



## Transition experiences during courses of incurable cancer from the perspective of patients

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### ABSTRACT

**Purpose:** The present study explores patients' experiences of transitions during courses of incurable cancer. So far, qualitative studies have primarily contributed with insight on what it is like living with incurable cancer related to predefined areas in patients' lives. Studies rarely focus on transition experiences and none have explored patients' transition experiences throughout the course of illness. Focusing on transitions in palliative care is important as it facilitates possibilities for healthcare professionals to support patients when needed.

**Method:** Ten patients living with incurable cancer were included from a specialised palliative care team and participated in individual semi-structured interviews conducted in participants' private homes. The study takes a phenomenological-hermeneutic approach and data analysis and interpretation were inspired by the French philosopher Paul Ricoeur.

**Results:** Two main themes were identified: "Everyday life changes" and "Approaching end of life". In total, seven sub-themes were identified. Three related to the first main theme: "Normal life changes", "People changing behaviour", "Changes hurting significant others" and four related to the second main theme: "Approaching death", "Preparing for leaving", "Holding on to life" and "Connecting with places and belongings".

**Conclusion:** Patients experienced multiple transitions within their everyday lives and in the process of approaching end of life. These transitions involved experiences of both suffering and well-being.

### 1. Introduction

Incurable cancer – two words causing a life event with extensive consequences for people having this diagnosis attached to their own body. In 2015, cancer was the second leading cause of death globally and caused the death of 8.8 million people (World Health Organisation, 2018a). In Europe, more than 3.7 million people are diagnosed with cancer each year and 1.9 million persons die every year from cancer (World Health Organisation, 2018b). Evidently, this diagnosis causes devastating changes in people's lives as it threatens their body and hereby also their existence (García-Rueda et al., 2016; Madsen et al., 2018). Standing on the outside trying to understand what life is like living with incurable cancer, questions could point in various directions. How does incurable cancer influence the experience of one's own body? How does the illness affect their social lives? Does it change people's view on life and how does age influence this view? And do patterns appear within people's experiences of living with incurable

cancer? A glimpse into the world of living with incurable cancer is offered within the following citation, where a young woman - Stine - described her thoughts related to living and dying. Stine died recently from cancer at the age of 33 and the citation is from her obituary:

*"Cancer isn't necessarily a death sentence. It is a life sentence. An order to squeeze as much as possible out of every moment. My dear friend called it a forced maturing. The recognition of our transience and hereby the necessity of living life. Eagerly and undaunted. (...) You're not a dying person. Either you're alive or you're dead. I'm not saying that we're not able to or don't have to relate to death. We have to, because we're sure that one day we have to die. (...) But in my eyes – don't live as if you were already dead. (...) Life is now. Not tomorrow - not yesterday. Right now. Life is now" (Glynstrup, 2017).*

Stine's words represent one way of entering and trying to understand perspectives on what it is like living with incurable cancer. But why is it important to enter this world and explore these individual

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experiences of living? In the context of palliative care, it is important to understand patients' perspectives in order to offer the best possible treatment and care for each patient. The present study focuses on patients' experiences of transition during courses of incurable cancer. The understanding of transition is inspired by Chick's and Meleis' research (1986). They describe that transition can be a process either short or long and that transition is a movement or development involving disconnectedness to ones' familiar reference points in life. From this perspective, transition is caused by changes in a person's life and Chick and Meleis underline that transitions are perceived individually, which implies that persons react and respond with individual differences to a transition event. The ability to identify patients' transition experiences within palliative care is important as it facilitates nurses' possibility to support patients through challenging periods.

Reviewing existing qualitative studies gives insight on transition experiences from the perspective of patients. A study by Ellis et al. (2015) found that patients suffered when being faced with their own mortality, but also, this suffering altered their view on life fundamentally and made them capable of discovering what was important for them in life. As to patients' emotional reactions during illness, Esteves et al. (2015) found that patients transitioned into experiencing emotional instability, which involved emotions of fear, anger, anxiety, hopelessness and also on the contrary: acceptance, hope, a will to live and fight the disease. Furthermore, a study by Morgan et al. (2017) found that patients experienced constant transitions related to their own bodily decline, which involved their bodies becoming unfamiliar, unpredictable and vulnerable.

A study by Öhlén et al. (2013) revealed that patients experienced existential transitions related to the perception of time as they were placed within a dialectic movement between living in a waiting position and living in the present. Waiting for changes in illness, results from palliative treatment and ultimately their own death made patients transition into experiencing living in a waiting position. Whereas experiences of living in the present were possible when patients could prioritise their own interests such as spending time with family and friends or simply enjoying a favourite drink.

