

✧ RESEARCH PAPER ✧

Suffering related to health care: A study of breast cancer patients' experiences

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A previous study indicated that patient narratives include experiences of suffering caused or increased by health-care encounters. The aim of this study was to interpret and understand the meaning of patients' experiences of suffering related to health care from an ethical, existential and ontological standpoint. Sixteen women with breast cancer in Sweden and Finland took part in qualitative interviews analysed with a hermeneutic, interpretive approach. The outcome showed that suffering related to health care is a complex phenomenon and constitutes an ethical challenge to health-care personnel. The women's experiences of suffering related to health care tended to be of similar seriousness as their experiences of suffering in relation to having cancer. In an ethical, existential and ontological sense, suffering related to health care is basically a matter of neglect and uncaring where the patient's existential suffering is not seen and she is not viewed as a whole human being.

Key words: breast cancer, caring relationship, ethics, hermeneutic method, suffering, uncaring.

INTRODUCTION

Clinical caring science aims at the understanding and development of good professional caring. In the caring theory presented by Eriksson, the patient's suffering is seen as the motive for caring and the alleviation of this suf-

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fering as the main purpose of care.^{1,2} The starting point of this article is a Nordic project entitled 'The face of suffering among women with cancer'.^{3,4} Findings from this study³ indicated that the suffering the women experienced could be described as 'a field of forces', where all those involved were mutually affected by the suffering. Five themes were distinguished within the field of forces, one of which was 'suffering related to health care'. A substantial part of the suffering described by the women was associated with experiences in health care. These experiences often implied acceptable physical care but the women's need for emotional care and general attention seemed almost endless. One aspect of the phenomenon was experiences of differences in the paradigms of the patient and the caring staff, which seemed to increase patient suffering. A pure biomedical paradigm—viewing mind and body as separate—was sometimes perceived almost as a violation by the patients.³ The fact that in many cases the women's experiences of suffering related to health care seemed to be more serious than that related to their breast cancer made reinterpreting the narratives to gain a deeper understanding of this finding ethically unavoidable.

As Halldórsdóttir and Hamrin maintain, patients' experiences of health care consist of both 'caring' and 'uncaring' encounters.⁵ That 'good things' have a tendency to emerge more prominently only when they are threatened⁶ is, however, an ethical presupposition in the present study. Roach also points to the fact that 'caring is most often obvious by its absence'.⁷ The intention was to study the possibilities of developing care by focusing on defective care and suffering related to health care. Halldórsdóttir stresses that as uncaring is an ethical and professional problem, continuing to focus on this issue is of great significance.⁸

Suffering

Suffering as a basic category of care is a concept that comprises the patient's whole experience of life, health and illness in a physical, mental and spiritual sense.¹ According to Eriksson, the concept of suffering is the basic category of care and alleviation of suffering is the motive for all caring.^{1,2} Eriksson emphasizes that the concept of suffering can give care a new dimension by a change in focus from the diagnosis of the illness and symptoms to suffering.^{1,9,10} In a deeper sense, it can be said that the struggle of suffering takes place within the human being's ontological dimensions.¹¹ Suffering violates human dignity and implies loss and dying, but also the possibility of new life

and reconciliation.⁹ This is, in many respects, analogous to the concept of suffering in nursing and caring theories that has been developed by other researchers.^{12–15}

Breast cancer

Breast cancer causes suffering in women in all dimensions of life.³ In our culture, cancer as a phenomenon has almost metaphorical overtones of death¹⁶ and causes the person with cancer to take an immediate stand on previously unconscious and unfamiliar existential questions.^{17–19} According to Rehnsfeldt *et al.*, a diagnosis of cancer places the patient in a situation in which a struggle to understand life occurs.^{20,21} In some cases, the breast cancer patient finds herself in a state of 'free fall', when an existential caring encounter can save the patient through loving care and can also prove to be a shared confrontation with death and suffering.

