

Activity and meaning making in the everyday lives of people with advanced cancer

KAREN LA COUR, REG. O.T., M.SC., PH.D.,^{1,2} HELLE JOHANNESSEN, PH.D., MAG. SCIENT.,¹ AND STAFFAN JOSEPHSSON, REG. O.T., PH.D.³

¹Institute of Public Health, Research Unit Health, Man and Society, University of Southern Denmark, Odense, Denmark

²School of Occupational Therapy, University College Sjælland, Naestved, Denmark

³NVS Department, Division of Occupational Therapy, Karolinska Institutet, Huddinge, Sweden

(RECEIVED February 27, 2009; ACCEPTED April 19, 2009)

ABSTRACT

Objective: This study aims to explore and understand how people with advanced cancer create meaning and handle everyday life through activity.

Methods: A purposive sample of seven participants was recruited from a larger study. Data were collected through qualitative interviews and participant observations conducted in the participants' home environments while they were engaged in activities to which they assigned particular value. Interpretive analysis was conducted using narrative theory and relevant literature.

Results: The study shows how people in conditions of advanced cancer fashion narratives useful for handling everyday life with advanced cancer. A meta-narrative of "saying goodbye in a good way" provided an overall structure for the participants as they attempted to create desired narratives negotiated in context of the individuals' sociocultural life and in the proximity of death. A narrative of "being healthy although ill" provided an arena for exploring the contrast between simultaneously feeling well and severely ill. Further employment of activities in "routines and continuity" was identified as a means to provide a safe, familiar framework stimulating participants' everyday agency. "My little Mecca" was identified as a narrative reflecting the activity of life-confirming experiences and taking time out.

Significance of results: The identified narratives performed and told in daily life may guide the development of palliative care services to support people with advanced cancer in creating meaning in the remains of their lives.

KEYWORDS: Activity in daily life, Advanced cancer, Narrative, Meaning making

INTRODUCTION

Advanced cancer often involves significant disruptions in an individual's everyday life, for example, through the loss of bodily functions, of social roles, and of the capacity to engage in basic daily activities (Taylor & Currow, 2003; Zachariae & Mehlsen, 2004; Grønvold et al., 2006). Furthermore, it has been argued that participation in meaningful activity is important for achieving a worthy life when facing disruptions due to life-threatening illness (World

Health Organization, 2002). Consequently, it is important to gain knowledge about how activity in daily life is related to meaning making and may be a resource in addressing the challenges of life with advanced cancer. Therefore, the objective of this study was to explore and understand how people living with advanced cancer find ways to create meaning and manage everyday life through engagement in activity.

A number of scholars have argued that humans understand themselves and their participation in a social/material world through narrative forms (Ricoeur, 1985; Polkinghorne, 1988; Bruner, 1990; Mattingly, 1998). That is, the creation of meaning and

Address correspondence and reprint requests to: Karen la Cour, J. B. Winsløvs Vej 9, 5000 Odense, Denmark. E-mail: klacour@health.sdu.dk

content in everyday life is linked to narrative processes, including both verbal constructions and emplotments in human action, and is therefore told as well as lived. Furthermore, Mattingly (1998), Hydén and Hydén (1997), and Charmaz (1991) suggested that, in times of difficult life transitions and trauma, such as advanced cancer, people draw upon narrative forms of meaning making. That is, people tell or enact stories to explore and create understanding of experiences of disruption and change in order to find new or alternative directions in life. Ricoeur (1985) argues that narratives do not simply mirror lived experience, and he points out that the telling or enactment of a story is a social process of constructing meaning. On the basis of these considerations, we find narrative theory to be a relevant framework for the exploration and understanding of possible relationships between activity and the creation of meaning and content in everyday life for people living with advanced cancer. Although many studies have explored the narratives of people dealing with severe illness (Hydén & Hydén, 1997; Charmaz, 1999; Ville & Khlát, 2007), they seldom address how narratives are used in the construction of meaning making through the emplotment of everyday life activities when people are facing imminent death.

In this study, *activity* is understood, in line with Jackson's (1996) definition of occupation, as the culturally and personally meaningful activities in which individuals engage on a daily basis or at various times throughout their lives. *Meaning making* has been described as a process of attaching significance to experiences through cultural participation (Polkinghorne, 1988; Bruner, 1990). The focus of this study is on meaning making guided by the activities that participants highlight as important for handling life with advanced cancer. According to Pörn (1993), *health and well-being* can be understood as a person's opportunity for action, where abilities and environment interact and influence activity in daily life. Consequently people's experience of meaning and well-being are not simply influenced by circumstance but also by what they do, by what they can do, and by the ways in which they handle their situation. Furthermore, Alsaker and Josephsson (2003) propose that daily activities be understood as arenas for ongoing negotiations of engagement in everyday life. Following that line of reasoning, activities of everyday life provide a relevant arena for exploring experiences of meaning making and well-being.