Moreover, a study by McTiernan and O'Connell (2015) identified that patients experienced changes within their social network as some people avoided them. These challenging transitions in patients' lives also involved observing and being involved in their own family having a hard time coping during the illness trajectory. Another perspective on altered relationships was identified within a study by Park et al. (2017). They found that patients with children under 18 years felt like bad parents because cancer made them unable to care for their children the way they used to. Some patients also felt guilt, because they would die before their children had reached adulthood. Even though patients hoped for long-time survival, they anticipatorily grieved that they would miss out on their children's future lives.

Studies have also identified patients' transition experiences related to places. Ellingsen et al. (2014) identified that some patients had difficulties finding a safe place during their illness trajectory, because they transitioned into feeling unsafe at home or being in a constant movement between different places. This left them with experiences of not belonging anywhere and this perception of being homeless affected patients existentially and made their vulnerable life situation even more challenging.

Furthermore, a study by Piredda et al. (2016) found that patients experience multiple transitions related to care dependency during hospitalisation and the perception of these differs among patients. Some had positive experiences with dependency of care as it made them feel at home and relieved to receive the needed care. Other patients perceived care dependence negatively, because they experienced challenges related to not being able to care for themselves anymore. Receiving care was also a process for patients to open themselves up towards others and surrender with trust to the hands of others.

To summarise, the presented qualitative studies often focus on

specific phenomena in patients' lives while living with incurable cancer. Hence, a study exploring patients' experiences of transitions during the course of illness has not yet been conducted. The present study strives to contribute with knowledge, which can be used in palliative care and give insight on patients' own perception of transitions during their course of illness.

## 2. Aim

The study aims to explore patients' experiences of transitions during the course of incurable cancer.

## 3. Method

This qualitative study is placed within the phenomenological hermeneutic tradition. Data was generated from individual semi-structured interviews, inspired by Kvale and Brinkmann (2009) and Fog (2004). The French philosopher Paul Ricoeur's theory of interpretation (1973, 1979, 2002a, 2002b) inspired the process of analysis and interpreting data.

### 3.1. Participants

A total of ten participants were included from a specialised palliative care team. Patients were initially informed and invited to participate by their primary nurse from this team. Participants were adults living with incurable cancer, able to speak and understand Danish, cognitively well-functioning and assessed by healthcare professionals - who were also gatekeepers (Hammersley and Atkinson, 2007) - to have the energy to participate in interviews. The participating patients were sent an information letter and if accepting to participate, they were contacted by phone and time and setting were decided. Patients suffered from seven different types of cancer and progression varied among them. Table 1 offers an overview of cancer types. Five men and five women participated and their ages ranged from 50 to 86, (mean age 68). Eight of them were living with their spouse and one also with a teenage son. Two participants were living alone. When citations are used, patients are referred to with pseudonyms.

### 3.2. Semi-structured interviews

All interviews were carried out within the private homes of participants - often around their dining table or their living room furniture. One patient was bedridden and the interview was carried out within her bedroom. Interviews were centred on participants' experiences of what it is like living with incurable cancer and their meaningful experiences of transitions during the illness trajectory. An interview-guide was developed prior to interviews in order to create a structure and examples of questions to be asked. However, being semi-structured, the interviews involved a process of being open towards the experiences of participants and hereby allowing interviews to develop. This way of conducting an interview is in accordance with Kvale and Brinkmann (2009). Also, Fog (2004) inspired the process of being aware of

**Table 1**  
Cancer types.

Cancer type	Number of patients
Bladder	1
Breast cancer	3
Lymphatic	1
Multiple myeloma	1
Prostate	2
Salivary gland	1
Unknown primary cancer	1
Sum	10

psychological processes during the interviews and seeing them as a conversation where questions appear when floating consciously during the conversation. Interviews were conducted in the period of April to June 2015 and lasted from approximately 1 to 2.5 h. All interviews were sound recorded and transcribed verbatim.

### 3.3. Ethical considerations

The study was approved by the Danish Data Protection Agency (Journal number 1-16-02-402-12).

Participants were informed orally and in writing about the study that participating was voluntary, withdrawal was possible at any time and data from each semi-structured interview would be anonymised. They signed a written informed consent before the interviews were conducted.

Additional ethical considerations in this study focused on how to invite participants as well as whom to invite and the importance of collaborating with healthcare professionals at the palliative care team in this stage, as they knew all patients. During the interviews, the first author, who conducted all interviews, was aware of the patients' well-being while talking about transitions in their illness. In total, two spouses were present during the interviews and their presence was left for participants to accept.

