

EMPIRICAL STUDIES

Suffering caused by care—Patients' experiences from hospital settings

MIA BERGLUND, PhD, LARS WESTIN, PhD, RUNE SVANSTRÖM, PhD, &
ANNELIE JOHANSSON SUNDLER, PhD

University of Skövde, Skövde, Sweden

Abstract

Suffering and well-being are significant aspects of human existence; in particular, suffering and well-being are important aspects of patients' experiences following diseases. Increased knowledge about existential dimensions of illness and healthcare experiences may be needed in order to improve care and reduce unnecessary suffering. Therefore, the aim of this paper is to illuminate the phenomenon of suffering experienced in relation to healthcare needs among patients in hospital settings in Sweden. In this study, we used a reflective lifeworld approach. The data were analysed with a focus on meanings. The results describe the essential meaning of the phenomenon of suffering in relation to healthcare needs. The patients were suffering during care-giving when they felt distrusted or mistreated and when their perspective on illness and health was overlooked. Suffering was found to arise due to healthcare actions that neglected a holistic and patient-centred approach to care. Unfortunately, healthcare experiences that cause patients to suffer seem to be something one needs to endure without being critical. The phenomenon can be described as having four constituents: to be mistreated; to struggle for one's healthcare needs and autonomy; to feel powerless; and to feel fragmented and objectified. The study concludes that there are problems associated with patients experiencing suffering at the hands of healthcare providers, even if this suffering may not have been caused deliberately to the patient. Consequently, conscious improvements are needed to lessen the suffering caused by care-giving, as are strategies that promote more patient-centred care and patient participation.

Key words: *Caring, suffering, patients' perspective, lived experiences, lifeworld, existential, attitudes, nursing, participation, phenomenology*

(Accepted: 16 July 2012; Published: 27 August 2012)

Health and well-being are essential for the understanding of caring (Dahlberg, 2011). The goal of caring is to improve health and well-being and to alleviate suffering. This paper begins with real-life stories of people's encounters with healthcare and situations when being in need of healthcare following varied diseases or health problems (Berglund, 2011; Johansson Sundler, 2008). Narratives of dissatisfactory experiences when being in the hands of healthcare professionals called for our attention. We found it necessary to further illuminate these experiences of suffering in relation to healthcare needs.

Background

From a caring science perspective, patients' experiences of illness or disease need to be understood as embodied experiences (Merleau-Ponty, 1945/2002),

involving both the body and the lifeworld of the patient. Being aware of the patient's perspective of health and care entails an emphasis on human subjectivity (Dahlberg & Segesten, 2010). Suffering and well-being are significant aspects of human existence; in particular, suffering and well-being are important aspects of patients' experiences following varied diseases. In the past few decades, the perspective of the patient and the notion of patient-centred care have gained importance. Mitchell, Closson, Coulis, Flint, and Gray (2000) argue that patient-centred care needs to be viewed from a philosophical perspective. The authors claim that a philosophy of care that emphasizes the perspective and needs of the patient is needed. The delivery of healthcare is also guided by professionals' values and beliefs. Dahlberg, Todres, and Galvin (2009) have developed a conceptualization of "lifeworld-led

Correspondence: A. Johansson Sundler, University of Skövde, Box 408, 541 42 Skövde, Sweden. Tel: +46500-44 84 11. Fax: +46500- 44 84 99. E-mail: annelie.johansson.sundler@his.se

©2012 M. Berglund et al. This is an Open Access article distributed under the terms of the Creative Commons Attribution-Noncommercial 3.0 Unported License (<http://creativecommons.org/licenses/by-nc/3.0/>), permitting all non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

Citation: Int J Qualitative Stud Health Well-being 2012, 7: 18688 - <http://dx.doi.org/10.3402/qhw.v7i0.18688>

(page number not for citation purpose)

care” with an emphasis on the complexity of personhood, health, and illness, founded in phenomenological philosophy. “Lifeworld-led care” embraces an existential view of being human that accommodates freedom and vulnerability by respecting patient preferences.

