



Transition experiences during courses of incurable cancer from the perspective of bereaved spouses



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ABSTRACT

Purpose: The present study explores transition experiences during courses of incurable cancer from the perspective of bereaved spouses.

Method: Ten bereaved spouses participated in individual semi-structured interviews conducted in participants' private homes. The study takes a phenomenological-hermeneutic approach and data was analysed inspired by the French philosopher Paul Ricoeur's theory of interpretation.

Findings: Two main themes were identified. The first one: "Being present when the life of their loved one is ending" consisted of three subthemes: "Challenged by suffering", "Transitions during the final days" and "Moving on in life". The second main theme: "Meaningful transitions in palliative care" consisted of two subthemes: "Changing direction towards palliative care" and "Transitions in palliative care".

Conclusion: Bereaved spouses experienced meaningful transitions when the life of their loved one was ending and related to receiving palliative care. Spouses were challenged by witnessing their loved one's suffering and experienced a deviation in the quality of professional palliative care offered in the system of healthcare.

1. Introduction

This study focuses on experiences of transitions during the course of incurable cancer from the perspective of bereaved spouses. The word "transition" originates from the Latin word "transire" and means: "To go across" (Chick and Meleis, 1986). In the present study, the understanding of "transition" is inspired by Chick and Meleis (1986), who describe transition as a process, disruption, change or movement to which persons respond individually. The meaning and awareness, which persons associate with a transition event often vary and individual responses hereby also often occur.

Exploring transitions is important because this is a central concept in nursing as nurses often care for patients and their significant others when they are experiencing changes within their lives caused by illness (Schumacher and Meleis, 1994; Chick and Meleis, 1986). Facilitating healthy transitions or offering support through problematic ones is therefore essential within nursing (Schumacher and Meleis, 1994; Chick and Meleis, 1986). Related to the present study, this could for instance involve helping patients and their loved ones to talk about their thoughts and feelings related to initiating palliative care. Critical events

often initiate transitions, which is a process of loss and detachment from existing ways of living (Schumacher and Meleis, 1994; Chick and Meleis, 1986). Also, periods of uncertainty are implemented when transitioning and this requires the people involved to find ways of coping. However, transitions are perceived differently by people even when circumstances are similar. Unhealthy transitions can appear for both patients and significant others and hence nurses' ability to both identify and support them through these difficult transitions is of great importance for the improvement of well-being and alleviation of suffering.

The World Health Organisation (WHO) places the patient's family central within their definition of palliative care as it aim to improve both the patients' and their family's life quality when facing problems associated with life-threatening illness (WHO, 2017). According to WHO, palliative care should involve supporting family to cope during the patients' illness and in the family's bereavement process (WHO, 2017).

But in order to offer this support, it is important that healthcare professionals have insight regarding how significant others experience their life situation. One could imagine it must be challenging on many

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levels and a major change in life to experience your loved one suffer from incurable cancer. The following citation offers insight regarding thoughts and feelings from the perspective of a bereaved spouse:

“I had cancer in my life for six years, but I think four years went before I really understood how difficult and lonely it actually was being the one having to stand by the side. When you are in the middle of it, then you just act and do things because – understandably – there is so much focus on the one suffering from cancer. As a result you become blurry and invisible to yourself”, (Boss Kyhn, 2016).

When reviewing existing qualitative studies, it is also possible to obtain further insight regarding these transition experiences. A meta-synthesis by Duggleby et al. (2017) identified that significant others experience a “life transition”, which permanently alters their life. This alteration is very stressful and is described with the metaphor of experiencing a “hurricane”. Also, a study by Grøthe et al. (2015) found that significant others experience a change in their normal life as they transition into living in a bubble during the course of illness, where the outer world has stopped existing. Furthermore, a study by Røen et al. (2018) showed that significant others transition into new roles and it is important for them to create personal relationships where they experience being seen as individual persons by healthcare professionals. However, a study by Devik et al. (2017) identified that healthcare professionals’ way of caring for their loved one could cause suffering among significant others. E.g. when healthcare professionals were perceived to underestimate or neglect the symptoms of their sick loved one. These experiences made significant others transition into experiencing mistrust and insecurity towards healthcare professionals.