In the literature, engagement in activity is identified as a source of meaning, linked to experiences of health and well-being throughout life (Breitbart, 2002; Pizzi & Briggs, 2004; Wilcock, 2006). However, research on how this occurs in everyday life is sparse. Furthermore, research on engagement in activity

among people with advanced cancer has primarily been conducted in institutional settings (la Cour et al., 2007). In previous studies, we found that when people with advanced cancer engage in activities like arts and crafts in a therapeutic setting, they also worked with ways of living in proximity to death (la Cour et al., 2005, 2007). These findings raised further questions about activity in daily life when one is facing life-limiting illness, such as what opportunities and meanings can be created through engagement in activity in the homes and in other arenas of daily living and how that takes place. At present, there is little knowledge regarding activity in everyday life settings from the perspective of individuals living with life-limiting illness. Increasing numbers of people with advanced cancer live at home for as long as possible toward the end of life. This brings a need for research-based knowledge of these people's experiences of the role of meaningful activities in managing the demands and challenges they face in their daily lives.

Existing research on activity for people with severe illness tends to focus on treating disease and providing symptom relief (for depressive symptoms, for example; Hutchings, 2007), rather than exploring activity as a potential resource in creating a meaningful life for the whole person living with disease. Although it acknowledges that activity may be complex and that it may present challenges and constraints, this study explores the potential for constructive meaning making as an aspect of activity that so far has received little attention.

METHODS

A purposive sample (Luborsky & Rubinstein, 1995) of seven participants was recruited from a larger Danish study exploring the daily activities of 45 people with advanced cancers where cure was no longer expected. The inclusion criteria for the present study were (1) a diagnosis of either lung cancer, colon cancer, or breast cancer (the three main cancer diagnoses at the oncological outpatient unit where the study took place), (2) a variety of social situations (such as individuals living alone or cohabiting), (3) a variety of ages, and (4) individuals engaging in a variety of activities in their daily lives (such as gardening or Internet activity). The participants were five women and two men between 39 and 67 years of age. The primary diagnoses were two with breast cancer, three with lung cancer, and two with colon cancer.

The study was approved by the Danish Data Protection Agency. The participants received written and verbal information about the project and were given time to consider their participation before verbal

consent was obtained. They were assured that any information given would be treated in confidence and reported anonymously.

Data Generation

Data were generated in qualitative interviews (Kvale, 1996) and participant observations (Davies, 2001). The qualitative interviews focused on the participants' experiences of their daily activities. During interviews, the participants were encouraged to talk about their activities. For example, questions were posed as to how the participants experienced the activities they engaged in during the day and what activities they considered significant in their daily lives under their current circumstances. Interviews were audiotaped and transcribed verbatim. Data were generated over a period of 18 months, with one to three visits to the participants' homes. A total of 12 encounters took place, comprising interviews and participant observation. The encounters lasted between 1 and 3 hours, and participant observations were conducted in connection with the interviews to achieve a thorough understanding of the context in which participants conducted their daily lives and to observe the activities as they took place. Field notes were made up of data from participant observations and were subsequently expanded into full texts. All data were collected by the first author, and an occupational therapist participated in some of the interviews.

Data Analysis

The data were analyzed using an interpretive approach based on Ricoeur's (1985) theory of narrative emplotment and with the reasoning of Polkinghorne (2004) and Mattingly (1998) of narrative as additional resource. Ricoeur (1985) identified narrative as an emplotment and as the establishment of relations between events, actors, motives, and desires so that these are linked in meaningful configurations. The analytic procedures implied, first, that all material from interviews and participant observations written into full-length text was read carefully to get the gist of each of the individual participant's narratives. Next, significant events were identified within the stories. Significant events were understood as events that people found worth telling stories about and that could therefore be considered as particularly meaningful to them (Mattingly, 1998). For example, participants reported that they had been told there was no cure for their disease, which was identified as a significant turning point motivating them to make the best of what remained of their lives and to "say goodbye in a good way" as they expressed it. With the structure of a

narrative in mind, emplotments around significant events were then identified and tentative narratives were constructed (Polkinghorne, 2004). This also involved returning to the participants to acquire more information on subsequent visits. The data were scrutinized to identify narrative structures such as beginning, middle, and end, and the plots within the individual stories, whether enacted or told (Mattingly, 1998; Polkinghorne, 2004). In that regard, plots were understood as narrative structures, within the participant's description of relationships between the events and choices of their daily lives, as identified by the researchers (Ricoeur, 1985; Polkinghorne, 2004). To understand the processes of activity and meaning construction, the material was analyzed to identify the reasons and motives that participants used to explain the actions and circumstances contributing to the narratives. The analytical questions concerned issues such as the following: What narratives did the participants share? How were the narratives created? What motives guided the narratives? For whom were they created?

In the following step of the analysis, common emplotments were identified across all of the participants' narratives and reconstructed into a few narratives conveying those significant to the participants. As an example, a common narrative of "I am healthy although I am sick" showed how the participants in various ways created narratives through which they could claim being both healthy and sick, according to specific situations and the demands and tasks implied in these. After the first author had conducted the initial analysis of data, these findings were discussed with the coauthors, who then contributed ideas for continued analysis. The final interpretations agreed upon by all authors were finally presented to a group of senior researchers and fellow doctoral students in a peer review.

RESULTS

Based on the analysis, a central narrative was identified as the meta-narrative of "saying goodbye in a good way." Within this meta-narrative, three smaller narratives evolved and were identified as "I am healthy although I am sick," "routines and continuity as a platform for agency," and "my little Mecca." In this article we use the term "meta-narrative" to refer to the overall plot that sets the framework for a number of smaller plots and narratives, that is, as a term referring to what Mattingly (1998) calls a story that holds smaller stories within it. The names given to the narratives derived either from quotes from the participants or from suggestions by the authors.