Eriksson (1997, 2002) highlights patients’ suffering as the motive for caring. In her theoretical framework, Eriksson describes suffering in three forms: as related to illness, as related to care, and as related to life. This framework states that the main purpose of care is to alleviate this suffering. According to Eriksson (1994), suffering related to care occurs when a patient’s dignity and human value are violated in care-giving situations. For most patients, being in need of care is associated with some degree of suffering (Fagerström, Eriksson, & Bergbom Engberg, 1998). In research, suffering related to healthcare has been described as an experience of being neglected and as a matter of uncaring. Healthcare has been reported to increase patients’ suffering (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004). Suffering in relation to care makes patients more wounded and vulnerable in situations when comfort was expected (Öhlén, 2004). When patients experienced healthcare staff not understanding their situation, their suffering increased and they felt mistrusted and rejected by the staff (Wiklund-Gustin, 2011). Morse (2001) described suffering as fundamental and normal responses to catastrophic loss. She describes suffering as two major behavioural states: enduring and emotional suffering. Morse, Beres, Spiers, Mayan, and Olson (2003) have described how suffering can be identified during nursing. Morse’s work on suffering is a more practical one at nursing level (Foss & Nåden, 2009), and we do not find that she focuses on suffering from care in the same way as Eriksson’s more theoretical work does. Suffering from care seems to be a phenomenon more studied in the Nordic countries, which probably has to do with the Nordic healthcare system. In Sweden, similar to many other western countries, healthcare policies and laws (SFS, 1982:763) highlight that patients need to be more involved in their care. This is to ensure that patients are informed about their conditions and that they are involved in the decisions about their treatment and their care.

The patients’ subjective experiences are important in relation to healthcare. It has been argued that the perspective of the patient is crucial if the aim is to include the patient in an active way and to decrease the risk of patients’ suffering from care (Dahlberg, 2002). Insufficient communication among healthcare professionals and patients, for instance, may be a matter of patient safety. Gallant, Beaulieu, and

Carnevale (2002) suggest that nursing care theories emphasize patient participation, but that nurses like other healthcare professionals often seem to see patients as a passive recipient of care. Dahlberg et al. (2009) have criticized that the approaches of patient-centred care in policy and practice not necessarily emphasize an existential view of well-being or illness in healthcare. The critique points to the value of involving the patient in his or her care and health processes.

It seems fair to suppose that increased knowledge about existential dimensions of illness and healthcare experiences is needed in order to improve care and reduce unnecessary suffering. Research is needed to gain ways of caring and nursing that lessen patients’ suffering. As a human condition of life, suffering is connected to illness and well-being, particularly when one is suffering from a disease. From this point of view, some degree of suffering may not be possible to avoid. However, when it comes to suffering caused by care, the question still remains as to how this suffering can be reduced. The phenomenon of suffering, in particular suffering caused by care, is of interest to nursing and caring. Therefore, the aim of this paper was to illuminate the phenomenon of suffering experienced in relation to healthcare needs among patients in hospital settings.

Method

Human experiences are meaningful, and people’s narratives communicate meanings (Giorgi, 2009; Polkinghorne, 1988). By interviewing people there is an opportunity to capture their experiences through their narratives of the phenomena that are scrutinized. When telling their stories they give voices to their lifeworlds (Giorgi, 2009). A phenomenon as suffering becomes a part of the patient’s lifeworld, and in order to capture the patient’s experiences we used a phenomenological approach (the reflective lifeworld approach) as described by Dahlberg, Dahlberg, and Nyström (2008). This approach is based on phenomenological epistemology and on Husserl’s theory of the lifeworld, which allows a phenomenon such as suffering to be illuminated in depth with an openness and sensitiveness as to how meanings come to be in people’s everyday life. One of the critical points when using a phenomenological approach is the bracketing of past knowledge (Giorgi, 2009). In the reflective lifeworld approach, when holding back past knowledge, the term ‘bridling’ is used. This means that the researcher attempts to have a critical and reflective attitude throughout the entire research process.

When studying a phenomenon using a phenomenological approach, the researcher tries to find the

essence of the phenomenon (Giorgi, 2009). The essence can be understood as the invariant structure of the phenomenon, i.e., the inner core of the phenomenon (Dahlberg et al., 2008). When using the reflective lifeworld approach, the essence is formulated as the first step of the description of the phenomenon. The second step in the descriptive phase is to describe the variations of the phenomenon, which is done by formulating the constituents. In these, the particular meanings are presented as quotations by the participants of the study (Dahlberg et al., 2008).

