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The meaning of having to live with cancer in old age

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The meaning of having to live with cancer in old age

Little is known about how older people with cancer experience their life situation. To increase the understanding of how illness is experienced in older people with cancer, the aim of this study was to investigate the meaning of living with cancer in old age. The hermeneutic phenomenological method as described by van Manen and referred to as 'phenomenology of praxis' was used. Ten persons (seven women and three men) aged 75 and over, who had a diagnosis of cancer and who had just completed cancer treatment, were interviewed in their own homes. The analysis revealed a life world affected to varying degrees by the cancer disease. The lived experiences across the interviews were revealed in four overarching essential themes: *transition into a more or less disintegrated existence, sudden awareness of the finiteness of life, redefinition of one's role in life for good and for bad, meeting disease and illness*. To provide individual support and appropriate care to older people with cancer it is important for health care professionals to identify and take care of disabilities and to support the reorientation in the disintegrated life situation. It is also important to have preparedness to meet the old person's thoughts about death. Thus, it is important to encourage the old person to describe her/his illness experience to increase understanding about what is meaningful for her/him.

Keywords: cancer, aged, lived experience, meaning, phenomenology.

INTRODUCTION

Little is known about how older people with cancer experience their life situation (Bailey & Corner 2003). Cancer at any age means being subjected to a life-threatening disease with several potential consequences (Colussi *et al.* 2001). Cancer in old age is often combined with other age-associated physical conditions, which may be hard to separate from the cancer disease. Old age also means a life

situation more or less influenced by various losses occurring simultaneously with the cancer experience, for instance, loss of family and friends, independence, health, functional abilities, financial resources and a narrowed social role (McCaffrey 1994). Further, old age means an awareness of the finiteness of life and the importance of the here and now (Colussi *et al.* 2001; Gianni *et al.* 2001). This complex situation could be seen as the lived reality (van Manen 1998) on which the old person bases her/his understanding of lived experience or the meaning of illness.

An earlier study, based on interviews with older people (aged 75 and over) with a diagnosed cancer in the preceding 5 years, showed the importance of older people choosing for themselves to handle the cancer disease and to make decisions about treatment and care (Thomé *et al.*

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2003). These decisions often mean a balance between possible cure and the price to be paid in terms of side-effects of treatments. Older persons may base their decisions on different aspects from younger people, and the endpoints of successful treatments may be differently defined (Redmond & Aapro 1997). Empowering old people with cancer in their choices requires an understanding of how they experience their life situation when they look ahead at available options of treatment and care. This may not have been fully revealed in the earlier study (Thomé *et al.* 2003) because most of the interviews had a more retrospective approach to the acute phase of the disease and the time of diagnosis and treatment. Thus, an increased understanding of how old people experience their cancer early in their process of diagnosis and treatment is needed.

In recent years there has been growing attention to issues of cancer in old age. However, these have been mostly restricted to the medical symptomatic perspective and less to the individual lived experience. Illness disrupting the lived body may have a different meaning for older people owing to other age-related conditions. Lived experience as described by van Manen (1997) involves the person's immediate, prereflective consciousness of life. Toombs (1988) described lived experience of illness primarily as a disruption of the lived body rather than as dysfunction of the biological body, reflecting two different dimensions of illness described as lived experience and scientific conceptualization (Toombs 1993). Different dimensions of illness could also be understood as related to the concepts gnostic and pathic (van Manen 1999). A gnostic relation to the patient means looking for causal patterns to explain illness whilst a pathic relation is specific and unique and means meeting the person in her/his life situation, striving to understand the illness experience, without trying to 'reduce the person as a diagnostic picture, a certain kind of case, a preconceived category of patient, a set of factors on a scale or a theoretical classification' (van Manen 1999). Successful treatment focused on the gnostic perspective, however, does not necessarily mean that the person has been reintegrated in her/his life world, and a pathic relation may be a complement to increase feelings of control and affirmation.

Curing or medically controlling a disease are not the same as recovery from an illness to regain a sense of wholeness and integration in one's world (Benner 2001). Illness experience is often talked about in relation to embodiment, which is defined as 'a unity that we live therefore we do not perceive the world in pieces or meaningless sensations but as a whole pre-given, prereflective world' (Benner 2000, p. 6). Embodied capacities, such as for instance embodied perceptions, change over time and

may be different in old age (Benner 2001). Thus, reintegration into everyday life requires not only medical explanation and handling of illness but also understanding the life world experienced by the older person.

Nursing care for older people with cancer means, among other things, maintaining the patient through the period of treatment and symptom management in a meaningful way and helping her/him to regain the best stage that can be achieved under the circumstances (Colussi *et al.* 2001). To increase understanding of how the meaning of illness is individually experienced, this study will investigate the person's lived experiences of living with cancer in old age.

AIM

The aim of this study was to investigate the meaning of living with cancer in old age.