“Saying Goodbye in a Good Way”

“Saying goodbye in a good way” was identified as a meta-narrative that seemed to be of importance to all participants and guided what they did and how they managed everyday life. Although cancer treatment has advanced considerably, cancer still tends to be associated with fear, suffering, pain, and death, which thus presents the sociocultural context for having to live with advanced cancer (Zachariae & Mehlsen, 2004), and all participants shared a genuine concern about this.

All of the participants gave an account of their experience of the discovery that they had cancer, even though they had not been prompted to talk about it. Most participants said that it had begun with subtle signs such as pains, and how these spurred growing suspicions of the onset of a severe cancer or a recurrence of previous cancer. However, this time the participants confronted the fact that they could no longer expect a cure. This recognition of incurable cancer appears to be a turning point and the beginning of a new meta-narrative. Yet, the participants’ emplotment of narratives seemed far from being a linear process; it was rather as though cancer led the participants on journeys that appeared to be under constant construction. Throughout our meetings, participants brought up issues they had to face in order to say goodbye in a good way, without knowing when that goodbye would actually be. As Ella, 46, living with her husband and three children, said:

I’ve been told there is no cure for my disease and therefore I have to employ my time so that it becomes a good and meaningful way forwards. We say goodbye in a good way; we get something out of it, not because the goodbye is just around the corner, but you never know.

The fact that there was no cure implied living with death on the horizon, which possibly motivated Ella to narrate and conduct her life by “saying goodbye in a good way.” In narrative theory Mattingly (1998) proposes that storytime is organized as “movement towards endings” (p. 85). In Ella’s example “saying goodbye” can be seen as such a narrative structure of moving toward the end of life, initiating the narrative that Ella outlines. Furthermore, saying goodbye is not just about Ella, for her inclusive “we” tells us that it also embraces saying goodbye in interaction with the family and the people she cares for, which seems to motivate her to shape the story of saying goodbye “in a good way.” So with this plot Ella expresses the drive to live the life that remains to her “in a good way” and to have that drive direct her activity.

Ella further reflected on activity with her family:

[W]hat I think is most important is that afterwards my children, my husband, and my friends can say that it was fun after all, that it was really a great time. . . . Now tomorrow we are going to a party—I’m looking forward so much to being with our friends on the beach. There we are not going to talk about illness—we will have fun. My husband has taken the day off, and we are going to have red wine and that’s how it should be!

It seems that the narrative of “saying goodbye in a good way” influences how Ella values and engages in activity so that the prospective end of life frames activities that are performed in an attempt to create those impressions and memories that she hopes to leave with her family.

Similarly, other participants also shared narratives of intentions to stage a “goodbye in a good way.” Chris, a man in his early 50s living with his partner and their son, suffers from advanced lung cancer and said that he found it very unfair that he had got cancer. How he appeared to others was important to him, as was how he handled his situation. He said,

And those cases where you hear—‘well then he sits in the corner and is bitter and sleeps all the time’, I don’t want to be remembered like that. . . . I don’t think I am perceived as negative; . . . humor is what I try to survive on.

Chris points out that sitting apathetically in a corner is not how he thinks people should behave when severely ill, indicating that to him it is better to take part in life. He has concerns about the impressions he makes and connects this to the end of life in his near future and to the memories others would have of him. In this, Chris seems to express a desire to “say goodbye in a good way,” which governs the story he creates and his way of life.

Chris and Ella, like most of the other participants, struggle to create narratives that emphasize positive and constructive approaches to living with the uncertainty of when life will end. With this “positive” narrative framework for saying goodbye, they possibly attempt to minimize the sorrow that they fear they may cause the family and ease the burden they themselves are experiencing.

From the onset of the recognition of advanced cancer it seems that participants integrate their desires to say goodbye in a good way into their everyday activity. This finding seems further supported by the identification of smaller narratives of “being healthy although sick,” by creating “continuity and

routines” and by comforting and enriching experiences associated with “my little Mecca.” This brings us to the next narrative.

“I Am Healthy although I Am Sick”

In this narrative the participants emphasize the importance of being healthy although severely ill. With its positive focus, this narrative can be seen to support and strengthen the ideas embedded in the meta-narrative of saying goodbye in a good way as the “good” way is more about the health-associated aspects of life rather than about being sick.

“I am healthy although I am sick” is a narrative that holds suspense in the contradiction between being healthy and sick at the same time and the challenge of how such ambiguity can be handled. “I am healthy although I am sick” was narrated in various ways. Participants talked about juggling experiences of being healthy although sick in encounters with other people and in the ways they approach and conduct activity. For example, Rita alternated between talk about walking the dogs, which she associated with being healthy, and talk about her illness. Further observations in the homes identified how participants conducted their lives both as sick and healthy; they kept up ordinary activities and at the same time were heavily affected by the disease. The participants not only told narratives of being healthy although sick; through their activities they also staged being healthy although sick as a form of enacted narrative. For example, both Linda and Beth were observed one moment making coffee and the next needing help carrying the milk because it was cold, and the side effects of chemotherapy prevented them from carrying cold items. In that regard, enacting a narrative of being healthy although sick is not just a matter of choice but also a mirroring of the women’s reality.

