

EMPIRICAL STUDIES

Four aspects of self-image close to death at home

IDA CARLANDER, PhD Student^{1,2}, BRITT-MARIE TERNESTEDT, Professor^{1,2,3},
EVA SAHLBERG-BLOM, PhD⁴, INGRID HELLSTRÖM, PhD⁵, &
JONAS SANDBERG, Associate Professor²

¹Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden, ²Department of Palliative Care Research, Ersta Sköndal University College, Stockholm, Sweden, ³Research and Development Unit, Stockholm Sjukhem Foundation, Stockholm, Sweden, ⁴School of Health and Medical Sciences Örebro University, Örebro, Sweden, and ⁵Department of Social and Welfare Studies, Linköping University, Norrköping, Sweden

Abstract

Living close to death means an inevitable confrontation with one's own existential limitation. In this article, we argue that everyday life close to death embodies an identity work in progress. We used a narrative approach and a holistic-content reading to analyze 12 interviews conducted with three persons close to death. By illuminating the unique stories and identifying patterns among the participants' narratives, we found four themes exemplifying important aspects of the identity work related to everyday life close to death. Two of the themes, named "Inside and outside of me" and "Searching for togetherness," represented the core of the self-image and were framed by the other themes, "My place in space" and "My death and my time." Our findings elucidate the way the individual stories moved between the past, the present, and the future. This study challenges the idea that everyday life close to impending death primarily means limitations. The findings show that the search for meaning, new knowledge, and community can form a part of a conscious and ongoing identity work close to death.

Key words: *Death and dying, identity, narrative research, palliative care, qualitative inquiry, self-image*

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Jaspers (1970) refers to death as one of mankind's existential limitations, and uses the term "border situations" to describe confrontations with impending death. When a person with life-threatening illness experiences limitations in bodily functions, this can undermine identity (see also Lawton, 2000; Rasmussen, Tishelman, & Lindqvist, 2010). Being close to death could mean a challenge to a sense of self (Briscoe & Woodgate, 2010) and, thus, threaten the sense of identity (Finlay, 2003; Mathieson & Stam, 1995). Furthermore, living close to death implies a loss of roles (Grant et al., 2004) and of gender dynamics (Broom & Cavenagh, 2010; Maliski, Rivera, Connor, Lopez, & Litwin, 2008). As Chochinov, Hack, McClement, Kristjanson, and Harlos (2002) previously observed, being able to sense the essence of who one is and the continuity of self was related to dignity. While distress may be

present during the end of one's life, this time can also be considered to be an important phase of growth and development (Dobratz, 2002). Ternestedt (2009) argues that positive experiences in daily life close to death could contribute to an extended self; but the opposite, a reduced self, is also possible. Humans continuously view themselves in the light of their previous experiences and their ideas of the future, (Erikson 1998). In line with this, identity can serve an integrative function in human lives, and the search to develop and arrange one's self gives life a measure of unity and purpose. In this way, a self-narrative can function as an organizer in fragmented and diffuse life situations (McAdams, Josselson, & Lieblich, 2006). Erikson (1998) also argues that identity is developed in a complex social context and is a configuration of the self that develops over time; it is not fixed and frozen. Hence, a fragment of a

person's narrative can be identified not as an expression of a distinct identity, but as a work in progress, as part of the ongoing construction of self-image over time (Taylor, 2010). People are meaning-generating beings; they construct their identities and self-narratives from the building blocks available in their common culture (Lieblich, Tuval-Maschiach, & Zilber, 1998). According to Erikson's (1998) development theory and narrative identity theory (Bruner, 2004; Lieblich et al., 1998; McAdams, 1996; McAdams et al., 2006), identity emerges from a complex interplay between the individual person as a biological and psychological being and the social context. Some authors argue that people create their own identity through personal narratives (Bruner, 2003; Lieblich et al., 1998; McAdams et al., 2006; Rapport & Wainwright, 2006). Telling stories allows people to discover themselves and at the same time reveal and construct their identity and self-image. Narrations of places form expressions of identity and self-image (Taylor, 2010). Identity is said to be about the interface between what might variously be characterized as "the exterior and interior, the peopled social world and the individual person within it, as well as the other people's views of who I am and how I see my self" (Taylor, 2010, p. 3). This can be related to the concept of self-image, which in this article is used to explore the narrative image of one self, at a certain time and in a certain situation, and contains a "body image" and a representation of the inner state in the actual point of time (Dewald, 1969). The aim of this study was to describe how people close to death narrate themselves in relation to everyday life and, thus, gain more knowledge about aspects of identity close to death.

Methods

A narrative approach was chosen in order to examine the participants' inner world and how they choose to speak about themselves in relation to everyday life over time. The stories and transcripts were examined using a holistic-content reading, which takes into consideration the whole story, theoretical understanding, and the interpretative steps taken (Lieblich et al., 1998).

Participants

Based on the narrative approach and the aim of this article, three individuals were selected due to their dense descriptions of themselves and their everyday life. The inclusion criteria for the study were: persons living at home with one or more other people; knowing they had a life-threatening illness,

with an unpredictable but probably short life expectancy; and willing to discuss their life, thoughts, and feelings. All three were participants in a project where we followed five persons with life-threatening illness and their family members, via recurring interviews over 6 to 18 months (Carlander et al. 2011). They were included over 5 months in 2008 from a department for advanced palliative home care, which at the time was responsible for 40 patients in a metropolitan area of Sweden. All patients had access to all the resources of the advanced home care team: specialist nurses, physicians, an occupational therapist, a chaplain, a social worker, and a physiotherapist. A nurse not involved in the research project approached the ill person, invited them to participate, and gave them a written information letter describing the purpose of the study and underlining its voluntary and confidential nature. All persons who were asked agreed to participate.

