Cancer as a life-changing process: Women’s experiences five years after treatment for gynaecological cancer

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Abstract
This article presents and discusses the essential structure appearing in a phenomenological study focusing on women’s experiences of living as long-term survivors after gynaecological cancer, namely Cancer as a life-changing process. The aim of the study was to gain a deeper understanding of living beyond gynaecological cancer. The study is founded on a phenomenological lifeworld perspective, and based on 32 in-depth interviews with 16 women aged 39 to 66, all free of illness. The interviews were made five and six years after treatment for cancer, respectively. Surviving cancer entails living with profound life-changes, demanding as well as enriching, even though the women have been declared cured. The essential structure consists of two interrelated constituents; “living between life courage and life anxiety” and “living between existential loneliness and relational caring”. The constituents are illuminated by the perspective of Danish life-philosophy, represented by Ludvig Feilberg and Knud Ejler Logstrup—and Mogens Pahuus’ interpretation of their thinking. The empirics clearly show that life phenomena are still “ploughed up” five to six years after treatment when the women have been declared long-term survivors. The study points out that experiencing cancer can move the women deeply in their lives. This may challenge health care personnel in their encounters with women surviving gynaecological cancer.

Key words: Gynaecological cancer, long-term survival, life phenomena, vulnerability, cancer care.

Introduction
Advances in treatment of cancer in general, and gynaecological cancer in particular, have improved the likelihood of survival. The survival rate of patients with cervical and uterine cancer is 78.6% and 45.4% for patients with ovarian cancer (Cancer Registry of Norway, 2007). Combined with a general increase in the number of older people, this yields a significant and growing number of long-term survivors of cancer (> 5 years).

The short-term impact of going through gynaecological cancer and the different treatment approaches are illuminated by research with respect to the patients’ physical, psychological and sexual functioning. Less data exists regarding long-term survivors. However, in recent years, survey studies of long-term survivorship after gynaecological cancer show that survivors overall enjoy a good quality of life (QoL) (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Rannestad, Skjeldestad, Platou, & Hagen, 2008; Stewart, Wong, Duff, Melancon, & Cheung, 2001; Wenzel & Donnelly et al., 2002; Wenzel & DeAlba et al., 2005). Some studies, however, do report bodily ailments, such as abdominal and gynaecological symptoms, and difficulties related to the survivors’ sexual life. For instance, Stewart et al. (2001) show that 89% of the long-term survivors of ovarian cancer regarded their physical, psychological, social and spiritual health as good or excellent, but 53.3% felt pain or discomfort. Furthermore, despite 57% reporting that their sex lives had been negatively affected by cancer and its treatment, their overall sense of loss related to sexual functioning was moderate to low. Stewart et al. (2001) discuss the positive
QoL-outcome in relation to these physical scars. The women, having survived a life-threatening illness, may have assumed a new perspective regarding their difficulties. Changing priorities may have outweighed other, more negative, changes. Molassiotis, Chan, Yam, Chan and Lam’s (2002) qualitative interview study also underlines the women’s positive perspectives on life regardless of symptoms. It seems reasonable to suggest that a positive outcome may balance challenges and discomforts many women must live with as long-term gynaecological cancer survivors.

Some studies report positive outcomes and post-traumatic growth after gynaecological cancer (Molassiotis et al., 2002; Stewart et al., 2001; Wenzel & Donnelly et al., 2002). Stewart et al. (2001) report that most women said their ovarian cancer experience had changed their views on life and relationships in an overwhelmingly positive way. They showed resilience and good physical and psychological health. Feelings of greater pleasure in life and deepened personal relationships were also emphasized. Molassiotis et al. (2002) echo these findings.

However, anxiety and fear of recurrence among long-term survivors after gynaecological cancer also appears significant (Hodgkinson et al., 2007; Wenzel & Donnelly et al., 2002). Hodgkinson et al. (2007) did a self-report questionnaire to assess psychosocial outcomes and supportive care needs on long-term survivors (disease-free, one to eight years after treatment). Nearly 90% of the survivors reported supportive care needs. Major needs were related to existential survivorship (e.g. spiritual beliefs, decision making, search for meaning) and comprehensive cancer care (e.g. team care, communication). Wenzel and DeAlba et al. (2005) show, in their study on cervical cancer survivors during childhood years, that a majority indicated that they would have desired counselling both at the time of diagnosis (69%) and at the time of current study participation (59%), to discuss psychosocial issues raised by the cancer experience. In a study by Wenzel and Donnelly et al. (2002), 43% of the women reported that they were likely to have participated in a counselling program today (>5 years after) to discuss psychosocial issues related to having had ovarian cancer. 56% stated that they would have attended a support programme during the initial treatment, had it been offered.