The complexity of being both sick and healthy was also part of Linda’s narrative. She was a young woman of 39, divorced and living with her two teenagers. She talked about projects she wanted to do and said, “It’s nice to do things because there is nothing wrong with my head. It’s only my body that cannot keep up.” Here Linda shared on one hand her desire to do something—activity in itself thus seems to be a symbol of health and well-being—and on the other the reality of not being able to enact activity due to the physical deterioration and restraints caused by the cancer. Linda’s example calls attention to an experienced split between body and mind regarding what she would like to do and what she is capable of doing. In addition, as Linda emphasizes being well and diminishes the illness affecting her body, she narrates herself as healthier

rather than sicker and so supports impressions of “normality.”

The notion of being capable of activity is addressed in the narratives of several participants and relates to the notion of being healthy. This comes to expression as participants share how, through activity, they enact a manifestation of being “healthy.” For example, when one arrived at Beth’s house, the driveway, the garden, and the house were all neat and tidy; no garden tools or superfluous objects were visible. Beth said:

Sweeping the driveway, I know it’s stupid for me to do it [since it causes pain] but I also enjoy feeling, what shall I say, healthy and . . . capable of doing such chores.

Despite the pain, Beth gave priority to an activity like sweeping as it confirmed her sense of being healthy; that she could accomplish such chores was literally a bodily manifestation of competence, and thus it became a significant event in her emplotment of being healthy although she was sick. Another narration of “I am healthy although I am sick” concerned social activity. About going to a party Ella said:

It means so much to me not just to be a patient all the time. I think that’s almost the hardest part about this. For example, when we attend a party at the school . . . then it’s as if people, . . . that I am afraid that people think when we are sitting at a table, that they feel obliged to sit and talk about illness with us, not that they don’t come and sit at our table, but I can sense when they do come . . . where you normally would say, ‘Hi how’s it going? Isn’t it a great party?’ to us they say ‘Hi, how are you? Are you still in treatment? How’re you managing?’ . . . My husband says, ‘Relax,’ but to me it is an enormous loss of prestige.

Ella attended social activities at her children’s school, which Danish families commonly do. This is associated with normality and health, but she believed that other people felt intimidated by her illness and obliged to inquire about it. Furthermore, she felt reduced to “the sick person” and that reduction made her feel a loss of face.

Ella’s narrative shows her creating her own drama through the constant tension between experiences of being simultaneously healthy and severely ill. Narrative time is dramatic, and Mattingly (1998, p. 85) proposes that, in times marked by conflict, there is an implicit dialogue between different points of view. In Ella’s example above, the drama is in the conflict between, on the one hand, being sick and, on the other, being involved in what she considers as

“normal and healthy” activity and having that activity recognized. This tension forces Ella to negotiate her situation of being both and reflects the fact that to enact a sense of “normality” in the social arena of daily life is not without friction.

Like Ella, Leo, who was living alone but in close contact with his ex-wife and children, shared a story about balancing sickness and health:

I do not want to be a cancer patient in chemotherapy, I don't. . . . I have been conscious of it all the time; it should dominate everything as little as possible. I am not bothered by anything. I think I live a totally normal life and no one can tell from looking at me that I am a cancer patient. I have done something about it because I know that I don't want to walk about looking like someone on early retirement and a cancer patient, bald and scuttling sideways with a walker. I have been so lucky!

Leo's story accentuated the importance of appearing and acting healthy in social situations in order not to be identified as a cancer patient. At the hospital he also always made sure he sat in a chair, not in bed. He explains being healthy although sick as a combination of luck in not suffering from stigmatizing side effects (like loss of hair) and of his determination deliberately to lead everyday life like everyone else. Yet, on another occasion, Leo admitted that he was fighting to resist lying on the sofa several times a day, which seems a contrast to his assertion that he was leading a normal life.

The above examples call attention to the contexts in which people find themselves and the ways in which they may influence the construction of being healthy although sick. That was exemplified by Ella, who reported how her children treat her as a mother even when she is vomiting. In such a situation her daughter once asked her, “Are you done, Mom? Because I need to talk to you about a pair of jeans I saw downtown,” and Ella comments, “It's incredibly rude, but also very life-confirming.” In this example Ella expressed her appreciation of the mother role and also of the way her children supported or “forced” her to remain a mother who could attend to “mother issues” whether severely ill or not. The children's expectations of Ella and the way they treated her can be viewed as exemplifying the influence of the sociocultural context on the narrative meaning making. Ella's narrative is not just configured by the immediate environment of family, however, but is also influenced by her struggle to maintain social roles and prevailing norms that support the positive connotations of being active and healthy.

Routines and Continuity as a Platform for Agency

The next narrative concerns routines and continuity that seem to be associated with order and security amid the humdrum of everyday life while providing a platform for agency. This narrative also subscribes to the meta-narrative of saying goodbye in a good way, as routine activity and continuity convey the reassuring sense that life goes on in the midst of life-limiting illness.