### 3.4. Data analysis and interpretation

Ricoeur's theory of interpretation (Ricoeur, 1973, 1979, 2002a; 2002b) was chosen to analyse data, because it guides a process of identifying themes and new meanings within a text. The application of Ricoeur's theory is inspired by Lindseth and Norberg (2004) who structured this as a process of three steps: naïve reading, structural analysis and comprehensive understanding (Lindseth and Norberg, 2004; Ricoeur, 1973, 1979, 2002a, 2002b). In the present study, the naïve reading consisted of transcribing interviews, reading them through several times and hereby getting an initial understanding of the dominating phenomena within patients' lives. The structural analysis focused on what Ricoeur describes as a texts' ability to open up a world in front of the text, where the text detaches from the author's intentions and offers new ways of interpretation and understanding. This involved a structural analysing process from "what the text says" to "what the text talks about". Also, metaphors were implemented, as Ricoeur stresses the importance of exploring metaphors because they contain a surplus of meaning and therefore are suitable for interpretation (Ricoeur, 2002b). Table 2 provides insight on the performed structural analysis. The comprehensive understanding includes a discussion where findings are compared with results from existing qualitative studies and discussed in the light of relevant theoretical perspectives. These are mainly based on central parts from the French philosopher Gabriel Marcel's theory about inter-subjectivity and changes within relationships (Knox, 2003). Also, the Danish philosopher K.E. Løgstrup's essay "The physician and death" (1993) describing different perspectives on how human beings relate to their own death is used to illuminate findings and so is Galvin and Todres' (2011, 2013) theory on existential well-being and existential suffering. Other theoretical perspectives are also included, where it is found relevant. The first author primarily conducted the analysis of

**Table 2**  
Example of the structural analysis.

"What the text says"	"What the text talks about"	"Themes and sub-themes"
"I don't like talking about death, I don't like that ... no, I prefer talking about the sun and harbour ... while I'm here, to think about those things. And let that time come by itself, but preferably without too much pain. That's how I would like it to be. Having a day in the sun and have a nice time ... but actually thinking about death ... I don't like that", (Dan).	Coping with death and existential transitions Hope related to death Ways of avoiding uncomfortable feelings related to death Finding peace in continuing normal life	Theme: "Approaching end of life" Sub-theme: "Approaching death"

**Table 3**  
Themes and subthemes.

1. Everyday life changes <ul style="list-style-type: none"> <li>- Normal life changes</li> <li>- People changing behaviour</li> <li>- Changes hurting significant others</li> </ul>
2. Approaching end of life <ul style="list-style-type: none"> <li>- Approaching death</li> <li>- Preparing for leaving</li> <li>- Holding on to life</li> <li>- Connecting with places and belongings</li> </ul>

data, supplemented with reflections from both the last and second author. Throughout the analysing process, there was awareness on the researcher's own pre-understanding in order to ensure that themes emerged from data and not the researcher's pre-suppositions.

## 4. Findings

Two main themes were identified from patients' experiences: "Everyday life changes" and "Approaching end of life". In total, seven sub-themes were identified and Table 3 offers an overview of main and sub-themes. This kind of breaking up experiences into sub-themes is done to illustrate meaning in our findings. However, in the life lived, patients' experiences are closely connected. Therefore, some phenomena are present in more than one sub-theme; however, they are approached from different perspectives within each of the sub-themes. It is important to notice that the presentation below of patients' transition experiences primarily involves using the words "challenges, coping, movement, adaptation, struggle or processes". These words are found adequate to illuminate nuances in patients' transition experiences and also in accordance with the understanding of transition described within the introduction of the present paper.

### 4.1. Everyday life changes

Patients experienced changes in everyday life in different ways. Maintaining everyday life as before incurable cancer entered their life was important for patients, but also challenging and for some patients impossible. Three subthemes were identified from patients' experiences and are presented in the sections below.

#### 4.1.1. Normal life changes

Before getting sick, patients all had an everyday life, which they referred to as normal life. It was important for them to maintain this normal life or at least elements of it. However, a large deviation was found related to this being possible or not and led to either well-being or suffering among patients. When experiencing few changes in everyday life, patients often lived with a slowly progressing incurable cancer and experienced few physical limitations. Some had also retired from work and had prior to their cancer diagnosis moved to a house or flat, which was appropriate for living in when getting old. But some experienced major changes in everyday life, as they were no longer able to live the way they normally did. For instance, when losing the ability to move freely and do everyday activities around the house due to

paralysation, force reduction or pain. But also experiences of being isolated became dominant and were perceived as a major change, when patients were not able to attend activities outside their house. For some patients, limitations also involved losing the ability to drive their own car due to medication or physical changes and this transferred them into feeling dependent on family or public transportation. Also, patients' well-being was affected negatively when changes prevented them from visiting family and friends or doing activities they used to e.g. sports, being in the nature, walking the dog, riding a motorbike or horse. For some, changes in everyday life were permanent, but could also be for a period of time. However, when happening patients had an experience of normal life disappearing. The following two citations give insight regarding the experience of transitioning into living a limited an isolated everyday life within your private home:

*"I'm in this big waiting room ... having to accept things. It started when I was told I had a bad life and that I was going to die. But I didn't want to accept it. I have so many things to do. I have to repair the outside wall on my house ... I have no strength. It is not easy living ... all the stuff I would like to have done ... painting windows ... I just feel everything is collapsing. But on the other hand, if my wife wants to sell ... break down the house, built one yourself", (Carl).*

*"All of a sudden just sitting in this room. I find that ... No, it has been hard sitting here. It really has. I cannot cope walking down the stairs. I wish they could just dump me down and pull me up again. Then you don't live well here and we have lived here for 26 years. We have a lovely garden and are allowed to have a dog. All that is important and I'm used to being an outdoor person. I really am", (Helena).*

#### 4.1.2. People changing behaviour

Some patients experienced a change in peoples' behaviour towards them when living with incurable cancer. Most of them had experiences of some people physically distancing themselves and avoiding contact - for instance by walking to the other side of the street, not visiting them anymore, not looking them in the eyes or talking to them when being together, friends not answering emails related to the severity of cancer development. These rejecting reactions from others were major changes in patients' lives and left them with experiences of being isolated, poisoned and outcasts. These changes in peoples' behaviour surprised patients and some of them experienced disappointment, anger, sadness and wonder. Furthermore, it made patients reflect on reasons why and they found answers related to for instance friends not knowing how to react and talk about the illness. Some experienced that people distancing themselves was related to incurable cancer being life threatening and potentially forcing them to confront anxiety surrounding their own death. The following citations illustrate transition experiences related to people distancing:

*"I more or less feel poisoned now, because they don't visit and if you see them, they walk the other way. Before, there were always a lot of people here. Also because I'm a mechanic, so everybody was always coming around. But now! No, nothing is happening ... they don't drop by. Because they know that I can't help them and can't do anything", (Carl).*

*"The person you have known and shared so much with is just "sticking their tail between their legs". What kind of behaviour is that? I don't know where that anxiety comes from. Actually, it is the fear of dying. I'm sure of that. It IS the fear of dying. People are so afraid of dying. It is hard being exposed to that, it really is", (Gabriella).*

#### 4.1.3. Changes hurting significant others

Some patients had experiences of hurting their significant others (SO) when involving them in their life with incurable cancer. For instance, these experiences appeared when telling their SOs they were suffering from incurable cancer. Also, the process of SOs adapting to these news or when patients were relating to their own imminent death

and hereby in the future leaving their SOs behind left patients with experiences of causing hurt. During these processes, patients perceived that SOs were reacting with sadness, anger and worry, which some patients found difficult to cope with. As a consequence, some relationships were challenged and in addition, patients were often undergoing a parallel process of adaptation themselves related to changes caused by incurable cancer. Patients' ways of handling these challenges were individual. For instance, some initially hid their problems and feelings and left other close relatives to help their SO, whereas others were talking and being honest with each other. Some experienced developing a closer relationship, but on the contrary, some distanced from each other. The process could also be an interchanging movement between these two positions and within the processes some managed to settle in a new joint way of coping together. The following citation enlightens the experience of hurting your SO:

*"Well of course it is hard on me, but I also find it hard on him (teenage son). I feel sorry for him. He doesn't have any siblings ... to do something with or talk to. But I talk with him and let him know he can come to me ... Sometimes I can tell he's thinking about it. Then he gets quiet and he is out of the house a lot. He spends time with his friends. He tells me, he is talking with them and I also think that is good for him", (Elisabeth).*

#### 4.2. Approaching end of life

Several patients experienced they were approaching what all people one day have to approach – ending life and dying. Patients hereby reflected on death being a general living condition for all people. However, when living with incurable cancer patients had an increased awareness on ending life and dying which inspired the following four sub-themes.

##### 4.2.1. Approaching death

All patients had experiences related to death and the phenomenon was addressed from different angles. When being diagnosed with cancer or incurable cancer, all patients experienced being confronted with their own imminent death. Also, when they received a terminal declaration or were assigned to a specialised palliative care team, patients often experienced being confronted with their upcoming death and were surprised and choked about facing the end of their lives earlier than expected. Patients wished to live; however, suffering could change this wish among patients having experienced severe pain for a longer period of time, where medicine or other interventions did not offer alleviation. Living became almost unbearable and therefore death was seen as a relief. But this transition of perceiving death as alleviation from suffering was ambivalent because no patients basically wished to die. Furthermore, patients described death as an unavoidable part of human life, a natural part of living. However, they related to this fact differently. Some deliberately resigned - and others resigned in periods - from thinking about or relating to death, whereas others found a need to explore death. This last group of patients' experiences were related to e.g., a patient reflecting on being buried and having difficulties imagining lying down there well knowing you are not able to feel anything. Also, patients expressed a belief in Christian resurrection or hoped for life after death. Whereas, others believed that death was the definite end of their existence. The following two citations illustrate different ways of relating to one's own death:

*"I don't like talking about death, I don't like that ... no, I prefer talking about the sun and harbour ... while I'm here, to think about those things. And let that time come by itself, but preferably without too much pain. That's how I would like it to be. Having a day in the sun and enjoying myself ... but actually thinking about death ... I don't like that", (Dan).*

*"It was so difficult for me, if life just ends ... Maybe I have got a small piece of a dream ... it is something lovely and of course I don't believe that we will live on in a physical way at all ... but I have, without being able to define it, some kind of belief that you are a part of something on a*

spiritual level. Something which is not me, but where some part of me is still living ... yes ... it has done me well, I think, to read those books (about near-death experiences)", (Gabriella).

#### 4.2.2. Preparing for leaving

Preparation was a dominant phenomenon among patients when approaching end of life. They experienced having an opportunity to prepare on both a practical and mental level before ending life. However, it was individual how much they chose to prepare. Some were detailed for instance about planning their own funeral: where the ceremony should be held, songs to be played, writing a speech, flowers and choosing a place to be buried or ashes to be spread. Patients preparing their own funeral were found to fulfil their own wishes and had a chance to say a proper goodbye to their significant others (SO). But planning one's own funeral was also meant as a helping hand to SOs in relieving them of demanding tasks at a time, where patients expected them to be in a process of bereavement. Feeling obliged to prepare on practical levels was also identified within patients' experiences related to making life easier for SOs. However, the process was in various degrees emotionally demanding on patients and in some cases too demanding and therefore, they resigned and left this to SOs. The following citation gives insight on the experience of having an opportunity to prepare:

*"We also need to have a talk about, when that time comes, how things have to be done. It is hard to talk about. But it is best for my husband that he knows how everything has to be. We have not talked about it yet, only a little. But I have to write some of it down. Because it will make it easier on them and then hopefully it will be how I wish things to be. It has to be done one of those days where you have a bit more energy. But I do have some ideas. I just have to write it down. It is hard to get it out. But it also helps talking about it. When I hear a nice song in the radio, I think: "That one has to be played in the church" and so on ... It comes quietly. But fortunately, I don't know when that time is coming and these things have to be done", (Elisabeth).*

#### 4.2.3. Holding on to life

Holding on to life was crucial to all patients and they wished to live life as long as possible and to share life with their loved ones. They strived to experience as much as possible in life and hoped for future possibilities to e.g. travel, spend time with family or experience the birth of a grandchild. The majority of patients experienced that life was going to end sooner than expected and this was a major struggle in their life as they felt disappointed and cheated. Even though they tried being realistic and tell themselves that all people die for various reasons, it was difficult to accept that this was happening to them. Some still felt that death was far off in the future, whereas others had an experience of death moving closer rapidly. Even though patients wished to hold on to life, they were willing to - or were forced to - compromise with their quality of life rather than length of life. For instance, when resigning from life-prolonging chemotherapy to avoid serious side effects and hereby suffering in life. However, others were willing to undergo another exhausting life-prolonging treatment in order to hold on to life.

Also, patients experienced an increased ability to appreciate what some of them called "small things" when approaching the end of life. It became important and of great value for them to fill life with these "small things" and likewise brought suffering in patients' lives if they, due to illness, were unable to implement these moments of joy within their lives. When talking about "small things" bringing joy, they were referring to e.g. enjoying the smell or beauty of flowers and having an increased appreciation of a summer day in the garden surrounded by plants and feeling the sunshine. Also buying seasonal fruit and enjoying their taste and freshness was among patients' experiences of appreciating small things. In the following, insight is given on the experience of enjoying "small things" in life:

*"I've been saying all along: "everything that makes me happy in life – I will do it". The physicians have also said to me: "Just do it". I care for myself a lot. I also buy myself flowers ... and yesterday my husband and I were out picking rhododendrons in a park and we took some buds ... damn, they are beautiful! The flowers were closed and look what happened after they came into the house ... I like doing those sorts of things ... having a nice time" (Flora).*

#### 4.2.4. Connecting with places and belongings

When approaching the end of life, patients also had experiences related to being connected to special places and belongings. They often transitioned into sensing a deep connection to their private home, an area in which they had lived for many years, the sea, their boat, motorbikes or other hobby objectives. It was important for them to stay connected to these places and belongings and consequently separating involved a great amount of suffering. Patients were therefore also relieved if solutions were found in order to remain e.g. in own house. They spent a lot of time worrying when reflecting on present or future threats of being disconnected from these special places and belongings. Sometimes patients resigned from separating themselves from places and belongings.

