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The First Thought is Death: A Qualitative Study of the Presence of Death in the Everyday Lives of People with Cancer

Corresponding author:

Suvi Holmberg, M.Soc.Sc

University of Tampere, Faculty of Social Sciences

Tel. +358405000453

Email: suvi.holmberg@tuni.fi

Postal address: Kalevantie 4, 33014 Tampere, Finland

ORCID: 0000-0002-0974-0975

Abstract

The purpose of this study was to explore how people with cancer and their loved ones process the presence of death in their everyday lives. The 'presence of death' is understood here as a phenomenon where the prospect of death becomes a solid part of daily flow after a cancer diagnosis, even when there is no concrete information about the prognosis. The data consists of writings by 37 Finnish participants and their loved ones. The data were gathered through a public call for writings on 'everyday life with breast and prostate cancer'. Cancer and death are approached from a sociocultural perspective, and the analysis focuses on death-related language and activities in the writings. The concept of frame was used as a theoretical and methodological tool. Four categories for framing the presence of death in everyday life were identified: social interactions in the presence of death, creation of a personal relationship with death, pragmatic acts and the reality of death. Each frame consisted of certain activities relating to social relationships, interactions and information, personal discussions considering cancer, the meaning of ordinary chores and the reality of death. The results reveal how people construct their own relationship with death through frames that help them organise the cancer experience and allow them to control the presence of death in everyday life. The findings are discussed in the context of practical health social work.

Keywords: cancer, everyday life, concept of frame, presence of death

Introduction

Cancer has a harsh reputation, and it is not unusual that the first thought connected to a cancer diagnosis is death. In fact, it appears to be more a rule than an exception that the presence of death becomes a part of daily life immediately after receiving a cancer diagnosis, even when there is no concrete information about the prognosis (e.g., Shaha and Bauer-Wu 2009; Willig 2009, 182). The purpose of this article is to explore how people with cancer and their loved ones processed the presence of death in their everyday lives. This perspective is important, as despite of the aggressive image of cancer, a diagnosis does not automatically mean certain death. For example, survival rates of cancer patients from 2015–2017 in Finland show that 91% of women with breast cancer and 92% of men with prostate cancer were still alive five years after diagnosis (Finnish Cancer Registry 2019). However, in the everyday context, the prospect of death seems to become a solid part of daily flow after the diagnosis; as one participant said: ‘I felt like death came in through the door and would sit on my shoulder for the rest of my life’. In this paper, this phenomenon is called *presence of death*.

Cancer’s association with the presence of death can be explained by the fact that people often know someone who has died of cancer and by the dominant cultural and discursive constructions that influence conceptions of cancer and other serious illnesses (Willing 2011; Lupton 2012). Thus, issues of health, illness and death cannot be seen simply as medical or biological facts; they are also interlinked with social processes and the sociocultural setting in which they are known and experienced (Charmaz 1980; Lupton 2012). Furthermore, the experience of illness is not bound merely to the healthcare environment or the bodies or consciousness of those who are ill; it reaches out to encompass households, families and communities (Kleinman and Seeman 2003). This

viewpoint may be overlooked in a rapidly changing healthcare environment, but it is pivotal in health social work (e.g., Auslander 2001).

The mere presence of death is frightening because in its totality, death forces us to forgo experiences in our lives, our bodies, our relationships, our plans and the possibility of living stable and painless lives (Kastenbaum 1998 as quoted in Hayslip and Hansson 2003). Still the phenomenon seems understudied, especially in cases where death is *uncertain*. In previous literature, death in the daily lives of people living with cancer has been approached, for example, from the perspective of informal palliative care in the home environment (Wong and Ussher 2009; Carlander et al. 2011a, 2011b, 2011c). According to Carlander et al. (2011b, 2011c), the closeness of death raises existential questions, causes bodily changes and invades the identities of all the individuals involved. These studies reflect well the everyday realities of living in the presence of death, but they lack insight on other stages of living with cancer, including, for example, circumstances where (curative) cancer treatments or annual follow-up appointments are over, and people continue their lives, which still are affected by cancer but in different ways (e.g., Hubbard and Forbat 2012; Balmer, Griffiths and Dunn 2015; Baker et al. 2016; Holmberg 2019).