This knowledge provides insight into the complex connections between quality of life, long-term physical and sexual sequelae and factors of resilience and growth. However, little is known about everyday experiences of living with these phenomena as long-term survivors from gynaecological cancer. Excepting Molassiotis et al. (2002), the studies referred to above do not delve deeply into lived through meanings of experiences that arise. In another article that will be published elsewhere, experiences of long-term surviving women are described in three core themes. However, we realized that there was an existential nature of the first core theme presented, that urged for future analysis. The aim of the current article is to gain a deeper understanding of the existential dimension of living beyond gynaecological cancer. This knowledge may help health care personnel to better understand the depths of these experiences and thus be able to meet the women in a more holistic way.

The perspective of life phenomena obtained from Danish life philosophy was chosen as a well suited perspective to expand the understanding of the identified essential structure. This framework came into play in the theoretical discussion of the essential structure.

**Theoretical framework—Danish life philosophy**

Life philosophy seeks answers to existential issues like the meaning of a human life, and what it entails to live “a good life” (Pahuus, 1995, p. 8; 1998). As humans we ask ourselves such questions at some point. One may say that we search for our own life philosophy, more or less consciously, based on our own experiences. When a crisis like a serious illness occurs, existential questions are vitalized in new ways that may influence our ways of living. In this article Danish life philosophy is represented by Knud Ejler Løgstrup and Ludvig Feilberg, supplemented by Mogens Pahuus’ interpretation and comparison of these two philosophers’ thinking.

Pahuus (1993, p. 15) says that life itself fathoms the main thoughts of life philosophy and these may be explained by distinguishing between two types of human activity; the drive to satisfy needs and the fulfilment of yearning. The needs reveal themselves as individually and socially formed desires and expectations that can be satisfied by targeted actions. Needs are expressions of something lacking. Yearning may be experienced as something missing or longed for, a longing not necessarily founded on the absence of something. The fulfilment of yearnings does not necessarily result in satisfaction, but in something more comprehensive. Life fulfilment entails feelings of being alive, of life courage, of a sense of coherence, joy for life itself—phenomena touching deeper dimensions in life (Pahuus, 1993, p. 16). The yearning itself can be called a *life phenomenon*, belonging to a deeper human dimension than needs.

The Danish nurse-researcher Charlotte Delmar defines life phenomena as “a generalized label for the various ethical and existential phenomena which are given with life” (2006, p. 237). These phenomena are
basic experiences, usually hardly thought about in all their commonness. Løgstrup (2000/1956, p. 37) says that the most elementary phenomena in life are the ones we discover the last, they are the most difficult to find. Life phenomena can be cultural or precultural. Trust is a precultural phenomenon, according to Løgstrup, while life courage is more culturally conditioned. Life phenomena are both typical and unique, but always significant. They are fundamental to humans’ search for meaning.

As Delmar’s definition points to, life phenomena can be separated into those that are more ethically or more existentially orientated. Pahuus (1995) refers to Løgstrup’s expressions of life, also called life utterances, as ethical life phenomena, and Feilberg’s life-enhancing and life-constraining experiences as existential life phenomena. Løgstrup’s ethical thoughts are based on life being bestowed upon us through togetherness with others, a fundamental condition for understanding life utterances, the ethical life phenomena. These life phenomena carry existence as co-existence, bringing attention away from selfish interests towards togetherness with fellow humans (Birkeland, 2002, p. 159; Løgstrup, 2000/1956). The ethical life phenomena—e.g. trust, openness of speech, charity, vulnerability, empathy, mercy, hope and respect for the other’s zone of untouchability are, according to Løgstrup, fundamental to being human. He says, for example, that being with each other openly and in trust belongs to life itself. Trust is a demand to take care of one another and is present, still mostly unspoken, in any human relationship. It appears as a silent mutual demand. Ethical life phenomena are more precultural. That means that they are ontological facts as well as basic dimensions of human life. Culture can, however, limit their expressions. Furthermore, ethical life phenomena are spontaneous and unselfish, no hidden agendas or self-interests are connected with them. Opposites exist, though, such as self-circling thoughts and feelings (Løgstrup, 2000/1956, p. 166; Pahuus, 1995, p. 40).

Løgstrup’s ethical life phenomena are about interpersonal phenomena, the good and moral life together. Feilberg founds his work on human interdependence, like Løgstrup, but emphasizes that people are autonomous in forming their own lives (Pahuus, 1995, p. 42). The basis in Feilberg’s life-philosophy is the difference between conditions for experiencing life phenomena that are life-enhancing, such as life courage, life happiness and hope, and those that are life-constraining, such as loneliness, hopelessness, despair and anxiety (Feilberg, 1949, p. 14). What are the conditions for feeling very much ‘alive’ or feeling that life is empty and meaningless? Feilberg says that this is dependent on conditions surrounding us, but at the same time also highly dependent on ourselves.