METHOD

In this study the hermeneutic phenomenological method as described by van Manen (1990, 2001) and referred to as 'phenomenology of praxis' was used. Phenomenological research is characterized by beginning in the life world, which means the natural attitude of everyday life (van Manen 1997). The combination of interpretative (hermeneutic) and descriptive (phenomenological) elements is summed up thus: 'phenomenological text is descriptive in the sense that it names something and hermeneutic text is interpretative in the sense that it mediates' (van Manen 1997, p. 26). Phenomenology tries to distinguish what is unique and what is the nature or essence of a phenomenon to better understand what the particular experience is like (van Manen 2001). Using 'phenomenology of praxis' is a way to a more sensitive understanding of the phenomenon or lived experience which in this study means 'living with cancer in old age'.

Sample

The sample consisted of seven women and three men and the age range was 75–88. Inclusion criteria were people aged 75 and over who had a diagnosis of cancer (regardless of type, stage or treatment) and who had just previously completed cancer treatment. Six persons were less than 6 months post-cancer diagnosis and four persons had a relapse in their cancer. The participants had been treated for different types of cancer: cancer of cervix/corpus uteri, lung cancer, colon carcinoma, prostate cancer, ventricle cancer, breast cancer and oral cancer. All persons lived in their own homes. At the time of the interviews four per-

sons were receiving help in personal and instrumental activities for daily living, seven persons lived together with someone, one lived apart and two lived alone.

Procedure

The sample was consecutively selected from an oncology clinic at a university hospital in southern Sweden. At the end of the cancer treatment session an oncology nurse asked the person if she/he wanted to participate in an interview study. The person was not dependent on the oncology nurse and voluntariness was emphasized. If the person agreed to participate the first author met the person in connection with the last treatment and informed about the study. The participant chose the place, time and date for the interview. The first author conducted all interviews. On the day of the interview the person was contacted to make sure that she/he had the strength to carry out the interview. All interviews except one were conducted in the person's own home and lasted for 45–150 min. Two interviews were shorter than 1 h owing to the condition of the interviewee. All interviews were tape-recorded. The first author asked the person as sensitive as possible to narrate her/his experiences during the cancer disease and the interview had the nature of conversation. Invitation to the interview somewhat varied depending on the interview context. In the beginning of the interview the respondent was invited to tell about the experience of and what it was like living with cancer in old age. The interviewer tried not to raise specific questions, but to encourage the respondent to 'see for him/herself', by striving to stay close to lived experience and to be concrete asking the person to think of specific situations by asking 'Can you give me an example?' or 'What was that like?' The interviewer also tried to balance the interview by sharing silence and waiting for the person to proceed or by talking about everyday problems. Ethical considerations that mournful thoughts could be aroused during the interviews seemed to be balanced by the attention given and the possibility to verbalize the life situation and thereby go through the experience thoroughly. Respect was also given to the interviewee's condition and the interview was discontinued if the interviewee was too tired or disabled to go on. The Ethics Committee of Lund University (LU 692-02) approved this study.

Analysis

The main objective of phenomenological research, described as 'phenomenology of praxis', is to transform personal meanings and experiences from interview texts

into disciplinary understanding (van Manen 1997). In this study the experience of 'living with cancer in old age' was investigated and the overall research questions were 'What is it that makes this lived experience what it is?' and 'What is unique about this?' (van Manen 1997, 2001) The interviews were transcribed verbatim by the first author. Initially two interviews were analysed simultaneously by the first two authors (B.T., B.A.E.) and discussed with the other authors (I.R.H., A.K.D.) to reach agreement on how to implement the analysis process. After agreement each interview was analysed by the first two authors.

Carrying out phenomenological research involves a set of activities that are inseparable (van Manen 1997). Each interview was read and reread and the text was approached to capture the fundamental meaning or main significance of the interview as a whole referred to as a 'holistic reading approach' (van Manen 1997). The authors strove to investigate how the lived experience showed itself in each interview. Aspects or qualities of the phenomenon were written as essential themes. Variations (characteristics) of the essential themes were reflected by a 'selective reading approach' (van Manen 1997), that is, what statements or phrases seemed to be essential or revealed the aspects of the lived experience (Table 1). The authors discussed the essential themes and the variations of the themes and finally each interview was described as unique essential themes of the lived experience (Table 2). The findings were presented across all interviews as a whole by four overarching essential themes revealed from the unique essential themes in the 10 interviews. Together they presented the participants' joint unique lived experience of living with cancer in old age.

Using phenomenology means working with a reflective method with bracketing, brushing away or reducing things, preventing the researcher from making primitive contact with the concreteness of lived reality (van Manen 1997). During the analysis process the authors (B.T., B.A.E.) tried to disregard their preunderstanding in oncology nursing by recalling and making it explicit and then trying to bracket it. However, orienting oneself to a phenomenon implies a particular interest (van Manen 1997), which in this study is that of the nurse.