A secondary analysis was performed, and in this study we reused the data originally collected in two earlier research projects (Berglund, 2011; Johansson Sundler, 2008). Secondary analysis in qualitative studies allows researchers to put a new research question to the data collected for other research purposes (Heaton, 2004). In this study, the new research question focused on the phenomenon of suffering experienced in relation to healthcare needs among patients in hospital settings, a question posed from earlier interviews. In these interviews, narratives of suffering called for our attention. At a meeting when the topic was discussed, four researchers found it unethical not to further explore this suffering. The meeting became the starting point for a continuous project on suffering from care, of which this study became one part. Two of the researchers (MB and AJS) had conducted and transcribed the interviews used in this article. The analysis and the writing of the manuscript involved a dialectic process where all four researchers participated.

Participants

The earlier studies and this study have followed the recommendation and laws of the Declaration of Helsinki and The Ethical Committee in Sweden at the time of data collection (Berglund, 2011; Johansson Sundler, 2008). Participants were recruited through hospitals, municipal care, and patient associations. All participants received a letter where he or she was invited to participate in the study. The participants were guaranteed confidentiality and were informed that participation was voluntary. After the participants gave their informed consent, the interview was conducted.

In the analysis, narratives from 22 participants were used. The participants were aged between 21 and 84 years, and they had been living with long-term and/or life-threatening diseases. All of the participants had been living with one or more diseases for at least half a year, even if most of them had been sick for a considerably longer period of time in their lives. The participants had had

frequent contacts with healthcare, both in local primary healthcare settings as well as at different hospital care settings. Experiences narrated by people with different ages and different diseases, as well as from varying contexts, formed a rich variation in the data.

Interviews

The interviews conducted were open phenomenological interviews (Dahlberg et al., 2008). In these interviews, the focus was on the participants' expressions and narratives of lived experiences. The interviews were open, but not without structure, with a focus on lived experiences of health and illness. From the beginning, the participants were asked to tell their stories of having been ill from a patient's perspective. In the interviews, they did describe detailed and different experiences when they suffered from care, descriptions which were then used in this analysis.

Analysis

The process of phenomenological analysis (Dahlberg & Dahlberg, 2003; Dahlberg et al., 2008) endeavours to allow varied meanings and the essence of the phenomenon to emerge and become visible. The analysis involves a reflective and sensitive dialogue with the text in order to understand both parts of the data as well as the meanings of the phenomenon. With a bridling approach used throughout the process, we attempted to maintain openness and not to make definite what was indefinite too quickly.

In the analysis all four researchers were involved in a dynamic interplay with a focus on the studied phenomenon. In this process, we moved back and forth between the data and our writing, which is a process of figure and background (Dahlberg et al., 2008). As a starting point all interviews were read several times, and meaning units were marked in the text. The next step was to cluster the varied meanings in order to get an initial view on the phenomenon as presented by the patient's narratives. The varied meaning units were interconnected with or distinguished from each other in the clusters. In this phase the clusters were figure, and the data were background. After this the process of describing the essence began, which was performed using the data and the clusters as background. In this process, the researchers extensively discussed statements from the interviews, meaning units, and the clusters in relation to the emerging essence. As the analysis moved further, it was possible to elucidate the phenomenon piece by piece, and the description of the constituents began, which was performed with

the essence as the background. In the result the essence is presented first, illustrated in five more concrete constituent parts that include examples and statements from the interviews.

Results

Suffering in relation to healthcare needs entails a suffering where the patient feels distrusted or mistreated. Suffering is experienced when the patients' perspective on illness and health is overlooked. When feeling ignored or objectified, the patients' autonomy is lessened, which makes them vulnerable and causes them to feel powerless. Healthcare experiences that cause patients to suffer seem to be something one needs to endure without being critical. Suffering could force the patients to struggle for their healthcare needs. Suffering was found to arise as a result of healthcare actions that neglected a holistic and patient-centred approach to care.