Moreover, a study by Collins et al. (2018) found that significant others change their communication needs within the final days of their loved ones’ life. It becomes important that healthcare professionals use the words “death” and “dying” explicitly in order to make them realise what it happening. Because even though significant others intuited death being close they could easily deny this as not happening. Furthermore, they wish that healthcare professionals also communicate to their sick loved one that death is imminent or clarify with significant others if they wish help to inform their loved one. In line with these findings, a study by Andreassen et al. (2015) found that healthcare professionals are able to explore sensitive topics and ask question related to these if it involves showing empathy and seeks to empower the patient.

When significant others transition into bereavement after the death of their loved one, a study by Holtslander et al. (2011) found that significant others experience this process as “walking a fine line”, where they balance between deep bereavement and moving forward in life. Also, another study by Holtslander and Duggleby (2009) identified that it is important for significant others to find new meaning and purpose in life. Ways of doing so is by letting go of the past, being grateful for life and trying to stay positive. These processes involve taking control of one’s own life bit-by-bit and focusing on the future.

In addition, a meta-synthesis by Madsen et al. (2018) revealed that significant others need hope during the course of illness. However, hope is constantly changing and periods of hopelessness and experiencing low levels of hope also dominate the life of significant others. But choosing hope deliberately helps them to experience having some kind of control of ups and downs within their challenged life situation. In line with these findings, a meta-synthesis by Fringer et al. (2018) identified that significant others’ transition experiences involved feeling helplessness during periods where they did not have the sufficient resources to manage and understand a situation caused by their loved one’s illness. Furthermore feelings of isolation and powerlessness became dominant as the disease progressed and significant others were found to loose their own identity because they became either “invisible or just a part of the patient”. Therefore, significant others had difficulties separating their own experiences from their loved ones, and when they were asked how they felt themselves, they often answered by

describing the condition of their loved one.

The present study explores significant others’ experiences of transitions during courses of incurable cancer. Such a study has not yet been conducted and hence our study will contribute with knowledge to the field of palliative care.

2. Aim

The study aims to explore experiences of transitions during the course of incurable cancer from the perspective of bereaved spouses.

3. Method

In this qualitative study, a phenomenological hermeneutic approach was taken and data was obtained through individual semi-structured interviews, guided by the theory of Kvale and Brinkmann (2009) and Fog (2004). Data was analysed and interpreted inspired by the French philosopher Paul Ricoeur’s theory of interpretation, which involves three phases: Naïve reading, structural analysis and comprehensive understanding (Ricoeur, 1973, 1979, 2002a; 2002b).

3.1. Participants

In this study, ten bereaved spouses participated and were included by a specialised palliative care team. Healthcare professionals from this team were gatekeepers and identified potential participants and inclusion was based on participants being adult Danish speaking bereaved spouses undergoing courses of incurable cancer. Participants had to be cognitively well-functioning and assessed to have the energy to participate in interviews. Bereaved spouses could be contacted no earlier than 3 months after the death of their loved one. Potential participants were invited by letter and when accepting to participate, they were contacted by phone to arrange the interviews. Table 1 illustrates the types of cancer participants’ loved ones suffered from. When participants are cited, pseudonyms are used. Participants were interviewed approximately 4 months after the death of their loved one. Five men and five women participated between the age of 50 and 85, mean age 70. All of the participants were living alone - nine of them in urban communities and one in a rural community.

3.2. Semi-structured interviews

Interviews were conducted within the private homes of the participants and interviews were centred on participants’ experiences of meaningful transitions during their loved one’s course of incurable cancer and participants’ own bereavement process. No one else was present during interviews besides the participant and first author. An interview-guide was developed. However, carrying out interviews was first of all a process of being open towards the experiences of participants and allowing conversations to develop, which was in accordance with the theory of Kvale and Brinkmann (2009). Also, focus was – inspired by Fog (2004) – centred on psychological processes during the

Table 1
Cancer types among participants’ loved ones.

Cancer types	Loved one
Bile ducts	1
Colon	1
Liver and bile ducts	1
Lung	2
Oesophagus	1
Prostate	2
Prostate and bladder	1
Throat	1
Sum	10

interviews and the importance of seeing interviews as conversations where questions appear during a process of conscious floating. 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 given information both orally and in writing and signed a written informed consent prior to the interviews. The spouses knew that participating was voluntarily, withdrawal was possible at any time and data from the interviews would be anonymised. Conducting interviews with bereaved spouses from courses with incurable cancer implied ethical considerations. In particular, these involved how and who to invite for participation and in this process collaboration with healthcare professionals at the specialised palliative care team was of great importance. Healthcare professionals hereby also had the role of being gatekeepers (Hammersley and Atkinson, 2007). During interviews, there was awareness on participants' well-being when talking about their own experiences.

