offered the strength to accept one’s own situation. A few also said that relying on life in heaven after death and religious mercy helped them cope.

Adapting the unstable future timeframe

Coping with the thought of time running out was demanding and the participants felt unable to make plans for the future because of their varying conditions of well-being. Normal daily living stopped in these situations when the participant was facing their ever-changing expectations of the goals they had set for the rest of their limited lives. Previous cancer care histories enhanced the ability to cope with incurable cancer. As time went by, the participants learned to live with incurable cancer-focused life and accepting the disease situation enabled them to move on in life. The hospice day care centre visits offered peer support.

“I don’t do plans for the future, or dying. I cannot do that, because if I did, it doesn’t apply. The future changes day by day.”

f14

Connecting with the symbolic future

Life after death was something that the participants occasionally thought about. The finality of death felt bad to think about, and it was comforting to rely on the hope that life would continue in some form.

“I’ve been thinking of life in heaven is dying the end of everything. It gives me hope to

have faith that there might be something more to come who knows.”

f1

The participants understood that their lives would continue in their loved ones. They also planned to leave their mark by writing a diary or notes of their lives. The memories and feelings of time spent together with loved ones were cherished. Not having a common future with loved ones was considered very sad.

Extrinsic factors influencing individuals' coping mechanisms

Relying on different support facilities

Empowering effect of loved ones

Important support in coping with incurable cancer was received from loved ones. The participants were empowered by family and friends from whom they received joy. The participants who were living with their spouse also mentioned that the relationship was valuable. Love and respect in an intimate relationship also allowed them to plan the rest of their lives together.

“Maybe it's because we've had such a long life together that we know and understand what we're thinking before it's said out loud. It helps.”

f15

Receiving help when needed

Most of the participants felt that the help they received enabled them to stay at home longer. Some said that they would not be able to stay at home at all if they did not have home care or loved ones. Moreover, the possibility of applying to the hospice ward if needed increased their sense of security. When they had regular episodes in the hospice ward, they described those incidents as feeling cared for and therefore having the possibility to rehabilitate to a condition that was manageable at home.

“It's good that they (home care and loved ones) allow me to do my things myself as long as possible. Having the knowledge of the possibility of applying to hospice whenever gives me so much security. I'll get help if I need it.”

m13

Hospice-related feelings of discomfort

Prejudices towards hospice care

Although dying was understood as natural, the participants had prejudices about hospice care. They would have preferred more time in familiarising themselves with the idea of the end of hospital visits and the care continuing in hospice. This prejudice mainly entailed the thought of the hospice being a place to die in a week or two.

“There was such a rush with transferring my care to hospice. They could've just said to me that when I want to, I can contact hospice. But it all had to happen on the same day. My mind didn't keep up with that and I felt that hospital doctors wanted to get rid of me.”

f4

Facing the overload of dying in hospice

Many of the participants voiced that in hospice, they had to face too much death. The ever-present presence of death was too distressing. Dying as such an everyday occasion in the hospice gave the participants a sense of insecurity. They had to face the knowledge of being on the last leg of their lives with no way out every day. It was like standing in the final position before death, waiting at its doorstep.

“I don't like seeing nurses transferring dead people from patient rooms to the chapel. And then the candlelight every day in the corridor just as reminding us that we're dying soon.”

f15

Questioning the responsiveness of healthcare

Lack of dialogue

Although most of the participants appreciated the treatment possibilities and care offered, they concurrently felt that they were not heard. To clarify, the participants were able to recognise the different actors in cancer care and common experiences were that once they referred to palliative care or to the hospice, dialogue became better. Despite this, some of them felt that they were invisible behind the illness. A few also experienced that their wishes and preferences were neither sought nor heard. Some of the participants also voiced that the HCPs were

not emphatic, they were too outspoken, and the different specialties in hospital organisations did not have dialogue among themselves to act in the best interest of the patient.

“Hospital and hospice staff don't always understand that there's no one way fits for all in offering the care.”

m13

Visits being a burden rather than a relief

A few of the participants voiced, that continuous visits to the hospital and meeting different oncologists each time were burdensome and stressed them because they had to be aware of what kind of bad news they would get. Some of the participants also perceived themselves as a burden to the HCPs. Therefore, they chose not to speak their minds during hospital visits, which led to a situation in which they did not prefer to have an active role in treatment-related decision making. They also felt that the diagnosis was not discussed directly and that they had to read between the lines to understand it. Moreover, it was emphasised that the decision to end the treatment could have been made earlier. This led to questioning not only the healthcare services' shortcomings but also the treatment-related decisions made.