When patients suffer from healthcare actions, there are negative consequences for their health and well-being. In addition to the effect on the patients' health process, this suffering has a negative impact on future contacts with healthcare providers. Suffering from healthcare experiences is also a threat to patients' autonomy and possibilities to participate in health processes. Suffering in relation to healthcare needs can be understood as unnecessary suffering. The essential meaning of suffering as the result of healthcare experiences can be understood from its four constituents:

- To be mistreated
- To struggle for one's healthcare needs and autonomy
- To feel powerless
- To feel fragmented and objectified

To be mistreated

Suffering caused by care was experienced in relationships and encounters with healthcare professionals when the patient felt mistreated, distrusted, or not listened to. When suffering from care, the patient's vulnerability increases. Negative experiences were described when the patient's symptoms were ignored or not taken seriously by professionals. The care that intends to help the patient sometimes appears to cause the patient to suffer and to endure this suffering without complaining, for example, tolerating side effects of drugs; experiences not always of interest to healthcare professionals:

There is no one who cares about this, about how I feel after taking my medications. You are

supposed to have side effects. One has to accept that after becoming ill. I feel somehow that I'm supposed to be happy that I'm alive after all. If I have side effects from my medication, that's okay, that's the negative aspect of it all.

Seeking help from healthcare providers with fear for one's life and without the patients' experiences being taken seriously by professionals makes patients suffer in silence. For example, a woman describes how she was mistrusted and not allowed to come to the local emergency ward when she had chest pain. Instead, she was redirected to a general practitioner. Similarly, other patients describe experiences of distrust in encounters with professionals. When there is no time or space for questions or dialogue, the patient becomes excluded from participation in healthcare, as one woman said "I wanted to ask some questions. Then he [the doctor] looked at me, and said: Here it is me who asks questions." In the long run, this can be a hindrance for the patients to take responsibility for their health.

The attitudes of professionals who overlooked the patients' experience caused suffering. This suffering also hindered patients in understanding and managing their own health and illness. When professionals did not pay attention to or ask for their patients' point of view, there was also a risk of incorrect treatment or misdiagnosis.

A woman with visual impairment described the instance when she sought treatment for a rash on her foot, which she had thought was shingles. At first, she was examined by a young doctor who did not understand what her trouble was. The doctor then brought in a more experienced colleague, and when he came in, he went straight to the woman's foot, without saying hello. "He stood with his back towards me, and so he said, 'Scalpel.' 'No,' I said, but it was already too late." She continued to describe how the doctor cut into her foot, without disinfecting. After that surgery, she had long-term problems with leg ulcers, which later led to an amputation of the lower part of her leg. The event caused this woman great suffering, which was aggravated by the doctor's nonchalant attitude.

When patients felt mistreated or distrusted by professionals, this caused them to suffer. When mistakes happened, the patients experienced that no one at the hospital earnestly cared or wanted to take responsibility for such faults. Being exposed to inappropriate healthcare means suffering, which increases even further if the patient faces inappropriate attitudes. Many of the diseases the participants live with have led to more or less life-long taking of medications and regular contacts with healthcare services. The suffering the participants experienced

when being, for example, mistrusted by professionals also affects the patients' reliance on professionals in future contacts with healthcare providers.

To struggle for one's healthcare needs and autonomy

When healthcare causes the patient to suffer, it results in a struggle where one has to fight for one's right as a patient or to give up. For example, one participant tells: "Yes, you must fight for everything, so I do not wonder that some just sit and die." The patient's vulnerability and disadvantage is obvious. Another participant faced having to begin treatment with a medication that would run the risk of severe side-effects. Following the treatment, she needed to have a medical examination. Earlier, at such an examination, the woman suffered a cardiac arrest. After the doctor informed her about the medical treatment and side-effects, he then let her make the final decision on whether or not to start the treatment. Together with her husband, she decided not to undergo the treatment. This led to pressure from the doctor, which meant that she could not have refused the treatment. Eventually, the doctor persuaded her to start the treatment; however, a few months later, they had to stop the treatment because of serious side-effects.

The patients feel that they are expected to follow the advice from their healthcare professionals. There seems to be a culture where they as patients are required to be polite and not make demands or question their care or the professionals. When the patients do not follow those unwritten rules, a struggle begins, experienced and recognized as a feeling of becoming an awkward patient. Some patients are too sick to fight for their rights, and they may just have to accept the care they receive:

I have accepted that. I do not think there is any reason to argue with them, because I cannot manage any more. If I do so, then my blood-sugar increases and my angina hurt. It is better not to raise any questions and just accept the way it is.

Another man tells about how he did not receive his medications when admitted to a medical ward at the local hospital. When he complained to the nurses at the ward, no one listened to him or believed what he was saying. Several times when admitted to the hospital, he received neither the right medications nor the correct diet, even though he was suffering from both diabetes and severe renal failure. On numerous occasions, this patient has had to fight for his health. The patient suffered both when he was not heard and when he had to fight for his rights.