Pahuus (1995, p. 42) draws on both similarities and differences between Feilberg’s more existentially oriented life phenomena and Løgstrup’s ethical orientation. He claims that they have much in common, but emphasizes that Feilberg’s existential life phenomena are much more comprehensive. Spontaneity is central both in Feilberg’s life phenomena and in Løgstrup’s ethical thinking. Pahuus emphasizes that among the most important hallmarks of the life-enhancing life phenomena is an openness and extendredness in life expression A genuine openness towards what may come is at the heart of the phenomenon, being openly attentive to and preoccupied with the situation itself. This is also important in Løgstrup’s ethical life phenomena. Life-constraining life phenomena on the other hand, are rigidly closed towards the world and life energy is withheld. Self-circling is about a closedness bound by static rules and methods, and ways of (re)acting (Pahuus, 1995, p. 59). Hence, one can say that life phenomena contain two different kinds of relationships to the world and two different forms of (re)action.

Life crises, such as serious illness and loss, are part of human life—unavoidable in any person’s lifetime. The women in this study have experienced cancer, which has challenged them to take hold of their lives in new ways. How they experience and handle the illness varies. The philosophy of life phenomena is considered useful in order to gain a deeper understanding of this life-changing process.

The study

The phenomenological perspective

The study is methodologically anchored in a life-world perspective and founded on a phenomenological approach. The aim is to elucidate essential meanings of phenomena in the lifeworld (Dahlberg, Dahlberg, & Nyström, 2008; Giorgi, 1997; van Manen, 1990). The study provides a deeper understanding of the existential experiences of women who are living beyond gynaecological cancer. As researchers we are part of the lifeword and, according to Gadamer (2007), immersed in it in such a way that we can never escape from it. Our pre-understanding is prerequisite in understanding the world—the basis for experiencing the world as meaningful. Thus, we bring our pre-understanding with us into any encounter with another person, text or phenomenon. We interpret what we do not know based on what we already know. In this way, understanding the world will always be hermeneutical. As such, understanding is always productive, not only reproductive. Gadamer
(2007) uses the term “horizon-melting” to describe how our own horizon merges with others’ to reach new understanding. The study has a phenomenological approach as it attempts to let the phenomenon speak for itself. However, if we wish to discover something new, we must have an open-minded and dwelling approach, which also means to question and reflect upon our own experiences and pre-understandings (Dahlberg et al., 2008).

Participants

The women were recruited from an out-patient gynaecological follow-up clinic at a university hospital in Norway. They received written information about the study and an invitation to participate by mail. The staff nurses selected the informants based on the following inclusion criteria: The women should be fully recovered from gynaecological cancer (uterine, cervical or ovarian cancer); free from recidive and metastasis after the first treatment; between 30 and 70 years of age; followed up for approximately five years but not yet completed the final control; in a physical and mental state that made interviewing possible. Initially, we wanted to recruit women in an employable age, between 40 and 60, who were finished with child bearing. However, in order to recruit enough participants, the age limit was expanded.

16 of 31 women accepted the invitation to participate. The women were between 39 and 66 years of age, with an average of 56. All lived with a partner. The majority had one child or more, and had finished childbearing. They were diagnosed with various gynaecological cancers in different stages. All the women had undergone surgery and five had received additional treatment—cytostaticum and radiation.

Data collection

Data were collected by means of in-depth interviews, from December 2005 to November 2007. Each woman was interviewed twice, approximately 12 months apart. All interviews, save one, were conducted at the hospital and lasted between one and three hours. The average interview time in round one, was two hours—and a little less in round two.

The first author conducted all the interviews. She encouraged the women to tell freely their own stories of what they had gone through, from the time of diagnosis throughout treatment and cure—but first and foremost of living their everyday lives after cancer. An interview guide with some broad topics was a useful tool. Topics were, for instance, telling about life today in comparison with life before cancer, about encounters with health care services, and experiences that were important for working through the cancer experience. The women’s stories led to follow-up questions, but it became equally important to let the women speak uninterrupted. The key was to be receptive, focused and open to their experiences. Thus, the interviews were planned to give sufficient time.

Interviewing the informants twice was very useful. Since the study dealt with some broad, but also some very intimate topics, the first interview became a basis for the second. Thus, topics could be probed into more deeply.

The first author is an experienced nurse in cancer care, which gave valuable knowledge. However, she has not worked specifically in the field of rehabilitation or with gynaecological cancer patients. Still, to question pre-understanding and work specifically with an open and dwelling attitude was an important aspect of the approach (Dahlberg et al., 2008).

Ethical considerations

All the women gave their written consent to participate. They were also informed that participation was voluntary and that they could withdraw from the study at any time without giving a reason. Permission to conduct the study was obtained from the Regional Medical Research Ethics Committee and was conducted in accordance with the guidelines of the Norwegian Social Science Data Services. The names of the women were altered to ensure anonymity.

Performing qualitative interviews with people who have been through very difficult times raises ethical issues (Fog, 2004). Talking about the cancer experience can arouse painful thoughts and emotions. This may cause distress as well as relief. The researcher was conscious about this aspect and worked on balancing closeness and distance in the interview situation. During the second round of interviews it turned out that three of the women had received a new cancer diagnosis. One had metastasis from her gynaecological cancer, while two had new cancers. Careful considerations were specifically taken underway to avoid probing too deeply into their traumatic situation.