“I had metastases everywhere and still they needed a biopsy. What's the point in taking it? The doctor should've have understood this. He consulted someone and biopsy wasn't taken.”

f24

DISCUSSION

The participants' coping was influenced by both intrinsic and extrinsic factors. Intrinsic factors, such as valuing their day-to-day living and accepting their impending death, showed that the participants used different coping strategies, such as focusing on positive sides of life and avoiding of negative issues. Avoidance did not mean denial; they accepted their situation and were realistic about it. This finding is in line with those of Nipp et al. [39] and Liao et al. [40]. In addition, according to our study and previous studies, coping was increased in situations where the participants had an active role in treatment-related decision making and where their opinions were valued. They felt like they were part of the team, playing on the same side as the HCPs [41–43]. It has also been shown in previous studies and further supported by the present study that increasing the active role of patients and offering more

care-related information decreases uncertainty and adds positivity [42, 44–46].

Notably, the participants did not find it essential to talk about death and dying. In line with Gorp et al. [47] and Lindhardt et al. [48] the participants experienced increasing fragility and had to manage the emotional stressors that were considered negative. As in other studies, some of the participants described life as meaningless, and living a reduced life sometimes made them feel less valuable than when they were in a better condition and independent. However, they tried their best to adapt to the deteriorating selves. This led to an understanding that they still had dignity and that they wanted to be acknowledged as vital and living [47, 49]. In these situations, they trusted the extrinsic factors influencing their coping and were confident that they would be helped if needed. In addition, they strongly relied on the support of loved ones. Similar findings have emerged in previous studies on patients with incurable cancer [5, 50, 51].

The participants in the present study sometimes felt invisible in the hospital or hospice settings. This is a worrying trend, that has not been previously reported to the best of our knowledge. They had feelings of discomfort related to hospice care, and they even questioned the HCPs' shortcomings in caring for patients with incurable cancer. Here the HCPs should increase their competence and monitor patients regularly to determine how they are coping. There are several patient-reported outcome tools that may be used in monitoring unmet needs in palliative care [24] and in hospice care [39, 52, 53]. In line with previous studies, our results have highlighted that a dialogue between patients and HCPs was often lacking, and the patients took this to mean that they were not being heard [54–56]. Even though the participants valued treatment and care, the communication itself needed to be better. Mead and Bower have described one of the PCC framework dimensions to be patient-as-person [56]. PCC may not be conceptualised solely based on patient experience because, then, the organisations might lose focus on other PCC key components, such as care integration and coordination [16]. However, in PCC communication is essential because there may be a significant difference between what is important for patients and what professionals assume is important. Indeed, respectfully listening to patients must be at the core of care in hospice, which is recommended by Gonella et al. [57] and is regarded to be of utmost importance by the participants in our study.

Strengths and limitations

By interviewing patients with incurable cancer, the unique experiences from the subjective perspective of this

patient subgroup were investigated, which was a major strength. Other strengths of the current study included the inclusion of patients with different types of cancer and the use of interviews as a data collection method. The interviews were carried out by a specialist cancer nurse with expertise in palliative care, which promoted trustworthiness. The interviews took place either in the participants' homes or in the hospice, facilitating genuine interactions between the participants and interviewer.

Credibility was increased by using the participants' direct quotations in reporting the results. Transferability of the results was enhanced by establishing the participants' characteristics. Dependability was confirmed by aligning the research aim and inclusion criteria and providing details of the data collection and analysis. Confirmability was increased by reflection on the analysis process and data abstraction between the authors [58, 59]. Using QDAS can increase the quality of analysis by increasing the accuracy, consistency and transparency [31, 32]. The inductive analysis allowed for capturing the key concepts driving the relationship between patients' experiences of their coping with incurable cancer [29, 30].

As with other qualitative studies, the limitations were related to the generalisability of the results. However, the present study provides insights into important aspects when improving PCC. Our results cannot be generalised to patients with chronic diseases other than cancer (e.g., ALS, Alzheimer's) because disease trajectories differ significantly. Nevertheless, we are convinced that our study provides important clinical implications that may also be transferable to other chronic diseases. In addition, because the current study was conducted only among patients taken care of by a hospice, our findings may not be fully generalised to patients in other settings of palliative care [58, 59].