One clear example of the presence of death in daily life is the constant fear of recurrence (Hubbard and Forbat 2012, 2036–2038; Balmer, Griffiths and Dunn 2015, 446; Baker et al. 2016, 184). Hubbard and Forbat (2012, 2037) argued that ‘constructing cancer as a disease to be feared is formulated both by cancer survivors who had recently been diagnosed as well as those who had diagnosed a long time ago’ (see also Balmer, Griffiths, and Dunn 2015, 446). Baker et al. (2016) called this the ‘existential threat of cancer’, which psychologically impacts the sense of identity, drives one to find meaning in the cancer experience and forces a confrontation with one’s own mortality (Baker et al. 2016, 185). The present study contributes to the discussion by scrutinising

how people with cancer and their loved ones process the presence of death in their everyday lives. The research question asks: How is the presence of death constructed and controlled in the everyday lives of those with cancer? Linking death to daily routines and separating it from biological and medical frames discloses the broad range of meaning that cancer has in everyday life.

Social work, cancer and the presence of death

Questions concerning death and dying are not unfamiliar in social work settings (e.g., Holloway and Taplin 2013), especially in the healthcare context where people face serious illnesses. Still, as referenced above, the role of social workers with issues of cancer and death is strongly linked to palliative and hospice care. In previous literature, social work and palliative care have been approached, for example, from the perspectives of informal caregivers and families (e.g., Gagle and Kovacs 2011), the professional needs of oncology social workers (e.g., Kovacs and Bronstein 1999) and the social worker's role in an interdisciplinary palliative oncology team (e.g., Jones et al. 2014). Common to all these approaches is the focus on situations where death is certain or has already happened. What previous (health) social work research lacks, is how the presence of death is constructed and controlled in situations where death is uncertain. This study contributes to the discussion from the perspective of the ill, their loved ones and their everyday life circumstances outside the healthcare environment. The perspective is especially important from the viewpoint of (health) social work, which aims to ensure that the daily lives of individuals and their families' (e.g., economic issues, social participation) are secured and can continue as trouble-free as possible in spite of the illness (Sipilä 1996, 61–62; Lindén 1999, 55). The findings are discussed in the context of health social work.

Theoretical and methodological approach

In this study, death in the everyday lives of people living with cancer is approached as a socially-constructed phenomenon. Conceptions of death, images of the social worlds where death takes place, and the everyday actions that constitute the process of dying are socially constructed. Although death is a biological fact, what it means is a result of socially-shaped ideas and assumptions. (Charmaz 1980, 17.) The ways the presence of death emerges in everyday life with cancer can be explored by scrutinising daily encounters and practices. The concept of ‘frame’ (Goffman 1986) is utilised as a theoretical and methodological tool (e.g., Peräkylä 1989, 1990). In the everyday life, ‘frames’ enable individuals to identify basic elements of reality and its social orders and events (Goffman 1986, 11). According to Goffman (1986, 8) ‘when individuals attend to any current situation, they face the question: What is it that’s going on here?’ in order to get a grasp of the social conditions and their possible contradictions. For example, when participants in the present study make a testament or refuse to talk about their cancer, these actions can be seen as attempts to understand ‘what is going on’ in their daily life in the presence of death.

Here frame is defined as a set of actions that help individuals understand the situations in which they find themselves, thus providing a way to organise their experiences (Manning 1992, 118). The frames are connected to established social practices and meanings, which are understood in relation to socially and culturally shared knowledge. This explains why people are able to separate practices like ‘play’ and ‘fight’ or ‘casual greetings’ and ‘last goodbyes’. (Peräkylä 1990, 156–157.) In life with cancer, the frames illustrate diverse social realities of living in the presence of death and ‘opens a particular perspective on death; the meaning of death is different in each’ (Peräkylä 1989, 118). In the current study, the concept of frame was utilised to explore the different constructions

of presence of death and how it could be controlled. At the core, are the death-related activities occurring in the frames.

Data and participants

The data were gathered for a doctoral dissertation in 2009 through a public call for writings on ‘everyday life with breast and prostate cancer’ directed at people diagnosed with cancer and their loved ones (also see Grinyer 2004). The call was published in Finnish cancer and patient organisations’ publications, rehabilitation courses and websites targeting cancer patients and their loved ones. Participants were asked to describe their everyday lives after their cancer diagnosis. They were further asked to state the type of cancer, the time they fell ill, how the illness was treated and the current status of the illness.