An atmosphere of trust was established in the interview situation. When topics that moved the women deeply were visited, the women were given the opportunity to take a break or to pass on to other topics. The researcher also gave opportunity for a debrief after the interview. Many expressed relief over just talking through their experiences of cancer to an interested listener. At the same time they felt that many vulnerable topics had surfaced. The researcher had, in advance, made sure that the head
nurse of the unit could give assistance after the interview if necessary. None of the women wanted further help and guidance, but some appreciated receiving information about people they could contact.

Data analysis

All the interviews were carried out and transcribed verbatim by the first author. Dialogues with the supervisors were, however, included in the entire analytical process. Research notes were written immediately after each interview to secure nonverbal information that seemed important. Reflections about the researcher's role and the issues raised were also written down (Dahlberg et al., 2008). Each interview was transcribed and carefully read before the next interview in order to get a general understanding and to reflect upon the interview material.

The analysis was inspired by Giorgi's (1997) phenomenology-based method, which Kvale (1996, p. 193) calls “meaning condensation”. It aims at the essence of the phenomenon under study, the existential nature of women's experiences of life beyond cancer. We stuck with Giorgi's five steps, but modified some (see below). van Manen’s (1990) thoughts about evocative writing has also been a source of inspiration. The presence of the words, language and tone of the women themselves has been important both during the analysis and in the presentation, which gave the written material a narrative style.

Analysis proceeded as follows: After collecting and transcribing data, in accordance with Giorgi, each and every text was carefully read as a whole to gain a general understanding. Then, repeated readings followed, noting topics and important words continuously in a designated column to the right in the transcribed text, and marking the units of the topics. This is slightly modifying the third step, identification of meaning units, as described by Giorgi (1997, p. 246). Next, the interview was re-read up against the aim of the study, as recommended by Giorgi, which resulted in identifying important, but still preliminary themes which were marked with different colours in the transcriptions. Then, a new and more condensed story for each of the women was written down. The story was read and discussed by all the authors. It contained condensed descriptions and quotes to elucidate the identified structure of main themes and sub-themes. In combination, these two steps represent a further identification as well as transformation of important meanings in each interview, still context-specific and individually described, and as such in accordance with Giorgi’s recommendations. However, descriptions of meaning structure at this level were built as a story, preserving the time-line in the identified main themes as well as the woman's voice (including quotes) in each interview, which differs from the steps as described by Giorgi. When the first round was completed, all the 16 condensed stories were read in parallel, in search of common core themes. The same procedure was repeated for the second round of interviews, one year later. When these two rounds were finished, all interviews were read across and three core themes were identified, representing essential meanings across the interviews and at a higher level of abstraction. These core themes will be presented elsewhere. In this process, notes on nonverbal communication and researcher's reflections, which were written down immediately after each interview, became increasingly important. Altogether, the condensed stories and notes gave a strong tone to the women’s existential experiences and vulnerability. This got us on track toward the deeper existential dimension of living as long-term survivors of gynaecological cancer, which urged us to further analysis. The research material and the condensed stories were therefore re-read in an effort to penetrate the existential dimension of the phenomenon. Gradually an essential structure that moved across the three core themes came into view. The structure was called Cancer as a life-changing process, consisting of two interrelated constituents. During discussion of the essential structure, Danish life philosophy was drawn into the analysis in order to deepen the understanding.

Findings

Cancer as a life-changing process

The essential structure, Cancer as a life-changing process, entails living with profound life-changes, both challenging and enriching—even though the women have been cured and declared long-term survivors. The alternation between changes that are either demanding or enriching is seen, more or less, as a dynamic process in which the women must learn to handle their everyday lives. Working through the existential crisis, and coming to terms with oneself again, is seemingly a more flexible process than not facing the crisis.

The essential structure describes two interrelated constituents of how the women are living between life courage and life anxiety and living between existential loneliness and relational caring. It is important to emphasize that there are gradual transitions between these two interrelated constituents.

Living between life courage and life anxiety

Joy and gratitude for life itself was a core topic in the women's stories, five to six years after cancer. Berit (59) expressed what all interviewees said in different
ways: “I am so thankful for life, yes, I am so happy that I am alive!” Life itself was no longer taken for granted. After having received a cancer diagnosis, a potentially life-threatening situation, the continuation of life seemed a gift. Life after cancer may also be expressed as life courage, a new presence in and deeper connection with the world, other people and oneself. The “small things” in life became more precious.

Increased openness and less self-concern were expressed, with a heightened awareness about the concreteness of everyday life. Grethe (62) put words to these aspects: “You are much more aware of what is surrounding you…things outside yourself. You experience nature, the birds, animals and sounds … a waterfall and a river!” The women cherished life and held what they had much dearer than before. The cancer experience had revitalized values which, in turn, opened up new dimensions. Haldis summed it up: “I notice [life] in another way … more intensely!”

