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Involvement in everyday life for people with a life threatening illness

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ABSTRACT

Objective: In many studies, everyday life has been shown to be of great significance in the context of life-threatening cancer. The aim of this study was to investigate how people with cancer who are receiving palliative care engage in and undertake activities in their everyday lives.

Method: This is a qualitative interview study adopting a grounded theory approach. The sample was composed of participants receiving services from palliative hospital-based home care and day care services. A total of 47 individuals were interviewed.

Results: Despite experiencing the threat of progressive loss of functioning, the participants were striving to remain involved in and to be active in everyday life. Continued involvement in everyday life with lowered expectations concerning performance gave the participants the possibility to continue doing daily activities as well as to perform new and engaging activities that were a source of pleasure and enabled the patients to feel a sense of competence.

Significance of results: This study has demonstrated the power of being involved in everyday life activities. The proposed model, explaining individuals' desire to continue to live an active life despite a progressive loss of functioning, can provide a model to help the reasoning of professionals when supporting patients in their everyday life.

KEYWORDS: Everyday life, Palliative care, Day care, Cancer, Grounded theory

INTRODUCTION

The activities involved in everyday life are of great significance in people's lives, and engagement in valued activities in everyday life has been shown to be strongly related to well-being (Argyle, 1999; Myers, 2000; Christiansen, 2000; Csikszentmihalyi, 1991). In addition to this, research on the well-being of people living with a disability shows that engagement in activity plays a central role in life satisfaction (Lundmark & Brannholm, 1996; Wikstrom et al., 2001).

Having incurable cancer has an extraordinary influence on an individual's everyday life. Advanced cancer affects life in physical, psychological, social, and existential ways and there are several studies describing the complexity of the experience of everyday life when living with cancer. Salander et al. (2000) defined the concepts of the "time of everyday life" and the "time of disease." By the "time of everyday life," they meant the time during which life continues as normal. By "time of disease," they meant the length of time when life is primarily occupied by the disease, during which life-continuity is disrupted. Benzein et al. (2001) described cancer patients' experience of belonging to both life and death, a dialectic experience of belonging to "two worlds simultaneously," the world of the sick and the world of the healthy.

Previous research has shown how cancer patients experience a feeling of well-being when they can perform activities in daily life. Lindqvist et al. (2006)

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described how cancer patients living with bodily problems lived a cyclical pattern between the experiences of wellness and of illness. When they were in control of their bodily problems and they were able to participate in their everyday life, it was possible to reclaim a feeling of wellness and to feel well. Vrkljan and Miller-Polgar (2001) found that those individuals, who were able to maintain their habitual pattern of daily life despite the limitations imposed by their life-threatening illness, defined themselves as being "healthy with cancer." In addition to which, Fryback (1993) noted that when individuals with a life-threatening diagnosis concluded that they were unhealthy, it was not because of their diagnosis, but because they were unable to engage in those activities they desired to do.

Through engagement in activities in daily life (Lyons, 2006; Lyons et al., 2002; Vrkljan & Miller-Polgar, 2001) and the performance of creative activity (la Cour, 2005; Reynolds, 2003), cancer patients are able to respond to and cope with psychosocial challenges. People turn to their everyday activities to regain a sense of control over and normalcy in their lives, and there seems to be a connection between engagement in meaningful activity and one's self-perception as being capable and healthy (Vrkljan & Miller-Polgar, 2001). Engagement in creative activity can also provide a positive boost to one's sense of identity (la Cour, 2005; Reynolds, 2003). According to Johansson et al. (2006), in a study of incurably ill cancer patient's perceptions of their quality of life (QOL), the participants emphasized what activities they could perform and enjoy in daily life, not their shortcomings.

Everyday life has been shown to be of great significance in the context of life-threatening cancer, and there are still important aspects in the field to explore, for example the experience of participating in activities in everyday life when living with a life-threatening illness. The aim of the present study was, therefore, to investigate how people with cancer receiving palliative care engage in and undertake activities in their everyday lives.

METHOD

This is a qualitative interview study adopting a grounded theory approach (Charmaz, 2006; Glaser & Strauss, 1967; Glaser, 1978, 1998).

Participants

The participants engaged in this investigation were selected to participate in a larger study aiming to explore different aspects of functioning in everyday life for people with cancer. The sample used was composed of participants receiving services from two Swedish palliative hospital-based day care services or/and receiving palliative home care. A total of 47 individuals with cancer were interviewed.

