Living with breast cancer – a challenge to expansive and creative forces

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The aim of this qualitative case study is to obtain a deeper and more profound understanding of the life world of women living with breast cancer focusing particularly on changes in life perspective. The study is based on a series of interviews carried out within the space of one year and involving four women with breast cancer; each woman was interviewed four times. The participants were between 42 and 54 years of age; three of the four interviewed were in an advanced stage, with metastasis or recurrent breast cancer. There was an increased awareness of the relationship between life and death, which constituted a disclosure rather than an actual change in life perspective. The four women were 'opening up' to the beauty and the essentials in life and experienced an increased desire to live their life in accordance with their own values. Their revitalised view of life increased their desire for authenticity. When it proved impossible to live in accordance with new insights the women were particularly frustrated. From a caring perspective our findings suggest that an awareness of patients' increased openness to their own needs and desires is an important resource in the healing and rehabilitative process of breast cancer patients. The paradoxes and the struggles involved disguise a hidden potential for health.

Keywords: breast cancer, life perspective, caring, qualitative method, case study.

INTRODUCTION

It has already been established that breast cancer as well as other life-threatening diseases are often a cause for personal revaluation and changes in life perspective both in a positive and a negative direction (Carpenter 1997; Collins *et al*. 1990; Ganz *et al*. 1996; Ferrell *et al*. 1997; Kornblith 1998). Many patients are able to transform such changes into a beneficial development (Collins *et al*. 1990; Taylor 2000). Self-transformation (Carpenter *et al*. 1999) and transcendence (Chiu 2000) have been studied and documented as factors for well-being among breast cancer patients. In Carpenter's study three different levels of self-transformation were established as a result of realization of one's mortality: positive transformation, minimal transformation and the feeling of being stuck (Carpenter *et al*. 1999). A higher stage of transformation was followed by higher self-esteem and well-being. In a study by Taylor (2000), the transformation of tragedy was seen as a process involving four phases: encountering darkness, converting darkness, encountering light and reflecting light. A contradictory report from Lampic (1999) showed no signs of changes in life perspective in a prospective study.

The women described in this article are part of a study of changes in life perspective among 60 women with breast cancer who were admitted to complementary care (Arman *et al*. 2001). A content analysis of the data showed that these women considered their relationships with others to be more valuable, their self-confidence and

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feeling of strength were increased, and they regarded life as more enriched. A tendency towards being more fragile and low-spirited was regarded as a hardship. Our findings support the view that beneficial and constructive as well as harmful changes are part of the experience of having breast cancer. The study reveals the need for a deeper understanding of patterns in life perspective among women with cancer.

'Life perspective' is a phenomenological concept. In its interest in aspects of concerns and meanings in life among the informants, the concept shares certain characteristics with the concept of 'life world' originally coined by Merleau-Ponty (1962) and used by such phenomenologists as Benner (1994) and van Manen (1997). In this research project it refers to a person's view about important aspects of his/her life. A theoretical assumption of the present study is the theory of caring developed by Eriksson (1997). This theory includes an understanding of the human being as an integrated unity of body, soul and spirit.

The aim of the study was, from a caring perspective to obtain a more profound understanding of the life perspective of women with breast cancer.

METHODOLOGICAL BASIS

A qualitative, phenomenological method was chosen to achieve understanding of the experience of illness and related life experiences. The multiple case method aims at embracing the phenomenon in its real life context (Yin 1994) and the overriding methodological approach used is that of the interpretive/hermeneutic phenomenology described by van Manen (1997) and Benner (1994). Asking phenomenological questions stems, according to van Manen (1997; p. 43), from the basis of our existence. This science, according to Eriksson, should derive from theoretical knowledge of human beings, health and caring, and involve the study of the clinical context as part of an attempt to confirm and deepen our understanding of the caring practice (Eriksson 1997; Eriksson & Lindström 2000).

Sample

Four women with breast cancer taking part in the study described by Arman *et al*. (2001) were chosen for our multiple case study. They were specifically selected because they were different and contrasting but also representative of the material as a whole. The cases are described in Table 1.