The cancer experience was also expressed as leading to increased and deeper knowledge of oneself. Going through the crisis, through grief and loss, meant confronting oneself and one's own ways of reacting. Elin (44) said:

In one way, I wouldn’t want to be without it [the cancer experience] … because, I can see that I had a very superficial way of living, actually … the way I related to my own feelings... Earlier, my life was on the fast track so to speak … covered somehow with a veil. It was how it had to be … everything was so easy ... I had solutions to everything … but suddenly the veil was not there anymore to keep it all together… Now more aspects and facets are present… Before, it was more a denial of life… This couldn’t happen to me … this is for weak people … Today, life is more on track again, but deeper… I have escaped from superficiality toward, myself and others!

The changed life situation was experienced with increased, as well as intensified, openness. Elin had experienced “the core of existence” and worked her way through what came in the wake of cancer, liberating energy and paving way for a richer life.

Gratitude and joy for life seemed to have its counterpart in the women’s bodily based preparedness for a recurrence of cancer. Although many said that they were more or less through with cancer, little was needed to spark distress or anxiety for a renewed threat. Uncertainty and distress was difficult to live with and handle after cancer. In the words of Alice (59): “It’s the uncertainty … so even if they say it’s going to be fine … you know they’ve been wrong with many others!” The distance between a strong sense of life joy and distress or anxiety was often very short.

Distress and preparedness was something that was triggered throughout the five-year polyclinical follow-ups. The anxiety that something may be wrong arrived almost automatically as these follow-ups came closer. However, even now, five to six years after, the women had the same feelings, despite the fact that they were cured and declared long-term survivors. A bodily change, like a pain or irregularity in the body, could trigger these feelings, as could a relative who became ill or a media story on cancer. The women felt they had to live with this anxiety. Elin (44) said:

It’s always there in the back of your head. It’s the first thing you think about if you feel a change or a pain or something that isn’t supposed to be there … so it’s the first thing that comes up: Cancer! It’s just like a sign that pops up. It will always be there.

The seriousness of the cancer experience, which influenced the whole life situation and future, kept the women alert for every possible sign of cancer. Life anxiety was especially prominent among those who had not managed to confront their cancer experience and worked their way through it. For them, life anxiety seemed almost overwhelming, holding them captive. Lina (47) said:

I can’t manage to work my way through things—No! But I’m good at getting it out of my way … like I kind of have a box to put it in. Once in a while—it pops up, no doubt about that! Then I just have to suppress it.

For these women, lots of energy seemed to be spent on keeping control when facing threatening emotions that cancer had unleashed. Lack of confidence in their own capacity to work their way through the crisis was expressed.

Living between existential loneliness and relational caring

Living through cancer and becoming long-term survivors gave the women new experiences, making them more emotionally and sensitively aware. A new vulnerability surfaced in encounters with others, implying a need to be met in a different way. Dina (39) described how cancer enhanced her feelings and sensitivity:

It [the cancer] changed my life. Of course it did! It’s a kind of luggage that you always carry with you … extra luggage … that weighs a lot more than other things … I live with it… But feelings are stronger, good things feel stronger and bad things feel stronger … I feel that after this … feelings are stronger both ways.
The common experiences of cancer survivors opened for a special and different understanding between them. Ingrid (46) spoke for several when she said “You have a story that other people cannot understand in a way, right?” The members of this “community” have the ability to see and understand without necessarily speaking. There exists a silent communication, a wordless language. Grethe (62) said:

“We don’t have to say anything [to each other] because we understand it anyway! To those who haven’t been there [experienced cancer] … you can say something, but they won’t understand you.”

This common experience gives the women a special and mutual understanding of each other, a basic and certainly tacit phenomenon that relieves some of the pains of loneliness related to experiencing cancer. The women, who experienced such fellowship with one or more, talked of a special trust between them.

The support from “close persons” such as family and friends cannot be valued too highly when cancer strikes. However, the women made use of their networks in very different ways. The most extrovert used the social network to share almost “everything”, in an open dialogue after cancer. Thus, the cancer-stricken women seemed to continuously work their way through their experiences and come to terms with themselves after the illness. Still, several of the women did not work through the cancer experiences with family and friends in such an open way. The women’s thoughts about the large burden friends and family already were carrying, led them to assume a more protective role which also freed them from difficult conversations about the cancer experiences. Furthermore, sexuality, anxiety and existential thoughts of life are topics that may be difficult, and not very desirable to share with others and find words for. A deeply felt loneliness related to the cancer experiences was a reality for many of these women.