3.4. Data analysis

Ricoeur's theory of interpretation (1973, 1979, 2002a, 2002b) 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 the theory as a method involving three steps. Within the *naïve reading*, the interpreter is trying to grasp the text as a whole (Ricoeur, 1973; 1979, 2002a; 2002b). Within the present study, this involved transcribing interviews, reading them several times and obtaining an initial understanding of the participants' experiences. The *structural analysis* is a process of analysing both "what the text says" and "what the text talks about". Within this process, the text detaches from the author's intentions and offers new ways of understanding. Hereby, the text opens a world in front of the text - also referred to as new references or new ways of understanding. Metaphors were found important to implement within the analysis and interpretation as Ricoeur described these containing a surplus of meaning and hence suitable for interpretation (Ricoeur, 2002b). Table 2 provides insight on the performed structural analysis. The *comprehensive understanding* involves an interpretation of central findings in the light of relevant theoretical perspectives, which mainly include theory centred on experiencing death and mysteries in life by the German philosopher Hans-Georg Gadamer (1996) and the French philosopher Gabriel Marcel (1956). Also, the Dutch researchers Margaret Stroebe and Henk Schut's theory on bereavement (Stroebe and Schut, 1999) is included to illuminate findings. Further findings are reflected on with results from other qualitative studies. The analysis of data was primarily conducted by the first author and both the last and second author contributed with developing comments. Themes emerged from the data and during the analysing process, the authors therefore had awareness on their own pre-understandings in order to reflect on the possible influence of these in the identification and interpretation of findings.

Table 2
Example of structural analysis.

"What the text says"	"What the text talks about"	"Themes and sub-themes"
"I caressed his chin and said: "You can sleep now" ... He breathed twice and then it was over. He looked so nice and one may wonder about that after such a long illness trajectory. But that is the thing, when death comes, everything relaxes and a special peace appears. And all the family came, also the young ones. I found that important, even though they were so terribly sad, but it was good for them to see, that death is something peaceful and also beautiful, when you have fought like that", (Frida).	Experiencing your loved one die Allowing your loved one to let go of living – to transition into death Experiencing death as an alleviation for your loved one Reactions on losing a loved one	Theme: Being present when the life of their loved one is ending Sub-theme: Transitions during the final days

Table 3
Themes and sub-themes.

1. Being present when the life of their loved one is ending
- Challenged by suffering
- Transitions during the final days
- Moving on in life
2. Meaningful transitions in palliative care
- Changing direction towards palliative care
- Transitions in palliative care

4. Findings

From the structural analysis, two main themes were identified concentrated on spouses' transition experiences in relation to 1) "Being present when the life of their loved one is ending" and 2) "Meaningful transitions in palliative care". The two themes and in total five sub-themes are presented below and Table 3 offers an overview. It is relevant to mention that the presentation of transition experiences also includes using words like "changes, challenges, difficulties and movement" as these words are found appropriate to describe nuances within the transition experiences among significant others and are related to the understanding of "transition" described by Chick and Meleis (1986).

4.1. Being present when the life of their loved one is ending

4.1.1. Challenged by suffering

All spouses experienced their loved ones suffering during the illness trajectory – especially in the process where their loved one approached end of life. During this period, they all tried to facilitate alleviation and protect their loved one from additional suffering. Some spouses had challenging experiences related to their loved one wishing to hasten death in order to escape both existential and physical suffering. This left spouses with ambivalent feelings as they actually understood their loved one's need for alleviation and logically death was a way out. But on the other hand, spouses wished their loved one to continue fighting. Also, it was difficult when their loved ones felt that they were becoming a burden for their spouse. This led to suffering among spouses themselves and witnessing their loved one suffering was difficult for spouses to endure. The following two citations illustrate variations of these experiences:

"That morning he had to call medical service because his back was hurting so bad and at the end of the afternoon he said – when pain was starting again: "If this is life, then give me death". He had said those words before and he knew it made me really sad. But right at that moment I told him: "I do understand", because actually I did. But it is hard saying it is okay, when you also wish to say: "Fight god dammit, with everything you got", (Hannah).