FINDINGS

The lived experience presented itself in the individual person and within the whole group of interviewed persons as interacting with a more or less disrupted life situation, and living with cancer in old age manifested itself as *transition into a more or less disintegrated existence*. The

Table 1. Example of the revealing of one essential theme in an interview

HOLISTIC READING APPROACH
 The illness means a time of unrest and distance from the ingrained social pattern and a reorientation to new demands. A reorientation in social life is experienced as a withdrawal from and a re-entry into the ingrained social pattern.

Theme
Reorientation in the social life situation

SELECTIVE READING APPROACH
 'It has been very nice and comfortable here [at the patient hotel], but when I came into my room I thought to myself. . .this is where I am going to be for the next five weeks. Then I went downstairs and got very good contact with the people here. We began to talk and they had a chance to talk about their illness as well. Everybody must be allowed to do that. Afterwards when we had got to know each other we began to talk about all kinds of things.'
 'I'm very active in clubs and societies and they have written cards to me about what is happening. So I can't say that I have been disconnected from life. I have been fairly involved in things. It will feel strange to come back, it sure will.'
 'Now I have been an outsider prepared for everything. Now I am going into that circle again.'
 'Well, I think it will feel good in one way except that everybody will say, "Oh how are you?" Then you have to steel yourself and find an answer which suits everybody.' (laughs)
 'Of course they will wonder where I have been, so it will be a small step back to society.'

WRITING AND REWRITING
The person's unique experience of the phenomenon shows itself as . . .
 The new life situation means a withdrawal from ordinary social life and meetings with new social situations. The life situation after treatment means re-entry into ordinary social life again but with a new experience added.

Essential theme
A reorientation in social life
 (Presented in the overarching theme 'A redefinition of one's role in life for good and for bad')

Table 2. Example of the unique essential themes from one interview

A life situation of constant changes
 A reorientation of the social life situation
 A new view and experience of the meaning of age
 Bodily expressions mean both good and bad experiences
 Different responses from those around to the new situation
 Cancer expected and not worrying
 An awareness of the value and meaning of life through the meeting with others in a similar situation
 A new view and perception of the family
 Importance of the encounters with health cares staff

lived experience also appeared as *sudden awareness of the finiteness of life, redefinition of one's role in life for good and for bad, and meeting illness and disease.*

Transition into a more or less disintegrated existence

Illness meant awareness of ageing and its influence on the life world. Age suddenly appeared as obvious and had to be attended to in various ways. It showed itself as bodily signs understood as caused by cancer, side-effects of cancer treatment, ageing per se or as ageing impaired by cancer. Old age also proved to have an impact on treatment conditions such as limited access to various methods of therapy. It also influenced the readiness to undergo treatment, which showed itself in bargaining about the price to be paid in side-effects in proportion to effect of treatment:

If it had been too trying during this time of radiation therapy then I would have terminated it. If it had

meant more harms than use I should have said no! But there was no harm and it turned out very well. (A man who just previously had completed radiation therapy)

The life situation was experienced as gradually or rapidly transformed with more or less influence on the life world. Illness showed itself as bodily signs. When illness presented itself as an age-related expected life situation with only a slight affect, it meant no feelings of sadness or loss. The life situation was undisturbed as long as no trying bodily signs intruded.

When losses of bodily capacities and signs of illness restricted the life situation with a rapidly decreasing ability to interact with everyday life, more marked feelings of change for the worse were experienced. Pain meant a situation with increasing doses of analgesics. Urinary and faecal incontinence meant a situation with diapers, smell, and helplessness. Appetite loss, nausea and vomiting meant worry about nourishment, feelings of insecurity and dependence on help from others. Excruciating bodily signs meant a life world transforming into a limited and hopelessly lost situation:

They (home help service) come and put me to bed at eight o'clock . . . yesterday they didn't come until twenty past nine and then it was very trying, you see. I didn't feel well. But you have to adapt yourself to it. They usually come about three or four in the night. I told them to draw up the blind because it is so tiresome to lie in the darkness if they don't come until

ten o'clock in the morning. (A man with relapsed cancer living alone and confined to bed)

Illness showing itself as altered body image presented both bad and good experiences. Interpretations of responses from other people around had great influence on approaching the life situation. In encounters with others, a bodily appearance of being well preserved proved to be encouraging and made things easier, whereas evident bodily signs of illness led to additional shrinking life space also affecting social life:

I have been a librarian for 13 years. I used to be in the library continually and now they can't understand why I never come any more. I usually send my husband. It's because I'm getting thinner and thinner. (A woman who lost a lot of weight in the last 6 months)

Bodily losses like alopecia was painful because it served as a reminder of the disease. On the other hand, alopecia was experienced as a source of happiness through the family's affectionate care and concern:

'You are so cute', they say and try to pep me up. My 17-year-old grandchild phones me every night and asks 'How long is your hair now?' (A woman with alopecia after cytostatic treatment)

The overriding bodily sign was fatigue. It meant a decreasing ability to do things that used to be important and decreasing power to resist mournful thoughts. Fatigue was interpreted as a bodily sign owing to either cancer or old age or a combination of both.