To feel powerless

Ultimately, the responsibility for health and one's own life lies in the hands of the patient. When hindered to participate or to take responsibility for one's situation, the patient can feel powerless. If healthcare professionals lack in their responsibility to empower the patient, it can increase the suffering of the patient, and health processes may be affected negatively. Missing the daily needed support to manage the disease causes the patient to suffer even more:

Yes, you have to manage it by yourself. I was at every pain clinic in the county. They had no medication that helped me. So, then I had to admit that I became an alcoholic, I had to drink alcohol, it was the only thing that relieved the pain.

The man experienced long-term pain problems, which he tried to solve on his own, without support and understanding from health professionals. The suffering may not always be visible, yet a seemingly happy patient can endure much suffering. Similarly, another patient says, "He [the doctor] said that I was too happy to have so much pain."

Experiences of powerlessness and fear seldom seem to be addressed in meetings with healthcare professionals. When patients' uncertainty or fears do not attract attention from professionals, health processes may be hindered. Without the support from professionals, it becomes more difficult to manage everyday life that follows the disease. It then can become easier to adopt a passive approach if not trusting one's own ability. Support and knowledge about the disease are needed for patients to have the power needed to influence or take responsibility of life in a healthy manner.

To feel fragmented and objectified

Patients experienced suffering in situations when they were objectified or when they experienced their health to become fragmented without meaning to them. The highly specialized care divided their illness experiences into different diagnoses, which may not have been meaningful to the patients. Additionally, the medical perspective was sometimes experienced as an objectification of one's situation. When the illness became the main focus of healthcare and the patients' experiences were neglected, patients felt objectified:

It's never the same doctor, one becomes mad at this. You do not feel ... how do I say it, you do not feel human, but ... as an object on a conveyor belt, no one really cares. They have

decided, medical science has determined, that's the way it is.

Adherence to human values and autonomy are experienced as weak when continuity and dialogue in healthcare meetings are missing. This may easily become a source of suffering for the patient. The fragmentation and objectification allow the patient to exclude and ignore the disease: "it [the disease] is not a part of me and who I am." Support is needed to understand and manage hindrances in everyday life following the disease, yet this support was often lacking. This created an ambiguity that facilitated the patients' avoidance of their own responsibility over their health and well-being following the illnesses.

Health and illness experiences were influenced negatively when patients lacked the support to deal with and understand what had happened: "There is so much I ought to do. But, is it any of this that will help me from becoming sick again." When professionals do not listen to or take patients' experiences into consideration, the patients' suffering increased. Yet, focusing on the disease and not the personal view was experienced as an objectification. Several of the participants had multiple diseases. They experienced being admitted to different special care units, for example, coronary care units or renal care units. At these units, one disease at a time became the focal point to professionals: "They often just see the disease, not me as whole human."

The patients' pliability and capacity to manage, for example, medications or life style changes, becomes complicated when the advices for different diseases are not harmonious with each other, and sometimes it is even conflicting. The patients then are left alone to put these pieces together in a meaningful way that supports or strengthens their health and well-being.

Discussion

In our study suffering from care was found to be the result of healthcare actions that neglected patients' perspectives and experiences. This suffering from care was shown to be a hindrance for patients' participation in their health and care. For example, patients' feelings of being mistreated, not listened to, excluded from decisions, objectified, and incorrectly treated lead to frustration and feelings of loneliness in the disease situation. These affect patients' ability to participate in their care and reduce patients' power and desire to manage their health situation.

The delivery of healthcare is supposed to be more beneficial if patients are to be given the opportunity to participate and influence their healthcare. Parti-

cipation has been reported to be important for women's well-being after a myocardial infarction (Johansson & Ekebergh, 2006). In that study, participation was found to improve well-being and facilitate managing the disease in everyday life. When a patient is diagnosed with a long-term disease (Berglund, 2011), the illness is something seldom easily accepted, but rather something one wants to repress from everyday life. We believe that patients who do not feel objectified and who do not miss support from healthcare professionals may have lessened tendencies to repress their disease. Health processes involve existential dimensions, and caring activities are needed that give emphasis on participation and that embrace respecting patients' experiences, needs, and preferences. On the contrary, experiences of violated encounters were found to have negative consequences.