"The physicians said there was nothing more to do than to keep her free from pain. But actually it was a painful death because my wife suffered as she felt she was a burden. That's how she felt, a burden, withering away and it degraded her. It also tormented me as much as my wife, because it is painful watching your loved one suffer. She asked me: "Can't we go to the harbour and jump in the sea together?" She meant it! But I said no, I didn't really like that idea. Of course there has always been the

possibility of suicide but that is so drastic and also it is a crime if I fail to act on her attempt”, (Bent).

Some spouses experienced a lack of professional guidance when needing to transform their private home into rooms for caring. This postponed alleviation of patients and led to spouses suffering as they stressed their bodies by carrying or lifting their loved one. Especially waiting time for assistive devices or professionals offering assistive devices too late was underlined as problematic. Furthermore, spouses described how long uncomfortable transportations and waiting time during hospital appointments contributed to their loved one's physical suffering and extreme exhaustion.

4.1.2. Transitions during the final days

The majority of spouses described experiences related to being present during the final days of their loved one's life and at the moment of death, which was very meaningful for them. Most spouses experienced death approaching over days, where they gradually lost contact and ability to talk with their loved one. Instead, spouses transitioned into sensing physical signs or sentiments and most spouses experienced their loved one was peacefully sleeping. However, spouses often experienced a change in their loved one's breathing when death was very near. A few spouses also experienced their loved one holding on to life and they tried to help them let go:

“He held his hand so strongly around the bed gallows and we simply couldn't get his hands free. He convulsively held on to it, but still he was far away. Then at last, he got his hands down and lay with them folded. I wanted to hold his hands, but I simply couldn't separate them. It was as if he was holding on to life – fighting. At the very end – a smile appeared on his face. It was so relaxed. He was not dead, but also there was no life. But still something was there. As if he thought: Now I am at peace”, (Johanna).

When death arrived, spouses noticed the absence of breathing and experienced a dominant presence of silence. This was a significant moment where peacefulness surrounding them and particularly the expression of their loved one. They experienced that death brought peace and relief to their loved one after a long period of suffering and struggle and it was important for spouses to share this moment with their deceased and family. However, the moment of death was also very emotional as they felt the presence of an initial deep grief over the loss of their loved one and also left them with a feeling of emptiness:

“I caressed his chin and said: “You can sleep now” ... He breathed twice and then it was over. He looked so nice and one may wonder about that after such a long illness trajectory. But that is the thing, when death comes, everything relaxes and a special peace appears. And all of the family came, also the young ones. I found that important, even though they were so terribly sad, but it was good for them to see, that death is something peaceful and also beautiful, when you have fought like that”, (Frida).

4.2. Moving on in life

Spouses felt distressed in various areas of life after the loss of their loved one. Emotionally they reacted to losing their loved one, which for several also meant losing their best friend and life partner. Furthermore, spouses felt exhausted after their deep involvement within the illness trajectory. However, initially there was not much time for regaining energy or processing their own reactions as they experienced a massive amount of practical tasks, which they had to take care of. However, a new kind of everyday life eventually appeared and they experienced a need to involve themselves in life again. They all experienced having to force themselves to take part in life again and meet with family, friends and join activities. Some experienced that people close to them gently helped and supported them. But others also

experienced a distancing change within relations, where new ways of being together did not develop. Even though all spouses felt a need to participate in life again, this was too demanding for some and hence they tended to stay within their homes, but felt isolated:

“What I fear the most is that I all of a sudden isolate myself. Because I don't get out – besides in the morning where I take my morning walk before I eat breakfast. But later on I stay within my cave and that worries me. I actually feel that I'm hiding, not because I wish to hide. I don't know why I do it. I just can't get out. I can't do it. I feel it very strongly now. You really feel that you are alone. And it has nothing to do with me wishing him to come back, because I understand that is silly, knowing how sick he felt. But it has to do with me feeling abandoned. Totally abandoned “, (Grethe).

Although spouses felt they moved on in life alone and their existence was dominated by missing and grieving over the loss of their loved one, they found ways of bringing them along in their new life. For instance, they connected with them through memories and imaginative talks or felt their presence at their grave and sometimes also within their homes:

“When I stand in the front door I can see his grave and his stone. Because Daniel had to lie so that he could see our home. It is just up that road ... I only have to step out of the door then I can look up to him, because that is how he lies and that is why the grave was chosen. He had to be able to look home everyday and he is placed so he is facing our home”, (Doris).