In total, 37 people replied; 21 participants wrote about breast cancer and 11 about prostate cancer; five wrote about the experiences of loved ones. The characteristics of the breast and prostate cancer participants are presented in Table 1. Unexpectedly, eight participants who wrote about their own cancer also wrote about their loved ones. Four of these writings dealt with cancer types other than breast or prostate cancer, but as the descriptions of death in everyday life were not perceived as dependent on the type of cancer, they were included. These writings were analysed from both viewpoints, which raised the number of writings written by loved ones to 13. The characteristics of the writings written by loved ones are presented in Table 2.

[Table 1. & Table 2. here]

The writings contained extensive narration about death, but as the participants were not asked to address death specifically, the unguided narration offered an opportunity to scrutinise the theme

‘naturally’ and how it occurred in the writings without the influence of the researcher (also see Grinyer 2004). The data amounted to 233 pages.

The research was not conducted under any specific cancer-related institution and any private person who saw the call for writings could contribute to the study. The call described how the writings would be used and gave a guarantee of anonymity and confidentiality. The researcher’s contact information was also available for further questions. In dealing with ethical issues, the Finnish research ethics guidelines (2009, 2012) were strictly followed.

Analysis

The analysis divided into three stages. First, all writings were carefully read and the data were imported to ATLAS.ti qualitative data analysis software, which was used to organise and code the writings. The analysis began with descriptive coding as presented by Gibbs (2007) focusing on the language the participants used when referring to death. They used direct references like ‘death and dying’ or indirectly referred to death through similes, images and metaphors. Preliminary, this phase helped perceive the everyday contexts where death was deemed to be present.

The second and the main analysis phase focused on the death-related activities that were described in wider textual contexts where separate direct and indirect references were used. The presence of death was recognised in numerous daily activities from social encounters and interactions to existential thoughts and ordinary daily routines. The concept of frame (Goffman 1986) was utilised to categorise the death-related activities by their contents and how the presence of death was controlled. The first explicit frame was connected to social relations and interactions, which seemed to run through all death-related activities. In addition, five more frames detailing daily flow and practices, concrete death and existential thoughts and feelings were identified. The frames were

not identifiable as clear separate sets of activities, and they often overlapped, and at times, were even contradictory.

In the third analysis phase, the six frames were reorganised by combining their emphasis on interaction and social issues, personal matters and practical actions. During this process, the activities linked to concrete death were separated and renamed as their own frame. Finally, four frames were identified. The analysis process is presented in Table 3.

[Table 3 here]

Findings

Frame of social interaction in the presence of death

In this frame, the central activity was the social interactions between people, which can be either direct (e.g., face-to-face communication) or indirect (e.g., phone calls). The focus here was on interaction as a way to share and control feelings and information. The presence of death is constructed and controlled through activities like ‘protecting’ and ‘silence’. This frame shows how strongly the presence of death affects the way people interact.

An important part of such interactions is sharing the cancer diagnosis, which brings the presence of death to daily life. Although some openly shared their diagnoses, some preferred to keep their illness a secret. One reason for selecting silence may have been that serious illness causes concern and calls forth all the cultural prejudices linked to cancer. Below, a participant with prostate cancer reflects on the situation of sharing:

On the day before Christmas Eve, I got a letter from hospital that said: ‘Malignant cancer cells have been found in your biopsy sample taken in November. We have reserved a skeletal scintigraphy for you on the 27th of December. Additionally, we have reserved a urologist appointment for you on the 10th of January; he will go through the treatment plan with you’. The information ruined my Christmas mood, and I told my wife that the kids would be told only after New Year’s Eve. (pc 9)

Because of the timing of the diagnosis letter, the upcoming Christmas with its cultural meanings, seemed to make the situation even more fragile. The presence of death is constructed through feelings of a ‘ruined Christmas mood’ and delaying sharing the diagnosis with ‘kids’. By delaying sharing, he was able to protect his children from information that would cause them worry and extend the presence of death in to their lives. This can be seen as a way to control the presence of death and the fragility of the situation. On the other hand, the data also shows that protecting others can sometimes distort the interaction, as in the next extract where an adult daughter describes her father’s way of talking about his prostate cancer:

During the illness, most of the conversations I had with my father on the phone were full of optimism from his side. Everything oozed with the feeling that he did not want me to worry about him or how he was feeling. [He said:] ‘The doctor said five years. I am feeling much better. I have been in the garden today to feed the birds’. [Daughter continues:] I heard from my sister that he had been helped to his chair so that he could look outside [at the garden] for a while. (lo1)

Father is trying to maintain an optimistic outlook and gives a more active and positive image of his situation than that provided by the participant’s sister. He is counting heavily on the doctor’s

prognosis of his length of life and uses it as a way to protect his daughter by insuring the ‘doctor said five years’. Still, the participant receives concrete information from her sister that contradicts the optimistic image her father tried to give her. The extract shows how complicated and confusing such interactions can be when loved ones are trying to protect each other. In addition, sometimes life with cancer can suppress interactions entirely, as in the next extract written by a participant whose husband had cancer:

My feelings go back and forth all the way to the deepest trenches. It is like I am walking through a dark tunnel and there is no way out. This is how I feel. My husband’s feelings are totally jammed. He has stopped talking. He can stay silent for days, and the way I see it, I don’t want to carry on living my life with him the way our life is now. (lo3)

Feelings and thoughts like these are unusual in the data. In most writings, the loved ones try to be as supportive as possible. In the extract, the participant describes how she is in a ‘dark tunnel’ without a way out. The simile reflects despair and reveals how interaction between husband and wife has ceased, which has had a negative impact on their daily lives. The extract shows how silence can cause complex and difficult situations that are not easy to resolve. This may indicate frustration over taking care of a (dying) family member or so-called forbidden thoughts of wishing for the death of a loved one (Carlander et al. 2011a).

Frame of creating a personal relationship with death

In this frame, the central activity revolves around considerations of one’s own or the loved one’s death. The presence of death is constructed and controlled through activities like existential and moral discussions, actively resisting death or defining it as a personal choice. The constructions

show differing personal ways of relating to the presence of death in everyday life. In the next extract, a participant with prostate cancer considers his possible death after diagnosis:

I am wondering, what are the odds that the samples were taken from spots where there were isolated cancer cells. Despite my optimism, I know that the chances are pretty much non-existent. Yes, it is cancer. Cancer that will capture my body. How quickly will it happen? What is my end going to be like? I was reminiscing about my father's last moments last winter. He did not die of prostate cancer, even though he had it, but the last moments of his life were not easy. (pc5)

Here, the personal relationship to death is constructed through existential thoughts when the participant is asking questions about his own death and uncertain future. The image of having cancer is strongly seen as a synonym to dying, and the participant is also comparing his situation to his father's death. The participant also describes death indirectly with the word 'end' and uses the military term 'capture', which represents the cultural framings of life-threatening illnesses (Hanne and Hawken 2007). The colourful language strengthens the image of cancer as a threat to existence. Still, the personal relationship with death can also be consciously resisted. In the next extract, a participant with breast cancer has decided she is simply not going to die:

In the beginning, I naturally rebelled and asked why this happened to me. There was no breast cancer in my family that I knew of. The kids were already adults. The only thing I was upset about was that I won't be around to see them graduate, or I won't see my grandchildren....And then I just decided, this is not going to kill me! During the sick leave, I kept in contact with my colleagues at work and relatives and friends were a big help. And the support I got from my family was and still is vital. (bc16)

The participant is reflecting on her own death through everyday life relationships and asking existentially, 'why'. She describes how death would rob her of future events she is not prepared to relinquish. She seems to empower herself and begins to resist death and its presence. She is not isolating herself, but instead, she maintains active social relations and seeks support. Her decision that cancer cannot kill her, emphasises her personal authority in the presence of death.