However, avoiding these adaptations resulted in some patients feeling ambivalent, as they both loved living in their house, but also felt isolated and witnessed accumulating maintenance and house decay. Others were satisfied choosing to keep e.g. their car, boat or motorbike and hereby maintain their possibility of looking at and being with these special belongings, while they cherished wonderful memories associated with them and also held on to a glimmer of hope that one day in future, they would get the strengths to use these belongings again. Another way of staying connected to special places and avoiding separation from e.g. their home was buying practical help for cleaning, keeping the garden and house. However, some did prepare and chose a new special place in case they were unable to live and end life in their private home. In such cases, hospice was mentioned, as they found that this was a homely and comfortably place to end life and patients were happy about having this possibility if needed in future.

Furthermore, patients also chose places where they wished to be buried or for their ashes to be spread. They felt a special connection to these places and it was important for them to know they would rest at this special place. In the following citations, the experiences of being connected to places and belongings are elucidated:

*"My children have promised me, that I will be burned and then I will be spread over the sea at Randers where I grew up. That thought is good for me. I feel so good about that. It is like the circle is completed. I was born in Randers and lived there till I graduated. So there is no doubt at all ... and if I have to go to hospice ... if I could have my wish fulfilled and come to the hospice near Randers. Then it would be absolutely perfect. Randers has always been the centre of my world. I have a thing with circles ... I like it when they are completed ... It gives me peace. It gives me peace. I would be so grateful, if things turned out that way", (Gabriella).*

*"I have a car, which I don't drive. It's in the garage, because I can't see properly. I open the garage door and look at the car (laughing). Then I close the door again. I can't bear selling it. I have a little motorboat down at the harbour and I've had it for many years. I can't really do without it. It is difficult getting down in and up from the boat. But I can sit on a bench and look at my boat. That little boat has given me so many memories. Soon it has to go in the water again; I'm looking forward to that. Maybe I can drink a cup of coffee, a beer or a soda on my boat. I can't really do without that boat. They have to scrap it when I'm gone. There is nothing else to do. The harbour has been my life. The water has always been my life. I have sailed from when I was a boy. My life has been on the water or near the water. So the water and the harbour mean a lot to me", (Dan).*

## 5. Comprehensive understanding and discussion

### 5.1. Types and dimensions of transitions

When reviewing the findings, it becomes clear that patients experience multiple transitions within their everyday life and in the process of approaching end of life and placed within the category, which Schumacher and Meleis (1994) define as “health-illness transitions”, because they are caused by changes from living with incurable cancer. In the light of Meleis' theory on transitions (2010), it is possible to identify that patients experience both unhealthy and healthy transitions. Unhealthy from the perspective of Meleis (2010), because they affect patients' well-being negatively e.g. losing the ability to attend activities outside their home, which left them with experiences of being isolated or experiencing difficult changes in relationships, when people are distancing themselves from them. According to Meleis, healthy transitions (2010) contribute to patients' well-being, which is also the case for some patients as they transition into experiencing appreciation for life and found joy in doing things, which previously was taken for granted. Furthermore, Chick and Meleis (1986) focus on individuality and underline that it is individual how a transition is perceived and what kind of meaning a patient applies to the experienced transition. This individuality is also dominant within our study as patients react differently on a mutual major transition – e.g. variations in patients' experiences of approaching and relating to own death. Additionally, Chick and Meleis (1986) describe how a difficult transition can be complicated when it involves several dimensions such as being unpredictable, undesired, unpleasant or having an extended duration. This increased severity of a transition is also dominant in our study e.g. when patients experience severe pain over a long period and an uncertain possibility of future alleviation. In the themes presented below, examples of both healthy and unhealthy transitions are included.

### 5.2. Transitions within relations

As described, some patients experience people distancing themselves from them. This is a major change in the patients' lives and leave them feeling isolated, poisoned and outcasts. Similar findings are identified within a study of McKechnie et al. (2007) and described as patients experiencing a “social death” when losing friends and family during an illness trajectory. Also, a study of Melin-Johansson et al. (2008) identifies related experiences and refers to these as “unintentional isolation” and McTiernan and O'Connell (2015) identify that some patients experience avoidance from people within their social network.