Raising difficult topics with close persons without being met in a way that helped the women to advance in their healing process was also a subject. Such conversations could easily turn into superficial comfort that may have a halting effect on the women’s process. This neither comforted nor helped them in coming to terms with themselves. Alice (59) said she had excellent contact and relations with her partner through many years, but found it difficult to share her cancer experiences. She had tried to confide in him at the beginning about her distressed thoughts and anxiety, but she did not feel understood. She said this about her attempts:

He said like: ‘You see this is going fine, right … it’s working out just fine and now you have to relax!’ … all the time he was driving at this: ‘You have to remember that in the letter they said chances are good’ … like, that’s what I’ve been thinking all along, but...

Alice’s vulnerability and her many thoughts were not met. She believed she would have been able to handle her situation better if she had had a confidant to share her physical and mental experiences with:

My mental state may have been different if I’d had someone to talk things over with afterwards … because you have many thoughts in your head, right … and you can’t air them and relieve yourself of your burdens … so I think that [talking with health personnel] would have been a big help!

Berit (59) was in critical need of someone with whom she could share her existential thoughts of life and death. She said:

“Sometimes I have thought about … when I go to the pharmacy, there’s a poster with a name that says you can call the Cancer-phone…. But, what do you ask about?”

Having nobody to share their grinding thoughts with seemed to have had a stopping effect on many of the women, causing the process of coming to terms with their lives to slow down or even stagnate. Had they been able to verbalize these thoughts to someone who knew the art of listening, they may have made more progress.

Despite their differing ways of handling cancer experiences—and whether they have come to terms with themselves or not—when the women looked back on what they had been through, they would have liked more commitment and involvement from health care professionals. Having cancer in the reproductive organs raises several intimate and personal issues that are difficult and maybe even undesirable to share even with people close to you. This seems to make the quality of encounters with health care personnel even more important. The women had a need for being met with receptiveness and trust in their vulnerability.

In different ways, the women talked of their feelings when their very existence was threatened by illness. Meeting health care workers, who often were focused on practical and concrete aspects of the illness, was almost surrealistic, incomprehensible and deeply existential. Elin (44) spoke for many of the women when she said: “They were very quick and efficient … [and I thought to myself] ‘Have you ever been ill yourself? Have you ever lain like this, not
knowing if you’d live until Christmas?” She sought empathy and charity:

The nurse, in such a place ... which is all about life and death ... I think it’s important to, in a way, give your heart a little to the patient... that you care... Not just say things and be efficient ... but show that you care ... in biblical terms ... suffer with the suffering and laugh with those who laugh ... kind of involving yourself...

The women showed an increased sensitivity in encounters with health personnel and in the way they tried to express their uncertainty, hoping they would be seen and understood, received and guided. It rarely resulted in any real conversation. In a meta-perspective, this is what they seek today.

**Summing up**

The women interviewed in this study are cured and have become long-term survivors of gynaecological cancer. The cancer has been removed. Five years later it has not spread and not returned. There has hardly been any negative feedback. Still, most of the women say that life has changed. Many of them feel more alive now than they did before cancer, with a greater presence and intensity in their own lives, their surroundings and in other people’s lives. Some values have clearly been revitalized. However, life-constraining emotions, such as life anxiety, existential pain and loneliness are also present in the women’s lives. Furthermore, the experiences related to cancer have made the women more vulnerable in their encounter with health care personnel and close others. This may be a challenge and implies that the women may need to be met in a different way.

**Discussion**

This article contributes to enlightening the life-changing process of women, who have survived gynaecological cancer and are declared healthy and long-term survivors. To live beyond cancer entails living with profound life changes that are demanding as well as enriching. This is also confirmed in various QoL studies, such as Stewart et al. (2001), Wenzel et al. (2002), Hodgkinson et al. (2007) and Wenzel et al. (2005). These studies, however, do not delve deeply into the changes and do not illuminate how they can be reflected in women’s lives. Nor do they describe consequences that changes may have on encounters with close others and health care personnel. This study is a contribution to bringing forth depths in and interrelatedness between the fruitful and enriching, and the difficult and demanding regarding living beyond cancer.

The study shows that during the time of crisis, when the women were diagnosed, operated and treated, both the ethical and the existential life phenomena were activated. It shows further that, as late as five to six years later, the life phenomena are still “ploughed up” in the lives of the women. Their tales about life and what lasting changes cancer has caused seem first and foremost to be influenced by the existential life phenomena; i.e. the life-enhancing and the life-constraining life phenomena. When the women talk about their cancer experiences and encounters with health care personnel and other people, the ethical life phenomena and their counterparts clearly enter the stage.