All participants had a similar general level of functioning in everyday life, in terms of being able to live at home and still being able to conduct the majority of the activities involved in everyday life. The Karnofsky performance measure (Schag et al., 1984) for rating the ability of a person to perform usual activities was used to assess the abilities of the participants. All study participants received a grade of 60 or 70 which indicates that the person being assessed is unable to work, but is able to live at home and take care of the majority of his or her personal needs; it also implies that some assistance of varying degrees is needed. Further characteristics of the participants are presented in Table 1.

Data Collection Procedure

The participants receiving home care were interviewed once and the interviews were performed in their homes. The participants from the day care programs were interviewed twice, with 5–6 weeks between the interviews, which were performed in the day care settings. This procedure took place in accordance with the plan for the study sample. The interviews lasted between 30 and 45 minutes and were conducted by the first author. An interview guide comprising open-ended questions was used to explore the topic of how the participants engaged in and dealt with activities in their everyday life. The questions placed an emphasis on learning about participants' views, experienced events, and actions (Charmaz, 2006). Notes were taken during the interviews (Glaser, 1998) and also the most interesting quotations or those that best illustrated particular issues

Table 1. *Characteristics of the participants*

Demographic data	No. of participants
Total number of patients	47
Gender (male/female)	8/39
Age	
<49	6
50–69	31
70–89	10
Marital status	
Married/cohabitating	20
Single/widow/widower	27
Time from interview to death (in months)	
0–5	17
6–10	6
11–15	4
>16	20

were written down verbatim. Immediately after the interviews had been completed, field notes were written to further expand upon and clarify the views expressed and experiences recounted by the participants. In addition, ideas were written down continually as they emerged, in the form of analytical memos (Glaser, 1978). Subsequently, the notes were transcribed on a computer.

Data Analysis

The data analysis was conducted concurrently with the data collection. According to the techniques of grounded theory (Glaser & Strauss, 1967; Glaser, 1978, 1998), significant phrases and sections in the interview notes were highlighted, and codes were inserted. Coded categories were then labeled and the categories that emerged from the data were, for example, structure, having something to do, challenge, and meeting others. A constant comparison of data with data, data with categories, and categories with categories was going on throughout the project, to develop the categories and the generation of further concepts. The writings of analytical memos (Glaser, 1978) enabled the documentation of theoretical ideas, insights, and interpretation during data collection. Through further analysis, categories emerged as tentative core categories, for example continuity, competence, and participation in everyday life. These ideas were examined through further empirical inquiry, and through theoretical sampling the participants were asked further questions, concerning experiences that had not been covered in the earlier interviews. Questions constantly changed during the data collection to probe issues relevant to the emergent categories and theoretical sampling. When a category became saturated, new questions was asked of relevance to new emergent issues. The data collection continued until the whole sample was completed. Theoretical saturation of the categories was achieved within this sample.

To enhance the process of data analysis and constant comparison, recurrent discussions were held with the co-authors. The analysis and findings were also discussed in a peer-review research group. In addition to this, the first author received approval pertaining to the relevance and workability when presenting the findings to a national group of qualified occupational therapy practitioners experienced in palliative care.

Eventually, a core category emerged in the analysis, which was termed *Striving for continued involvement in everyday life through the performance of activities*. Through theoretical coding, categories related in some way to the core category were selected and linkages and relationships between the various categories were sought. The categories were identified as phases in a process, i.e., the process of *Striving for continued involvement in everyday life through the performance of activities*. At this stage, a sorting of ideas and analytical memos, rather than of data, took place. The categories that emerged as phases in the process of *Striving for continued involvement in everyday life through the performance of activities* (Figure 1) were *experiencing progressive loss of ability to perform activities in everyday life*, *revaluing*, *being involved and active in everyday life*, and *experiencing pleasure, feeling competent and being able to participate*.

RESULTS

Experiencing Progressive Loss of Ability to Perform Activities of Everyday Life

The participants with incurable cancer living at home were faced with huge challenges in their everyday life. Living with cancer meant that there were disruptions to everyday life related to losses of a physical, social, and psychological nature. This meant that the individual had lost some degree of physical ability, and some roles and relations that had previously been taken for granted, for example,