Data collection

The present article is based on interviews taking place at the kitchen table in the participants' homes, in some occasions in company with family members, if that was preferred by the participants. The interviews lasted from 1 to 2.5 h, and were recorded and transcribed verbatim. In order to generate stories relevant to the aim of the study, the interviews started with an open question, "How are you today?" Probing questions were asked to further explore and gain a deeper understanding of the participants' feelings and thoughts about themselves, their illness, and everyday life. Hence, the stories were constructed within the frame of the interview situation in order to explore the phenomenon of identity close to death. The first author conducted all 12 interviews, with the three participants in this article named "Viggo," "Ella," and "Flora." Eight interviews were carried out with "Viggo" over 18 months with 2 weeks to 5 months elapsing in between the interviews. One interview was performed with "Ella" 11 weeks before she died and three interviews were carried out with "Flora" 2 weeks in between the first 2 and 14 months elapsing to the last interview. The person with a life-threatening illness decided when and if they were interested to participate in additional interviews and, hence, there was no particular schedule, as the intention was to be adaptable to the participants' life situation and interest to continue the talks. In addition, at the end of every interview, the interviewer asked the participants to reflect on the interview situation and the subjects discussed.

Data analysis

The narrative approach, according to Lieblich et al. (1998), emphasizes a creative process and does not label each step. Theory on narrative identity acknowledges that identity is constructed in a social context (Lieblich et al., 1998). Our study included interviews with the ill person and one to three family members were present at four of the interviews. The present article is concerned with the analysis of the narratives from the dying person. The analysis was inspired by Lieblich et al. (1998) and performed in the following steps:

1. The three stories were analyzed as a whole, and the researcher's initial impression of the narrative was written as notes in the margins of the interview transcripts. This initial impression

was put into the form of a unique descriptive written story that remained close to the data (see Table I) in order to detect the meaning of the text.

2. The material was re-read several times, and the notes of initial impressions guided the interpretation and formulation of key aspects in each story. The inquiry was enriched by the concurrent reading of data, theory, and literature on the methods used, as these readings and interpretations shaped and reshaped the emerging themes (see Table I).
3. The identification and naming of the themes was taken beyond the individual level of analysis, to combine the common and unique stories across the narratives. The authors frequently discussed the interviews, the analytical process,

Table I. An example of the analysis showing how the themes were built from the narrative, initial impression, and key aspects.

Narrative	Initial impression	Interpretation	Theme
But that this disease, the symptoms it has caused, partly the neck injuries, even if I hadn't had cancer, my neck injuries—the fifth vertebrae had collapsed, I got something like half an inch shorter, my spine marrow was bulging, and it has restricted me a great deal physically, so I can't do the things I used to do. Forget about skiing with the kids. And I can't dive either. No climbing, no rock climbing, no . . . the orthopedist there actually said, in mid-February, the orthopedist said they wanted to limit my movement, but that I should walk for an hour everyday, and that I wasn't allowed to do anything more than that. But I had been thinking, if I manage to survive this longer than anybody else, I feel like I have to do more than just walk for an hour.	In Viggo's earlier life, his body was a well-functioning tool that he used to get the most out of life. Viggo was a well-traveled, outgoing, and physically active person. In this way, his body had been an essential part of him, enabling him to do the things that defined him as a person.	Viggo's narrative is grounded in a sense of self based on having a strong, active, and capable body.	Inside and outside of me.
But he said "It would be good if we got this done as fast as possible before you become paralyzed." . . . That felt a little scary, because it was after that . . . after I was given the radiation treatments, we were supposed to go skiing . . . What the hell, should we really take a trip up there like we usually do at Easter, just after I've gone through an entire week of radiation? . . . Sometimes I've had a hard time just walking from here to the school a block away. I thought "No, we have to make the trip to Åre," trying to keep things as normal for the kids as possible, since it has already become . . . they usually have to walk home or walk to school by themselves. They have seen how I walk, have understood that I'm in pain.	Immobilization eliminated exercise as a way to overcome his difficulty, which was a significant change from the way he had handled illness in his previous life. Skeletal pain was the main reason for his physical limitations and added to his stress as it immobilized him.	A modification of Viggo's self-image is needed in order to mirror his increasing physical limitations. Viggo's story contains narratives of the physical and emotional changes he had gone through.	

interpretations, and the findings to identify, explore, validate, and reach agreement on the initial impression, interpretations, and themes in the data.

Ethical considerations

All participants had read a written information letter about the study, and each interview started with information about the purpose of the study and the assurance that anyone could withdraw from the study at any time with no questions asked. The principle of autonomy guided the research in that the participants were considered to be capable of deciding whether to participate and which subjects to discuss (Beauchamp & Childress, 2008). Although the family member was not the focus in the present study, each family member, except the children, signed a consent form. For those, their parents had approved. The children possibly changed the participant's way of talking, but their answers and talks were not included in the analysis. The participants were orally informed that pseudonyms could be used in the study report, and that details in the quotations would be changed to decrease the likelihood of identification (Kaiser, 2009). All interviews were guided by respect for the participants' feelings and a high sensitivity and awareness of the emotional nature of the deeply personal questions asked. Crying and laughing were not unusual occurrences during the interviews and were seen as natural reactions to the subjects discussed. When the participants clearly avoided a topic, this was respected though sometimes the subject would come up again, initiated by the participants, in a later interview. The study was approved by the Regional Ethical Review Board in Uppsala 2008-03-26 Registration number 2008/051.