CONCLUSION

The present study extends the knowledge and enriches the limited literature concerning the experiences of coping among hospice patients suffering from incurable cancer. The results have shown that mainly their coping was emotion focused, which may be understood as human beings' ability to cope with even the hardest situations in life. Quite surprisingly, even though most of the participants stated that they had accepted their situation, death and dying was something they did not find important to discuss often. The more valuable issues for them — without actually being in denial —delt more with focusing on positive thinking and facing life and not thinking of death. The participants presented multiple forms of coping. This provides directions for future studies in the

end-of-life care field and for interventions to improve the patients' well-being. The field of end-of-life expertise will also benefit from examining how the early integration of palliative care for patients with any incurable disease influences their coping strategies over the course of their illness.

AUTHOR CONTRIBUTIONS

AV conceived and designed the study, undertook data collection and analysis, and wrote, revised, and finalised the paper. PÅ-K and MP checked the coding of the analysis and PÅ-K, JTL and MP supervised the study, advised on study design and conceptually commented on and revised the article. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICAL APPROVAL

This study was approved by the independent local Regional Ethics Committee (58§ ETS R19110H).

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REFERENCES

1. Vaartio-Rajalin H, Huuononen T, Iire L, Jekunen A, Leino-Kilpi H, Minn H, et al. Development of an inter-professional screening instrument for cancer patients' education process. *Appl Nurs Res.* 2016;29:248–53.
2. Madsen R, Uhrenfeldt L, Birkelund R. Transition experiences during courses of incurable cancer from the perspective of patients. *Eur J Oncol Nurs.* 2019;38:13–20.
3. Lazarus RS, Folkman S. *Stress, appraisal and coping.* New York: Springer Publishing Company; 1984.
4. Surakka T, Mattila KP, Åstedt-Kurki P, Kaunonen M. Palliatiivinen hoitotyö: parantumattomasti sairas ja hänen