The French Philosopher Gabriel Marcel (1889–1973) reflects on relationships between people and describes how interpersonal relationships can be founded on openness or closure (Knox, 2003). When openness is present, the relationship is based on seeing each other as a “me and you”, meaning a personal relationship is developed and the persons respond to each other's call for openness. However, closure within a relationship involves a distancing based on seeing each other as a “you and it”, which means that the other person is objectified. In relation to closure, Marcel describes anxiety as being a potential reason for people distancing as he underlines that anxiety is compromising openness between people. When a relationship changes from being either open or closed, Marcel refers to this as a relationship changing its “ontological face”. Using this metaphor in relation to our findings, Marcel's theory offers an understanding that patients experience a change within the “ontological face” of some relationships because other people are distancing themselves and no longer respond to their call for openness. Patients' themselves explain this distancing as being evoked by people's anxiety of death, which is consistent with Marcel's thoughts of anxiety compromising openness. However, other people's

inexperience talking about death and being with a person who is living with an incurable illness may evoke anxiety and explain why people are distancing themselves.

### 5.3. Transitions when approaching end of life

Findings further show that patients have transition experiences when approaching end of life. Death becomes present and is for some patients evoked by specific events such as receiving a diagnosis of incurable cancer, terminal declaration or entering palliative care. This causes a change within patients' lives as they transition into a state of living where their awareness of death becomes dominant. In a study by McTiernan and O'Connell (2015), the change related to receiving a diagnosis of incurable cancer is described as a confrontation with one's own mortality which made some patients perceive a need to say goodbye and prepare for death. Also, a study by Ellis et al. (2015) identifies that patients experience suffering when confronted with death and mortality, and they were also affected emotionally by the anticipated loss of their loved ones.

The fact that patients transition into having increased awareness of their own death is not surprising given their life situation. However, the Danish philosopher K.E. Løgstrup (1905–1981) offers an understanding of why this changed perspective on life appears when living with a life-threatening illness (Løgstrup, 1993). Løgstrup describes how people normally live as if they are not going to die. We do so because we are able to suspend the knowledge of our own death and live life with our future wide open, because the date of death is unknown. But a change happens when a life-threatening illness enters our lives as awareness now is directed towards the knowledge of our own death. Løgstrup describes this as transitioning from living with a suspended to an unsuspended knowledge of one's own death. Taking Løgstrup's perspective, the interviews hereby reveal that patients transition into living with an unsuspended knowledge of their own death especially when they experience specific transitions within healthcare, which left them shocked and overwhelmed. Actually, Løgstrup also argues - in his description of the relationship between the physicians and patients - that physicians should have in mind that it is patients' own matter how much they relate to this knowledge of their own death as it may imply hopelessness. This leads us to another interesting finding within our study.

It is found to be individual how much patients relate to their own death - some patients refrain from dealing with it whereas others immerse themselves in thoughts and preparations. These individual differences are also identified within the study of Berterö et al. (2008). They identify that patients initially have difficulties absorbing information related to receiving a diagnosis of incurable cancer. But after a while depending on personality and support, patients take action in different ways when relating to their own death.

The German philosopher Hans-Georg Gadamer (1900–2002) also reflected on death and people's ways of relating to their own death. According to Gadamer (1996), people are able to repress the knowledge of their own death, which reflects a strong will to live and a general demand of not wanting to have certain knowledge concerning their own death. However, Gadamer argues that some people experience this demand stronger than others which offers an understanding of why some patients in our study in particular feel a strong wish not to relate to their own death. In light of Gadamer's thoughts, these patients have a strong connection to the general human demand of not wanting to have certain knowledge of their own death.

Furthermore, our study shows that some patients feel cheated, as they expected life to be longer. In a study by Sarenmalm et al. (2009), similar findings are identified and patients experience dying a premature death, where they also perceive losing their future and living under the shadow of death. From a caring perspective by Galvin and Todres (2013), it can be understood that these patients' suffering involves, what they characterise as, having a “blocked future” because

patients experience that their own future is closing down. This experience of having a “blocked future” can also explain the metaphor used by a patient describing that he feels as if he is “living within a big waiting room”. This metaphor can with Galvin and Todres (2013) be understood as an experience of feeling blocked or cut off from any sense of future and having a feeling of being frozen in time, which they define as being in “no man's land” or a “limbo”.

#### 5.4. Transitions related to places and belongings

Moreover, it is identified that patients experience being connected to places and belongings: their house, car, boat, motorbike etc. Devik et al. (2015) also identify that patients feel a deep connection to the area in which they had lived their lives. But their study also shows that this connection – which they call rooting - is furthermore founded on patients' social relations with other people living in the same rural area. Patients have memories attached to these people, who they have shared their life with and based their self-identity upon. Thus, staying connected to these social relations is of great importance for the patients' well-being. Other studies also identify patients being connected to special places and belongings and refer to these as patients' experiences of “at-homeness” (Rasmussen and Edvardsson, 2007; Saarnio et al., 2018). In the study of Saarnio et al. (2018), it is found that at-homeness among older people with severe illness is fostered by familiar furniture and personal belongings from earlier in life and from new things, which they have chosen themselves. Also, familiar places contribute to the feeling of “at-homeness” and through these items and places, patients are able to recognise themselves and hence make them feel at home. Further, in the study by Rasmussen and Edvardsson (2007), it is found that environments in palliative care facilitate experiences of at-homeness among patients when these make them feel safe and secure, which involves being able to recognise themselves and experience a relatedness to significant things and places.