Findings

The unique stories were analyzed to discern patterns among the participants' experiences. Although life stories and experiences varied between the participants, there were patterns and common themes. The significance and the scope of the patterns differed for each person. The following findings have been organized by the themes that represent a structure in the stories. The stories often switched between the current situation and the recent or distant past and childhood, as well as the unknown future and their own death, revealing how these three dying persons spoke about themselves in relation to everyday life. The stories of Viggo, Ella, and Flora illustrate

these issues further, as they elucidate identity work and different paths of meaning-making and ways of defining oneself in the struggle to maintain the everyday-ness of life when one is near death.

The story of Viggo

At the time of the interviews, Viggo was a 46-year-old man living in his own home with his wife and three school-age children. Less than a year before the first interview, Viggo learned that his life was to be considerably shortened; during the investigation of a minor fracture, metastasized cancer related to his prostate cancer was found in almost every bone in his body.

Inside and outside of me

In Viggo's earlier life, he was a well-traveled, outgoing, and physically active person. In this way, his functioning body had defined him as a person. Some symptoms of his cancer and its treatment bothered him more than others saw from the outside, for example, the side effects of chemical castration as recurring sweating and impotence. Viggo also suffered from subjective symptoms such as fatigue and side effects related to morphine treatment and a reduced ability to concentrate. His bodily limitations hindered him to be the type of father he wanted to be. In later interviews, he spoke about how this challenged his feeling of dignity and will to live.

And I get sad, because I don't have the energy to do much with the kids, it's been preying on my mind, has been the most important part of the whole fight, just having the strength. Often when they come to me when I'm in bed, I can't get up and do anything with them. That's the biggest difference right now . . . that I can't manage very much. Just like I said, when you're in pain, it becomes so palpable that it overshadows everything else that you would like to experience.

Despite being fully aware of the severity of his health situation, Viggo believed that exercising was crucial in order to increase his chance of surviving. Immobilization due to skeletal pain eliminated exercise as a way of overcoming his weakness. He could not prioritize his intellectual input, due to his lack of ability to concentrate. Viggo's bodily decline restricted his interactions with his children; for example, he could not carry them or play wild games any more.

Searching for togetherness

Several years previously, Viggo had changed his focus in life and became a devoted husband and father, representing the most important part of him and his life. Now, his life situation involved two parallel processes; keeping everyday life as normal as possible, while at the same time struggling with the fact that everything had changed. Being a man and a husband to his wife was not what it used to be, and their relationship was affected by his illness.

It's like I have to try somehow to recreate what we had before all of this started, it feels . . . I just don't want to lose what we had together, you know . . . Oh, it feels awful. I told her that a few weeks ago. I miss how we used to go and lie down together, you know . . . it's like it's always about how we have to work on keeping what we have together. . . . But we haven't talked about one part, about explaining to her how my energy is limited and that I really don't have the strength to do everything I'd like to do, especially when it comes to her.

In his search for a modified self-image, he looked for new communities and other people who were in similar situations. Although he found such people at groups for sufferers of prostate cancer, his physical limitations made it difficult for him to get continuity in these gatherings. However, the Internet allowed him to communicate with people in similar life situations all over the world.

That there are so many . . . they are open people who really talk about their situation. About the disease itself and about how they feel, family life, everything, even work. They talk about almost everything you need to hear; some of the members are people who have lost someone, for instance . . . And on that site I wrote: Interests: My family. And I thought: "I don't have anything else right now." So back to all of that about being a dad, right now, you know, it has been the most important, the most, the highest priority in my life . . . I have realized that it can be, I mean, things can turn around so fast for me now. I mean, I might die in two months, if I get an infection. And you know, because I don't know if I have two months or twelve years.

Viggo searched for information and advice to help him deal with having to leave his children. The literature he read inspired him, but also gave him a bad conscience, because he was unable to realize and live up to all the "musts."

My place in space

Viggo had access to the world through the Internet, but his spatial world had declined; going outside his home was an activity that needed planning and was often postponed due to fatigue and pain. After the rest of the family left for work and school, Viggo's day was controlled by his medication schedule, bed rest, housekeeping activities, and care contacts. Viggo recognized the burden that his illness placed on his wife. Because he was the one who spent the most time at home, he took the responsibility for the household.

So, mentally, emotionally, she [his wife] is tired, she's carrying a heavy load. It's just that . . . when she gets home from work, she is often totally exhausted. . . . if I feel a little better, I don't want to spend every single hour just cleaning up after the family, because then it feels like my quality of life has declined drastically on that point, it's the only meaningful thing I have, to make sure I clean the house.

Viggo devoted some of his energy to tidying the house, being dependent on the state of the house. However, when he spoke about his contribution to the world and what had become of him, he was satisfied and did not wish to have done anything different.

