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Day by Day, Moment by Moment – the Meaning of the Caring Encounter

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Abstract

Background: For women diagnosed with breast cancer today's streamlined care entails brief encounters with caregivers where increasingly more and more issues need to be taken care of. This is why it is important to investigate how these short encounters can become caring and supportive for patients.

Aims: The aim of this study is to gain a deeper understanding of the prerequisites for and the meaning of the caring encounter in the care of women with breast cancer.

Methodology: Secondary analysis was performed using hermeneutic text interpretation according to Ricoeur.

Results: Promises of encounters, trust that bears from day to day, moments of time together – giving time, receiving time and having time – being allowed to be a human being and a patient from one moment to the next are prerequisites for a caring encounter in this context. The promise of future encounters and trust in the caregivers' expert knowledge make it possible for the woman to safely surrender her body to the caregivers. When the woman is allowed to be both patient and human being she can to a greater extent be herself in her changed body.

Conclusions: In a caring encounter, mutual time is created between caregiver and patient, between human beings. This time is a timeless moment that exists on a deeper level. In this moment, the woman gains the insight to live day by day, moment by moment, which, in this context, becomes the most important message and meaning of the encounter.

Key words: Breast cancer, caring encounter, secondary analysis, hermeneutic text interpretation

Introduction

Having breast cancer entails entering a lifechanging situation and experiencing a suffering that creates a great need for support from one's caregivers. Arman (2003) emphasizes the need to create possibilities for caring encounters between patient and caregiver in this context. The patient's suffering can be alleviated as well as intensified in a health care environment partly depending on qualities in the caring encounters (Arman, 2003). Today's increasingly streamlined care involves short patient-caregiver encounters in which more and more needs to be taken care of in a short period of time. Therefore, it is important to investigate how these short encounters can be made caring and supportive for patients. From an external perspective health care organizations are places of encounters, where an infinite number of encounters take place and peoples' paths continuously cross. These external encounters with a set purpose can, however, make possible encounters on a deeper level, where caregivers and patients foremost are human beings (Nåden 2000; Nåden & Eriksson 2002). These caring encounters may represent a source of strength for the patient, and help the suffering human being to find meaning. In today's short patient care time it may be difficult to create proper health care relationships and this is why these short caring encounters may be crucial. For patients who suffer from a serious illness these encounters are even more important.

Therefore, the purpose of this study is to gain a deeper understanding of the caring encounter in the care of women with breast cancer, by further studying the prerequisites for caring encounters and the meaning of these encounters in this context. Because meaningful encounters in health care take place between patients and several different occupational groups the concept caregiver will in this study include representatives for both medicine and healthcare.

Background

In the diagnosis phase women are in great need of information and support. It is important to meet caregivers with whom it is possible to discuss issues such as uncertainty about the future, how others will react, what will happen. It is important to feel that the personnel has time and shows an interest in the patient (Boehmke & Dickerson 2006; Koinberg, Holmberg & Fridlund 2002; Luker et al., 1996; Pålsson & Norberg 1995; Webb & Koch 1997; Ödling, Axelsson & Norberg 1995)

Research shows that the physician-patient relationship determines if the care of the woman will be successful or not. The physician's way of behaving sets the tone for the patient's behaviour and consequently for the relationship as a whole. (Ptacek et al., 1999) The physician's way of talking (words, language) is significant for how the woman can understand and work over her illness and comply with treatment (Meyskens, Hietanen & Tannoc, 2005; Rees & Bath 2000).

According to Arman (2003), women who have been diagnosed with breast cancer have an increased openness for their own needs and desires, and from a caring perspective it is important to view these as an important resource in the re-creation of health. These women spend much energy on searching for something they experience as powerful enough for them to endure and help them affirm their suffering. To them, experiencing true encounters and receiving support from the care that treats the illness is a self-evident right; yet they often feel they are left alone or abandoned in their struggle for meaning, re-orientation and hope. Caregivers who with their bearing can get in touch with the patient's struggle as regards the deepest questions can turn a situation of unbearable suffering into a new struggle in the light of new life and possible meaning, Arman (2003) believes. The encounter renders manifest the essential in life thus making it caring.