Suffering related to care

'Suffering related to care' is a concept in Eriksson's theory on caring.²² According to Eriksson, the dignity of patients is very easily violated in care-giving because of all the situations in which they are not believed or taken seriously.⁹ Pressure occurs in care when carers decide, based on their authority, what is good for the patient. Exercise of power is also associated with the carer's use of authority, routines and factual knowledge. Neglect of care is a form of uncaring where the caring dimension is missing.

Health-care personnel have at their disposal powerful means of either empowering or discouraging patients in their care. This is shown in Halldórsdóttir's and Hamrin's consideration of the concepts of 'caring and uncaring'.^{5,23} Attree and Lövgren *et al.* studied patients' experiences of care as a whole, 'good' as well as 'less good',^{24,25} while Sundin *et al.* focused on patients' experiences of deficient care.²⁶ Sundin *et al.* interpreted their findings as an indication that undesirable care most often results from lack of caring or 'non-care'. Attree and Sundin *et al.* conclude that the central issue with regard to how patients experience care involves the interactional and interpersonal aspects of caring.^{24,26}

Ethical basis

The study had an ethical aim. Suffering related to health care often arises in ethically difficult situations in which the carer and the patient are in close contact with one another. The patient's situation, which compels this person to seek help with full confidence, creates a profoundly

ethical relationship with regard to both large and small questions. The connection between ethical and existential aspects of caring was studied here from the standpoint of an ontology that comprises the physical, mental and spiritual dimensions of a human being. According to Eriksson, ethical questions present themselves at all levels, and on the ontological level, questions arise concerning how we see the human being and patient and how we, as carers, relate to this individual.²⁷

Ethics, existence and ontology

Pre-understanding (familiarity) entitles us to assume that suffering related to care is a question with a strong ethical and interrelational charge. Therefore, the results were interpreted at the three human levels of life: ethics, existence and ontology. Ethics, in our understanding, finds expression in people's attitudes and behaviour in relation to their fellow human beings and their own lives.^{27–29} The level of existence can be described as human beings' experience of their life in the world, including all experiences and feelings in connection with life and their situation.^{28,30,31} Ontology is understood as human beings' deepest conception of their being and understanding of life, which is considered as an ontological understanding of life.^{20,21,28} With these assumptions as a starting point, this study focused on the experiences of patients with breast cancer that caused or increased their suffering.

Aim

The aim of the study was to interpret and understand the meaning of patients' experiences of suffering related to health care from ethical, existential and ontological standpoints.

METHOD

To the patient, it is the holistic experience of professional care and the health-care culture that seems essential. That is why we decided not to distinguish between different personnel categories, instead speaking of all the actors in caring as 'carers', 'caregivers' or 'health-care personnel', thereby including all those who actively participated in the care of patients.

The data were derived from a qualitative teamwork project on women's suffering in connection with breast cancer. In previous studies, we used phenomenological methodology to focus on the women's comprehensive experiences of suffering and on the lived experiences of being a significant other of a woman with breast cancer.^{3,32}

As experiences of suffering related to health care are seldom explicitly verbalized, we believed that interpretation of the topic required several steps. The earlier comprehensive, phenomenological analysis^{3,32} comprised the first steps, whereas this interpretive re-analysis represented a second and more in-depth step. As the aim was to interpret the patients' situation from an ethical, existential and ontological standpoint, a hermeneutic method was chosen.³³ The data consisted of tape-recorded, qualitative interviews focusing on experiences and suffering in connection with breast cancer. The narratives were transcribed verbatim. The same interview guide was used by the four researchers (Appendix I).

Subjects

In the research project, an appropriate sample of 16 women from four different health-care areas in Sweden and Finland were asked to participate (Table 1). A significant other, chosen by the woman, was interviewed as well, but these interviews were not part of the present study. The data were collected during the period 1997–1999 by four researchers. The health-care areas repre-

Table 1 Characteristics of the sample

Patients	Age (years) [†]	Stage of disease [‡]	Time since first diagnosis (months) [§]
A	42	Generalized	27
B	42	Localized	15
C	42	Localized	36
D	49	Localized	36
E	46	Localized	58
F	53	Localized	18
G	48	Localized	36
H	35	Localized	59
I	57	Localized	36
J	53	Localized	24
L	55	Localized	30
M	69	Generalized	30
N	44	Generalized	18
O	65	Localized	12
P	45	Generalized	36
Q	42	Generalized	24