My death and my time

Viggo decided to focus on his survival and on living as long as possible so he could be around and in his children's lives. Regularly searching the Internet for new medicines and new research results published throughout the world became a new part of his everyday life. At the same time as making plans to survive, he also realized that the illness and its treatment were restricting his life in all aspects, meaning that some things needed to be dealt with in an accelerated manner. One example of this was giving a lifetime's worth of love in a limited amount of time. Thoughts about his future and impending death made him sad and sometimes also filled him with anxiety, leaving him struggling to find any joy in life at all. In contrast to this, Viggo presented his thoughts of death as rather unproblematic.

I have a very strong belief that . . . when I die . . . I don't believe it will be painful in any way. It will be more of a relief. Then you end up, then I'll get to see my grandfather and grandmother and other relatives. And yes, meet Jesus and God, and ask

forgiveness of the angels who have had to ... who have worked so hard to keep me alive.

Life took a turn when Viggo's medical caregivers unexpectedly informed him that his prostate-specific antigen value had normalized. This value was a strong symbol of the future; what just a moment ago had entailed a time perspective of months had now turned into an undefined and blurry cloud of uncertainty.

It doesn't seem like the cancer is going to kill me any time soon, at any rate, and when I think about [his wife] and the kids, it's a relief of course, but if you are going to be a little selfish, it's a bit of a disappointment ... I might think it's enough ... I have done everything I can do.

The new uncertainty of time gave him feelings of guilt; he had said he was going to die, that he felt it in his body. Now it seemed that he would not in fact die, and he felt in a way like a faker. It also raised the question of who he was now to be. He was no longer a dying fighter, but a limited wreck of his former physically active self.

Key aspects in Viggo's story

Viggo's narrative was grounded in his self-image as a man with a strong, active, and capable body. A modification of his self-image was needed in order to mirror his increasing physical limitations and personal inner journey. Viggo's story contained narratives of the physical and emotional changes he had gone through, from being a dying fighter to a struggling survivor. This can be described as a process of defining a changing physical appearance, the outside, and the way he dealt with the changes, the inside. This included aspects of relating to others in a new way, experiences of time, physical appearance, thoughts of his illness and upcoming death, and coming to terms with his place in space—both in the physical sense and regarding his role in the world. Viggo's story uncovered his ways of making meaning of his life, primarily as a father and a husband. Despite this, he did not always find feelings of togetherness and a we-ness within his closest social network, and his longing for shared experiences resulted in a search both globally over the Internet and among his dead family members. Everyday life in Viggo's story was grounded in the place where he spent most of his days at home, his place in space, space expanded through the Internet. Viggo's story has a beginning when he understands he is going to die, a middle where he finds out that his time is not as limited as it first appeared, and an

end where the death is a threat but also an escape from his limited everyday life. Viggo struggled with being in limbo and not fully living, at least not in the way he defined it before his illness but he was also not dying. Viggo was the same person as he was before, but the themes also exemplified the extension of his self-image to include his former and current self-image into his present me-ness.

The story of Ella

At the time of the interviews, Ella was a 50-year-old woman living in her own home with her husband and one of their two children. She had lived with cancer for 2 years, and her life had contained a series of different cytostatic treatments. Four months before the interview, she realized that the treatments could not reduce the cancer and that her time was considerably limited. She died 11 weeks after the only interview performed.

Inside and outside of me

Ella had always viewed her body as a loyal tool that enabled her to live the life she chose. She presented her relationship with her body in a rather unsentimental way, including the changes in her physical appearance; she was now visibly marked by her illness. The presence of limitations such as a poor food intake, fatigue, and other symptoms related to accumulating liquid primarily in the area of her abdomen, rose more practical than emotional concerns for her.

Otherwise, my body, I've hardly ever been sick ... I never even get a cold, you know. And I kept fit. I wasn't overweight, I was active, was in good shape. Rode my bike a lot, walked a lot, went to the gym. But I have a tendency to objectify my body. That this is happening to my body, this just doesn't happen to me. And that was probably how I managed to handle the chemo pretty well. Because I could just somehow push it away, and try to, you know ... oh, keep it, keep it at a distance a little. But ... when it's hard to take a deep breath, I'll never be able to eat properly again. And I know that it's going to get worse, you know, and it is going to be hard. No, I don't know. I can accept that my body looks like it does with everything, all the flaws and imperfections. That's not hard for me.

Ella estimated that she had only a short time to live. Her own future and her past were closely interlaced with the vivid memory of her mother dying from the same illness at the same age. For Ella, the vivid

memories represented her own plausible future and the loss of basic control over her bodily functions.

Oh, I get so sad when I think about this. Because, you know, I was twenty years old and I look at my kids, because they are the same age I was then . . . And Mom, she was quite a, just like me, quite a, how should I put it, private person, or very reserved, so she didn't talk about it a lot either. And I didn't ask her . . . And she went in to the hospital and was admitted, and just vomited and vomited and vomited. And the worst thing was when she got openings in her abdomen . . . a spontaneous colostomy. And that meant the colostomy bag, it wasn't in a good place, it sagged open a lot, so there was a stench around her, and she thought it was so horrible when it smelled. Then she got, what do you call them, fistulas, right into her abdomen. It was horrible, and she was so fastidious about her body. I hope I don't have to go through that.

Searching for togetherness

Ella was a well-educated woman, and a leader in a people-oriented occupation. Although she had been fully committed to her work for many years, this was no longer of importance. Ella was losing strength every day and she described the complexity of living with her children, as they were in the process of leaving home to start their adult lives. It made her long to have the apartment to herself and to have time for herself, not needing to take anyone else into consideration. She turned her thoughts and engagement from the problems of the living to a new relationship and togetherness with her long-dead mother.