Procedures

The data derives from a clinically controlled study, with matching procedures of the life situation in two different samples of women with breast cancer (60 + 60 patients), those who have chosen complementary care and those in conventional medical care solely (Hamrin 1999; Carlsson *et al*. 2001). The women were followed up for a period of one year after admission using a test-battery including instruments registering quality of life and coping, interviews and medical data. Four interviews were carried out: on inclusion in the study, three and six months later, and as a telephone interview conducted 12 months from the

Table 1. Women with breast cancer, sample background ($n = 4$)

A	Age: 42 Marital status: married, 3 children. Diagnosis: local limited breast cancer, no metastasis or recurrence. Time since diagnosis: 15 months. Treatment: Surgery, chemotherapy, radiation, endocrine therapy.
B	Age: 54 Marital status: married, 2 children. Diagnosis: breast cancer, metastasis discovered during the study. Time since diagnosis: 10 months. Treatment: Surgery, chemotherapy, endocrine treatment.
C	Age: 47 Marital status: cohabit, 1 child. Diagnosis: breast cancer with metastasis. Time since diagnosis: 10 months. Treatment: Surgery, chemotherapy, endocrine treatment.
D	Age: 50 Marital status: divorced, 1 child. Diagnosis: breast cancer, with recurrence of metastasis. Time since first diagnosis: 5 years.

Treatment: Surgery, chemotherapy, radiation, endocrine treatment.

date of inclusion. The four cases in the study, all of whom were admitted to a clinic offering complementary care and medicine (antroposophic medicine), followed these procedures.

The interviews followed an interview guide comprising open questions on the following themes: history of the disease, the women's own perception of the impact of the disease on their relations with their family and friends, work and activities, and the impact on perceived changes in personality and values. The same researcher (MA) conducted all interviews. They were tape-recorded and transcribed verbatim before being analysed.

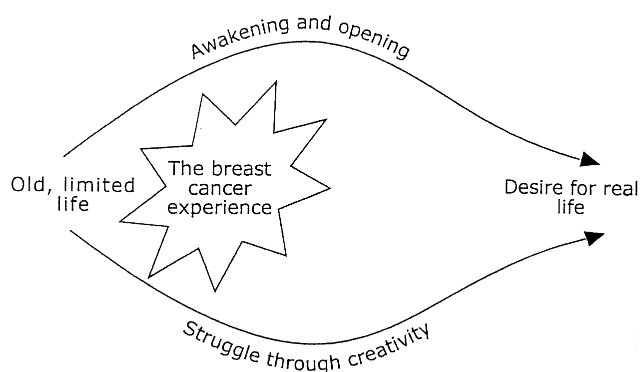

Figure 1. Expansive forces among women with breast cancer

Data analysis

The content and the purpose of the present study necessitated a qualitative analysis of the interviews. Each case was analysed separately by repeated and reflected reading. A story of the case based on the data and the informant's own words emerged in order to understand the essential meaning of the data. A reflective interpretation followed in the light of each case. All interviews were also read and the case stories discussed and validated with a co-examiner (the second author of this article, AR).

Ethical considerations

The Regional Research Ethics Committee at the Karolinska Institute, Stockholm, approved the main project (project leader E. Hamrin) after ethical investigation in 1995. The patients gave their consent after receiving verbal and written information from the researchers. Steps have been taken to disguise the identity of the cases.

FINDINGS

The findings are presented as separate cases introduced from experienced life perspective after breast cancer. Because an understanding of each woman's perspective was attained, the analysis is not aimed to present different themes but synthesized under a 'heading'. In the interpretive reflections, light is shed on the individual cases from different perspectives. A concluding figure, illustrating a theoretical model, is illustrated in Figure 1.

The four cases A, B, C, and D.

Case A: stuck in one's life situation and with a hidden desire

Case A viewed her life situation as basically caught or locked up in a situation of full-time work and care-giving to husband and children. She had experienced very little relief from her duties once it was discovered that she had cancer and during the course of treatment. She noted a few changes. These took the form of a new insight into her situation and a desire to lead a new kind of life.

Breast cancer made her think about the meaning of life and increased her awareness of a number of important values. These new insights were buried under a general feeling of being stuck. Her openness to new values had also lead to a new view of relationships, leading to a withdrawal from others in an attempt to find a space of her own and in a response to a need for true and supportive relationships. The longing for a sharing and close relationship had not yet been met, causing intense suffering.

Case B: disease as a blessing and arouse of the return to the original life

Case B felt that the disease had brought about fundamental changes in her way of life and views of life. She had revaluated work and her social position, dealt with existential questions and found a renewed way of sticking closer to her own intentions. She found a blessing quality of the disease in the revaluation of roles, where she gave herself time and space and experienced a feeling of 'letting the mask fall'. She pointed out that the most significant change resulting from cancer was that she was able to gain control over her own life.

Case B that was able to continue to lead a good life despite her cancer thanks to a renewed appreciation of what is essential in life. This she achieved by returning to an atmosphere and to values from earlier periods of her life. Cancer had given rise to an ongoing inner process which had brought her back to a more authentic life. She thus saw the disease in a positive light irrespective of the consequences for the future.