From the perspective of Galvin and Todres (2011), these findings from the present study have to do with an existential dimension in life called spatiality, in which well-being can be experienced when belongings or places bring patients to a state of stillness and settling – also referred to as dwelling. The essence of dwelling is a person's ability to “come home” in the present situation, which involves an experience of peacefulness and rootedness from allowing everything, which is there to simply be present without trying to change anything (Todres and Galvin, 2010). Assuming this perspective, it can be understood that patients experience this kind of well-being while they spend time looking at their car, boat or motorbike and transition into an experience of feeling at home.

Also, another dimension of spatial well-being is combined with dwelling as some patients at the same time went on imaginative journeys or drift into memories centred on their special belongings. This kind of well-being is described as “adventurous horizons” (Galvin and Todres, 2011), which means to obtain well-being from the existential ability of moving forward and hereby experiencing an energised flow. When patients combine these two kinds of spatial well-being, they obtain, according to Galvin and Todres, the highest level of well-being where dwelling-mobility is united and the person experiences a rooted flow containing both peacefulness and movement at the same time. From this perspective, it is understandable that patients hold on to their special belongings or areas because it is a powerful source for well-being.

However, when illness changes the patients' ability to join normal activities outside their house or move freely within their home, this can result in spatial suffering. Galvin and Todres (2013) call this kind of suffering “imprisoned”, which means a suffering caused by experiences of being hemmed in, unable to move or being trapped – also described with the metaphor of “contracted horizons”. Taking this perspective underlines the severity of patients transitioning into living a limited life within their private homes.

## 6. Methodological considerations

A phenomenological-hermeneutic interpretation never finds its ending, because new ways of understanding always appear within the continuous spiral movement of interpretation (Ricoeur, 2002a, 2002b). However, an interpretation has to be more likely than another and Ricoeur states that validation of a specific interpretation is obtained through argumentation based on probability logic rather than proving and verifying the truth of an interpretation. Hence, in the present study, themes have been identified, which were found to be the most prominent related to the study aim and - inspired by Ricoeur - the most probable interpretations of these findings have been obtained. Yet knowing that other ways of interpreting are also probable.

According to Kvale and Brinkman (2009), an interview study is normally based on approximately 15 participants,  $\pm 10$ . This recommendation guided the present study and it was found that interviewing 10 patients contributed with rich data suitable to explore the aim of the present study in depth through analysis and interpretation.

## 7. Conclusion

This paper offers knowledge related to patients' experiences of transitions during the course of incurable cancer. Our study showed that patients experienced multiple transitions and individuality in perceptions and meanings associated to the experienced transitions were dominant. Challenging transitions were experienced in relation to changes in everyday life, where patients experienced difficulties in adapting to changes in their normal life. Also, patients were challenged by some people transitioning into having a distancing behaviour towards them and they had to endure that illness also caused hurt among their significant others. Other major transitions were related to approaching end of life, where patients experienced transitions related to approaching death, which also evoked a need to prepare for leaving life. However, patients also transitioned into experiencing a strong will to hold on to life and appreciating life, and within this process, patients experienced moments of well-being. Furthermore, they experienced being connected to their special places and belongings, which also facilitated experiences of well-being among patients.

## 8. Implications for practice

Our findings contribute with knowledge relevant for nurses and other healthcare professionals, who offer palliative care to patients suffering from incurable cancer. In the system of healthcare, we find it important that an identification of challenging transitions is implemented in palliative care during these illness trajectories. The present study offers insight on existential areas, where patients are challenged – such as relating to their own death, changes in social relations and living an altered everyday life. In the process of identifying challenging transitions, Chick and Meleis (1986) offer guidance on emotional reactions, which indicate that patients experience a challenging transition. This would, according to Chick and Meleis, involve that healthcare professionals in palliative care pay attention when patients express e.g. disorientation, distress, irritability, anxiety, and depression or if their self-consciousness, self-esteem or role performance change. Furthermore, our study contributes with knowledge on patients' experiences of well-being during the course of illness – especially related to spatiality, where they experienced well-being when spending time at special places or with special belongings, but also when going on imaginative journeys. In palliative care, this insight stresses the importance of trying to support patients to experience these moments of well-being.

## Declaration of conflicting interest

The Authors declare that there is no conflict of interest.

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