You can do less and less all the time. The aches and pains mean more, get more and more important. You get less and less patient with others. And you sink further and further inward somehow. And I think it helps. Or I hope it's going to help me accept my death that I am dying. Because I think you get, the worse you get, the less able you are to think about what you would like to have done. You don't have the energy to care.

She now found herself less able to take an interest in and maybe contribute to the daily activities of her family. Ella found that in this respect she had changed her priorities regarding what it was important to be in control of. Ella hinted that she had a hard time supporting and consoling her grieving family and the professional care team gave her a way

to let go and let others take over. Her connection with the palliative home care team offered her immense relief, as it acted as a support system for her husband and children. Even if in some ways Ella distanced herself from her family, she treasured those situations that emphasized peace, togetherness, and closeness; for example, when she was lying in her bed resting, with her dog by her side and her son on the other side, talking about his day.

My place in space

As described above, Ella's body told her that death was near. Ella found that the ordinariness of everyday life became meaningful. Being able to go to the store and choose a top that fitted her edematous waist gave her satisfaction and brought a sense of meaning to the day. She actively planned her day just for the joy of making plans and having a program.

So, yes, I'm well aware that I am going to die soon. But somehow, it's this insight. Sometimes, you know . . . when I am sitting around, and I start to feel this sense of pressure somehow, that it feels like the realization that I am going to die soon, but I don't want to. And it is probably that, or I believe so, that hopeless feeling, it's probably the powerlessness. That's when I feel that I have, how should I put it, control over my body, actually. Because I can never control anything now with the energy I have, with my mental capacity. Because I can actually choose right here and right now if I want to rest awhile, or if I want to try and pick up a little or clean a little, or . . . so, I can, I am satisfied with small things like this, in this situation.

Ella organized the family's paperwork so it would be easy to look over when she was dead. As a person who liked to be in control, one way for her to avoid being drawn into feelings of powerlessness was to do things that gave her a feeling of well-being, for example, having a clean kitchen. This also included dealing with the practicalities of her own upcoming death in a way that gave her peace of mind. Organizing her earthly belongings thus helped her organize, process, and in a way do something about her death.

My death and my time

Death was not a stranger in Ella's life, but her ambivalent feelings towards death surprised her somehow. Her relation to her death became self-evident and tangible. It made her see her future in the mirror of her past, as her mother's situation had

many parallels to her current situation. Ella's thoughts of her own death were grounded in the image of death as the end of everything, as nothing. She also believed that dying is an event one must meet alone. She contradicted this view, however, in the following quote:

When I sort of go there, in these daydreams and thoughts, then I can have one of those . . . A kind of daydream, or some kind of thoughts that can fill me with joy somehow, that for the moment, a brief moment, it is like being picked up, and yes, it would be Mom [who died when she was twenty]. And I guess it is like that somehow, that there is somebody there to help you through it [moment of death].

Knowing she was going to die did not mean that she accepted this every day, or that she wanted to give up or to die. She described it as a process involving both body and mind in which her bodily sufferings and fatigue helped her to live with the inevitable. Even though she was clear about her approach to her death, it was still not easy for her to communicate her thinking about her death to her husband or children.

Key aspects in Ella's story

Ella's narrative was captured only weeks before she died. The narrative integrates her life history, shaping the way she addressed her everyday life close to her impending death. Keeping together her inside and outside was related to her acceptance that her physical body no longer had the capability to live for a very long time. This acceptance also meant that she had incorporated the image of being a dying person into her self-image, where being a mother and a person devoted to her job now had a diminishing part. She understands she is going to die and her way of nearing her death is a key feature in the story. This process moved her back and forth in time, between the present and the past when she lost her mother. Her own situation made her renew her relationship with her mother. This renewed togetherness seemed to appear at the same time as her limited strength distanced her from her family. In this way, she let go of her former self-image as an engaged and active mother, wife, and anchor of the family. Her interest and mind were increasingly set on her inner world. She focused on small units of time and got pleasure from having control over the areas closest to her, finding it troublesome to be disturbed in her place in space. This narrative also shows how it is possible to be in control during the

weeks before one's death, something that stood out as being important to Ella.

The story of Flora

At the time of the interviews, Flora was a 50-year-old woman living with her husband; they had two grown-up children living in the same city. Six years previously, Flora was informed that she had cancer that had metastasized. Since then, she had gone through a variety of treatments aimed at keeping the tumors and metastasis to a minimum.

Inside and outside of me

Flora said that she was not friends with her body; fatigue affected all aspects of her everyday life. She longed to feel the strength in her body, to run fast, and really use her body. She also missed her ability to taste and smell. Over the years she had had to use antidepressants, which negatively affected her sexual relationship with her husband. She compared them to an old retired couple, in the platonic sense, but also carrying the meaning of safety and a well-known relationship. She now saw herself as a desexualized person. Although her bodily capacities were reduced, this was not visible to the eye; she was not physically marked by her illness. She said about this: "my body does not show how it feels on the inside." Her experience of her situation was not in line with her appearance and this caused misunderstandings, the need for long explanations, and sometimes the urge to defend herself. She actively searched for information sites on the Internet and kept up to date on her illness, new treatments, and therapies to help her fight side effects and symptoms. She saw a clear connection between her mind and body and used complementary and alternative medicine to enhance her mental and bodily strength and keep fear and loss of control at bay.