4.3. Meaningful transitions in palliative care

4.3.1. Changing direction towards palliative care

Spouses often experienced a clear distinction when healthcare professionals were changing direction in treatment by introducing palliation. Spouses remembered wordings related to their loved one “having limited time left” and a need to “focus on quality of life” or their loved one being “assigned to a palliative care team”. They were often shocked when the healthcare direction changed towards palliation and could not believe that it was real. However, some spouses already had a feeling this was where things were heading. But still, this was a significant shift in direction also because some spouses found that their loved one was less prepared for this change. Spouses experienced that hope was taken from their loved one and they found it difficult to balance between being realistic and protecting the hope of their loved one. However, spouses found it important that healthcare professionals informed them about their loved one having limited time left and asked questions and introduced topics related to their life situation. Even though it was challenging to talk about, it created opportunities for them to plan and opened up conversations about practical and existential matters with their loved one and family. The following two citations illustrate experiences of being supported and not supported by healthcare professionals:

“In my heart, I could not bear telling my husband: “You are going to die soon and what do we do then?” even though these thoughts were also haunting his mind. But healthcare professionals at the palliative care team were able to ask us directly and helped us talk about these topics in a more simple and natural way ... and afterwards my husband - on own initiative - made remarks which he normally was passive about”, (Frida).

“If we had been given a time horizon, then maybe we would have been better at talking about those things. I think in our situation, it could have been a good idea to give us a time horizon. It would probably have been a shock initially. But then maybe we would have pulled ourselves together and we would have done some of the things, which we postponed”, (Christian).

4.3.2. Transitions in palliative care

In general, spouses spent a lot of time and energy on helping their loved one and contacting healthcare professionals. Assuming this leading role was a demanding job and spouses were especially challenged when acute problems arose at home. They were depending on support from healthcare professionals and they expressed a deep appreciation, when experiencing this support and often it was related to having specific healthcare professionals supporting them throughout the illness trajectory:

But the home district nurse and home care. They helped us so much. They stood by our side! And I know the district nurse aimed for us to have contact with the same group of professionals and we did almost all of the time. But of course there were weekends, Christmas and so on ... I don't know where she had her experience from ... but it was clear that she knew exactly where we were in the course of illness and what we needed ... But I can't say ... Not all home district nurses are like her", (Anna).

However, for some achieving this support was sometimes difficult and involved them persistently contacting different people within the system of healthcare or advocating for the preferred care before finally receiving support. Sometimes, the support was also experienced as unsatisfactory. This struggle left spouses with feelings of being rejected or misunderstood by healthcare professionals. Furthermore, at the end of the illness trajectory, all spouses experienced a weakening process of their loved one and thus a change in palliative care needs. This was a demanding process for them, especially when their loved one was no longer able to express his or her own preferences and the possibility of discussing options with them hereby disappeared. In these situations, spouses transitioned into feeling a huge amount of responsibility, as they had to take the final decision related to for instance moving their loved one to hospice and hereby depriving them of the possibility of dying at home. It also became clear that the quality of palliative care varied within and across illness trajectories. Major difficulties arose for spouses when they experienced their loved one being placed in situations where healthcare professionals were not able to fulfil palliative care needs. Especially busy hospital wards offered inadequate palliative care:

"If we were not there, there was no one to help her eat. Several of the nurses said that the unit was overcrowded with 3-8 patients – including patients in isolation – and no extra healthcare professionals. So it is logical that they can't handle all the tasks. One day I found my wife on the toilet, where she had been waiting at least an hour for someone to return her to bed. The last day when I came to pick her up, I found her in bed undressed. They had been interrupted when changing her diaper and she was left on the side leaning towards the safety rail. We don't know for how long she was left like this. But my wife said it was for a long time and so did the pressure marks on her body. When we came home my wife said, she would never go to that hospital again, never! And she didn't (cry)", (Ivan).

5. Comprehensive understanding and discussion

The sections below focus on transitions related to the death of a loved one, the time of bereavement and transitions related to palliative care. Hereby the main focus in the comprehensive understanding is centred on transition experiences related to death. However, the present study includes transition experiences throughout the illness trajectory and these experiences – related to their loved one's illness, palliation and life before death - are intended to be embraced in the last section: "Transitions related to palliative care".