In addition to existential considerations and resistance, death is sometimes constructed as a personal choice that can be made if living with cancer gets too hard. This refers to thoughts of euthanasia or suicide as ways to control the presence of death. Although they can be seen as easy and dignified ways to die, there are also moral considerations relating to selfishness and unfairness to other people (also see Elliott and Olver 2008). In the next extract, a participant with prostate cancer that had spread considers the possibility of suicide:

Other thoughts or feelings? I really do not know what to say. But anyway, I have not yet decided to hang myself. I think I have taken the situation quite well. If someone asked how I have been, I have told them about my situation. If I happen to see someone I know, I am certain that s/he cannot see any abnormalities in my presence except for the slight weight increase. (pc7)

The participant sees suicide as a distant choice; he has 'not yet decided to hang himself'. He has been honest concerning his situation with cancer, but he thinks that it does not show outwardly. In this frame, references to suicide can be seen as a tool to control the distress caused by the illness and the presence of death. According to Nissim, Gagliese and Rodin (2009), in the context of advanced cancer, the possibility of hastening one's death can be seen as a hypothetical exit plan,

an expression of despair and as a manifestation of letting go. In here similarly, contemplations of suicide construct a self-controlled alternative to a possibly painful death.

Moral considerations also play a part in creating a personal relationship with death. In particular, thoughts that the cancer has somehow been self-inflicted may emerge. In the next extract, the participant contemplates her cancer as a result of the mistakes she has made earlier in her life:

The fatigue persisted, and I was off work constantly because of the flu, etc. until I found the lump in my breast and the reason for the weariness became apparent. When I heard I had cancer, I hit the shock and withdrawal phases simultaneously. I was feeling guilty about some things I had done during my life. I thought that cancer was a consequence of all the bad things I had done. You get what you deserve. A thought that I would fall seriously ill had never crossed my mind [before]. (bc6)

This extract is representative of the moral concern related to life-threatening illnesses—what if it is my own doing? Cancer explains the participant's tiredness and morbidity. She tries to explain her illness and control the presence of death by contemplating her 'doings' in her past. Willig (2009, 2011) has argued that the construction of cancer as one's own creation may lead to the view that it is ultimately due to personal moral failing. In this study, contemplating the reasons for cancer can be seen as a way of coping with the uncertainty, fears and anxiety caused by the presence of death no matter how irrational the connection.

Frame of pragmatic acts

In this frame, the central activity is the continuation of everyday life in the presence of death, which is constructed and controlled through actions people take to ensure everyday functionality. Such acts include, for example, planning childcare and everyday chores or preparing financial matters.

Pragmatic acts are often taken to ensure that the everyday lives of others continue in the presence of death. In the following extract, the participant is making arrangements as a way to ensure the continuation of the everyday lives of her children:

I am relieved that my debts are almost paid off, but especially, I am relieved that my youngest daughter has become an adult and that no matter what, my daughters will have each other. When I found out about the malignant findings, I talked to my sister, and she promised to take care of my daughters if I wasn't able to. (bc19)

In this extract, pragmatic acts are constructed mainly from the position and obligations of a mother. The fact that 'my debts are almost paid off' and the daughters are adults and have each other constructs solace in the presence of death. Still, when the participant got the diagnosis, she made preparations for the possibility that she might not be able to take care of her children if she got too ill or died. In the breast cancer writings, in particular, questions relating to the care of children are sensitive issues that cause uncertainty. This can be connected to the cultural definition of women as primary nurturers. However, the coping of the spouse also raises concerns, as shown in the next extract written by a participant with prostate cancer:

When you are told that you have cancer, it is a bit of a shock. Even though I consider myself mentally strong, it got quite silent at home after the diagnosis. I went through my life in my head quite far ahead into the future and even considered the worst scenario. I was especially worried about my wife as we still had some unpaid debt. Her income wouldn't be enough to cover the payments. (pc1)

In spite of constructing himself as 'mentally strong', the presence of death seems to 'silence' the customary sounds of daily life. At the core of the 'worst scenario' is the spouse and how she is

going to manage financially. The participant is contemplating financial issues from the cultural position of a man as the breadwinner. The extract shows how the presence of death brings ordinary but important issues like money into the discussion. Similarly, organising daily chores seems to be important as they offer a way to do something concrete in the presence of death. In the next extract, the participant wants to make sure that her husband has a comfortable home if she dies:

Today I felt ugly. My hair was flat, I felt fat and my face was red because of the flu. Everything feels wrong, my clothes are worn out, etc. I wonder whether this is actually a sign of getting better. Before the surgery, I could not have cared less about anything, and I had decided not to buy new clothes as I thought I probably would not be needing them anyway. I have been buying a few small things for the home as well...secretly, so that Pekka will have a nice looking home if I'm no longer here. (bc12)

The participant reflects her illness and the presence of death through her appearance. She feels 'ugly' but at the same time connects her sudden interest in her looks as a sign of possible healing. At the onset of cancer, she 'could not have cared less about anything' because she could die. Because of the strong presence of death in daily life, the participant has been buying 'small things for the home as well...secretly, so that Pekka will have a nice looking home if I'm no longer there'. The extract shows how pragmatic acts that aim at making everyday life easier for the people left behind can be seen as a way to take control in the presence of death (Lindqvist et al. 2008; Carlander et al. 2011c). Pragmatic acts make it possible to prepare for the risk of one's own death. What is common to all the extracts above is that the words 'death' or 'dying' are not used; rather the possibility of dying is expressed indirectly, which can be seen as a way to soften the brutality and finality of the image of death (Charmaz 1980).

Frame of reality of death

In this frame, the central activity revolves around describing the realities and facts of death. The presence of death is constructed and controlled through describing the weakening of the body, reminiscing about death and the process of dying and the place and time of death.

One crucial part of this frame is the weakening of the body, which involves physical symptoms and different aids like diapers and wheelchairs. Bodily changes are extensively documented in the data throughout the illness process. These changes become more and more dominant as the reality of death gets closer (Lindqvist et al. 2008). In the next extract, the participant describes her husband's last few months with prostate cancer:

It was a big thing for Mikko to accept that he had to wear diapers for the last few months. He had no appetite for food or nutrition supplements. Everything came out at once because of the diarrhoea or nausea. Water - cold water - was the only supplement that seemed to work. He refused to go to hospital, and I also thought it wouldn't have been a good thing. (I05)

Weakening of the body makes the presence of death visible and concrete in everyday life. The ill person cannot manage alone anymore and needs help. In the extract, the reality of death seems hard for both the person who is ill and for the loved one. The home environment represents a safe space to face impending death. The extract shows how the weakening of the body can be challenging in everyday life as people are forced to stretch their limits of intimacy and privacy (Carlander et al.2011a).

In addition to bodily changes, different locations are also part of the frame. In the extract above, home was constructed as a fitting place to die. In the next extract, the participant describes her sister's dying process. The death takes place in a hospital and another pivotal part of dying—the last goodbyes—is also described:

I had called my brother on Thursday to say that he and my mother should go and say their last goodbyes to our sister on Saturday. I had a feeling that it wouldn't take long. Her eyes were pale. Her handshake felt different; my husband noticed that first. It felt terrible to say that they should go and say 'the last goodbyes'. They went. I was glad that my sister got to see her mother and brother one last time. (lo10)

The participant describes how the presence of death becomes evident through physical changes and prompts certain actions. The extract shows the importance of death rites, such as 'last goodbyes', when someone close is dying. These are important for the dying person and for those left behind as they carry significant social and symbolic value (Charmaz 1980, 203–205). Furthermore, 'saying goodbye' can be seen as a positive aspect as it facilitates the dying process (Wong and Ussher 2009). Constructions of 'last goodbyes' demonstrate the emotional pressure of the reality of death.

Two other central themes in the frame are details on the time of death and reminiscing over the process of dying. The duration and the exact time of death seem important like in the next extract, where the participant is reminiscing about her husband's death:

On Saturday morning the kids came to visit with their families and Mikko got some of his strength back. He knew everyone and greeted them one by one but then started get tired again. Then he cheered up once more and said: 'bye now, Grandpa has to take a

little nap.’ Mikko died on Sunday morning 3.40 a.m. The girls and I were there to send him off and to comfort each other. Dad is no longer in pain! We went home and because of the sleepless nights, we all fell asleep right away. (105)

In the extract above, the presence of reality of death is constructed by ‘last goodbyes’ and tiredness. In the end, the participant and her daughters face the reality of death together. They were all there ‘to send him off’, which references death as the last journey. Giving the exact time of death may be important, especially when the process of dying has been lengthy and both the ill person and loved ones have endured uncertainty and strain for a long time. In the extract, death is also portrayed as a relief, an escape from pain. Reminiscing over one’s reactions in the presence of death is also a typical aspect of the frame. According to Dyregrov (2004) and Grinyer (2004), reflecting on the death of a loved one may be painful, but at the same time, it may have a positive impact on the bereavement process (also see Wong and Ussher 2009).