- perheensä. Palliative nursing; the incurably ill patient and patient's family. Helsinki: Fioca; 2015.
5. Viitala A, Saukkonen M, Lehto JT, Palonen M, Åstedt-Kurki P. The coping and support needs of incurable cancer patients. *J Hosp Palliat Nurs*. 2018;20(2):187–94.
 6. Mishel MH. Reconceptualization of the uncertainty in illness theory. *J Nurs Scholars*. 1990;22(4):256–62.
 7. Bužgová R, Jarošová D, Hajnová E. Assessing anxiety and depression with respect to the quality of life in cancer inpatients receiving palliative care. *Eur J Oncol Nurs*. 2015;19(6):667–72.
 8. Mishel MH. Uncertainty in illness. *J Nurs Scholars*. 1988;20(4):225–32.
 9. World Health Organization (2020) Palliative Care. WHO. [Palliative Care\(who.int\)](https://www.who.int/palliative). (last assessed 28 July 2022).
 10. Twycross RG. *Introducing palliative care*. Abingdon, Oxon, U.K.: Radcliffe Medical Press; 2003.
 11. Glasdam S, Bjerström C, Engberg de Carvalho C. Coping strategies among patients with malignant lymphoma – a qualitative study from the perspectives of Swedish patients. *Eur J Oncol Nurs*. 2020;44:101693.
 12. Fliedner M, Zambrano S, Schols JMGA, Bakitas M, Lohrmann C, Halfens RJG, et al. An early palliative care intervention can be confronting but reassuring: a qualitative study on the experiences of patients with advanced cancer. *Palliat Med*. 2019;33(7):783–92.
 13. Haase KR, Drury A, Puts M. Supportive care and eHealth: a narrative review of technologies, interventions, and opportunities for optimizing care in patients with cancer. *Clin J Oncol Nurs*. 2020;24:32–41.
 14. Kuluski K, Ho JW, Hans PK, Nelson MLA. Community care for people with complex care needs: bridging the gap between health and social care. *Int J Integr Care*. 2017;17(4):2.
 15. Sander R. A long-term approach is needed to ensure the well-being of older adults with cancer. *Nurs Older People*. 2018;30(1):11.
 16. Fix GM, VanDeusen LC, Bolton RE, Hill JN, Mueller N, LaVela SL, et al. Patient-centred care is a way of doing things: how healthcare employees conceptualize patient-centred care. *Health Expect*. 2018;21(1):300–7.
 17. Li B, Mah K, Swami N, Pope A, Hannon B, Lo C, et al. Symptom assessment in patients with advanced cancer: are the most severe symptoms the most bothersome? *J Palliat Med*. 2019;22(10):1252–9.
 18. Henson LA, Maddocks M, Evans C, Davidson M, Hicks S, Higginson IJ. Palliative care and the management of common distressing symptoms in advanced cancer: pain, breathlessness, nausea and vomiting, and fatigue. *Clin J Oncol Nurs*. 2020;38(9):905–14.
 19. Catania G, Zanini M, Signori A, Dal Molin A, Pilastrri P, Bottino M, et al. Providing a nurse-led complex nursing INTERvention FOCused on quality of life assessment on advanced cancer patients: the INFO-QoL pilot trial. *Eur J Oncol Nurs*. 2021;52:101961.
 20. Stormoen DR, Baeksted C, Taarnhøj GA, Johansen C, Pappot H. Patient reported outcomes interfering with daily activities in prostate cancer patients receiving antineoplastic treatment. *Acta Oncol*. 2021;60(4):419–25.
 21. McQuellon RP, Duckworth KE, Campbell CR, Russell GB, Miskewicz KR, Alsobrooks A, et al. Fear of cancer recurrence, distress, depressive symptoms, and quality of life in hematopoietic stem cell transplantation patients. *J Psychosoc Oncol*. 2019;1(2):1–8.
 22. Sanchez L, Fernandez N, Calle AP, Ladera V, Casado I, Sahagun AM. Long-term treatment for emotional distress in women with breast cancer. *Eur J Oncol Nurs*. 2019;42:126–33.
 23. Thronicke A, von Trott P, Kröz M, Grah C, Matthes B, Schad F. Health-related quality of life in patients with lung cancer applying integrative oncology concepts in a certified cancer Centre. *Evid-Based Complement Altern Med (eCAM)*. 2020; 2020:1–9.
 24. Huda N, Shaw MK, Chang H-J. Psychological distress among patients with advanced cancer: a conceptual analysis. *Cancer Nurs*. 2022;45(2):E487–503.
 25. Lee G, Kim HS, Lee SW, Park YR, Kim EH, Lee B, et al. Pre-screening of patient-reported symptoms using the Edmonton symptom assessment system in outpatient palliative cancer care. *Eur J Cancer Care*. 2020;29(6):1–9.
 26. Holloway I. *Qualitative research in nursing and healthcare*. 4th ed. Chichester, England: Wiley Blackwell; 2017.
 27. Evers JC. From the past into the future. How technological developments change our ways of data collection, transcription and analysis. *Forum Qual Soc Res*. 2011;12(1). <https://doi.org/10.17169/fqs-12.1.1636>
 28. Paulus TM, Lester JN. ATLAS.ti for conversation and discourse analysis studies. *Int J Soc Res Methodol*. 2016;19(4):405–28.
 29. Kyngäs H. Inductive content analysis. In: Kyngäs H, Mikkonen K, Kääriäinen M, editors. *The application of content analysis in nursing science research*. Switzerland: Springer International Publishing; 2019. p. 13–9.
 30. Vaismoradi M, Snelgrove S. Theme in qualitative content analysis and thematic analysis. *Forum Qual Soc Res*. 2019;20(3). <https://doi.org/10.17169/fqs-20.3.3376>
 31. Friese S. *Qualitative data analysis with ATLAS.ti*. (For version 8.). 3rd ed. London: Sage; 2019.
 32. Soratto J, Pires DEP d, Friese S. Thematic content analysis using ATLAS.ti software: potentialities for researches in health. *Rev Bras Enferm*. 2020;73(3):e20190250.
 33. WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects. 2018.
 34. Aho AL, Kylmä J. Sensitiivinen tutkimus hoitotieteessä – näkökohtia tutkimusprosessin eri vaiheissa/sensitive research in nursing science – viewpoints on different phases during research process. *Hoitotiede*. 2012;24(4):271.
 35. Ivanova E. Ethical aspects of vulnerable group of patients in clinical trials. In: Getov I, editor. *Clinical trials in vulnerable populations*. Rijeka: IntechOpen; 2018 Ch. 8.
 36. Finnegan M, O'Donoghue B. Rethinking vulnerable groups in clinical research. *Ir J Psychol Med*. 2019;36(1):63–71.
 37. MacKenzie AR, Parker I. Introduction to quality issues in vulnerable populations. *J Oncol Pract*. 2015;11(3):185–6.
 38. Qu S, Dumay J. The qualitative research interview. *Qual Res Account*. 2011;14(8):238–64.
 39. Nipp RD, El-Jawahri A, Fishbein JN, Eusebio J, Stagl JM, Gallagher ER, et al. The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer*. 2016;122(13):2110–6.
 40. Liao YC, Liao WY, Sun JL, Ko JC, Yu CJ. Psychological distress and coping strategies among women with incurable lung cancer: a qualitative study. *Support Care Cancer*. 2017;26(3): 989–96.