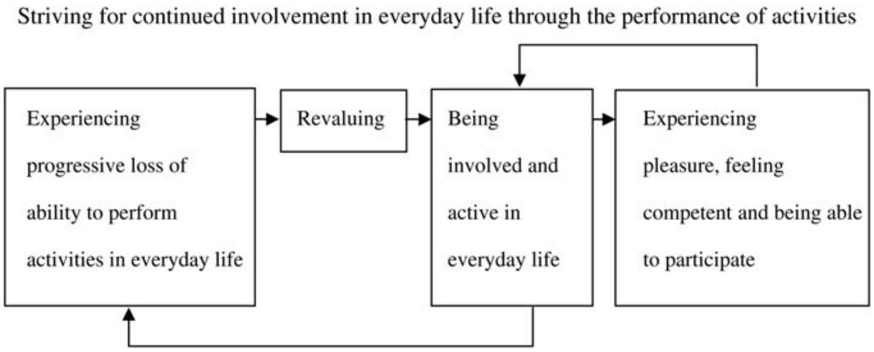

Fig. 1. The phases in the process of Striving for continued involvement in everyday life through the performance of activities.

losing their job, and also no longer being able to participate in leisure activities. However, in spite of the ongoing deterioration of their skills and ability, the participants were highly engaged in everyday life. They held a strong wish to retain their daily routines and to continue to be active in daily life. Therefore, *experiencing the progressive loss of ability to perform activities in everyday life* is the starting-point of the process of *striving for continued involvement in everyday life through the performance of activities* (Figure 1). The following quotation from a participant illustrates the importance of continuing to be involved in daily life in spite of a progressive loss of ability to perform activities.

> You must have something to do, otherwise you get crazy. You feel out of sorts when you wake up in the morning, you have to force yourself to get up, but then it is all right. You are not very happy – but still you can be in a good mood.

In discussing the process of *striving for continued involvement in everyday life through the performance of activities* it is further described how they continued to handle the activities involved in everyday life.

Revaluing

The participants had a strong wish to continue to be able to live their everyday life and to keep to the routines they had had before. But with an ongoing deterioration in their health, it was not possible to continue to do things in the same way they had been done before the illness. In order to enable themselves to continue to participate, the participants changed their attitudes towards how much they believed themselves to be capable of, and lowered their expectations concerning how the activities most important to them should be performed.

The participants learned that they could not go on in the same way as before and that they had to see and value things in a new way. The following quotation illustrates this.

> Everything takes much more time to do, I have had to change my routines, and it has been very difficult. I see things in a different way now. I can't do things I did before, but instead of doing nothing I prefer to do something, just a little.

The participants felt that it was more important to continue to do something than to do nothing. In adjusting their expectations, the participants began to value and feel satisfaction from small gains. Furthermore, they also reassessed what was important for them in their daily life to enable them to continue to do the most important things. The next quote is an example of this.

> The illness has taught me to see what is important in life, to see beyond trivial matters and unimportant things. It has given me a new freedom.

The participants chose what they found most important to do more carefully and became selective after the onset of the disease. They continued to be involved in their daily routines and learned how to continue life with lower expectations concerning their performance.

Being Involved and Active in Everyday Life

It was important to the participants to be able to maintain as normal a life as possible, to continue to live as before despite the functional limitations imposed by their cancer disease. Living a normal life meant participating in different activities with family and friends. This could include helping to finish a project at work, maintaining leisure activities, with lower demands being imposed on performance to make this possible, or just engaging in housework to the fullest possible extent.

Participation in activities could be made possible, but for this to be achieved, it was important to organize the daily routines and keep up old habits. The participants accommodated to their reduced capacity in a number of different ways that could include prioritizing and modifying their activities and adapting their environment, as well as planning the activities themselves to facilitate engagement in them. For example, daily routines could be organized to include breaks and they could be spread out throughout the day. Even if the participants did not have to take care of the housework themselves, it felt satisfying to keep to their daily routines and to have something little to do every day. Otherwise the whole day could pass without doing anything at all, which they felt was no satisfying. As one of the participants said,

> I can't just sit and wait and see what happens, I try to do positive things, but I can't do everything I want to do. Routines are important if things are to work.

When more and more of the tasks involved in everyday life became too demanding, for example, when the individuals were obliged to give up work and other valued activities, it became important to create new challenges. It was still important to have goals to achieve in everyday life, because activity goals continued to evolve during this time of loss. The participants chose new challenges to compensate for the activities they were not able to do any more, for example they might choose to attend a day care setting regularly as compensation for not having a job to go to. Attending a day care setting gave the participants the opportunity to participate in different activities and to meet other people, as illustrated in the next quote.

> You don't have many challenges when you are ill, so you need to make an effort yourself. You must take up challenges when they arise; you need challenges, otherwise you get bored. When you have this illness you aren't really expected to do anything. When working, one had to deal with new problems all the time. Now I am planning to knit a pair of woolen socks, I have always wanted to learn how to do that. Now I have the opportunity, there are people here [at the day care center] who know how to do this!