5.1. Transitions related to death

Spouses were found to have transition experiences related to death and central findings were presented on this topic within the first main

theme. In particular its sub-theme: "Transitions during the final days" shows that spouses experience a special silence just after the moment where their loved one had died and they feel a need to share this moment with their deceased and close relatives. Also, it is found that significant others experience a contrasting presence of both relief and initial turbulent bereavement reactions within themselves. Similarly, a study by [Koop and Strang \(2003\)](#) also identifies that the death of a loved one, who suffered from incurable cancer, brings relief and gratitude to significant others because they find that death brings closure to their loved one's suffering. Furthermore, a study by [Pusa et al. \(2012\)](#) identifies that significant others feel a relief from their own suffering, when their loved one had died, because the emotional burden from being involved in the illness trajectory had been enormous. Being freed from this burden and allowed to refocus on themselves again is perceived as a relief.

Gadamer (1900–2002) writes about "the experience of death" (1996) and stresses that you experience "the mystery of death", when being present while a person is dying. He describes that an "uncanny silence" – which means a mysterious silence - accompanies the final parting of the person, who was just among the living and what happens is difficult to grasp or explain. The fact that spouses particularly notice this special silence following the death of their loved one indicates that they experience what Gadamer refers to as "an uncanny silence" accompanying the final parting of their loved one. Also, spouses are found to silently dwell within this moment together with their deceased and close relatives. Their way of talking about these experiences during interviews also involved pauses – silent reflections - which are interpreted to reveal that experiencing death and trying to explain this experience involves silence and a lack of words. This underlines Gadamer's point that experiencing "the mystery of death" is difficult to grasp and explain.

[Marcel \(1956\)](#) - who lived from 1889 to 1973 - writes, prior to Gadamer, about mysteries and also refers to these as meta-problems, which are connected with the content of being. According to Marcel, these ontological mysteries involve existential dramas, which occur in everyday life and people are either available and open towards meta-problems or reject engaging in them. The fact that spouses are deeply involved in the moment surrounding the death of their loved one can from the perspective of Marcel be understood as spouses engaging with the mystery of death. This engagement makes spouses reflect and sense themselves and their loved one, which also involves a change in the presence and expression of their loved one when death arrives. Hereby, in the light of Marcel's thoughts, spouses make themselves available and open to experience what Marcel describes as the mysterious, paradoxical and unconceivable structure of death, which for spouses involves experiences of both peacefulness and on the contrary - emotional and existential distress.

5.2. Transitions during bereavement

It was identified that spouses had transition experiences in relation to their process of bereavement. Within the first main theme, central findings from the sub-theme "Moving on in life" show that spouses feel an initial deep bereavement and emptiness after the death of their loved one. Also, it is found that spouses were distressed in various areas in life after their loved one's death and experience a massive amount of practical tasks, which left only little time to cope emotionally with their great loss. Furthermore, it is identified that a new kind of everyday life appears at a point in their bereavement process, where spouses feel a wish to re-join life and force themselves to take part in life again. Similarly, a study by [Pusa et al. \(2012\)](#) finds that moving forward is important for significant others in the process of bereavement and involves a discovery of the importance of expressing their own emotions. Furthermore, a study by [Holtlander et al. \(2011\)](#) also identifies that significant others experience a need to move forward, in order to try to regain control and balance in life. However, this need is challenged by

their deep bereavement, which involves an unpredictable process dominated by overwhelming emotions, fear and loneliness that makes them experience a loss of control. But allowing themselves to experience this deep bereavement is found to restore and renew their strength.

Stroebe and Schut (1999) have conducted research and developed theory related to these experiences of grief and they describe that bereavement is placed within the everyday life of the bereaved and involves two processes: loss and restoration. The first mentioned is dominated with feelings related to the loss and also involve that the bereaved re-organises his/her relation to the deceased, so that a new way of bonding is developed. The restoration process includes a focus on establishing a new everyday life, new identify and further involve interpersonal relations and how these relationships affect the bereavement processes. Stroebe and Schut place oscillation very central within their theory and this involves an oscillation within and between these processes. The ability to oscillate is essential for the bereaved as it reflect the ability to cope with the loss in ways, which are harmonious.