[†]Mean age = 49 years; [‡]stage of disease totals = 5 generalized, 11 localized; [§]mean time since first diagnosis = 31 months.

sented were a university hospital (the chemotherapy treatment unit), a regional hospital (the outpatient department), a private complementary hospital (anthroposophical medicine) and the follow-up support clinic of a cancer association. The samples represented a logical combination of locations in Sweden and Finland where there are women with breast cancer (see Table 1). Socially, the sample consisted of 12 married and four single women. All of the women had employment outside the home before the illness. They represented typical middle-class professionals, such as teachers, nurses and administrative personnel.

Analysis

Analysis of the data in this study was based on a hermeneutic (interpretive) approach according to Gadamer.³³ The task was to seek an understanding of the inherent meaning of the topic in question. This was done by means of a movement between familiarity (pre-understanding) and alien status (openness to the new things that emerge), as well as between parts and the whole.

Interpretation proceeded as follows:

1. Pre-understanding: from previous studies, the theoretical perspective of the study of caring science and caring ethics, and the professional clinical experience of caring, provided a foundation for questions and research.
2. Units of meaning were attained through analysis, and a dialogue was carried out with each of the 16 women separately.
3. The analyses of the 16 cases resulted in interpretive hypotheses, which were reformulated as new questions to the text.
4. The questions were tested through a renewed scrutiny of the units of meaning in order to open up the inherent meaning of the text.
5. The dialogue continued by associating the pre-understanding, in the form of earlier knowledge and experiences, with the interpretation of the patients' narratives.
6. A final text and modification of the new understanding were attained through a return to all the interviews.

Ethical evaluation

The project was approved by the Research Ethics Committee at the Faculty of Health Sciences, University of Linköping, Norrköping, Sweden, and the Regional Research Ethics Committee at the Karolinska Institute, Stockholm, Sweden. Ethical considerations focused par-

ticularly on integrity and non-maleficence. In accordance with ethical principles, usefulness in relation to risks, integrity, non-maleficence and respect for human dignity were considered.³⁴

FINDINGS

The interpreted findings with respect to suffering related to health care are presented from their three levels of interpretation, each with its own theme:

1. Ethical dimension: the caring relationship that fails to materialize and the carer's choice.
2. Existential dimension: not being regarded as a whole human being with experiences and needs.
3. Ontological dimension: an imperceptible call for help in a disintegrating, incomprehensible life.

The caring relationship that fails to materialize and the carer's choice

The patient's suffering related to health care was, in terms of an ethic, conceived of as attitude and action in relation to whatever took place in the caring relationship. Suffering from care was often caused by the relationship having failed to materialize or by the patient's feeling of not having been seen as a unique fellow human being. One of the ways this manifested itself in clinical reality was that patients felt they were not given enough time and information:

I felt I was not in good shape, I would have liked to ask her and talk to her (the doctor), ask her whether one can feel mentally unwell afterwards and so, but I got stuck as it were, for she was in such a hurry and didn't have time to listen. I think she should almost be able to see when somebody feels as rotten as I did.

When the caring relationship failed to be established, the patient was well aware that at each meeting and at each level the carer had a choice, either to receive the patient or not to do so. Health-care personnel were not conscious of the fact that patients were aware of this choice. Patients' awareness was implicitly illustrated in phrases like 'does not take the time':

But she does not take the time, perhaps, to listen to patients, she has only got those fleeting moments for examining them.

The encounter that failed to take place created additional suffering for patients when they felt that the carer

hid behind health-care culture and routine. Patients realized that a caring relationship might demand courage on the part of the carer, courage to resist external pressure and an inner courage to open up to the patient's suffering and, thereby, run the risk of being affected as well:

For it is a question of daring to sit down, of daring to meet this, not to say we must pass on, for it is of course easier to do that, as it were ...