Discussion

In this study, detailed analysis resulted in the identification of four different frames used by the participants to construct and control the presence of death on both abstract and concrete levels. The presence of death is not just about uncertainty, sorrow or loss; it is also about activities that help gain control over the situation. What is more, the frames and death-related activities often aim to ensure the functionality of the everyday lives of other people (also see Lindqvist 2008; Shaha and Bauer-Wu 2009; Carlander et al. 2011b).

The frames found here illustrate how the medical diagnosis is brought from the confines of the healthcare facility into daily life where the presence of death becomes evident through language, death related acts like silence and protecting loved ones, existential thoughts, resisting death or

contemplating suicide. In addition, acts like maintaining cultural positions and reminiscing about the facts of death construct and control the presence of death in everyday life with cancer. Next, these elements and their connection to the health social work practice are contemplated.

First, by using language in specific ways, the participants were able to reflect on and share their emotional and bodily experiences related to the presence of death. The language they used to depict death illustrates powerful cultural prejudices as well as a sensitive and respectful attitude towards cancer and death (see also Charmaz 1980, 78–80). It can be argued that health social workers should pay close attention to the ways they speak about cancer and death. Being aware of the language they use, professionals are in a key position to help the ill person and their loved ones share their concerns about the presence of death and maybe even change the cultural images connected to cancer.

Second, frames demonstrate how abstract acts like ‘silence’ and ‘resistance’ are used actively to construct and control the presence of death. At the same time, more tangible activities like making arrangements for childcare or preparing financial matters, show the importance of processing everyday life events and ordinary chores in the presence of death. These elements can also be found from previous studies focusing on informal palliative care (e.g., Carlander et al. 2011b; Carlander 2011c), but the present study shows that these acts are similarly meaningful when death is uncertain. This highlights the fact that people living with cancer need a sensitive and practical way to reflect on the presence of death in different stages of cancer. This reflection related to daily activities can be done with health social workers, but it demands high level of professionalism.

This study shows how sensitive acts like protecting loved ones, resisting death or securing the fluency of daily life can be seen as ways to control the presence of death in daily life with cancer.

However, controlling the presence of death is not trouble-free, which becomes evident, for example, with problems in interaction or self-accusations. In the health social work context, offering a sensitive and practical way to reflect presence of death, can mean, for example, enabling a low threshold for raising discussions on the presence of death and encouraging people to follow individual death-related activities. This means permitting sufficient space for open discussion of future hopes and fears, problems with interactions, previous experiences of death and dying or even supporting the ill in planning their own funerals.

However, maintaining these compassionate ideas in practical health social work can be difficult as this study indicates; even though death becomes a part of everyday life at the time of the diagnosis, the subject becomes almost a taboo from which people try to protect themselves and their loved ones. Surprisingly, for example, in a study by Auslander (2001, 209) that scrutinised the accomplishments of health social work, the 'greater openness with regard to previously taboo topics' was not selected as being one of the most important achievements of health social work by any of the participants. In this sense, finding ways in which health social work can support people in uncertain situations like the presence of death seems to be even more important. Kovacs and Bronstein (1999, 61) suggested integrating content related to coping with death into variety of courses in social work education, not just to those dealing with late adulthood. Educational issues are also relevant here and there is a need for a further research where ill people and their loved ones are given an opportunity to describe how they felt about the presence of death and how they would have liked death to be discussed with them after diagnosis.

There are several limitations in the present study. First, research data that consisted of writings by people living with cancer or by people whose loved one had been diagnosed with cancer can be methodologically challenging. Study data contained views from people who were ill and might die,

people whose loved one had died and people whose loved one had not died. This can lead to interpretations where constructions of the presence of death are portrayed from multiple and often varying perspectives. Nevertheless, in the context of life-threatening illnesses, multi-perspective data of this kind are common (see e.g., Carlander et al. 2011c). Second, the data gathering method favours participants who are skilled in expressing themselves in writing. It is possible to argue that if the data were to have been collected through interviews, there might have been more participants. Still, the characteristics of the participants and the variation in the contents and styles of the writings show how diverse set of people were able to participate in the study. Third, in some scientific discussions, the age of the research data is directly linked to the value of the findings. Here the data was collected in 2009, but in the light of the detailed analysis and previous literature, it is possible to argue that the cultural associations of cancer and death have not changed significantly between then and now.