Suffering from care as it has been shown in our study needs to be understood as a barrier to patient participation that causes feelings of powerlessness. In nursing, patient participation has been demonstrated in the sharing of information and knowledge as well as active engagement in activities that take place in the relationship established between healthcare professionals and patients (Sahlsten, Larsson, Sjöström, & Plos, 2008). Patient participation requires a focus on the interpersonal relationship between patients and caregivers, demanding that care-giving be performed in a caring atmosphere that enables patients to be met as subjects taking part in the care (Enehaug, 2000). Frank (2010) described participation at an emergency ward as established in patients' encounters with healthcare providers and in care-giving situations and mutual participation was found to occur occasionally and often unexpectedly. This is in line with our results where it seems to be no distinct structure to involve the patient in the care as the healthcare policies and law demands. This suffering caused by care is unnecessary, and it prevents the patient's health processes. However, the delivery of healthcare is influenced by healthcare professionals' values and beliefs. Eriksson and Nâden (2004) describe how values are actualized in communication and encounters, and they refer to our values as guiding principles for caring acts. Healthcare professionals have their specialist expertise, even though the patients are experts on their situation and experiences. The importance of patients' participation and involvement in healthcare must not be neglected; however, these also put demands on healthcare professionals allowing patients to step forward.

The findings in our study on suffering from care when not being listened to or patients having to fight for their rights point to the importance of a more

patient-centred approach to care. Being ill as Toombs (1992) describes leads to questions about the meaning and understanding of illness and changes one's lifeworld. Our study indicates that professional skills and attitudes need to pay attention to the person behind the disease and the patient's experiences. The idea that the values and beliefs of healthcare professionals influence caring encounters is not new; it has been highlighted previously in the literature on nursing. Still, strategies are needed to decrease the unnecessary suffering caused by care. The question pertains to whether strategies for creating participation and not causing increased suffering have been vague. We argue for a care that meets patients' experiences of illness as embodied experiences (Merleau-Ponty, 1945/2002), where all aspects of being a person are included.

Patient-centred care and patient participation have received international focus, as well as in Sweden. Even if patient-centred care has been the focus of healthcare (Dahlberg et al., 2009; Mitchell et al., 2000) and even though healthcare policies in Sweden highlight patients' participation, there seems to be a need for further improvements in today's healthcare. Eriksson (1994) draws attention to the importance of alleviating suffering and not causing increased or unnecessary suffering for the patient. However, experiences of suffering caused by care have been found both in this study and in the earlier research (Arman et al., 2004; Dahlberg, 2002; Öhlen, 2004; Wiklund-Gustin, 2011). The healthcare of today needs to be transformed into a more patient-centred care (Dahlberg et al., 2009), and healthcare providers' attention needs to be more focused on patients' experiences and their needs. Highlighting patients' narratives and listening to patients' experiences and storytelling can be healing (Frank, 1995; Fredriksson & Eriksson, 2001). Do organization requirements need to be increased on how to improve patient participation? There may be a need for more clarity about how to change attitudes and promote caring activities that improve participation and a more patient-centred care. In the future, the suffering from healthcare needs to be decreased. Healthcare today is guided by the conventional positivistic perspective of the biomedical model; our study shows that the care culture adopted by health professionals makes the patients suffer unnecessarily.

The suffering caused from care must be seen as a motive for improvement. The unnecessary suffering pointed to in the *Results* section is a challenge in healthcare, and the responsibility for this suffering can be viewed on different levels. The encounter is fundamental in nursing and caring, and a shift in perspectives is needed to establish patient participa-

tion and a more patient-centred care, while the accountability for improvements rests on those responsible for the organization of health care, on health care professionals, and educators. Questions remain on how to organize healthcare differently from today to reduce suffering caused by care. Nordman, Santavirta, and Eriksson (2008) confirm that suffering from care exists, and they have developed an instrument to assess suffering related to care. The instrument demonstrated a reasonable level of consistency and reliability, and the authors claim that the instrument needs to be further developed in order to be used in healthcare to continuously evaluate the quality of care, thus allowing suffering from care to be revealed. Our study indicates that there are many things to be done to reduce suffering from care. We argue for the importance of changing the prevailing healthcare culture to a more patient-centred and holistic care.