The patients' suffering became pent-up and it increased when they tried to protect themselves against disappointments by avoiding contact with carers. According to the patients, the interest of health-care personnel was fundamental to ethical and loving care. That which finds expression in a great deal of the present health-care culture caused the patients increased suffering, when what was expected of patients was adjustment and understanding. Patients who suffered were expected to accept a health-care culture in which suffering was made invisible:

... it is, of course, not very pleasant to always be the one who causes anxiety, but that is what one does to the health-care staff as well, and one's own expressions of anxiety give rise to ... everyone wants one to cope with this exceedingly well ...

Health-care culture in such cases dominates ethics and seems to cause patients suffering by dissociating itself from the caring values and upholding the biomedical values as the essence of health care.

Not being regarded as a whole human being with experiences and needs

In an existential sense, the breast cancer patient's suffering as related to health care was associated with the paradigm of health care, that is, the picture of the patient was linked to what the task of caring was supposed to be:

What then, if you are not seen as anything but a physical thing, not seen in your suffering, that really makes the suffering more intense, for there you are. I thought sometimes I could cut a piece of myself off and send that, I don't have to go along myself, for they are not interested in me, are they?

The patient's suffering related to health care had its origin in experienced disappointments. Women who suffered acutely in their whole existence did not feel they had been offered care as whole human beings. Instead, the women

often felt that they had been treated as bodies, as numbers or as diagnoses. This increased their suffering and feeling of insecurity, forcing them to carry on an undignified fight for themselves in an existential sense. The patients suffered a great deal when they were forced to fight for themselves in order to get their rightful care. They felt 'it depends on themselves' (the responsibility):

... then the suffering when you feel that you don't get any help, any support, that there is nobody who understands except doctors who, in one way or another, think they understand, who think that they can, but they just meet you for part of the way, as it were. They don't care to ask more.

Everything depends on myself, I can't feel I get any support from health care.

In the patients' view, health care did not show any interest in women's existential situation. Health-care culture is based on curing cancer in a physical sense; whatever else is present seems to be ignored, pathologized (seen as pathology) or explained away. Instead of getting sympathy, support and opportunities to discuss how they felt, worried patients were referred to psychiatry, therapy and non-profit cancer organizations for support:

Of course, they know that there are psychic problems in this connection, but it is as if this were not taken care of equally well. If the patient organization for cancer patients had not existed, I would not have received any kind of psychological conversational therapy. In my opinion, whenever you get that kind of information, the right and proper thing would be for you to immediately get someone to talk to!

Caregivers who ignored the patient's experiences could also make her feel ashamed of her mental and spiritual suffering:

... or asking for help with your psychological problems ... because you ... don't want to confess in any way or you're afraid of ... being told you're becoming emotionally unstable or something ...

The need to be seen as an individual and fellow human being also appeared in a clinical sense in breast cancer patients' metaphorical use of the concept of routine. Routine as expressed by the patients described a reduced and inhumane form of care. The patients were

in dread of being regarded simply as a number in a crowd, and every such hint increased their insecurity and suffering:

... it is extremely important that you're not just patient number 32 that day.

The medical paradigm could have a disturbing effect on the patient's approach to life and view of her situation. Medical knowledge and information could hurt and cause suffering from the point of view of patients. The different paradigms also took the form of a power struggle, disguised by routine and by knowledge:

It is tremendously tiresome all the time to have to fight one's way through, all the time to turn a deaf ear, keep oneself, as it were, protect oneself like this from the nursing personnel ... For it is exactly as if I said that I will get well, I know I will get well, I don't care a hoot about what you say—they will take their stand and say 'We know best, you won't get well'—do you see?

An imperceptible call for help in a disintegrating, incomprehensible life

In the ontological and most fundamental sense, suffering related to health care seemed to originate in making patients' cry for help in their threatened ontological understanding of life and death imperceptible. Empirically, our earlier investigations and other studies showed that cancer and death as phenomena were very closely connected and were almost inseparable. Experiences of total disruption of life were common:

Things have namely changed radically since I got sick. Everything cracked ... one can say.