Everyday life during treatment presented a disintegrated life situation occupied with the conditions of treatment, side-effects, travelling and residing away from home. The life situation was experienced as more or less influenced and limited by trying side-effects of cancer treatment. Side-effects such as eating difficulties did not only mean pain and appetite loss but also affected social life:

At our age we usually see each other and have nice dinners together. You normally invite people and so on. You see each other at home. But I don't want to eat together with other people because it is so hard. Well, not hard, but I think I cough and behave in a manner that I don't want people to see. (A woman suffering from side-effects of radiation therapy)

The readiness to undergo treatment was related to values in life and how current life presented itself and hope about treatment outcome did not necessarily mean cure but achieving a standstill with no trying symptoms. Involvement in cancer treatment meant on the one hand a

life situation with feelings of being privileged and chosen, and when the decision to undergo treatment was made encouragement from family and personnel was important. On the other hand, treatment decisions were influenced by the general attitude to cancer treatment in old age and meant being exposed to questioning by people of the same age about the value of undergoing treatment at that time of life:

I was prepared for the treatment so I just thought that now they want to help me as well as they can and I have to be strong meanwhile. Many people asked me why I chose to go through a thing like that and said that they wouldn't have. That was what most of the people said. Yes, but why not if they can help you? Maybe I would have managed anyhow but . . . (A woman reflecting on the decision about whether or not to undergo treatment)

When everyday life was affected by fear of side-effects appearing, the spatial life world was limited owing to worry about unforeseen things happening, and home was perceived as the safest place to be. Although the life situation during treatment was physically and psychosocially trying, it was felt to be possible to accomplish. After completing treatment feelings of relief and content appeared and treatment was a valuable experience as time went on.

The relation and interaction with the family were interpreted in new ways. The family's capacity for loving care appeared to be unexpectedly great, and this would not have been disclosed if the person had not contracted cancer:

I have had a very great response from my family, very great indeed. I was hospitalised almost the whole autumn with those side-effects and they wrote to me every day. It is fantastic to feel as much concern as I have felt and so much loving care. I must say that I have learned a lot from this. I am almost thankful to have been through all this and to have experienced this much, really! Now I am talking so much that tears are coming. (A woman after a long period of strenuous treatments)

Support and sharing with the family were experienced as unique, valuable and crucial for handling everyday life, giving strengthened feelings of confidence and being valued. Encounters with grandchildren meant having access to the world outside one's own limited life space. Interacting with the family also meant avoiding the cancer by talking about everyday things with the intention of not worrying them. When the life situation was dominated by excruciating symptoms it intruded on relations and interaction with the family:

And then came Christmas in the middle of everything and Christmas is so emotional. I felt that I had to be capable of everything. I can understand my daughter who probably thought, this is the last Christmas that you'll be with us. I was so tired. I just wanted to lie in bed and I couldn't eat either. Everything was so awkward. (A woman about family life)

Sudden awareness of the finiteness of life

Having lived a long life affected life with cancer as a whole. Looking back on earlier life, experiences mainly on the credit side made the current life situation easier to endure:

I have lived my life for 80 years and have had a good life and I feel good. So there is much on the credit side. You evaluate your life a bit like that. Which side weighs more in the balance? I have had a good life with just the right proportions of sorrow and joy like we all have. (A woman with newly diagnosed cancer)

Various conditions of lived life showed themselves as strength and readiness to meet difficulties in present life constructively:

Life is like that . . . and I don't think that life would be worth much anyhow if you just go on in the same groove and don't look at what is around you. Yes, that's the way it is to get to know things around you and not just walk on. (woman having completed treatment)

Consciousness of the values in life was present with a wish to have some more years left. Also an acceptance of finiteness of life was shown in an awareness about the future as limited in time and a readiness for things to happen due to age were present when approaching future life:

I know that I am old and that I shall not live so much longer. You have to take one day at a time when you are this old and do the best you can with it. But the cancer, I never think of it, I don't care. (A woman with relapse)

Illness experience showed itself as awareness about death as inevitable. Death in itself meant no fear and anxiety, whereas dying was talked about as a fear of excruciating symptoms such as pain and/or ending up confined to bed and dependent on help from others:

If you were lying there sick in bed, that is the worst thing I think. Yes, that is the worst thing. (A woman who had previously cared for a spouse)

When life presented itself as dominated by excruciating symptoms, death was considered as a possible way out because life was considered to have come to an end anyway:

When I was lying there in all that pain I thought, 'is it worth doing all this for an old man?' Well, I thought they should let me go peacefully from this world. (A man with a lot of pain)

The strength to face future fights with the cancer was affected by how current life presented itself:

Just now I am fighting with Saint Peter and I don't know who is winning. He called for me a couple of times before but he failed. Now he is calling for me again and I don't know who is going to win. He is more aggressive this time. (A man with relapse about confronting death)

Another approach to the future showed itself as an acceptance that life had come to an end, which was not experienced, as frightening or sad. Gradually saying farewell to life, by phasing out different things in life that were previously felt to be essential, was a way of handling the life world:

I don't think about it. It is something that should come and I suppose that is the way it is. I feel no fear or any thing like that. Now I have lost everything. Now I am very tired. (A woman with relapse about confronting end of life)

Redefinition of one's role in life for good and for bad

The transformed life situation made great demands of the ability to adapt to and handle everyday life. The limited life world made redefinition of one's role in life crucial. Lack of understanding from those around about the new conditions and limitations of life made it necessary to redraw the limits to their expectations and to set new limits for themselves:

I have helped a lot of people and they don't understand that now it is me who decide. Now I have decided to say no to everything that is demanding. Now is the time to draw the line. (A woman about her social situation after treatment)

Readiness for investment in future life was presented in various ways. Having survived meant feelings of happiness and a wish to fight on to recover. A way of handling the life situation presented itself as using earlier habits in a new creative way, such as keeping a diary as a way of

venting thoughts. Illness experience presented an unexpected consciousness of the personal power and strength to have gone through the tough period of illness and treatment which meant a reappraisal of things in present life:

I managed and many people ask me how I could. and now I feel happier than ever because I have been through this and we have experienced it as good. At the same time I perceived it as very interesting to go through this. So I think that I have added one more experience to life. (A woman after completing treatment)

The lived experience manifested itself as a strengthened relation between the spouses as well as awareness about their vulnerability. Thoughts about what was going to happen with the ageing spouse and those who would be left behind appeared at times with regret and worry. The mutual experience, however, meant feelings of confidence in meeting future challenges together.

Solidarity and engagement on behalf of others in a similar life situation meant a strengthened awareness of the value and meaning of the life situation and made the new role in life easier to face. This was particularly emphasized in encounters with younger people when experiences from a long life were felt to be valuable. Reflecting on illness by recalling others who were affected by cancer and comparing one's own life situation with theirs showed that no matter how affected the old person was she/he always felt better off than others. Meeting the future revealed itself as a reorientation to social life. Illness meant withdrawal from ordinary social life and meetings with new social situations and after treatment a re-entry into ordinary social life again but with a new experience added:

'Life is going to feel different from before. You are wiser from the experience' (A woman just completed treatment and residing away from home).

Meeting disease and illness

Encounters with physicians and health care staff proved to be important when approaching illness. Information given about the cancer was remembered in detail. Encounters with the physician marked by comfort and sympathy meant a relieving experience. The visit to the physician after completed treatment was interpreted as an important milestone for approaching future living with cancer. Supporting and confirming encounters with personnel also embracing family members made treatment easier to go through:

The last time I was at radiation therapy my daughter drove me there and she brought her daughter who is

about seven years old. She said, 'now I want to see what you are doing with my grandmother.' They said, 'OK, we will show you' and they showed her around. They didn't mind telling her everything, a little child. I think that was exceptional. She didn't think it was terrible. (A woman about radiation therapy)

Unreasonably long waiting times and vague information from the physician were interpreted as a consequence of low priority because of age. Feelings of being abandoned with uncertainty and different interpretations were consequences of indistinct and conflicting information given about the cancer progress. The diagnosis point meant that the life world was transformed into a situation of dependence on the physician and personnel, which sometimes meant feelings of being vulnerable and exposed. An unsympathetic attitude from the physician when giving information about the cancer diagnosis meant a violating experience leading to anxiety, sleep disturbance and feelings of dejection:

Then a doctor came and said, 'well, you have got cancer but you have to die of something anyhow.' I wake up in the nights and I hear his voice. He was so arrogant and supercilious. Then he sent me for X-ray and some weeks later he phoned me and said that I had cancer in the liver and everywhere. (A woman with lung cancer)

DISCUSSION

The meaning of living with cancer in old age could be said to correspond with the four fundamental existentials described by van Manen (van Manen 1997) as pervading the life worlds of all human beings: lived body, lived space, lived time and lived human relations, also referred to as the fundamental features of embodiment by Toombs (1988). According to van Manen (1997) these four existentials can be differentiated but not separated. The presence of the four existentials in the findings will guide the discussion.