But, sure, the holistic thinking about body and mind and about your needs as a patient on various levels, of course, but also this off-handedness and lack of interest, you know, lack of interest that patients may have to deal with in their life situation, and which I believe can affect how the disease progresses, and that depends on how well you can manage it. And I think doctors should be interested in this.

Flora had thoroughly thought through her situation countless times, while making meaning of her illness and impending death. She described her own change and the maturation she had gone through over the

years. She described her development as a result of hard work. Two areas of personal growth that she specifically mentioned were being more able to stand up for herself and being more grounded in her priorities in life. Another thing that made life meaningful was the feeling of being in charge and acknowledged as a person with strength and capacity, a need that was not always met by her professional caregivers:

...but I am still the one in charge, what I said about not being allowed to sit down and read my chart, not being allowed to know exactly where my tumors are. That seems pretty absurd. And there I suppose I haven't, well, I've given up the battle; I don't have the strength to keep on fighting and nagging. I'm afraid of fighting and nagging too much, because there's also some kind of, I have to strike a balance with how much they can handle.

Searching for togetherness

When talking about her life Flora often used the word "we" referring to herself and her husband. She recognized that everyday life had been affected in several aspects over the years. Earlier family traditions had now become unplannable events, as they were dependent on Flora's condition that day. This created some tension in the family and gave her a bad conscience.

Oh yes, it wasn't that I sat and thought about it until I figured out a new attitude, it just evolved, that's how it was. And it took quite a while. And I talked with [her husband] a lot. And I've also talked to the pastor about it. ... And specifically this issue that you must have the right, just like I choose to give up other things when I don't think I can manage, that I would also like to be able to prioritize in order to survive, and still be here for [her husband].

The threat of death had made Flora begin her search for meaning and reevaluate her life and ways of thinking. A congregation with a chaplain who offered regular talks on existential matters and an opportunity to discuss questions related to her existence was important. Finding meaning and togetherness was a process that did not come easily but rather involved a lot of work, taking place via talks with different constellations of family, chaplain, and therapists. She had deliberately excluded some people in favor of other people interested in discussing subjects relevant to her present life situation. Discussing questions of existence together with

others offered her a new togetherness with people. Flora had found her faith and a congregation that offered her support and community.

My place in space

Flora's everyday life had narrowed to the closest blocks and her apartment. She and her husband lived in a lively neighborhood and just by looking out of her window she could see people carrying on with living their lives, which offered a sense of life to her own now less busy life. Flora had previously lived in a house with a garden and moved to the apartment after she found out about her cancer. She appreciated the elevator and the practical layout of the building, which was newly built and easy to clean and to maintain.

Yes, I keep pretty active, but I don't actually use my bedroom for anything but sleeping. It's not very big ... I stay in these open, bright areas, in the living room and the kitchen, and sometimes in [her husband's] room too, which is sort of a combined home office and where his bed is. So, we have separate bedrooms, because I need to be able to toss and turn in peace, and he snores. ... And the balcony, like I said, it's very important to me in the summer, to be able to garden a little. Since I used to have a big garden, I love it, so it's super important.

Living with her life-limiting illness offered a chance for reassessment of the importance of material things relative to spiritual values; the result of this was that Flora got rid of many of her things, as she did not want to leave them behind for others to take care of after her death.

My death and my time

Flora described how her grief over her situation had changed over time. She recalled her initial desperation over the shortness of time she had to live; now, she thought that she was further through the process of accepting the way things were and her current perspective of time.

So, I suppose I have all the time in the world, you might think, but since my energy is so limited, what I can manage to do during the days is very limited too. I suppose I try, well, the time not spent on treatments and feeling pain and lack of sleep and this, that, and the other thing, all of it. I try to do as much good as possible and make the best possible use of the day. But I do that with very simple things, just being, talking to the kids, being

with [her grandchild]. Seeing friends and my acupuncturist, seeing [the chaplain], and getting my treatments . . . I can't do any more than that, but they are good things to do.

Time had an important meaning for Flora. Her everyday life was organized around her medical treatments and its side effects and had been for many years; as far as she knew, this would also continue into the future. She called the time when she was struggling with symptoms such as nausea and pain "grey time" and said that this grey time was increasing. This meant that death often was present in her mind; in order to figure out death in general and her own death specifically.

I can't say what it [death] is. I can say what I believe it is not. I don't believe it is, well, if you're not talking about the actual moment of death or the process beforehand, but when you are actually dead, I don't think there is anything scary about it. I don't believe you have anything to answer for. . . . I believe it's, if it is anything, warm and beautiful. I don't know if it's painful. And I don't know whether people can somehow feel each other afterwards. So, I am not finished with it all, then you die. The dying, it . . . but I still think about it every day.

Key aspects in Flora's story

Flora was dealing with combining her inside and outside into a single unit and, thereby, becoming a more whole person. Her narrative was that of a person who had lived with a life-threatening illness for a long time. She spoke about processes and about her own maturity and growth over the years. Flora had, in a way, left her former communities for new ones that offered her the sense of we-ness and support that she needed to help her handle her current everyday life. When Flora spoke about herself and her thoughts and beliefs, she often used the word "we." Her self-image was closely related primarily to her husband but also to her children. Flora had changed her former sources of we-ness in favor of a new togetherness that better agreed with her present everyday life. Former friends and workmates were absent and her close family and existential guides were now more important. Flora had fitted her life in to a smaller apartment and fewer belongings, easily cleaned and taken care of, being physically reminded of death by the tiredness that permeated all the hours of her day.