Few studies have penetrated to the core of how encounters are created. these Research emphasizes the importance of the caregiver's presence, encounters where the quality of this presence is of great import. True and full presence enables an encounter with the patient in the life situation in which she finds herself (Melnechenko, 2003; La Cava Osterman 2010). Nåden (2000) states that caring encounters take place on a spiritual level that we cannot really understand. This can be compared to Watson's (1999) caring moment, which is characterized by consciousness and genuine presence leading to a specific connectedness between two human beings. Cameron (2004) refers to ethical moments that are created when caregivers truly respond to the call of the patient, while at the same turning back to who they are as caregivers and asking themselves "who am I?". In this study, we will further delve into the prerequisites for and the purpose of encounters with a deeper meaning for patients and caregivers alike.

Methodology

Secondary analysis

This present study is a self-contained continuation of a project where the focus was on vitality in women who have been diagnosed with breast cancer. The results show that the care

gives them vitality through trust and availability, communication, knowledge and understanding along with participation and communion (Mäkelä & Lindholm 2006; Lindholm, Holmberg & Mäkelä 2005). The collected data material consisted of statements about caring encounters which created prerequisites for further analysis, a so-called secondary analysis. In a research context, a rich data material has often been collected for a specific purpose. During the course of the research, however, aspects and theses may emerge which fall beyond the scope of the study because these do not coincide with the original aim of the study. In these cases it is more productive to make a secondary analysis of the material. Secondary analyses of data material usually involve seeking the answer to a specific research question, which departs from the original research question that was posed in the primary study and for which the material was originally collected (Hinds & Vogel 1997; Owen, 2004).

The data material consisted of 49 questionnaires containing both open and closed questions concerning the women's health and vitality. The questionnaires were distributed during four months to women who attended follow-up control visits for breast cancer at an oncological clinic, Vaasa Central Hospital, Vaasa Hospital District, Vaasa, Finland).

The selection criterion was that they had developed breast cancer no more than three years previously. In this study, a secondary analysis was carried out on the answers to the open questions. The answers dealt with experiences of health care with a focus on meaningful healthcare contacts linked to vitality, joy of living and hope; indirectly it was also possible to deduce the opposite, i.e., when these contacts led to lack of vitality and hopelessness. A desire and need for encounters that would make it easier, that bear further, could also be noted from the women's responses; this is why the overarching question in this study is: how are caring encounters shaped in these women's responses?

Analysis

The method of analysis is phenomenological hermeneutics inspired by Ricoeur (1988). The material is seen as a text free from intent. According to Ricoeur's hermeneutics, we try to create an interaction between the women's intention and the researcher's interpretation without there being a true dialogue, since the researcher is absent in the writing and the women are absent in the reading. The meaning of the text is realized in a process of interpretation with repeated re-readings. The object of interpretation is the world that opens up before the text, not the text itself. In the reading, the world of the text and the world of the researcher meet. As researchers, we use in the interpretation our preunderstanding, i.e., the knowledge we already have about the content of the text and that of which we seek further understanding.

Ethical considerations

Ethical approval for this study which is a part of a doctoral thesis has been given by the ethical Committee of Vaasa Hospital District, 30.12.2005, § 344.

Good scientific practice according to the National Advisory Board on Research Ethics (2002) was used as a guideline throughout the entire research process.

Results

The first reading of the text gave us a picture of how the encounter takes shape in this context. Next, the text was re-read, this time for the purpose of finding prerequisites for the encounter with a focus on its meaning. After that, the text was read once more for the purpose of capturing its core message. The interpretation of the women's texts resulted in four theses on prerequisites for caring encounters and the meaning of the encounters in this context: promises of an encounter, trust that bears from day to day, moments of mutual time – giving, having and receiving time, being allowed to be a human being and a patient from one moment to the next.

Promises of encounters

The women's responses bespeak a desire to be able to contact the caregivers during the different phases of treatment. It is important to have someone to call or to know that there is someone to talk to at the clinic. This possibility may not be used, but in itself entails a promise of an encounter if the woman needs it. Booked appointments for treatment or control visits can also be promises about future encounters. Time and space are available for the woman as patient. When the scheduled visits for treatment cease the women often experience a sense of emptiness, they feel left out when there is no longer an explicit promise or possibility of an encounter.

"After completed treatment one found oneself in a vacuum, one felt left out, alone, no more scheduled visits. A great comfort is the knowledge about future control visits" Future control visits provide a sense of comfort, but they also give rise to insecurity, "each time one goes on a control visit there is a certain amount of fear, is everything OK or..." An invitation to a control visit may entail the promise of an encounter, which can make it easier and reduce the fear before the visit.