Discussing the steps taken to increase trustworthiness will validate the findings. Trustworthiness is obtained in a qualitative study when credibility, transformability and dependability are achieved (Guba 1981). To increase credibility, efforts were made to inform the participant about the study as carefully as possible. The first author conducted all interviews. To strengthen dependability the analyses were performed simultaneously and discussed by the first two authors, who had different degrees of closeness to the interviews, which may have given a more comprehensive interpretation and description of the lived

phenomenon. To further validate the findings quotations were used to illustrate and provide more concrete examples of the thoughts, feelings or moods of the persons interviewed. The transferability of the findings in qualitative studies depends on the degree of similarity between the context of the interviews in the study and the actual setting, and thus findings cannot be wholly applied to another setting. In our study transferability is tied to the fact that all participants represented the same point in time in their disease, that is, having just completed their treatment, which made them focused on the research question. The participants represented various diagnoses and degrees of the disease, which meant that persons with severe illness were also included. Little is known from earlier studies about how older people with cancer experience the meaning of their illness. The findings may thus be used to generate understanding about older people's meaning of living with cancer and then be applied to new similar settings. The findings may also add understanding to the basis on which clinical recommendations for older people with cancer are made.

The meaning of illness was based on what was important within the life of each person as she/he was affected by cancer. Van Manen (1997) relates the lived body to how a person always is corporeally in the world and it is through bodily appearance that he/she first meets other persons. In our study losses of capacities meant a transition into a more or less disintegrated existence where the previously unreflective lived body was transformed into a body restricted by the available physical capacities. Age suddenly appeared as obvious and the body became an object of scrutiny and could not be simply unreflectively lived as before the illness. In a study on patients with life-threatening injuries and illnesses Morse and colleagues (1995) identified various reflections on corporeality. Four of these reflections could be used to elucidate our findings, namely, corporeality described as the diseased body, the disobedient body, the vulnerable body and the enduring body. The diseased body could be said to apply to our study when symptoms and side-effects engendered a profound disruption of the lived body and made it impossible to forget and to be attentive to things that used to be important. In our study the disobedient body applied to the life situation with an unreliable body no longer possible to trust owing to symptoms and side-effects and when the easiness of everyday life was diminished. The vulnerability of the body was revealed in awareness of decreasing bodily capacities in addition to old age. In our study when illness and treatment meant relentless discomfort, the enduring body, also described by Ohlen and colleagues (2002) as the endurable body, may have a special impor-

tance as the absence of trying symptoms was perceived as more essential than the approaching death. Thus, the person's own familiar body was experienced as changed and the life world as transformed into disintegration, with consequences and significance not only for the person her/himself but also for the family and those around. Therefore care for older people with cancer should comprise support in how to handle the consequences of a life world disintegrated by illness by helping to bring consciousness about how the lived body is disturbed and what may be done to develop meaningful and worthwhile liveable relations between illness experience and the life world.

The most conspicuous bodily sign proved to be fatigue, which affected the life situation as a whole and meant additional decreased resistance to handle everyday life. The pronounced affect of fatigue on the life situation in cancer patients (aged 23–88) also showed itself in a qualitative study by Magnusson and colleagues (1999) as a process of experiences of loss, social limitations and decreased ability to handle daily life. Similar experiences of fatigue were present in our study, in which fatigue may also be seen as particularly trying, appearing in a complex situation of cancer and old age because both are related to fatigue.

Disintegrated existence also appeared as a lived space more or less different from before cancer. Available lived space was constricted by limited bodily capacities, and the life space that had formerly been taken for granted sometimes became difficult to handle. The effects of cancer on the lived space meant everything from small limitations with only a slight effect to a situation of being confined to bed and thereby heavily restricted. Van Manen (1997) describes lived space as 'felt space' or 'the nature of lived space that renders that particular experience its quality of meaning' (van Manen 1997, p. 102). Lived space has also been described as: 'the subjective experience of space is intimately related both to one's bodily capacities and to the design of the surrounding world' (Toombs 2001, p. 249). Lived space in our study also meant an involuntarily expanded lived space owing to treatments requiring quite a number of journeys and residing away from home, which sometimes made the life situation hard to handle as it did not allow any further meaning outside the conditions of treatment. Thus, as an affected lived space may additionally aggravate the life situation, especially in old people with vulnerable lived space, it is important for health care professionals to pay attention to how the illness influences lived space to facilitate handling the life situation.

The social role in life engendered by illness meant both painful insights into limitations and the awareness of new possibilities demanding a redefinition of one's role in life.