In the afflicted patient, a cry for help in order to understand both death and life could be discerned. The cry also contained a question as to how cancer is to be understood as destiny and as a struggle to find meaning and understanding, as well as reorientation and hope, in the situation that had arisen. The breast cancer patient's distraction and loneliness in this disintegration and sudden incomprehensibility were part of her vulnerability:

The way I felt, I really needed to meet and talk to a human being, but one makes oneself all the time ... I pretended all the time that I was braver than I was then ...

Suffering related to health care turned out to be, in the ontological sense, suffering that was protracted and that increased when questions regarding the innermost essence of life remained unheard. It took time for patients to realize that this help to enable them to understand life's meaning was not forthcoming. The patient's call for a caring encounter was often in vain.

DISCUSSION

Health care causes patient suffering through uncaring

This empirical study shows that from the standpoint of patients, health care in many cases causes increased suffering. In the framework of an ethically complex situation of expectations, trust and clashing paradigms, patients suffer from the care that has failed to take place and the suffering that has been denied affirmation. Patients' disappointment at the absence of a deeper, caring relationship, in connection with an unclear responsibility for the care of the patient as a whole human being, emerges clearly. The suffering related to health care has an essence of neglect and uncaring when, for example, the caritative question regarding the patient's suffering is not asked by the carer.³⁵

Suffering related to health care takes place, as we have argued, to a great extent in the relational sphere of caring. In cases where the caregiver chooses to regard the patient mainly as an object, and the patient and the disease as something that is to be treated or attended to, this view will be of decisive importance.³⁶ The patient is in this way encouraged to give up her experiences and bury the significance of her illness in her life.³⁷ In such cases, the patient suffers from the struggle for wholeness and dignity that this involves.

Caring ethics as a complex relationship

Patients' experiences of health care are conditioned by the quality and depth (i.e. ethics) of the human relationship in the caring situation. The idea that what can be regarded as a relationship in caring is central to the experience of good or poor care is in agreement with other research focused on patient experiences.^{6,25,35,38,39} Experiences of uncertainty, insecurity, distrust and increased (rather than alleviated) suffering come to the fore in this study. Disclosing the consequences of patients' perceived lack of being received in an ethical way is, however, fraught with an element of complexity. In spite of sometimes serious experiences of insufficient care, we noted,

in accordance with Attree, that the patients did not openly complain.²⁴ This fact contributes to the complexity of the topic.

The findings reveal that ways in which patients who experienced injuries protected themselves against new violations included displaying a false front of health, pretending to understand the carers, reducing their own needs and hiding their signs of suffering.⁴⁰ Frank draws from his own experiences to explain that he actually feared caregivers who could not tolerate his suffering.⁴¹ How are we, as carers, to discover and meet patients' needs when they hide these from those who are involved with them? Or does health-care culture involve a paradigmatic agreement where patient and carer jointly avoid being confronted with the unavoidable suffering in life?

A new aspect which emerged is that patients seem to have seen through health-care culture more effectively than caregivers themselves. From an ethical point of view, the patient's awareness of the carer's choice appears to be a main factor in the increased suffering. In spite of the strong paradigm that supports health-care culture, it seems that at each moment patients know that the carer has the possibility of crossing paradigm boundaries and making a choice in favour of the patient. In the patient's view, the carer can always switch sides and become a fellow human being in the common struggle. Everything that prevents this, to some extent, increases the patient's experience of suffering.

The ethical demand and trust

In terms of Løgstrup's thesis regarding an inescapable, interpersonal ethical demand by the force of ontological understanding of life,²⁸ patients with breast cancer experiences seem to be quite relevant. When the caring that the patient in question expected is not forthcoming, she is offended and loses some of her dignity through the increased suffering that results from a struggle to conceal feelings and experiences.