Rita, a 63-year-old mother of two adult children and living with her husband, spoke about her daily life structured around firm routines and rituals. Rita stated, “I love my routines” and referred to her coffee in the morning and the regular grooming and walking of her dogs. Further, she said:

It is impressive, my illness has lasted for 15 years and when I first got ill my neighbor made this path around the fields where I could walk and scream and really act out. And I did that for many years. . . . Actually it wasn't until I got sick the second time, 5 years ago, that my neighbor started walking with me. It's so funny because she has had this wonderful field to walk in but she never did. . . . But I knew everything much better than her. So I've taught her a lot out in the field about birds and suchlike. We do it every day. . . . I have rituals for everything from when I get up at 6:50 in the morning.

Rita has walked around the field over and over, and within that routine she found space where she could shout out her frustration and sorrow about her illness. Simultaneously, that same context has stimulated her to gather information about birds and nature, which she then taught her neighbor. The daily walk is emplotted as a routine that helps Rita in her everyday life and at the same time forms a platform for developing an expertise that enabled her to give something back to the neighbor. This bears a relation to narrative theory, which suggests (Ricoeur, 1985; Mattingly, 1998) that the self is composed of an ongoing stream of continuity that functions to ensure sameness over time, interwoven with discontinuity characterized by change and human development. In Rita's case we see continuity enacted in the daily dog walk and qualities of discontinuity in finding ways to rid herself of frustrations and engage in new dimensions of exchange and friendship with her neighbor.

Leo said he always liked to cook, and for fun his family gave meals stars for quality. Arriving at Leo's house, the first author observed that he had set the table with neatly folded napkins, wine glasses, and

homemade sandwiches. He had made lunch for us, although the interview was before noon. It seemed that Leo used the occasion, in this case of two people coming to interview him, as an opportunity to prepare a meal, a favored activity. Leo has always enjoyed cooking, and creating a homemade lunch can be seen as an enactment of continuity, supporting him in taking agency. Both Rita and Leo seem to integrate and emplot aspects of continuity in their desired activities. By conducting activity that they have always engaged in, they enact the continuity of daily life; it is not so bad and has not changed much despite severe illness, which, in turn, contributes to the meta-narrative of making it a good way toward their end. They do as they have always done as a way of emplotting each day as usual, which may, in turn, give the impression of control and normality. In addition, striving for days to be “normal” seems to provide a platform from which the participants explore new forms of activity and approaches to everyday life.

“My Little Mecca”

“My little Mecca” is a narrative in which, despite the despair accompanying the loss of basic skills, participants seem to find their own ways of performing activities that enable them to access individual resources facilitating experiences of pleasure, consolation, and enrichment. During an interview Ella said,

I’m in the garden as much as possible and I “force” Niels [her husband] to carry the heavy things because I am the only one in the family who really cares for the garden. I give it high priority.

Interviewer: And what is it about the garden?

Ella: It’s just so wonderful, because it’s life, it grows out of the soil. I cut and weed and I imagine these flowers blossoming.

Here the symbolic meaning of the flowers growing and representing life in the light of Ella’s situation facing life’s end is significantly life-confirming. Once Ella showed us her greenhouse, pointed out a plant, and said “I didn’t think it would survive the winter but look how it is growing now.” Ella did not think she would survive herself, and while still alive possibly found a sense of hope in working with the plants that can be seen as symbolically mediating her desires and actions. Through the plant-growing activity it seems that Ella is able to approach existential issues in her own situation. This relates to the narrative function of distancing. On the understanding that every emplotment is one configuration

of meaning out of myriads of possible emplotments, Ricoeur (1985) argued that distancing may function as a loop in providing space and freedom from reality to shift ways of understanding of a given situation. For example, in Ella’s case, it is conceivable that by gardening she can distance herself from her situation of cancer and impending death. At the same time, gardening can symbolize Ella’s situation and become a means of creating meaning in her current circumstances. That is, by working with plants and nurturing them so that they survive and blossom, she comes into contact in the plant world with aspects of life and death, hope, and survival as a parallel to her own situation. Following Ricoeur’s (1985) line of reasoning about distancing, Ella’s involvement in growing flowers is a way to extend the possibilities for other interpretations of her current situation.

On a later occasion Ella explained that, “Just carrying the soil is a major problem for me, and I can spend 3–4 hours just on a project of making this little flower grow. That isn’t something I can entertain the family with. They couldn’t care less. It’s my little Mecca.” Ella underscores her investment in gardening, and, with the Mecca image, she underlines the meaning and importance of the activity. Moreover, through the emplotment of gardening activity as Mecca, Ella seems to create a space for activity through which she can achieve experiences of enrichment and completion.

Another example of creating an individual “Mecca” is given by Beth, who enjoys painting and decorating her house. She said that, if it was up to her, she would repaint the house every second year. Beth once ran a kindergarten at home but stopped that due to illness. Her own children are grown up, yet Beth wished to keep and decorate a children’s room. She had painted it in bright colors with matching curtains and made wall decorations herself. The decorations were children’s pictures downloaded from the Internet, painted in her favorite colors and laminated. According to Beth, she used this room when feeling ill, and she said, “It gives me something, so now I have a bed in that room; it gives me peace.” Beth described how she turned the room into her own, using her creative capacities and even making it a place that was soothing to her when feeling ill. Like Ella, Beth crafted narratives about a certain kind of activity through which she accessed her own resources and created something pleasurable. The example illustrates how experiences of richness, consolation, and completion are created through narrative processes of emplotment developed through activity.