New challenges and revised goals for activities made it possible to experience the satisfaction of attaining a goal, which contributed to the pleasure of doing something.

Experiencing Pleasure, Feeling Competent and Being Able to Participate

Having the possibility of engaging in creative activities offering just the right level of challenge enabled the participants to experience joy and pleasure and made it possible for them to forget their illness for a while.

> I feel happy when I am here [at the day care center]. I get my self-confidence back. I can do things. It is still possible to accomplish something, and when I feel happy I feel stronger and healthier, this/which raises my spirits, and I forget my pain for a moment.

Creative and diverting activities were appreciated by the participants engaged in the palliative day care program, and were the source of positive experiences.

Continuing to be involved and being active provided a message to the participants that they were still capable and alive, despite the threat of progressive loss of functioning. Here follows a statement from one of the participants illustrating this idea.

> I try to take care of myself and to make my meals. On those days when I am able to, I try to do as much as I can; otherwise one might just as well lay down [sic] and die.

By retaining those activities that were important to them, the participants recaptured a sense of satisfaction with their daily lives that helped to motivate them to get up and get moving.

Being able to engage in everyday activities served as proof that the patients were still able to be capable individuals and the fact that they were capable gave them the experience of being healthy. As one participant said

> You feel good when you are doing something. Here at the day care center I have learned to do new things that I didn't think I could do. When you feel capable, it makes you feel healthier.
>
> The ability to do activities in everyday life was, therefore related to feeling healthy.

In daily life, interactions with others are usually embedded in the performance of activities, for example, people socialize over dinner or while engaging in a hobby or leisure activity. For the participants, this was a source of joy and pleasure.

> Every day I try to do something to enjoy myself. I can't live without social contact. I want to do things and meet friends. On Sunday I am going out to have lunch with friends.

For many of those who attended the day care program, the possibility of meeting people and doing things with others was a main reason for their attendance. Also, for those who could not perform activities by themselves, just watching and supporting their peers in doing a creative activity enabled them to have the feeling that they were participating. They still felt enjoyment and had a sense of well-being from their social participation in an activity.

Striving for Continued Involvement in Everyday Life through the Performance of Activities

The process illustrated in Figure 1, named *striving for continued involvement in everyday life through the performance of activities*, shows how the different categories are related to one another and explains how a driving force for continued involvement in everyday life was created. The possibility of doing things was crucial in this process. "*I want to do things that make me feel well — I want to keep in touch with reality.*" When the participants were involved in activities, positive and encouraging experiences could occur, such as pleasure, and a feeling of self-confidence, of having accomplishments and of being competent and able to participate. The condition for these experiences to occur was that the participant had revised her/his own expectations of his/her performance so that appropriate goals could be attained.

When the activities of daily life again became too demanding and difficult for individuals to perform, following increased deterioration, there was the possibility to continuously revaluate and revise their expectations of their performance in order to achieve their experience of pleasure and of competence in performing the activity.

In conclusion, experiencing pleasure and feeling competent when doing activities became a driving force for continued involvement in activities and for participation in daily life. Thus, there was a process (Figure 1) that was initiated by a need to revalue how best to perform activities of daily life, and this revaluation lead to a revision of the goals of the activities and the creation of new challenges as a prerequisite for the participant to experience the pleasure of being engaged in an activity. Consequently, the motivation to remain involved and to be active in everyday life was developed through the experience of performing an activity.

DISCUSSION

The findings in this study shed light on the possibilities inherent in the experience of doing. When individuals continuously revalue and revise their expectations in everyday life following the progressive loss of functioning, they are able to retain the possibility of experiencing positive meaning when performing activities and participating in everyday life. The ability to keep doing the regular activities, and to engage in new ones, serves as a source for experiencing pleasure and for feeling competent. The motivation for continuing to perform activities is developed through the experience of doing.

The continuous revaluation of expectations in everyday life could be the same type of phenomenon as that described by the concept of response-shift, which is discussed in the research on health-related QOL (Schwartz & Sprangers, 1999). QOL is increasingly being used as a measure of outcome in clinical trials on patients with cancer. However, findings have raised questions concerning what these quality of life measures actually assess and how the scores should be interpreted, as people with life-threatening diseases report a QOL equal to or superior to that reported by less severely ill and even healthy people (Rapkin & Schwartz, 2004). Rapkin (2000) argued that this lack of association between physical health problems and reported QOL is a function of coping with chronic or life-threatening illness. Changes in goals and priorities have the potential to attenuate threats and people's goals and concerns continue to change during the course of serious illness, perhaps to the end of life (Rapkin, 2000). The finding in the present study not only supports these assumptions, it also suggests an explanation for the reasons for the phenomenon of response–shift, which is that the participants are revaluing their priorities in order to enable them to perform activities.

