

Suffering Related to Care

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Abstract

Introduction: The meaning and objective of caring is to alleviate suffering. In spite of this fact patients sometimes perceive the provided care as a source of suffering. Care that causes suffering has many forms, ranging from all forms of omission or neglecting the patient and ending with (ab)using the caretaker's power, ultimately resulting in threatening patient's life and health and violation of his/her human dignity.

Objective: The aim of this study is to outline the concept of suffering related to nursing care.

Method: A bibliographic survey focused on the phenomenon of suffering related to care.

Results: Suffering related to care (uncaring) arises due to healthcare actions that neglect the holistic and patient-centred approach to care. Inspired by D. J. Riemen, S. Halldorsdottir constructed a theory of caring and uncaring encounters in nursing and health care.

Conclusion: Suffering related to care exists but is not inevitable. Reflection on this phenomenon can contribute to changes in the healthcare personnel's behaviour and attitudes.

Keywords: caring, nursing care, suffering, uncaring

Introduction

Both care and suffering represent important concepts in the nursing theory while especially the concept of care occupies a very significant position in the discourse of nursing and nursing ethics even though its processing and the overall approach to it involve significant difficulties (Drahošová & Jarošová, 2016; Stasková, 2015; Šimek, 2016; Watson, 1999).

Many authors characterize care as a response to suffering (Gastmans, 1999; Smith, 2013), so that suffering tends to be understood as a motive for care (Berglund, Westin, Svanström, & Sundler, 2012; Nordman, Santavirta, & Eriksson, 2008) in its broadest meaning – to care for, take interest in and look after others and see their needs, like another person, sympathize with someone, be empathic and be concerned about another person's health (MacLeod, 2000). In her description of the three different forms of suffering differentiated by their source – illness-related suffering, life-related suffering (existential suffering) and care-related suffering (uncaring), K. Erikson points out that in practice we encounter suffering caused by the care itself although its real meaning is to alleviate suffering (Alligood, 2014). This is mainly the case whenever the caring person fails to fulfil the patient's needs, not only in the biological but mainly in the psycho-social area (Ptáček & Bartůněk, 2014).

Care inflicting suffering may take many forms, starting from all types of omission or neglecting the patient and ending with (ab)using the power by the caring person, not only threatening the patient's life and health but also trampling on his/her human dignity, representing an urgent ethical and professional issue.

Objective

The objective of the present study was to find out how the phenomenon of care-related suffering is reflected in the professional literature.

Methodology

The keywords GOOD (and) BAD NURSING (or) CARING (and) UNCARING NURSING (or) SUFFERING RELATED TO CARE were used to find articles dealing with the related problem area in the CINAHL plus database. The search was limited to articles in the English language with an available full text version. No time limitation was applied. The search yielded 52 articles, of which only 9 were relevant.

Additional articles and studies (including one doctoral thesis) were found using references in these articles, focused on the given problem area (4) and the related concepts and theories (16).

Results

In the 1980's, D. J. Riemen started to dedicate herself to suffering related to care, publishing her phenomenological study focused on patients' testimonies concerning their interaction with nurses in 1986. In the description of caring interaction she identified three groups of topics – **existential presence of the nurse**, who was available to the patient, **patient's uniqueness**, identified by genuine listening, and **results** of individualized care, described as pleasant feelings of comfort and safety. The description of non-caring interaction also involved three groups of topics – nurse's **presence only on physical level** for the absolutely indispensable period of time (or not at all) despite the patient's requests, **misunderstanding patient's uniqueness** (the nurse did not listen and appeared too busy to pay attention to the patient) and **consequences** such as feelings of frustration, fear, depression, anger, concerns and anxiety (Bailey, 2010; Halldorsdottir, 1996).

S. Halldorsdottir resumed D. J. Riemen's work, further developing this theory in her doctoral thesis called *Caring and Uncaring Encounters in Nursing and Health Care*. This doctoral thesis was based upon several studies, predominately focusing on patients' testimonies on their experience of care – both good and bad.

To provide a deeper insight into both kinds of interaction, S. Halldorsdottir uses the metaphor of the bridge and wall. Caring interaction is called bridge building. Such professional care includes three necessary components: **competence, care and relationship**, where competence involves professional knowledge and skills, care involves openness and responsiveness towards others, true interest in the patient, moral responsibility, true (existential) presence, dedication and courage to be engaged in an appropriate manner. Relationship is characterized by mutual respect and may be understood as a certain highly specific kind of friendship, combining closeness and distance at the same time. Contrariwise, non-caring interaction is described as wall building and involves **incompetence, indifference, distrust and mutual avoidance**. Indifference takes the form of lack of interest, unfeeling attitude, coldness and inhumanity (Halldorsdottir, 1996; Halldorsdottir & Hamrin, 1997; Wiman & Wikblad, 2004).