Case C: to live in a border experience without shrinking back

Case C had recently received very serious information about her disease in which it was made clear that her cancer could not be cured, and that the disease would shorten her life considerably. Her life changed from then on in many dimensions.

Her courage in not shrinking from her border situation between life and death enabled her to live with her despair and find the support and power she needed to live an authentic and meaningful life. The changes that C had experienced and the path she had followed allowed an 'opening up' of the essentials in life and in death as the end of life. C pointed out that this meant a huge change in her view on life, from a mainly materialistic to a more spiritual outlook. These changes were consequences of her struggling with the existence in confrontation with her own mortality. She was not searching for meaning: everything already had meaning. Her struggle and suffering were visible. To seek meaning and pleasure became her weapon against threatening meaninglessness and death. The paradox about her views, of both enriching and harmful experiences from the disease, was apparent and visible in its context. In her appreciation of 'life itself' there was a spirit of joy, humbleness and thankfulness. Yet, in the same time there were signs of an intense fear of recurrence and possible death in which she hovered between enjoying life and preparing for death.

Case D: dialectic between insights and ability to bring about changes

Case D had a holistic view of her cancer: it was an integral part of her personality encouraging her to search for new impulses and to try to change life patterns. In addition to conventional care she had invested in a number of complementary therapies, e.g. healing, meditations, diet, health resorts and herbal and homeopathic medicine.

Case C lived with a desire to search for inner development and growth as well as to live a meaningful life. Her cancer had worked like an 'alarm-clock', forcing her to make significant changes in her life. However, her insights into life and her holistic view of her cancer and its cure were not compatible with the changes in her life that she was able to effect. She lived with her own demands to achieve harmony while at the same time suffering in her realization that she was not able to achieve the balance. Probably because of loneliness, her struggle against threatening passivity and meaninglessness had not begun yet and she was largely unable to lift herself out of the groove of stagnant suffering.

INTERPRETIVE REFLECTIONS

Dialectics and apparent contradictions

The data contains several apparent contradictions. Benefit and harm, strength and vulnerability, meaning and meaninglessness, confidence and fear are all related to one other. The women's descriptions form a dialectic field (of tension) between life and death. The polarization process in one's life-perspective creates new levels of awareness and wisdom. The complexity of the findings in these cases raises questions when viewed in the light of recent studies on self-transformation by, for example, Carpenter *et al.* (1999) as well as Taylor (2000). As a result of the simultaneous presence of both benefit and harm in each case included in our long-term study, there is limited agreement with transformation process theories. The transforming phases described in the above mentioned theories are too quickly and easily adopted in our view. The transforming of life perspective is, we believe, part of dialectic, a complex struggle with no definite stages or ends. Rehnsfeldt (2000) points out with reference to suffering that there is a salient dialectic struggle between hope – hopelessness, meaning – meaninglessness and so on.

Relationships

Close and supportive relations seem to be connected with a higher acceptance and realization of renewed, deepened views of life and meaning. Our earlier study supports the importance of the role of relationships (Arman *et al.* 2001). Cases A and D both had visions of and insights into life but neither was able to bring about the changes or actions that corresponded to her inner needs and desires. Cases B and C seemed more confident about their level of control over their life. One decisive factor may be if the afflicted person obtains the companionship of a compassionate person. Rehnsfeldt (2000) claims that people create meaning in communion with others, and that the effort involved in combating suffering may prove unbearable when support is lacking. The sharing of all experiences, emotions and thoughts with another person could, according to Rehnsfeldt, save someone's life when he/she is undergoing significant changes in life. In a clinical circumstance a caring encounter could be the answer to the patient's inner needs for creation of meaning, hope and creativity. This means that medical personnel has the eth-

ical possibility in a caring encounter to be a part of the patients creation of new meaning.

Hardships and obstacles

In each of the four cases cancer inevitably opened up insights into life and death. The awareness of death encouraged consideration of the essentials in life and a demand for an authentic life of one's own (compare Carter 1993; Carpenter *et al*. 1999; Utley 1999; Chiu 2000; Taylor 2000). Relationships as well as control over one's life, balance, creativity and pleasure were essential components of the women's renewed view of life. External features such as material values, status and other people's demands became less important. Although insights and perspectives were disclosed or renewed for the women as a consequence of the disease, actual transformations in outer and inner life were harder to achieve. This caused strain and frustration. This phenomenon is seldom found or discussed in earlier studies of cancer patients, but recently Carpenter *et al*. (1999) have noted that some female cancer survivors 'appeared to become stuck or trapped in their process of transformation'. The same author found that these women had significantly lower self-esteem and well being.