The desire to continue living a normal life is a phenomenon considered in the continuity theory, developed by Atchley (1999), which has been applied to physically healthy as well as to physically frail middle-aged and older adults. The continuity theory states that individuals wish to continue the lifestyle to which they have become accustomed over the years and holds that individuals make adaptive choices that allow them to feel a sense of continuity between past and current events. The process described in the present study supports the continuity theory, and adds to the ideas covered by it by including the suggestion that the positive experiences conducted when striving to retain continuity in everyday life are based on the "experience of doing," which serves as a source for the experience of pleasure and competence.

Different models of coping are suggested to explain how people handle the psychological strain of living with a life-threatening disease (Folkman, 1997; Lazarus & Folkman, 1984; Taylor, 1983; Taylor et al., 2000). According to the cognitive theory of stress and coping (Folkman, 1997), people constantly appraise their interactions with their environment. Interactions that are appraised and considered to be stressful, e.g., receiving a diagnosis of cancer, require the adoption of coping strategies to reduce the stress. When coping, an individual must first be able to relinquish unrealistic beliefs about how things are, revise those beliefs, and then substitute new, downwardly revised expectations that are consistent with the revised expectations. Once this stage has been accomplished, the individual must be able to attach positive value and meaning to his/her new expectations. The process identified in this study suggests that what makes it possible to attach positive meaning to the new expectations is the performance of activities and the pleasure experienced from so doing.

In the theory of cognitive adaptation Taylor (1983), Taylor and Brown (1988) and Taylor et al. (2000) suggest that psychological beliefs such as meaning, control, and optimism, may represent a reserve of resources that assume special significance in helping people to cope with intensely stressful and life-threatening events. Taylor et al. (2000) have found that many people respond to threatening events by developing positive illusions, for example remaining optimistic, even unrealistically optimistic, in the face of deterioration. Taylor suggests that positive illusions may be adaptive in the face of life-threatening illnesses because they help people to find meaning in the experience they are undergoing. The process identified in this study illustrates how the experience of doing in everyday life is a link between revised expectations and attaching positive meaning. The study illuminates the importance of doing and clarifies how the driving force to continued participation in everyday life is developed through the experience of doing things, which offers the individual the experience of pleasure and competence.

How long the process described continues in a person's life, and how much functioning a person can lose in everyday life and still be able to revalue activities and experience pleasure from performing them, is not addressed in this study, as the findings are based on individuals who were still able to live at home and take care of most of their personal needs.

Activities in everyday life are only one part of an individual's life world. It should be emphasized that the process described, that of continuing to perform activities and of participating in everyday life, is one of many processes individuals with a life-threatening disease are engaged in and that it does not represent the individual's entire being. All participants in this study were patients connected to specialist palliative home care or day care units. They were receiving the highest quality of symptom control, as well as the psychosocial counseling required in dealing with fears related to the future and preparation for advancing illness and death. These interventions could have influenced how they experienced their everyday life, and it may have enhanced their ability to handle the strain of living with a life-threatening cancer. Another circumstance regarding the sample is that only one-fifth of the study participants were men. It is possible that the experiences of women and men differ to some extent where everyday life is concerned.

During the interviews for the data collection, notes were taken. Using a tape recorder gives one more detailed data, but according to Glaser (1998), field notes are preferable to taping when using the grounded theory method because they are not so time-consuming and they make it possible to code and analyze the data before conducting further data collection, which is an important part of the constant comparative method. In addition to this, field notes make it easier to conduct brief interviews based on theoretical sampling on particular issues (Glaser, 1998).

This study has demonstrated the power of being involved in everyday life activities. Continued involvement in everyday life with lowered expectations concerning performance gives those with life-threatening illnesses the possibility to continue doing daily activities as well as to perform new and engaging activities that are a source of pleasure and enable them to feel a sense of competence. The proposed model, explaining individuals' desire to continue to live an active life, can provide a model to help the reasoning of professionals when supporting patients in their everyday life. Patients in the palliative phase of cancer who do not receive active support from their family and friends to make it possible for them to engage in positive experiences through the performance of activities, could benefit from professional support in the form of palliative day care programs. A palliative day care program can offer support for continued involvement in everyday life and also enable patients to participate in creative activity and to meet others in a pleasant environment.

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