The suffering from care was in this study found to influence the patient's health and well-being as well as future contacts with healthcare providers. In earlier interviews, suffering from care was something that was obvious, and the researchers therefore found it unethical not to explore the phenomenon further. To ensure the analysis and the rigor of the present study, all interviews were re-read. We tried to describe the whole research process and how the analysis was performed. The pros and cons of secondary analysis can be discussed, as there are both strengths and weaknesses with a secondary analysis. In this study, a secondary analysis was performed as it is a method that allows researchers to analyse pre-existing data for the purpose of illuminating new questions (Heaton, 2004). In our study, we found the method to be suitable for the research question, and the phenomenon was possible to illuminate from earlier interviews. We argue that the secondary analysis performed offered an increased opportunity for us to extend earlier empirical work with a new research question. The earlier empirical work used shed light on the meanings of suffering caused by healthcare; accordingly, this paper highlights this suffering with the aim to decrease and make improvements to alleviate suffering from care.

Conclusions and implications for practice

This study shows that the experiences of suffering among patients in Sweden hospital settings are related to healthcare needs, which exist in various forms. It was mainly encountered between caregivers and patients who seemed to cause this suffering even if this suffering might not have been caused deliberately to the patient. Instead of alleviating patients'

suffering, these encounters seemed to increase suffering, which resulted in feelings of powerlessness and feelings of being an object with no rights. This affected the patients' possibilities to participate and take charge in their own health process. Improvements of the care in this setting are therefore needed to lessen this form of unnecessary suffering. New caring strategies are needed that can promote a more patient-centred care, which will increase the patients' involvement of the care for themselves. A more patient-centred care is important to ensure that patients do not suffer from care-giving, and this knowledge must be translated into practice and actions in the delivery of health care. Healthcare professionals may constantly face difficult situations they have to deal with in relation to patients, families, and the healthcare organization. We believe that continuous supervision in group sessions that reflects on patients' stories are meaningful in order to influence attitudes and values and to make healthcare professionals more aware of how these are expressed in caring actions. We strongly believe that the ways to make a real change in attitudes and existing care culture are to be found in healthcare professionals' ability to always give care outgoing from the patients' perspective. Patients' experiences are important for the quality of care, and the patients' views need to be acknowledged in order to reduce and alleviate patients' suffering.

Acknowledgements

The study was conducted with support from the Skaraborg Institute for Research and Development and University of Skövde, Sweden.

Conflict of interest and funding

The authors declare no conflicts of interests with respect to the authorship and/or publications of this article.

References

Arman, M., Rehnfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: A study of breast cancer patients' experiences. *International Journal of Nursing Practice*, 10(6), 248–256.

Berglund, M. (2011). *Att ta rodret i sitt liv—lärande utmaningar vid långvarig sjukdom* [Taking charge of one's life—Challenges for learning in long-term illness]. Växjö, Sweden: Linnaeus University Press, Dissertations. ISBN: 978-91-86491-76-5.

Dahlberg, H., & Dahlberg, K. (2003). To not make definite what is indefinite: A phenomenological analysis of perception and its epistemological consequences in human science research. *The Humanistic Psychologist*, 31(4), 34–50.

Dahlberg, K. (2002). Vårdlidande—det onödiga lidandet [Suffering from care—The unnecessary suffering]. *Vård i Norden*, 22(63), 4–8.

Dahlberg, K. (2011). Health and caring—From a European perspective. *International Journal Qualitative Studies Health and Well-being*, 6, 11458. doi: 10.3402/qhw.v6i4.11458

Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd ed). Lund, Sweden: Studentlitteratur.

Dahlberg, K., & Segesten, K. (2010). *Hälsa och vårdande i teori och praxis* [Health and caring in theory and practice]. Stockholm, Sweden: Natur & Kultur.

Dahlberg, K., Todres, L., & Galvin, K. (2009). Lifeworld-led healthcare is more than patient-led care: An existential view of well-being. *Medicine, Health and Philosophy*, 12, 265–271.

Enehaug, I.H. (2000). Patient participation requires a change of attitude in health care. *International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services*, 13(4–5), 178–181.

Eriksson, K. (1994). *Den lidande människan* [The suffering human being]. Stockholm, Sweden: Liber.