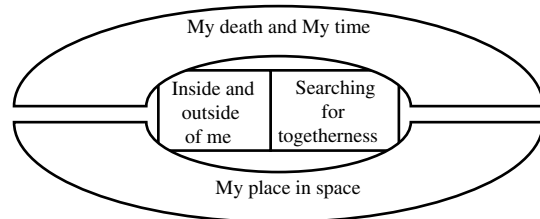


Figure 1. A representation of the two core themes "Inside and outside of me" and "Finding we-ness" and two framing themes "My death and My time" and "My place in space."

Comprehensive understanding

The main finding in this study was that everyday life close to death embodies an identity work in progress. The unique stories of Viggo, Ella, and Flora revealed four themes related to identity and everyday life: "Inside and outside of me," "Searching for togetherness," "My place in space," and "My death and my time." We interpreted the themes "Inside and outside of me" and "Searching for togetherness" as being the core themes of identity work; they elucidate how everyday life influenced the dying persons' image of self (Figure 1). The changing body, pain, fatigue, decreasing physical capacities, and changed appearance appeared to influence the participants' need for altered knowledge and community and, hence, the patterns of interactions within the families changed. These core themes are framed by the themes "My place in space" and "My death and my time"; the arena of identity work and the conscious search for meaning, knowledge, and community, limited by time and the inevitable death.

Discussion

Friberg and Öhlén (2007) describe a seriously ill patient and his striving to view himself as the same person as he was before the illness. Our results further elaborate on this in the first core theme, "Inside and outside of me," where the experience of the illness-changed body added to a modified self-image. Similar findings are reported by Cayless, Forbat, Illingworth, Hubbard, and Kearney (2010), who use the term "disrupted identity." Charmaz (2006) discusses the ways in which people construct, make meaning of, and measure their illness and bodies and calls these markers of self. The way the participants used and saw their bodies in their earlier lives influenced the way they dealt with the current situation. The uncooperative and sometimes visually changed body—the outside—had to be contrasted with the former image of a healthy, reliable, and strong body. Dealing with feelings and reactions to symptoms such as pervasive tiredness, pain, or nausea—from the inside—as well as their personal

appearance in everyday life thus seemed to have an impact on their self-image. They saw themselves as living with an inside that was not congruent with the outside; the body limiting the everyday life and being a constant reminder of the impending death (see also Melin-Johansson, Odling, Axelsson, & Danielson, 2008). These findings bear similarity to those from a study of men with advanced metastatic prostate cancer, which revealed the cyclical experience of illness as interwoven feelings of being well and being ill at the same time (Lindqvist, Widmark, & Rasmussen, 2006). The feelings of wellness could be interpreted as being able to, despite bodily decline, experience a feeling of being oneself and in harmony with one's image of self.

We interpreted the second core theme, "Searching for togetherness," as the search for people to talk to and groups to belong to and share mutual interests in. This search for social interactions and feelings of togetherness was important in the individual struggle to deal with everyday life. Everyday life close to death meant that old patterns of interactions within the families had changed and that family interests and lifestyle needed to be reworked. Moreover, relations with people in general, such as colleagues and old friends, had also changed due to lack of fortitude and limited interest in things that used to be important. However, human connection was highly valued (see also Thorne, Con, McGuinness, McPherson, & Harris, 2004). The result of this was a search for new togetherness, with people who could meet this new need for knowledge or the exploration of existential questions. This complements the findings of Roger and Medved (2004) who studied couples in which one suffered from chronic illness and described the importance of searching for and finding a joint identity built on couplehood (see also Hellström, Nolan, & Lundh, 2007). In the identity-work close to death, two of the participants in this study had an increased relationship with their dead loved ones and, in this respect, the search for togetherness was not limited to the living; in addition, they could access the whole world through the Internet.

The framing theme "My place in space" had a dual meaning. Firstly, in concrete terms, the home was seen as an arena for identity work; it was the place where daily life was organized, carried out, and negotiated. This was related to the meaning of the dying persons' decreased access to their former physical radius. Now, when the body was more inflexibly located in a specific place and, thereby, contextually situated in time and space, the home and close neighborhood became the arena for life and living and the place they spent the most time. As

explained by Dyck, Kontos, Angus, and McKeever (2005), privacy, safety, comfort, and control are key aspects of the home, which thereby serves as a shelter for the vulnerable body, but also gives room for negotiation and offers one the ability to maintain control over one's social identity. In this respect, the stories illuminate the physical arena of the home and closest surroundings as part of the modification of self-image and identity work. Wrubel, Acree, Goodman, and Folkman (2009) reported similar findings, pointing out the importance of preserving connections to aspects of life that define who one is as a person, something that in our study we understood as the participants' "place in space." They argue that a relocation, cognitive impairment, or ongoing substance abuse can be seen as an aspect that could risk and weaken one's relation to oneself, resulting in an interrupted lifeworld. The second meaning of "My place in space" was related to the existential question of coming to terms with one's contribution to mankind and being sufficiently satisfied with what one has accomplished in life. When the participants spoke about these matters, they seemed to see the loss of close relations and not being a part of their loved ones' lives as the greatest loss.