The above stories show how certain activities can represent spaces that are both a physical place, a

materialized creation communicating the individual's creative forces, and a life-confirming expression. However, these activities must be understood in a context that comprises the daily struggles of suffering and being severely ill in a situation of limited resources. In that context the individual is trying to establish some sense of "being healthy" and "making the best of it." As Ella said, moving the soil was a big problem for which she needed her husband's help, and thus she pointed to the obstacles that may be involved in creating a Mecca. It is not an easy task but a challenge for individuals who are sick to build the narrative space in order to carry out activities that are important to them. Within these activities they find opportunities for taking the initiative and appreciating their lives as meaningful.

DISCUSSION

According to Ricoeur (1985), the trustworthiness of narratives is a question of the plausibility of the plots identified as well as their explanatory potential in relation to existing knowledge. Therefore, we have attempted to address the plausibility of the findings in this study in the following discussion, while we acknowledge that the narratives identified can only represent a selection of potential interpretations out of myriad possibilities. In that regard it should be noted that narratives are not simply a recounting of what happened. Narratives are meant to persuade the narrator and the audience (Mattingly, 1998) and must be seen as co-constructions in the meeting between the participant and the researcher. Hence, the narratives presented in this study are configurations developed from experiences and events as they are told by the participants and reordered by the research team in an attempt to understand ways of meaning making for people living with advanced cancer.

The aim of this study was to explore and understand how people with advanced cancer create meaning and handle everyday life through activity. The results illustrate that the participant's everyday life is directed toward the future, and, in the case of these individuals, that means toward the time before the end of life. "Saying goodbye in a good way" was a narrative prompted by the diagnosis of an incurable cancer, and thus the narrative has a distinct beginning, but it extended through the present toward the future in that it was identified as guiding the participants in their everyday life and providing for an emplotment of everyday activities that reached beyond the activities *per se*. Therefore the narrative structure of beginning, middle, and end can be considered as constantly developing. The implications of "saying goodbye in a good way" captured not only

what participants talked about but also what they did, seemingly guided by their concern with life and their awareness of imminent death and of a time after they have died.

According to the sociologist Erving Goffman (1971), social interaction implies that people position themselves dramaturgically in ways that support the impressions they give of themselves with the aim of supporting social approval and self-enhancement. Within this framework, the participants' insistence on being active and maintaining their good humor can be seen as a position they adopt in order to handle concerns about having cancer and to avoid becoming a burden to the family. In this way they mobilize certain narratives that present favorable impressions intended for family and friends, who in turn become audiences. With the ideas of Goffman (1971) in mind, we can see how the findings from this study illustrate the way in which the participants' narratives are not only negotiated to the advantage of the person with cancer but also serve the needs of family and the immediate social context. As Goffman (1971) emphasized, the performer is not only performing for an audience, but at the same time becomes the viewer of the performance of the audience. In this way, the emplotments and narratives created through daily activities become frames for social interaction between the sick people and those around them, and the audience–performer relations are active on several levels simultaneously.

As we followed the evolution of narratives through series of events, the meta-narrative of "saying goodbye in a good way" seemed to imply several smaller narratives. One important narrative revolves around the desire to be healthy and not just concentrate on illness. This finding relates to a study by Salander et al. (2000), in which they proposed that "time of everyday life" and "time of disease" were co-existent for people with cancer. However, in contrast to the distinction proposed by Salander et al. (2000), the results in this study identified that being healthy and severely ill were perceived as coexisting through activity. Thus, the complexity of life with advanced cancer reaches beyond distinctions between "time of everyday life" and "time of disease" and implies questions about how people negotiate experiences of being both severely ill and being healthy. To discuss how the participants in this study used the narrative of being healthy although sick, it may be useful to draw on Merleau-Ponty (2002), who stated that people are in the world by virtue of bodily experiences, sensory processes, and associations that help give directions and meaning. Merleau-Ponty (2002) suggests here that meaning and experiences of being healthy are linked to physical activity. In this study, when the participants drink red wine with friends

or sweep the driveway despite the pain, these activities can be seen as examples of how activity is used to negotiate and shape time and construct stories of being in the world—healthy although sick—through embodied practice.

Furthermore, the results demonstrated that several participants experienced a sense of being intimidating to others due to severe cancer; they no longer felt treated in the usual way and associated this with a loss of social recognition. These feelings relate to theoretical concepts of the stigmatized person who, in some respect, has changed from a normal person to a discounted person (Goffman, 1963). The findings that participants felt stigmatization and negotiated such experiences show that their narrative explications may be a means to interpret and give meaning to deviations from “normal” states of the human condition in order to negotiate the idiosyncratic (of having an advanced cancer) and make it socially acceptable for the individual. In that regard the participants’ narrative of being healthy although sick might be viewed as a pointing toward a certain view of themselves as a way to breach the tension in their situation and the diversity that severe cancer represents. In this way individuals with severe cancer may counteract the misery of their illness by using activity to engage and enact the character they are and that they would like to be. Moreover, these crafted narratives not only provide ways to explore and experience the fluid boundaries between being sick and being healthy but also generate health-associated activity that can be viewed as an active resistance toward the illness itself and toward the way in which participants are seen by other people and society.