Eriksson, K. (1997). Understanding the world of the patient, the suffering human being: The new clinical paradigm from nursing to caring. *Advanced Practice Nursing Quarterly*, 3(1), 8–13.

Eriksson, K. (2002). Caring science in a new key. *Nursing Science Quarterly*, 15(1), 61–65.

Eriksson, K., & Nåden, D. (2004). Understanding the importance of values and moral attitudes in nursing care in preserving human dignity. *Nursing Science Quarterly*, 17(1), 86–91.

Fagerström, L., Eriksson, K., & Bergbom Engberg, I. (1998). The patient's perceived caring needs as a message of suffering. *Journal of Advanced Nursing*, 28(5), 978–987.

Foss, B., & Nåden, D. (2009). Janice Morse' theory of suffering—A discussion in a caring science perspective. *Nordic Journal of Nursing Research & Clinical Studies/Vård I Norden*, 29(1), 14–18.

Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago, IL: The University of Chicago Press.

Frank, C. (2010). Tillfället gör delaktighet: patienters och vårdarens erfarenheter av patientdelaktighet på akutmottagning: en deskriptiv, metodutvecklande och utvärderande studie [Opportunity makes for participation: Patients' and caregivers' experiences of patient participation at an emergency department: A descriptive, methodological and evaluative study]. Växjö, Sweden: Linnaeus University Press, Dissertations. ISBN 978-91-86491-15-4.

Fredriksson, L., & Eriksson, K. (2001). The patient's narrative of suffering—A path to health? An interpretative research synthesis on narrative understanding. *Scandinavian Journal of Caring Sciences*, 15(1), 3–11.

Gallant, M.H., Beaulieu, M.C., & Carnevale, F.A. (2002). Partnership: An analysis of the concept within the nurse-client relationship. *Journal of Advance Nursing*, 40, 149–157.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology, a modified Husserlian approach*. Pittsburgh, PA: Duquesne University Press.

Heaton, J. (2004). *Reworking qualitative data*. London, GBR: SAGE Publications Inc.

Johansson Sundler, A. (2008). *Mitt hjärta mitt liv: kvinnors osäkra resa mot hälsa efter en hjärtinfarkt* [My heart, my life: Women's uncertain health journey following a myocardial infarction]. Växjö, Sweden: Linnaeus University Press, Dissertations. ISBN: 978-91-7636-633-2.

Johansson, A., & Ekebergh, M. (2006). The meaning of wellbeing and participation in the process of health and care—Women's experiences following a myocardial infarction.

- International Journal of Qualitative Studies on Health and Well-being*, 1(2), 100–108.
- Merleau-Ponty, M. (2002). *Phenomenology of perception* (C. Smith, Trans.). London: Routledge. (Original work published 1945)
- Mitchell, G.J., Closson, T., Coulis, N., Flint, F., & Gray, B. (2000). Patient-focused care and human becoming thought: Connecting the right stuff. *Nursing Science Quarterly*, 13, 216–224.
- Morse, J. (2001). Toward a praxis theory of suffering. *Advances in Nursing Science*, 24(1), 47–59.
- Morse, J., Beres, M., Spiers, J., Mayan, M., & Olson, K. (2003). Identifying signals of suffering by linking verbal and facial cues. *Qualitative Health Research*, 13(8), 1063–1077.
- Nordman, T., Santavirta, N., & Eriksson, K. (2008). Developing an instrument to evaluate suffering related to care. *Scandinavian Journal of Caring Sciences*, 22(4), 608–615.
- Öhlén, J. (2004). Violation of dignity in care-related situations. *Research and Theory for Nursing Practice*, 18(4), 371–385.
- Polkinghorne, D.E. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Sahlsten, M., Larsson, I., Sjöström, B., & Plos, K. (2008). An analysis of the concept of patient participation. *Nursing Forum*, 43, 2–11.
- SFS. (1982:763). *Hälso-och sjukvårdslagen* [The Health and Medical Services Act]. Revised 1998:1659. Stockholm, Sweden: Social Ministry.
- Toombs, K. (1992). *The meaning of illness—A phenomenological account of different perspectives of physician and patient*. Boston, MA: Kluwer Academic Publishers.
- Wiklund-Gustin, L. (2011). To intend to but not being able to: Frequent attenders' experiences of suffering and of their encounter with the health care system. *Journal of Holistic Nursing*, 29(3), 211–220.