Important lived relations were those with family, friends and health care professionals. Van Manen (1997) defined lived human relations as: 'through lived relation to others we maintain with others in the interpersonal space that we share with them' (van Manen 1997, p. 104). Lived relations were more or less affected. The support and care from the family became very important and meant a renewed appreciation of them. The strength to handle the life situation, also including the spouse, transformed illness to a positive experience. The closeness to the family gave illness a new meaning. The importance of family support was also found in a qualitative study by O'Connor and colleagues (1990) about search for meaning in illness in cancer patients (aged 36–67) and in a phenomenological study on survivorship in cancer patients (women aged 33–69) by Breaden (1997). In our study, however, lived experience also showed itself as painful insights that illness meant limitations in interaction with the family and friends, which aroused feelings of insufficiency. A limited ability to perform the usual life role was felt to be a loss, revealed as an imbalance between available capacities and expectations from family and friends, which meant a redefinition of the usual role in interaction with the nearest relations. O'Connor and colleagues (1990) showed that there is a risk that limitations in performing the usual life role may diminish a person's perceived role in life. In our study, however, the redefined role could be seen to be balanced by the awareness of sharing with others the experience of living with cancer, in earlier studies phrased as 'sharing the journey' (Allison *et al.* 1997; Breaden 1997; Utley 1999). The lived experience showed new possibilities in encounters mainly with younger persons with cancer. Being in a new position of ability to give support and understanding minimized the importance of the person's own life situation. Comparing the life situation with that of others with cancer showed that no matter how affected the old person was she/he always found her/himself better off. This was found also in earlier studies about people with cancer (Heidrich & Ryff 1993; Utley 1999; Thomé *et al.* 2003) and could be referred to the theories of downward comparisons (Wills 1981). Thus, it is important to confirm the old person's positive experiences and action to endure the painful insights into limitations engendered by the cancer. It is also important to support the interaction with family and other people around to minimize the experiences of loss by helping them understand how to balance the old person's abilities and their own expectations.

Meeting illness and disease was influenced by the behaviour of health care professionals in clinical encounters, which proved to be important for how the old persons perceived the meaning of illness. The physician's words and

attitude were decisive for illness experience and the ability to handle the life situation. Toombs (1988) has described how the body, when the physician examines it and diagnoses the cancer, may be experienced as an object and designated as a thing outside one's own control and as 'other-than-me or outside my subjectivity'. In our study the diagnosis point meant that the life situation was experienced as surrendered to the trust of the physician and the health care personnel and thereby disintegrated. If the life situation aroused feelings of abandonment and uncertainty about how illness would affect future life, suspicions about being treated less carefully owing to old age further exacerbated it. This agrees with the findings of Thomé and colleagues (2003) that older people with cancer who felt neglected and doubted in encounters with health care personnel mostly related it to age. Thus, health care professionals should consider the person as a unique individual when providing support and care to old persons with cancer, so that they can recover a liveable relation with their lived body and thus maintain a meaningful existence.

Illness meant a sudden awareness of the finiteness of life and lived time meant retrospective reflections and reevaluation of life as a whole with other frames of reference leading to a reorientation in present time. Lived time is defined by Husserl as: 'appearing time, appearing duration, as appearing, the time of my lived experience' (Husserl 1991, p. 5). Lived time was experienced as more or less disoriented, as the disease was more or less imminent and ever present. Having lived a long eventful life meant that the new life situation with a sudden awareness of finiteness of life was easier to endure and the uncertain and maybe lost future became easier to handle. The meaning of loss of future time was experienced according to how current life presented itself, showing itself as anything from being a probable way out of an undesired life situation to feelings of grief about a probable loss of more desired time in life. Irrespective of how future time was approached, the presumptions of future time were more or less expected and mostly met with no fear. This approach is probably related to old age and different from that of younger persons, because earlier studies of cancer show that uncertainty about the future is one of the most frequent concerns among younger cancer survivors (Pelusi 1997). Another approach to time coloured by age was facing death. The lived experience made thoughts about death inevitable. However, death itself did not arouse feelings of fear. The concerns and fears were more about how the end of life would turn out. The findings thus emphasize the importance of knowing the history of the old person's lived life and ultimate life goals to come closer to an understanding of how she/he approaches and handles the

life world disintegrated by cancer and old age. Thus, addressing the person's past meanings, awareness of finiteness of life and perhaps future fears in a realistic fashion, may enable her/him to live more effectively in the present.

CONCLUSION

The meaning of living with cancer in old age showed itself as a disintegrated existence. The old persons who had just completed cancer treatment lived under the pressure of being in a transition stage. The meaning of illness showed itself as bodily signs, owing to the cancer or cancer treatment, which limited the life situation physically, spatially and socially. A sudden awareness of finiteness of life meant a re-evaluation of present life with new frames of reference as well as a renewed view of future life and the end of life. The future was met with uncertainty and with a fear of ending up dependent on help for daily living. Death in itself meant no feelings of fear or disquiet, whilst dying was experienced as frightening. To handle the new life situation the old person changed her/his view of her/himself, which meant a redefinition of one's role facing both limitations caused by the cancer and possibilities using experiences from a long life. The findings indicate how important it is for health care professionals to identify and take care of the disabilities owing to the cancer and treatment and to support the reorientation in the disintegrated life situation. It is also important to have preparedness to meet the old person's thoughts about death. Thus, it is important to encourage the old person to describe her/his illness experience to increase understanding about what is meaningful for her/him to provide individual support and appropriate care.