The presence of life-enhancing life phenomena such as life joy and life courage, was striking in the women’s stories. In various ways, many were less determined by, and lived more freely with, their everyday chores. They were more focused on values that had been revitalized. Stewart et al. (2001), Wenzel et al. (2002) and Molassiotis et al. (2002) echo this revitalization. Pahuus (1995) says that suffering may open up for experiencing profound joy of life. Experiencing a life threatening illness seemed to move the women toward letting go of the superficial in exchange for more existential dimensions of life. Pahuus says that we must always take hold of the situation we are in. By taking hold of the situation, we show who we are. Both Feilberg and Logstrup are in a Kierkegaardian tradition in perceiving the human being as existence. In this term lies the notion that the human being is never already “given” but must always become him or herself. Kierkegaard says that every person’s task or mission is simply to “become the self you truly are” (Kierkegaard, 1962). The experience of having had cancer has touched the women’s existence in such a way that they feel more truly themselves. In the encounter with cancer, the women find a life courage that otherwise may be veiled by ambition and hastening toward the future. The existential meeting robs one of all that one is fond of and occupied with. When this is all gone, one can open up to the fundamentals of existence—that which is “given” without our own efforts (Pahuus, 1995).

Feilberg (1949) emphasizes spontaneity in the life-enhancing life phenomena. This is about longing for activity as active intervention (also called life courage) and a longing to associate with and be one with something (also called life joy). As such there is an openness and extendedness in the life utterance. The women describe this as greater involvement in what is outside of themselves, including less self absorption. The openness reaches beyond itself, out towards the concrete world and towards being more
present in what they are already involved in—and which they had earlier taken for granted. The women's encounter with existence seemed to give them an openness and resilience in their meeting with life, themselves and others in profound ways. The encounter with, and openness toward existence, through the cancer experience, made life more alive and intensive. For some, it gave a deeper contact with themselves and with other people. However, the path leading to the clarification of their own lives to making use of the experience—was not easy. The women had to take hold of the situation they were in, which demanded energy.

The experience of openness yields space for life courage, life desire and vitality, but also for suffering and anxiety. Pahuus (1995) says that suffering and anxiety, the difficult and dark issues, are often handled superficially in a person's life. As such, they are justified—or even necessary—in order to come to terms with one's own situation. They are essential experiences. Carrying one's fate means taking on the heavy parts of life—or looking sorrow and suffering straight in the eye. The difficult things in life are just as natural as the easy things. There is a developing and strengthening power in that which demands something from a person. If one manages to take on one's fate, sorrows as well as the good life, and hold on to it all—there will be a synthesis, according to Pahuus. In any case you have to go on, but you become a deeper person when your pain has melted together with the good, so to speak. This is to carry one's fate (Telléus, 2005, p. 23). Such depth of life was most present in those women who, in an open and active way, had worked their way through the cancer experiences. These women seemed to live in a greater openness in the encounter with themselves, as well as with other people and life in general.

However, the existential crisis upon receiving a cancer diagnosis is not the only challenge. The anxiety and uncertainty related to recurrence, or a second cancer, are lifelong challenges for many. These feelings arise every once in a while and are reminders of what the women have been through and, therefore, what they possibly may encounter again. The experiences become embodied as a preparedness or alertness, activated when changes occur. For those women, who had worked their way through the existential crisis of receiving a cancer diagnosis, the uncertainty of recurrence must also be dealt with in order to attain greater clarity of their own lives. Hence, these continual revisitations of a bodily alertness for recurrence or second cancer may enhance the movement between life joy and life anxiety. One might ask if this movement or reminder—that life is not eternal—maintains or even strengthens personal growth and a positive outcome.

Tedeshi and Calhoun (1996) use the term “post-traumatic growth” to describe positive life changes following stressful experiences. Studies show that there is an increased attention to this issue, both related to going through life-threatening situations in general (Helgeson, Reynolds, & Tomich, 2006; Linley & Joseph, 2004), other forms of cancer (Carver & Antoni, 2004; Cordova, Cunningham, Carlson, & Andrykowski, 2001) and gynaecological cancer in particular (Molassiotis et al., 2002; Stewart et al., 2001; Wenzel et al., 2002). Aspinwall and MacNara (2005) claim that it is a common finding that 30 to 90% of people experiencing serious illness and other forms of adversity report increased quality of life and other positive life changes. Their study shows that the positive emotions and beliefs seem not only to be associated with good outcomes, but also play a role in realizing them.

The movement between life courage and life anxiety seems more evident among those who had worked their way through cancer than among those who had not. Among the latter the situation seemed more “locked” within the life-constraining life phenomena. These women said that life had not changed much. They had not actively confronted their existential challenges and had not come to a clarification of their own lives. In a situation where life is threatened by cancer, life changes its character from being mere existence to being a challenge or task that must be met, taken hold of and mastered. This makes life difficult, challenging and also enriching. Pahuus (1995, p.130) says a person is thrown into anxiety when he or she cannot manage what life offers. If this anxiety lasts it will turn into a permanent state of despair. Characteristic of the life-constraining life phenomena is a certain degree of closedness; the keeping of yourself, ’in the back of your mind’ and managing yourself, so to speak (Pahuus, 1995, p. 137–138). It means following fixed rules and methods, driven by a plan. Some of the women describe the cancer experience as something sealed in a box they try to keep closed, but the lid keeps popping open. This is a good illustration of their attempts at controlling their lives. Cancer threatens the women’s whole existence—but these women do not confront this challenge in an active way. An overwhelming amount of energy seemed to be mobilized to keep anxiety under control. Consequently, life became at times an escape into routines and daily chores. What these women still have in common with the other women, when they look back on the process they had been through, is a genuine need and desire for help and guidance.