The emplotment of activity as a set of routines was identified to provide a safe and familiar framework that structured everyday life and from which agency was stimulated. Similar findings were highlighted by Luoma and Hakamies-Blomquist (2003) in a study of women with advanced breast cancer, who strived to keep their life as normal as possible by continuing to engage in activities similar to those they were engaged in prior to becoming ill. By narrating routines and threads of continuity, the severely ill person may construct platforms from which it is possible to take action and influence their situation while allowing for change and transformation. Strauss (1993) made a similar point when he addressed the relationship between routines and nonroutines and suggests that routine can initiate innovation and creativity. As our study shows, everyday routines may provide space for trying out alternative ways to understand the situation. Furthermore, Mattingly (1998) argued that repetition, as identified in everyday routines, can represent hope, which is especially important

when one is facing incurable illness. Thus, by emphasizing routines the person with advanced cancer may experience a sense of hope, embedded in moments of activity repeatedly returning in daily life. In addition it appeared that through familiar activity such as cooking, the participants found ways to construct and embed new meanings in an activity they had pursued before their illness. These can be seen as ways of using activity to transcend the losses that follow upon advanced cancer. These results are in line with other studies (Bury, 1982; Charmaz, 1991; Hydén & Hydén, 1997) showing how, in times of disruption, people do biographical work by transcending their experiences through narration. Contributing to such ideas, this study provides empirical insights into how biographical work may take place, not only through verbal narratives but also through emplotment of routine activities supporting new ways of daily living in the midst of advanced cancer.

The narrative of “my little Mecca” is noteworthy, as it was identified as representing a backdrop for the individual whereby she can renew her energy and take a break from the pressure entailed in the quest of having to stage everyday life as saying goodbye in a good way. Our finding that activities provide place and space for revitalization and recharging resembles findings from a study by Öhlen (2000), who identified meanings of palliative care as alleviation of suffering and a lived retreat. In parallel Lawton (2000) also found that palliative care could be experienced as a retreat. This study complements those studies in showing that retreat can be created through engagement in activity in various contexts of everyday life.

Polkinghorne (1988) suggested that narrative can organize and connect events and experiences over time. The narratives identified in this study, whether told or enacted, demonstrate how people use activity over time to create spaces for creativity and meaning making. The flowers grow over time, redecorating the house takes time, and likewise the rituals and routines presented in the narratives involve time as a crucial factor. Time becomes significant, and narrative plots that organize time become inevitable as ways to negotiate life and death, health and illness, and the existential issues involved. Such ways of creating meaning and meaningful moments may not differ much from what most healthy people do, but, in the persistent awareness of the end of life, existential concerns impact on the activities that people undertake and the way in which a storyline such as “saying goodbye in a good way” is cast.

Furthermore, the awareness of death may provoke an enhanced need for proximity to life and meaning, which spurs people to engage in activity through

which they narrate a good life in the face of their circumstances. However, as the empirical material shows, the influence from the social world should not be underestimated as regards the ways in which people with advanced cancer narrate their current situation. Moreover, wanting to “say goodbye in a good way” is also influenced by contemporary perceptions of death and dying in Western society, hence depicting current discourses in social life. Murphy (1990) drew attention to a similar trait when he pointed up the key social rule for being a successful sick person: “Don’t complain.” Given this idea, the meta-narrative of “saying goodbye in a good way” may be an emplotment that serves to fulfill the social role of the “good” sick person. Murphy (1990) elaborated on the idea and explained that, confronted with a future fraught with danger and uncertainty, most sick people admit to what, from the outside, may come across as courage in taking a positive attitude. To Murphy, however, this seems a form of disembodiment and a necessary strategy. Hence, by emplotting daily life as “saying goodbye in a good way,” the participants seem to take on a tremendous task in constantly having to strive for “the good way” in spite of their suffering. Indeed, creating meaning in what remains of life in the face of death is not only guided by a personal quest to appear healthy, by a striving to maintain routines, or by the creation of spaces for completion. It is also determined by sociocultural environments and rules.

In summary, the findings of this study contribute to the understanding of engagement in activity and meaning making in daily practice. By approaching experiences of activity from a narrative perspective, the study identifies how activities provide people with arenas for creating alternative meanings and strategies useful in handling everyday life with severe illness. Through activity, people embody their situations and create meaning under circumstances that are fluctuating and ambivalent. These insights may guide the development of palliative care services to develop support of engagement in activities that facilitate experiences of being healthy, help to establish routines to carry people through difficult days, and help to create spaces where they can take time out and experience enrichment and completion.

ACKNOWLEDGMENTS

We are grateful to the participants who shared insights to their daily life under circumstances of severe illness. The study was supported by the Danish Cancer Society, Stor Stroems Amt, the Medical Region III fund, and the Centre for Health Care Sciences (CfV), Sweden.