When assuming the perspective of Stroebe and Schut, it can be interpreted that everyday life for the spouses just after the death of their loved one is overshadowed by bereavement. Especially the process of restoration is initially dominant as spouses experienced being overwhelmed by practical tasks, which leaves only little time for processing their own emotional reactions within the loss-oriented process of bereavement. Furthermore, with Stroebe and Schut, it can be understood that spouses re-organise their relationship with their deceased loved one within their loss-oriented process of bereavement, as they find new ways of bringing their loved one along through e.g. imaginative talks or by feeling their presence at their grave. Also in the light of Stroebe and Schut, spouses experience - within the restoration process - relations with others that support them in their effort to re-join life and hereby ease their bereavement process, but others experience the opposite, which further complicates their bereavement.

Furthermore, considering the theory of Stroebe and Schut, it can be understood that spouses experience a profoundly challenging process during bereavement as it massively dominates their everyday life after the loss of their loved one. However, within their chaotic emotional reactions and effort to re-build a new everyday life they show the ability to oscillate, which from the perspective of Stroebe and Schut's is a harmonious way of grieving.

5.3. Transitions related to palliative care

Spouses were also identified to have transition experiences in relation to palliative care. Within the second main theme, central findings from the sub-theme “Changing direction towards palliation” describe that spouses experience the transition into palliative care as challenging and some find it difficult to talk with their loved one about their own burdensome thoughts and feelings related to entering palliative care. It is also identified that specialised palliative care professionals help spouses to develop a language and ways of talking about topics related to entering palliative care and the end of life. Similar findings are described in a study by Klarare et al. (2017), who found that specialised palliative home care (SPHC) teams facilitate experiences of security and continuity in care among patients. Security was related to the fact that healthcare professionals from these SPHC teams could be contacted at all hours and all days during the week. Also, security was facilitated from healthcare professionals' sensibility to changes and ability to immediately assess the situation and strive to meet the new needs. Furthermore, patients experienced continuity in care because healthcare professionals knew the patient and their situation. Receiving this care was a relief for patients and a contrast to their earlier experiences in the system of healthcare. Also, they highly appreciated the SPHC team's ability to attend to family needs.

A study by Sekelja et al. (2010) found that palliative care is highly valued by significant others because palliative care professionals show

respect and understanding and they are able to ease and humanise the dying process. Also, they were able to support significant others in their process of bereavement by offering counselling and showing concern about the whole family. Further, a study by Royak-Schaler et al. (2006) identifies that significant others find it crucial and highly appreciated when they receive accurate information, which is communicated clearly by healthcare professionals. A study by Collins et al. (2018) found that significant others experience a change in their communicative needs during their loved one's final days. It becomes important that the healthcare professionals explicitly use the words “death” and “dying” to help them to understand what is happening. Otherwise they could easily deny the reality – that the death of their loved one was drawing closer.

Similar findings was identified in a study by Andreassen et al. (2015), who found that healthcare professionals are capable of asking questions and exploring sensitive topics in palliative care, if they use a straight forward way of communicating. However, according to Andreassen et al. (2015) healthcare professionals need to show empathy and seek to empower the patient during these conversations.

Swedish palliative care researchers have developed a model for person-centred palliative cancer care communication (Öhlén et al., 2016). Taking their perspective, it can be understood that professionals at the palliative care team show a readiness to talk – in honest and sensitive ways - about issues surrounding the patients' fatal illness and approaching death. Further, from the perspective of Öhlén et al. these dialogues are placed in a “communicative arena”, which can be experienced as unsafe because all actors may take risks. These words “unsafe” and “risk” very well covers spouses' initial challenges and it can hereby in the light of Öhlén et al. be understood that professionals at the palliative care team support spouses to transfer into finding new ways of talking with their loved one, which also contribute to an alleviation of the existential suffering spouses' experience of suppressing their own thoughts and feelings. The fact that healthcare professionals experience taking a risk and feel unsafe in the “communicative arena” of palliative care, is also identified in a study by Alftberg et al. (2018). In their study, barriers in communication was centred on assistant nurses experiencing an emotional strain when having to care for older patients' existential needs and for some, it could feel too intrusive to talk about death and dying. For others, it was experienced as an intimate nature of care, which however, in some cases became too much to cope with emotionally for the healthcare professionals.