Interpretation of how unethical care causes suffering is facilitated by Løgstrup's understanding of the strong reaction that occurs when the offered confidence is misused or misunderstood. Each meeting with the carer can be interpreted by the patient as an offer of trust in the caregiver. As the result of a careless attitude, or by reserving too little time for a dialogue, the caregiver can cause the patient to experience immediate violation in the form of frustrated expectations. This can occur on the existential level when, through offered trust, the patient expects the carer

to be able to provide further guidance in the vital questions aroused by the disease. The carer's failure to respond or react on that level makes the patient existentially insecure and increases the pressure on her to struggle on her own to alleviate her suffering.

Ontological caring

Caring, in the sense of alleviating suffering, can be seen as a conclusion of ethics, existence and ontology. The patients in the study wanted to be seen as whole human beings and to be inspired to continue their struggle to understand life. Such ontological affirmation is largely lacking according to patients' accounts of their experiences of caring. From time to time, patients who are receiving care find themselves in a darkness of ontological understanding²¹ and have an almost unquenchable desire for deeper human fellowship and confirmation. As contended by Whitehead, illness and suffering are often a trigger for existential health.⁴² It might be difficult for carers to discover that desire in the ontological dimension; it seems that strong defences are in operation in both patients and carers in order to avoid confrontation with suffering. But if or when the spiritual component of the other person is affirmed, this can result in a caring communion that alleviates the patient's suffering.

Limitations of the study

When analysing the data in this study, it was necessary to make a choice: whether to study patients' total experience of care as alleviating or increasing suffering, or to focus on what pre-understanding had indicated, that is, suffering related to health care. Emphasis could have been placed on contrasting the empirical factors related to good and bad experiences in order to arrive at increased understanding of alleviated suffering. In that case, however, it is probable that neither the ethical aspect nor the meaning of suffering related to health care would have been illustrated as clearly.

Interpreting the data concerning the ethical, existential and ontological components might seem difficult, especially in the case of the ontological and existential levels. The differentiation between ontology and existence is by no means philosophically unambiguous. We consider the choice of making such an attempt to be a fruitful way of presenting the widened understanding of empiricism when, according to our view, the ontological and the existential components appear as different but not separated dimensions of life.

Implications for nursing and research

The first task in alleviating patients' suffering must proceed through conscious efforts to eliminate the suffering that health care can cause. Suffering related to health care might arise in a situation where the ethical challenge of a caring relationship is not understood. A deeper ethical or existential, as well as ontological, understanding of patients' experiences of alleviated and increased suffering in relation to health care might be translated in a natural and professional way into the ability to eliminate the unnecessary suffering that care might cause. A genuine understanding of the 'patient's world', based on seeing the patient as a wholeness of body, soul and spirit, might lead to changes in attitude as well as acting in nursing care. With a focus on these components, caregivers would benefit from studying biographies and research reports regarding patients' experiences, discussing these in ethical supervision groups. Along with studying the international nursing research on suffering, a gradually increased awareness regarding 'the suffering patient' could lead to improvements in health care. Further research in 'the patient's world of suffering' is of importance.

CONCLUSION

The essence of suffering related to health care becomes evident through avoidance, neglect and uncaring. The women's experiences of suffering related to health care tended to be of similar seriousness as their experiences of suffering in relation to having cancer. From a caring, ethical point of view, the absence of responsibility, compassion and communion between patient and caregiver appears to be a threat to good care that aims at alleviating suffering. On an existential level, the failure to acknowledge a human being as an entity of body, soul and spirit expressed in pain, despair and suffering can prevent the alleviation of suffering. Also, a denial of the importance of existential questions like the meaning of life and death might block the way to alleviation of a patient's suffering. In an ontological sense, unless caregivers' basic attitude to life and their duty as a carer includes charity and compassion, it might constitute an obstacle to the alleviation of patients' suffering.

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APPENDIX I

Interview guide: Suffering among women with breast cancer

1. Can you describe what having breast cancer has been like for you?
2. What is the significance of suffering for you in your life today?
3. What significance did suffering have for you before your breast cancer?
4. Do you think that your immediate family and friends have suffered because of your situation? If so, in what way?
5. What have other persons meant to you during your suffering?
6. What is the most important message about your own suffering that you'd like to give us health care workers?
7. Information about disease history, family, work, finances and residence.