REFERENCES

- Alsaker, S. & Josephsson, S. (2003). Negotiating occupational identities while living with chronic rheumatic disease. *Scandinavian Journal of Occupational Therapy*, 10, 167–176.
- Breitbart, W. (2002). Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive Care in Cancer*, 10, 272–280.
- Bruner, J. (1990). *Acts of Meaning*. Cambridge, MA: Harvard University Press.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4, 167–182.
- Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New York: McGraw-Hill.
- Charmaz, K. (1999). ‘Discoveries’ of self in illness. In *Health, Illness, and Healing. Society, Social Context, and Self*, Charmaz, K. & Paterniti, D.A. (eds.), pp. 72–82. Los Angeles: Roxbury Publishing Company.
- Davies, C.A. (2001). *Reflexive Ethnography, A Guide to Researching Selves and Others*. London: Routledge.
- Goffman, E. (1971). *The Presentation of Self in Everyday Life*. Middlesex, England: Penguin Books Ltd.
- Goffman, E. (1963). *Stigma, Notes on the management of the Spoiled Identity*. London: Penguin Books.
- Grønvald, M., Pedersen, C., Jensen, C.R., et al. (2006). *Kræftpatientens verden. En undersøgelse af hvad danske kræftpatienter har brug for. [Cancer patients’ worlds. An investigation of Danish cancer patients’ needs]*. Palliativ Medicinsk Afdeling, H:S/Bispebjerg Hospital.
- Hutchings, D. (2007). Struggling in change at the end of life: A nursing inquiry. *Palliative and Supportive Care*, 5, 31–39.
- Hydén, L.C. & Hydén, M. (1997). *Att studera berättelser [Studying narratives]*. Falköping: Liber.
- Jackson, J. (1996). Living a meaningful existence in old age. In *Occupational Science: The evolving discipline*, Zemke, R. & Clark, F. (eds.), pp. 339–362. Philadelphia, PA: F.A. Davis Co.
- Kvale, S. (1996). *Interview. An Introduction to Qualitative Research Interviewing*. Thousand Oaks, CA: Sage.
- La Cour, K., Josephsson, S. & Luborsky, M. (2005). Creating connections to life during life-threatening illness: Creative activity experienced by elderly people and occupational therapists. *Scandinavian Journal of Occupational Therapy*, 12, 98–109.
- La Cour, K., Nygård, L., Tishelman, C., et al. (2007). Experiences of engagement in creative activity at a palliative care facility. *Palliative and Supportive Care*, 5, 1–10.
- Lawton, J. (2000). *The Dying Process. Patients’ Experiences of Palliative Care*. London: Routledge.
- Luborsky, M. & Rubinstein, R.L. (1995). Sampling in qualitative research: Rationales, issues, and methods. *Research on Aging*, 17, 89–113.
- Luoma, S.W., & Hakamies-Blomquist, E. (2003). Quality of life in patients with metastatic breast cancer receiving either docetaxel or sequential methotrexate and 5-fluorouracil. A multicenter randomised phase III trial by the Scandinavian breast group. *Journal of Clinical Oncology*, 36, 1411–1417.
- Mattingly, C. (1998). *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge, UK: Cambridge University Press.

- Merleau-Ponty, M. (2002). *Phenomenology of Perception*, Colin Smith, C. (trans.). London: Routledge (original work first published 1945).
- Murphy, R.F. (1990). *The Body Silent*. London: Norton.
- Öhlen, J. (2000). *Att vara i en fristad. Berättelser om lindrat lidande inom palliativ vård. [Being in a lived retreat: Narratives of alleviated suffering within palliative care]*. Doctoral dissertation. Göteborg: Institutionen för vårdpedagogik, Göteborg Universitet.
- Pizzi, M.A. & Briggs, R. (2004). Occupational and physical therapy in hospice, The facilitation of meaning, quality of life, and well-being. *Topics in Geriatric Rehabilitation, 20*, 120–130.
- Polkinghorne, D.E. (1988). *Narrative Knowing and the Human Sciences*. Albany: State University of New York Press.
- Polkinghorne, D.E. (2004). Ricoeur, narrative and personal identity. In *Changing Conceptions of Psychological Life*, Lightfoot, C. et al. (eds.) pp. 49–70. Mahwah, NJ: Lawrence Erlbaum.
- Pörn, I. (1993). Health and adaptedness. *Theoretical Medicine, 14*, 295–303.
- Ricoeur, P. (1985). *Time and Narrative* (Vol. II). Chicago: University of Chicago Press.
- Salander, P., Bergenheim, A.T. & Henriksson, R. (2000). How was life after treatment of a malignant brain tumor? *Social Science and Medicine, 51*, 589–598.
- Strauss, A. (1993). *Continual Permutations of Action*. New York: Aldine de Gruyter.
- Taylor, K. & Currow, D. (2003). A prospective study of patients' identified unmet activity of daily living needs among cancer patients at a comprehensive cancer care centre. *Australian Journal of Occupational Therapy Journal, 50*, 79–85.
- Ville, I. & Khlal, M. (2007). Meaning and coherence of self and health: An approach based on narratives of life events. *Social Science & Medicine, 64*, 1001–1014.
- World Health Organization. (2002). *National Cancer Control Program: Policies and Managerial Guideline* (2nd ed.) Geneva: Author.
- Wilcock, A. (2006). *An Occupational Perspective of Health*. Thorofare, NJ: SLACK Incorporated.
- Zachariae, B. & Mehlsen, M.Y. (2004). *Kræftens psykologi, Psykologiske og sociale aspekter ved kræft [Cancer psychology, psychological and social aspects of cancer]*. Copenhagen: Hans Reitzels Press.