Return to a desire for authenticity

The question posed as a result of our earlier article on changes in life perspective among 60 breast cancer patients (Arman *et al*. 2001) was: is it right to talk in terms of changes, and how may such changes be characterized? One way to answer this question is by pointing to the fact that a person is able to recognize his/her own inner world. The changes in life perspective are more a question of disclosure or expansion of inner potentials and creativity than just changes. The sudden awareness of mortality among the afflicted women required courage to open-up to their own reality and to go beyond earlier limitations in their life. The experience created a desire to return to authenticity. The women in this case study were primarily concerned about such phenomena as taking control of one's life and daring to be oneself. This is related to a phenomenon found in a study of healthy young people's views of suffering by Lindholm (1998) where suffering is seen as an inability to live in accordance with one's own meaning. When one is forced to live an untrue life it causes the person suffering. An assumption supported by the above named study is that the experience of authenticity and truth is based on something already given to the person. However, the dreams of a good, true life which originate in one's childhood may have become hidden and limited in the process of adapting to life, while a traumatic, life-threatening event could disclose one's original ideas and values again.

The desiring, experiencing and creating person

In accordance with the holistic view for which the women were aiming, Eriksson (1987) asserts that in addition to the biological view of life one also has a 'cosmic' life view. This holistic view of life and human beings sees life as something that involves *desiring*, *experiencing* and *creating*. According to Eriksson (ibid), when a person 'desires' she shows her wishes and longings, when 'experiencing', the person is self-assured and good to herself while being 'creative' the person manifests herself in production or activity. These levels are at once present in a person but with different intensity and emphasis. The women in the cases studied revealed that they were struggling for wholeness by striving for authenticity and control over their lives (in all four cases) and a space of their own (e.g. case A), experiencing specific personal needs and new priorities (all four cases), and by deciding to obtain and derive more pleasure and creativity from life (e.g. case B, C, D). However, as the four cases show, and as Eriksson also indicates, a transformation of a life perspective involves a confrontation with one's old life style and habits. For those used to a life where they had adjusted to their environment to a considerable extent, it could seem hard or even impossible to achieve another sort of life where not only basic needs but even deeper needs are satisfied. Our findings illustrate that there is a need for further research highlighting the clinical relevance of the above holistic factors in the care of cancer patients.

CONCLUDING REFLECTION

The multiple case study method using four cases separately analysed combined with reflective discussion has been a useful means of coming closer to the phenomenon of life perspective among breast-cancer patients. We have striven after an essential structure, initially in each separate case, and subsequently by comparing all four cases as part of the reflective discussion. The validity of the study has been increased by the fact that two co-operated in the analytical process. The value of the study was to open up several possible views' of the phenomenon and stimulate new questions and perspectives. Stake (1995) points out that when readers are familiar with a phenomenon and have already formed their own 'natural generalizations' they can add these new experiences to make their own

generalizations on clinical knowledge broader. In studies of experiences of cancer, informants and researchers tend to avoid the issues of suffering and hardship (see, for example, Rodgers & Cowles 1997). Methodologically, these risks were reduced by the long-term perspective and by allowing repeated contact between researcher and informant during a one-year follow-up period.

The study indicates how the closeness of death brought about an awakening and a disclosure of life and its value among the women. Life suddenly becomes more beautiful, valuable and worth fighting for. The transformation of one's life perspective seemed to encourage introspection, resulting in an increased awareness of personal needs and desires as well as of the meaning of life. But it also places greater demands on a person to make certain resolutions, accept greater responsibility for his/her life and to be true to oneself. The struggle to adopt a new and less limited life paradigm based on desires and values requires creativity, courage, and creative forces and could be seen as a sign of the person's ability to live in health. Supportive relationships are of decisive importance in the individual's struggle for a new life. When one's previous life style and habits or lack of support prevented the realization of one's new resolves, suffering resulted and the patient felt as if she was stuck in a rut. To be in the flood of renewed openness and awareness of existence truly challenges the person's expansive and creative forces.

From a caring perspective the question must be raised: are those of us working in health care aware of the width of experiences and depth of suffering of our patients? In an awareness of the dialectic between life and death, meaning and meaninglessness that the patients are living under, it is important that the creative forces the patients are developing are understood and supported to help detection of sources of strength and a desire to live. The patient's increased openness to her own needs and desires are a valuable aid in the effort to improve her health. Patients can achieve a balance through an open attitude towards life and death. It is necessary that nurses have the courage to enter a caring encounter and support their patient's inner demands for authenticity. Nurses need as well to adopt a view of the necessity of seeing their suffering patients' creative struggle for balance and health. In the dialectic, the contradictions and the struggle itself is a hidden potential for health.

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