41. Sutton E, Hackshaw-McGeagh LE, Aning J, Bahl A, Koupparis A, Persad R, et al. The provision of dietary and physical activity advice for men diagnosed with prostate cancer: a qualitative study of the experiences and views of health care professionals, patients and partners. *Cancer Causes Control*. 2017;28(4):319–29.
42. Thomas TH, Jackson VA, Carlson H, Rinaldi S, Sousa A, Hansen A, et al. Communication differences between oncologists and palliative care clinicians: a qualitative analysis of early, integrated palliative care in patients with advanced cancer. *J Palliat Med*. 2019;22(1):41–9.
43. Ozdemir S, Tian Y, Malhotra C, Harding R, Koh GCH, Kumarakulasingham NB, et al. Discordance between advanced cancer patients' perceived and preferred roles in decision making and its association with psychological distress and perceived quality of care. *Patient*. 2021;14(5):581–9.
44. Sajjadi M, Rassouli M, Abbaszadeh A, Alavi Majd H, Zendehelel K. Psychometric properties of the Persian version of the Mishel's uncertainty in illness scale in patients with cancer. *Eur J Oncol Nurs*. 2013;18(1):52–7.
45. Hagen KB, Aas T, Lode K, Gjerde J, Lien E, Kvaløy JT, et al. Illness uncertainty in breast cancer patients: validation of the 5-item short form of the Mishel uncertainty in illness scale. *Eur J Oncol Nurs*. 2014;19(2):113–9.
46. Pahlevan SS. Locus of control, quality of life, anxiety, and depression among Malaysian breast cancer patients: the mediating role of uncertainty. *Eur J Oncol Nurs*. 2017;27:28–35.
47. Van JLP G, Ebenau AF, Van der Burg S, Hasselaar J. Living and dying with incurable cancer: a qualitative study on older patients' life values and healthcare professionals' responsiveness. *BMC Palliat Care*. 2020;19(1):109.
48. Lindhardt CL, Winther SB, Pfeiffer P, Ryg J. Information provision to older patients receiving palliative chemotherapy: a quality study. *BMJ Support Palliat Care*. 2021. <https://doi.org/10.1136/bmjspcare-2021-003074>. Online ahead of print.
49. Corr CA. The 'five stages' in coping with dying and bereavement: strengths, weaknesses and some alternatives. *Mortality (Abingdon, England)*. 2019;24(4):405–17.
50. Jiang Y, Gentry AL, Pusateri M, Courtney KL. A descriptive, retrospective study of after-hours calls in hospice and palliative care. *J Hosp Palliat Nurs*. 2012;14(5):343–50.
51. Lemetti T, Partanen E, Hupli M, Haavisto E. Cancer patients' experiences of realization of relatives' participation in hospital care: a qualitative interview study. *Scand J Caring Sci*. 2021;35(3):979–87.
52. Goldberg SL, Paramanathan D, Khoury R, Patel S, Jagun D, Arunajadai S, et al. A patient-reported outcome instrument to assess symptom burden and predict survival in patients with advanced cancer: flipping the paradigm to improve timing of palliative and end-of-life discussions and reduce unwanted health care costs. *Oncologist*. 2019;24(1):76–85.
53. Rodenbach RA, Althouse AD, Schenker Y, Smith TJ, Chu E, White DB, et al. Relationships between advanced cancer patients' worry about dying and illness understanding, treatment preferences, and advance care planning. *J Pain Symptom Manage*. 2021;61(4):723–31.
54. Tulskey JA, Beach MC, Butow PN, Hickman SE, Mack JW, Morrison RS, et al. A research agenda for communication between health care professionals and patients living with serious illness. *JAMA Intern Med*. 2017;177(9):1361–6.
55. Slavova-Azmanova N, Newton JC, Hohnen H, Johnson CE, Saunders C. How communication between cancer patients and their specialists affect the quality and cost of cancer care. *Support Care Cancer*. 2019;27(12):4575–85.
56. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*. 2000;51:1087–110.
57. Gonella S, Basso I, Clari M, Dimonte V, Di Giulio P. A qualitative study of nurses' perspective about the impact of end-of-life communication on the goal of end-of-life care in nursing home. *Scand J Caring Sci*. 2021;35(2):502–11.
58. Polit D, Beck CT. *Nursing research: generating and assessing evidence for nursing practice*. 9th ed. Wolters Kluwer Health: Lippincott Williams & Wilkins, Philadelphia; 2012.
59. Thomas E, Magilvy JC. Qualitative rigor or research validity in qualitative research. *J Spec Pediatr Nurs*. 2011;16:151–5.

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