Further, the sub-theme “Transitions in palliative care” shows that some spouses experience that their loved one did not receive the palliative care they needed when being admitted to busy hospital wards or when healthcare professionals are not able to alleviate their loved one's suffering. A study by Royak-Schaler et al. (2006) identifies that some significant others find that healthcare professionals are too busy to provide the care their loved one needs, and this makes them doubt the competence of healthcare professionals. Moreover, a study by Pusa et al. (2012) finds that significant others feel they had to struggle for good professional care, which make them transition into being demanding and pushy in their attempt to make sure that their loved one receives appropriate professional care.

Taking the perspective of the nursing researcher Katie Eriksson, it can be understood that spouses experience their loved one being exposed to “suffering related to care” (Eriksson, 1995), because they feel that suffering is caused by inadequate care. According to Eriksson, “suffering related to care” involves lack of or neglect in care and using her words, spouses witness a violation of their loved one's dignity, which is a way of exerting power over a powerless person. This interpretation broadens the understanding of why spouses experience the lack in palliative care as severe and deeply frustrating, because it has to do with the system of healthcare causing even more suffering to their loved one and also violates the dignity of their loved one. Therefore, it can be understood that spouses experience powerlessness, because they do not have the ability to change these conditions and hence help their

loved one to receive the palliative care they need.

5.4. Critical reflections on the study

During interviews, it was clear that spouses related their experiences from the illness trajectory of their loved ones to what happened around loved ones and their feelings and reactions. It was important for spouses to evaluate on the course of illness within healthcare and share experiences related to difficult but also successful transitions. Hereby, spouses also became a voice for their loved ones particularly when describing experiences from the late illness period when approaching end of life and offered insight to a life situation, which patients would be to ill themselves to share knowledge about. This way of conducting interviews may have dimmed focus on spouses themselves and potentially also additional experiences related to their personal challenges during the illness trajectory.

The trustworthiness of our study is strengthened as findings emerged from participants' responses and researchers reflected on their own pre-understanding during the analysing process. In some studies using interviews as a method to collect data, it is chosen to send transcripts and findings to participants in order to let them comment on these. However, this was deselected in the present study, because it is not in concordance with the method applied for analysing data. According to Ricoeur, a text is detached from its author and hence a text opens a world of new references in front of the text. Therefore, in the present study, it is not relevant to ask participants to comment on transcripts and analysis of their responses.

6. Conclusion

This paper offers insight on experiences of transitions during the course of incurable cancer from the perspective of bereaved spouses. Our study found that spouses experienced meaningful transitions when the life of their loved one was ending and related to receiving palliative care. These transitions were centred on spouses' own difficulties enduring witnessing their loved one's suffering and their attempt to relieve suffering for their loved one. Also, spouses had contrasting transition experiences within the moment of death as it was both surrounded by peacefulness and a relief, but also initiated an overwhelming bereavement process. Spouses transitioned into moving on in life after the death of their loved one by coping with chaotic emotional reactions and creating new ways of bonding with their loved one. Also, they moved on by re-joining life and adapted to living without their loved one. Within the system of healthcare, spouses experienced meaningful transitions when entering palliative care. This transfer was challenging and the support received by healthcare professionals affected their ability to cope. Also, spouses' experiences revealed a deviation in the quality of palliative care offered within the system of healthcare.

7. Implications

The present study contributes with knowledge relevant for nurses and other healthcare professionals, who offer palliative care to significant others during courses of incurable cancer. Findings stress the importance of focusing on transitions when caring as the present study shows that significant others experience complex transitions throughout the course of illness and time of bereavement. Therefore, we find it important to implement transitional care in this context of palliative care and treatment, which should include healthcare professionals' ability to identify transitions on both organisational and existential levels. Also, we find it important that politicians, hospitals and community administrations work to further improve the organisation of healthcare in order to ensure that palliative care and treatment can be facilitated within all relevant areas in the system of healthcare. The present study shows a need for improvement within the context of basic

palliative care especially in busy hospital wards. Furthermore, knowledge is needed on how to implement transitional care related to both organisational and existential transitions during courses of incurable cancer. Hereby focusing on transitions in palliative cancer care would strengthen the effort to meet the needs and wishes from both significant others as well as patients.

Declaration of conflicting interest

The Authors declare that there is no conflict of interest.

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