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REFERENCES

- Allison P.J., Locker D. & Feine J.S. (1997) Quality of life a dynamic construct. *Social Science and Medicine* **45**, 221–230.
- Bailey C. & Corner J. (2003) Care and the older person with cancer. *European Journal of Cancer Care* **12**, 176–182.
- Benner P. (2000) The roles of embodiment, emotion and life world for rationality and agency in nursing practice. *Nursing Philosophy* **1**, 5–19.
- Benner P. (2001) The phenomenon of care. In: *Handbook of Phenomenology and Medicine* (ed. Toombs K.), pp. 351–369. Kluwer Academic Publishers, Dordrecht, the Netherlands.
- Breaden K. (1997) Cancer and beyond: the question of survivorship. *Journal of Advanced Nursing* **26**, 978–984.
- Colussi A.M., Mazzer L., Candotto D., De Biasi M., De Lorenzi L., Pin I., Pusiol N., Romanin C. & Zamattio V. (2001) The elderly cancer patient: a nursing perspective. *Critical Reviews in Oncology/Hematology* **39**, 235–245.
- Gianni W., Cacciafesta M., Pietropaolo M., Perricone Somogyi R. & Marigliano V. (2001) Aging and cancer: the geriatrician's point of view. *Critical Reviews in Oncology/Hematology* **39**, 307–311.
- Guba E. (1981) Criteria for assessing trustworthiness and naturalistic inquiries. *ERIC/ECTJ Annual Review Paper* **29**, 75–91.
- Heidrich S.M. & Ryff C.D. (1993) The role of social comparisons processes in the psychological adaptation of elderly adults. *Journal of Gerontology* **48**, 127–136.
- Husserl E. (1991) *On the Phenomenology of the Consciousness of International Time (1893–1917)*. Kluwer Academic Publishers, Dordrecht, the Netherlands.
- Magnusson K., Moller A., Ekman T. & Wallgren A. (1999) A qualitative study to explore the experience of fatigue in cancer patients. *European Journal of Cancer Care* **8**, 224–232.
- van Manen M. (1990) *Researching Lived Experience*. State University of New York Press, New York, NY, USA.
- van Manen M. (1997) Researching lived experience. *Human Science for an Action Sensitive Pedagogy*. The Athlone Press, Toronto, Canada.
- van Manen M. (1998) Modalities of body experience in illness and health. *Qualitative Health Research* **8**, 7–24.
- van Manen M. (1999) The pathic nature of inquiry and nursing. In: *Nursing and the Experience of Illness: Phenomenology in Practice* (eds Madjar I. & Walton J.), pp. 17–35. Routledge, London, UK.
- van Manen M. (2001) Professional practice and 'doing phenomenology'. In: *Handbook of Phenomenology and Medicine* (ed. Toombs S.K.), pp. 457–474. Kluwer Press, Dordrecht, the Netherlands.
- McCaffrey D. (1994) Realities to guide novel and necessary nursing care in geriatric oncology. *Cancer Nursing* **17**, 125–136.
- Morse J.M., Bortoff J.L. & Hutchinson S. (1995) The paradox of comfort. *Nursing Research* **44**, 14–19.
- O'Connor A.P., Wicker C.A. & Germino B.B. (1990) Understanding the cancer patient's search for meaning. *Cancer Nursing* **13**, 167–175.
- Ohlen J., Bengtsson J., Skott C. & Segesten K. (2002) Being in a lived retreat – embodied meaning of alleviated suffering. *Cancer Nursing* **25**, 318–325.
- Pelusi J. (1997) The lived experience of surviving breast cancer. *Oncology Nursing Forum* **24**, 1343–1353.
- Redmond K. & Aapro M. (1997) *Cancer in the Elderly – a Nursing and Medical Perspective*. Elsevier Science, Amsterdam, the Netherlands.
- Thomé B., Gunnars B., Dykes A.K. & Hallberg I.R. (2003) The experience of older people living with cancer. *Cancer Nursing* **26**, 85–96.
- Toombs S.K. (1988) Illness and the paradigm of lived body. *Theoretical Medicine* **9**, 201–226.
- Toombs S.K. (1993) *The Meaning of Illness – a Phenomenological Account for the Different Perspectives of Physician and Patient*. Kluwer Press, London, UK.
- Toombs S.K. (2001) *Handbook of Phenomenology and Medicine*. Kluwer Academic Publishers, Dordrecht, the Netherlands.
- Utey R. (1999) The evolving meaning of cancer for long-term survivors of breast cancer. *Oncology Nursing Forum* **26**, 1519–1523.
- Wills T. (1981) Downward comparisons principles in social psychology. *Psychological Bulletin* **90**, 245–271.