Trust that bears from day to day

Trust means trusting expert knowledge, trusting that physicians and caregivers know what they are doing, that they are doing their best for the woman at this point. The woman does not then need to feel in control of her body and her illness, of what is taken care of by the caregivers. In this way she may feel safe, she can surrender that specific part knowing she is in good hands. In regards to that particular part she feels safe.

"I did what the doctor and the nurse told me to do, trusting that they knew best. One has to believe that the doctors know what they are doing, and trust them."

"In order to make the waiting period easier one should tell the patient not to worry, you will be well taken care of"

"Don't worry, you're safe. Trust us; we know what we are doing!"

This is precisely the time that trust is created, for this phase of the illness and treatments. The fear may still be there, a fear that everything will not work out in the end. Yet, for the moment, the woman can trust that this particular part of the treatment will go well, in this phase the rest is left outside and will be dealt with later. At this point, caregivers do not need to "give promises" that cannot be kept in regards to the course of the illness and prognoses. They do not have to reply to questions that have no answers, the trust is enough for the woman to feel safe right now, in this very moment. That the woman in the encounter before the treatment is seen the way she is in her current situation creates trust, "it feels safe to resign oneself" to what is about to happen. The trust that is created in the encounter bears further, giving strength to cope with the difficulties of the situation. Lack of trust, on the other hand, can lead to denial of the illness and suffering for fear of showing how one truly feels.

"Everyone seems to be afraid to show how they feel; one hides one's own fear within, looking calm and dignified despite the fact that one's thoughts are in a tumult".

Giving time, receiving time, having time – moments of mutual time

The woman needs peace and quiet, time to understand and make sense of what is happening. It may be difficult for her to see what is going to happen; she will need to take one step at a time, and to get used to it to be able to deal with everything in her own way.

"As long as one receives treatment one takes one step at a time. Health care is good if there are no long waiting times, everything runs smoothly, but there is not time for discussions.

Give sufficient time at each encounter. I feel safe with those physicians who take time to see me"

The caregivers do not always have time to listen to the woman; sometimes they just go through papers. Could it be that the caregivers lack the courage to listen? Is there a fear of getting to grips with the woman's situation in life and help her to take one step at a time? The time of waiting feels long, what is she waiting for? Things are uncertain, is this why time seems so long? But what if time in reality is too short, if it soon runs out? The woman wants to talk about existential matters, the state of uncertainty of what it will be like. This is difficult to express in words, sometimes caregivers make time in order to give the woman time to talk. Sometimes the woman is given time to cry, to react, to be herself, to mourn something that was and that she can never get back. When caregivers take time the woman feels she is being treated as a person and seen; this, in turn, gives her a sense of safety. An encounter has taken place, "you have seen me and I have seen you, we have given each other time, we have had mutual time".

When the woman becomes ill she is also given time, time to do things that otherwise would have remained undone. To pause gives her the opportunity to think about what is important in life. The period of waiting can also be forgotten if, for instance, she spends a great deal of time with other people. This can make the uncertain wait easier to endure.

The women need time to talk to someone in order to give themselves time to react and understand, and this in turn makes it easier to endure and reconcile with not knowing how much time they have left.

Being allowed to be a human being and a patient from one moment to the next

The woman's attitude toward her body changes when she becomes ill and becomes a patient. The body does no longer feel as her own, it feels unfamiliar and she loses control over it. The body, which is a human being's way of being in the world (Marcel 2001) can feel as a foreign object being pushed around hither and thither, "one felt like a package that is being moved in and out". When the woman has surrendered her body to the caregivers she feels secure, but she still wants to be seen as a human being, to be herself. Being allowed to be a patient simultaneously means being allowed to be oneself in one's current circumstance of life.

"if someone knows who I am as a person behind the illness is not clear and has never been stated. I feel like a number in a never-ending queue."

"it would be wonderful if someone somewhere would perceive that a cancer patient is also a human being with all that the illness involves, not just taking care of and examining the breast cancer but the whole person"

The encounter can help the woman be herself by allowing her to "let go of what weighs on her", and in this way the caregiver can help the woman understand why she reacts in a certain way. If the woman in the encounter finds herself as a human being she can also recover her body as a part of herself. The encounter can help her become herself in the situation in which she finds herself at that point, as a patient, to find harmony in the movement between being a patient and a human being. The encounter helps the woman to find herself also when the treatment is over so that her life afterward becomes easier.