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Table 1. Characteristics of the breast and prostate cancer participants.

Characteristics	Women with Breast Cancer (N=21)	Men with Prostate Cancer (N=11)
Age		
Mean	57.5	66
Range	37–76	58–86
Timeline between getting ill and writing the narrative		
Year of getting ill	1985–2009	1995–2008
Range between getting ill and participating in the study	0–24	1–14
Marital status		
Intimate relationship	13	10
Single	2	-
Widow	4	-
Unknown	2	1
Employment status		
Employed	11	2
Unemployed	2	1
Pensioner	8	4
Unknown	-	4
Treatments received¹		
Surgery	21	6
Chemotherapy	11	-
Radiotherapy	9	8
Hormones	7	5

¹ Most participants received more than one form of treatment.

Table 2. The characteristics of the writings written by loved ones.

Characteristics	
Participant's relationship with the ill	
Partner	10
Daughter	1
Son	1
Sister	1
Timeline when loved one got ill	
Range	1995-2008
Was not declared	4
Cancer type of the loved one	
Prostate cancer	6
Breast cancer	2
Liver cancer	1
Stomach cancer	1
Skin cancer	1
Loved one died	8

Table 3. Steps of the analysis process.

Analysis steps	Example	Summary
<p>1 Descriptive coding focusing on the language participants used when referring to death.</p>	<p>‘I can’t choose my <i>ending</i>. I feel like I am hanging on a noose, hands tied behind my back. I am not afraid of <i>dying</i> but I am scared that the <i>end</i> might cause pain.</p> <p>Direct and indirect references emerging from the example:</p> <ul style="list-style-type: none"> • dying, end, ending 	<ul style="list-style-type: none"> • Direct references: death, dying • Indirect references: similes (e.g., erratic or unwelcome guest), images (e.g., death sentence, punishment, capture), metaphors (e.g., the end, eternal sleep)
<p>2 Coding death related activities and frames from textual contexts where indirect and indirect references were used.</p>	<p>‘I got three days to decide how the illness would be treated. I <i>tried to find information</i> about radiation therapy and surgery on the internet, but could not find much. At the time, <i>uncertainty was the hardest thing to endure, because making a wrong decision could considerably shorten my expected lifespan. I had a discussion</i> with one peer-group by phone about their experiences. That was excellent help. [...] <i>We discussed about the issue also together with my wife</i>. What a difficult decision! Eventually, we ended up with radiation therapy, which, at least, was a way to avoid risks of the surgery. Additionally, <i>future sex life had to be taken in to account, because I was not going to die any time soon – if it was up to me.</i>’</p> <p>Death-related activities emerging from the example:</p> <ul style="list-style-type: none"> • daily flow, feelings, interactions, existential thoughts 	<ul style="list-style-type: none"> • Death-related activities and frames: <ol style="list-style-type: none"> a) interaction: e.g., talking about illness or keeping silent, touching, hugging, phone calls, e-mails b) daily flow: e.g., regular treatments and control check-ups, searching for information, daily chores c) practices: e.g., making testament or planning funerals d) concrete death: e.g., reminiscing people who have died or situations where death was close e) existential thoughts: e.g., trying to understand own or loved one’s illness, resisting death f) feelings: e.g., worrying, uncertainty, fear
<p>3 Reorganising death-related frames</p>	<p>Identifying frames based on activities</p>	<p>Final frames</p>
<ol style="list-style-type: none"> a) interaction b) daily flow c) practices d) concrete death e) existential thoughts f) feelings 	<ul style="list-style-type: none"> • interaction and social issues: a,b,c,d,e,f • personal matters: a,b,d,e,f • practical actions in daily life: a,b,c,d 	<ul style="list-style-type: none"> • Frame of social interaction • Frame of creating a personal relationship to death • Frame of pragmatic acts • Frame of reality of death