The other framing theme, "My death and my time," described individual ways of experiencing time close to death, and revealed the dichotomy in longing for life while simultaneously accepting death also described by Feigenberg (1977) and Qvarnström (1978). Thinking about the impending death implied sadness and anxiety, which displaced joy in life, which in turn influenced the will to continue living. Growth and change were implicit and explicit aspects of the participants' everyday lives, where self-image was continually constructed and reconstructed. One assumption in this study is that death is associated with involuntary stretching of personal limits and the development of self-insight. A number of authors have emphasized the importance of coming to terms with impending death (Glaser & Strauss, 1965; Mak & Clinton, 1999; Steinhauser et al., 2000). The findings in this study elucidate the impact of time as an aspect of identity work in everyday life with a life-threatening illness. Do self-image and identity matter close to impending death? According to Rapport and Wainwright (2006), the relationship between the self, health, and illness can be seen as self-evident. When a person knows she or he is dying, this can trigger existential questions and an examination and summarization of the life lived. The three stories described in the present study expose thoughts of death and dying, but also the experience of difficulty talking about the things that

really mattered in this situation. It seems to be important to let the past and the former identity, as well as the new, be a vital part of the present situation. Accordingly, narrating one's own life story could be a way of becoming more whole, and a way to reclaim a decreased self-image. Further research is needed to answer the question of whether the participants in this study are unique in their way of performing their identity work. The findings also point out the need for togetherness and knowledge close to death. In conclusion, while working on modifying their self-image, the participants in this study seemed to have an urge for an altered togetherness that was not always fulfilled by their closest family or even by the living. There is a need for further research on how this togetherness is constructed, is experienced, and can be supported for persons living close to death.

Methodological issues and trustworthiness

One purpose of this study was to explore the phenomenon of self-image and identity close to death. Erikson (1998) considers that human development takes place in a social context. Our study was based on the idea that interviewing individuals together with family members could help in examining aspects of the self-image of individuals living close to their own death. In this way, the research draws on the stories told by the person close to death. It must be kept in mind that the researcher has been told only one version of a story, constructed for, in, and by the interview situation. This also applies to the fact that different stories are told when the person talked about is present. This also means that the relationship between the interviewer and the participant is an important one, especially when interviews are repeated over time. In this way, the interviews enabled sharing of the understanding of everyday life close to death (Friberg & Öhlén, 2009). In the acts of being together in a room, stating the purpose of the encounter, asking questions, relating to the responses, and participating in the creation of an atmosphere some interpretive choices have already been made (Lieblich et al., 1998). This can be seen as strength of the present study, as the phenomenon of interest was discussed in different settings and with different participants. The participants in this article could be characterized as capable, well-informed, competent, and very able to articulate their thoughts and feelings. In order to reach the standard of quality in narrative research described by Creswell (2007), we used a thickly described contextualized phenomenon in order to reveal the processual features of the experience.

Other aspects of quality in this study are the focus on three individuals. The stories collected are about significant experiences related to these individuals' lives, and the analysis elucidates how these experiences affected the participants' sense of self and identity (Harnett, 2010). This made it possible to report the themes that were built from the analysis of the individual stories. The reading presented in this study does not aim to display the truth but rather to offer a way to understand the phenomenon under study. The intention of the study was to tell a story that restored the story of the participants. When analyzing the experience of another person, it is necessary to discuss the concept of "interpretive level." We argue that no reading is free of interpretation. According to Mishler (1990), reading and interpreting a narrative involves a continual dialectic between data, analysis, and theory. The theoretical understanding of the present study was underpinned by Erikson's (1998) developmental psychology theory and narrative identity theory (Lieblich et al., 1998; McAdams et al., 2006; Taylor, 2010). The findings cannot be generalized, but it is reasonable to assume that the stories told and their interpretations are transferable to similar situations. However, more research in this area is needed.

Clinical implications

Listen to the subjective story

This study is concerned with the dying person's experience of their situation and understanding of upcoming death. This can be contrasted with the routine practice in palliative care of objectively recognizing and deciding the breaking point when the patient is dying and responding with actions directed toward the patient and family. The clinical implications of our analysis of the participants' stories lie in the articulated connection between aspects of self-image and identity and the person's life-story and the way everyday life and the upcoming death are experienced and met. In order to enhance palliative end-of-life care and, ultimately, a dignified death, it is important to recognize this ongoing identity work. Professional caregivers can offer time to talk with their patients but above all listen, which seemed to be truly important but not always recognized.

Person-centered care

What is the role of a professional caregiver who cares for a dying person? One implication of the present study is that people can only be understood by means of their world of ideas and point of view. Living with

life-threatening illness and impending death is a unique life situation and, consequently, every person has their own pictures and ideas of its meaning and consequences for themselves and the people close to them. This study has also shown that it is not only possible but essential to be in control when one is close to death and to recognize a person's strengths, assets, and capabilities as a way to promote identity and self-image. This could also mean organizing end-of-life and palliative care by placing the ill person and their family at the center, rather than letting economical or staff-related issues be the steering values in the organization even though these frames must also be handled responsibly.

A shared care plan

Our findings give support for including the subjective view on everyday life when making an end-of-life care plan, in collaboration with the dying person. The aim of this increased participation in the care plan is to give the dying person power and control over his or her life.

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