Conclusions

The invitation to treatment and visit is a prerequisite that gives a promise of and creates a possibility for an encounter where trust for the caregivers' expert knowledge is created or affirmed. When the woman can trust the caregivers' expert knowledge she feels safe to surrender her body to them, so that in that particular situation it is in capable hands. In this way, the woman can allow herself to be a patient, "I get to be a patient". In this situation this is sufficient, the caregivers do not at this point need to "promise" anything above and beyond that her body will be taken care of in the best possible way. Therefore questions to which there are no answers are rendered meaningless in this situation. Safety and trust make the woman feel that life is bearable also in between treatments. Through future encounters the woman can regain her body. The body is changed, but through the encounter she can still feel that it is her own, she can become herself in her body again. Then she can be whole as a patient and this means that she can also be whole as a human being.

A prerequisite for an encounter to take place is that caregivers take time and give themselves time so that the woman finds time and gives herself time. This is how the mutual time in the encounter, which really becomes a timeless moment, is created. This moment gives the woman the strength to live with the insight that time was limited. The message and the purpose of the encounter are to learn to take one step at a time, to live moment by moment. The period of waiting becomes a wait for future encounters, which then becomes more of an expectation than a wait.

Discussion

The caregivers' promise to the patient is to be available and prepared to meet the woman in the specific life situation in which she finds herself. This is a life situation which entails a death sentence creating chaos in her life. The threat to life puts the meaning of live in a new light. She can never get back her old life after this experience (Pelusi, 1997; Cohen, Kahn & Steeves 1998; Kralik, Brown & Koch 2001). The woman finds herself in a field of suffering where she struggles to survive while simultaneously she strives to protect her near and dear ones from worry and pain (Hilton 1996; Hilton, Crawford & Talko 2000; Arman et al., 2002). Existential questions about meaning mix with experiences in which the woman's body feels unfamiliar and no longer her own (Thomas-MacLean, 2004). Rehnsfeldt (2005) says that the motive or ethos to care the way in which caregivers care for the patient is a reflection of their choice of understanding life. This is why one should not talk about lack of time or economic resources but instead about how the patient can receive the best

possible care. This can mean that caregivers are brave enough to enter the patient's inner world also when said patient experiences unbearable suffering.

In the care of women with breast cancer caregivers are constantly reminded in their work about how fragile life can be. The caregivers talk about everyday matters and do not have the courage to talk about illness and fears (Ödling, Norberg & Danielson 2002). The women may perceive this as lack of time and insecurity. This study shows that in moments of mutual time both the woman and the caregiver are allowed to be human beings, with all the fears and uncertainties that this entails. When caregivers can show their fear also before the patient in the caring encounter they are human beings in that they recognize and understand the patient's fears. In the encounter they show their own vulnerability but also that they feel secure in their expert knowledge. This makes the woman trust the caregivers and their expert knowledge so that these can instead help the woman to take one moment at a time, and the encounter leads to a dialogue about life, death and their purpose. This encounter is, as Nåden (2000) states, on a deeper level. In the encounter also everyday matters can be discussed, but here the woman's everyday life and its meaning are emphasized. The caregiver then becomes, as Arman (2003) suggests, a witness to that the good in human beings has not been obliterated. This can be expressed through a caring act, a well-balanced reply or through right action in a specific situation.

The uncertainty that the illness brings places the woman before a choice as to how she wants to lead her life in the midst of the illness (Predeger & Mumma 2004) and the encounter with the caregiver can help her to make the right decision to have the strength to go on in everyday life between treatments and visits. Communion with the caregiver is created in the mutual encounter where the woman and the patient both are allowed to be human beings. The encounter opens up possibilities for the woman to be in touch with herself, to be whole, to be more of a human being by understanding her life's purpose in a wider context. The caregiver's message in the encounter is that the communion of everyday life gives strength so that the body can recover and heal while the woman simultaneously can

understand more about herself and her purpose in life.

The caring encounter helps the women to gain control over certain aspects of their lives despite the fact that the control over their bodies lies in someone else's hands. The caregivers can in the encounter stand by the woman and talk about tomorrow, even though the woman talks only about today. In that moment the woman's suffering is alleviated and she gains the strength to live another day, one moment at a time with uncertainty and fear about the future, but with a trust in that future caring encounters after all carry her further.

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