The women describe an increase in their sensitivity and emotionality after cancer and they seek both close relations and health care personnel who are able to meet and receive them in this vulnerable
situation. According to Løgstrup (1983), the person’s senses and her tunedness is the door-opener and source for activating the life phenomena. He says that one cannot be in the world without being tuned—or without a resonance for all that happens in the world. The women seek a helper to receive them in this tunedness. They wished to be accepted and met with the feelings and thoughts that they had. They did not want superficial comfort that covered up difficult feelings like anxiety and fear. This superficial comfort may halt important processes which the women must work their way through. The women have experienced that their feelings are not taken seriously and this may result in increased loneliness and helplessness.

Davidsen-Nielsen and Leick (2001) say life pain can be redeemed and eased in the company of a person who has the will and ability to listen. Knowing that someone understands makes you feel that you are not alone. We belong to each other. Lang (2002) says that experiencing understanding is a state. When you are in this state you are present in your own life. As such, understanding is belonging—an experience of fellowship. Feeling understood by someone in the same situation, has a very strong effect and gives a special understanding. The similarity makes it easy to identify with the other person’s situation. Feeling understood may also carry the seeds that grow into seeing things in new ways—as the women describe.

Health care personnel may easily fail to see the women’s vulnerability and need for caring while they participate in a five year follow-up program. At the time of the first interview, all the women were still cured and none had had any recurrence or metastasis during the five years after the primary treatment. All responses from health care personnel had been positive. The women were on the threshold of being declared cured and so called long-term survivors. Health care personnel, who treat patients in all stages of cancer, might be prone to, consciously or not, thinking of these “cured and long-term surviving” patients as the most fortunate ones and that they have no need for more than ordinary controls. The empirics, however, show something else and are supported by the studies of Wenzel et al. (2005), Wenzel et al. (2002) and Hodgkinson et al. (2007). Hodgkinson et al. (2007) show that women seek counselling not only related to medical information and the treatment they have been through, but also to fill their needs for supportive care in relation to their experience of existential survivorship, spiritual beliefs and meaning of life. Life phenomena, such as existential loneliness, vulnerability and life anxiety may be difficult to spot for health care personnel in the midst of a busy day. These phenomena are not obvious and often remain inside the women’s internal life and thoughts. The women may also find it difficult to verbalize their vulnerability and need for caring. If health care personnel have little knowledge of, and pay little attention to, the basic life phenomena, these may easily be missed. Delmar (2006) suggests that the nurse’s focus on needs may be a reason for lack of attention to the life phenomena.

The women in the study challenged health care personnel to reflect on their engagement and compassion. Løgstrup emphasizes that feelings are door-openers to understanding and thinking: “[…] without emotion, no understanding. All understanding, all thinking is grounded on emotion” (Løgstrup, 1976, p. 93). Life phenomena cannot be met with other than emotions, because emotions constitute the very understanding of life phenomena (Delmar, 2006). Emotions give us access to “life itself”, says Martinsen (2006). A person-oriented competence is required for the health care worker in order to take good care of these patients, while minding the life phenomena that are set in play (Delmar, 2006; Martinsen, 2006). The exercise of good judgement is necessary to keep a balance within the framework of professional care and to avoid the pitfalls of paternalistic or sentimental care.

**Study limitations**

The participants, who were all from the same ethnic group and had similar cultural backgrounds, were recruited from the same outpatient follow-up clinic and were all treated at the same hospital. A wider variety in experiences of long-term survivors of gynaecological cancer could have been included if participants from other ethnic groups, cultural backgrounds and treatment institutions had been recruited. However, the “tremor” experience of surviving an existential crisis, such as being stricken by gynaecological cancer, involves several fundamental aspects. The essential structure, *Cancer as a life-changing process*, is at a general level of abstraction, which implicates relevance to a wider range of cancer patients and to health-personnel involved. Illuminating cancer as a life-changing process from the perspective of Danish life philosophy adds to a deeper understanding of the existential dimension of being stricken by cancer.

**Clinical implications**

The women’s stories about encounters indicate that a relational care may help them to handle their cancer experiences and make progress in coming to terms with themselves and their situation. This is a challenge for health care personnel. The women’s sensitivity and emotionality in their encounter with
cancer shows that they need an engaged health care professional who is able to meet them in their emotions. Thus, the health care worker must be open to emotions because they are the key to life phenomena. To be open and to integrate emotions into professional competence requires somewhat more from the nurse than need-based nursing. The health care worker is challenged to apply all her holistic and person-oriented competence in order to meet the patient’s impressions and utterances and to return them “tuned”. Focusing on yearning and life-phenomena can help personnel to look beyond needs and to implement a deeper and more holistic way of caring in this existentially demanding field.

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