Also Björkdahl, Palmstierna, and Hansebo (2010) tend to use metaphors to better explain the results of their research, focused on the nurses' attitudes to patients in the environment of psychiatric intensive care. Nurses' testimonies revealed two different attitudes – one called by

the authors “ballerina attitude” and the other called “bulldozer attitude”. The ballerina attitude involved nurse’s sensible and helpful behaviour, aiming to create trust and to provide care. The same nurses, however, sometimes applied force and pressure to secure safety and order at the ward. This attitude was called by the authors “bulldozer attitude”. In this case, the patient becomes an object that can be dominated by the nurse-bulldozer anytime. The authors refer to S. Halldorsdottir’s theory as it was easy for them to identify the ballerina attitude as caring attitude, but it was less easy to identify the bulldozer attitude as uncaring interaction because the nurses were convinced that they acted in the patient’s best interest (applying force was understood as a valuable lesson for the patient) and their attitude (however paternalistic) often contained certain caring potential.

But this attitude also builds a wall between the nurse and the patient and, to say the least, leads to patients dehumanization – nurses are not concerned with the patient as a unique being but turn their attention to rules for securing good order at the ward. The environment of intensive psychiatric care is highly specific but a similar nurses’ attitude can be found anywhere.

The authors identified studies that were focused on the experience of patients after stroke (Widar, Ek, & Ahlström, 2007), patients with oncological diseases (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Halldorsdottir & Hamrin, 1997), patients on surgical wards (Mako, Svanäng, & Bjerså, 2016), patients with chronic or life-threatening diseases (Berglund et al., 2012) and women in labour (Eliasson, Kainz, von Post, & Högskolan, 2008). The study by E. Wiman and K. Wikblad (2004) was organized in a completely different manner, as it focused on nurses’ behaviour towards patients during their treatment in the emergency department. Situations were recorded and then analysed.

All these studies describe uncaring interactions reported by patients (or in the latter study by researchers) and point out the negative consequences of such interaction. Suffering related to care involved an omission of the holistic attitude and occurred when the patient was not in the centre of the caretakers’ interest, when the patient’s autonomy was trampled on and his perception of the illness was disregarded but also when patient and his description of difficulties were paid insufficient attention to, resulting in neglect in care. The above-mentioned consequences include not “only” feelings that negatively affect the health condition and course of treatment but also an impact on the patients’ future contact with healthcare personnel and, last but not least, neglect in care resulting in patient’s death were reported (Berglund et al., 2012; Halldorsdottir & Hamrin, 1997).

Discussion

Suffering related to uncaring is receiving attention especially in North European countries, following the works by D. J. Riemen, S. Halldorsdottir and K. Eriksson. While trying to bring this concept closer to our environment, we faced multiple issues. The first one was to find adequate expressions for important words so as to cover all levels of the meaning. As an example we can state the multiple levels of meaning of the word CARE that cannot be covered all by one single Czech expression to make obvious that it is not only care in a limited sense but also stands for interest and sympathy. This was reflected also in difficulties while searching for various articles and studies concerning the problem area. The original plan was to search for articles and studies written in English in ProQuest and EBSCO databases and to use the Google search engine using keywords CAR*, UNCAR*, GOOD,

BAD, NURS*, SUFFER* but the search in the ProQuest database alone yielded more than 170,000 results with no possibility to effectively filter them.

No less important is the issue of overreaching impact and mutual complementarity of the various concepts tightly related to the subjective problem area, such as *compassion* (see a review article by Bradshaw, 2011), *presence* (see a review article by S. Bozdogan Yeşilot and F. Öz, 2016), *caring relationship* (e.g. Gastmans, 1999, 2002), the understanding of which is vital for the reflection of the demands made by D. J. Riemen and S. Halldorsdottir on (nursing) care.

All these concepts point to the fact that the basis of care (not only in nursing) is a caring relationship, meaning reciprocity (Gastmans, 2002) and true presence, a “Me and You” relationship, not a “Me and It” relationship (It develops when efforts enabling to enter the relationship are weakened) to use the words of M. Buber (2005). In his understanding of relationships, E. Lévinas goes a lot further than M. Buber as he places the other person above freedom. According to Lévinas, a free person is betrothed to and responsible for another person, meaning that a helpless person must not be abandoned (Arman, 2007). M. Buber’s reciprocity is not mentioned by Lévinas, so that his idea of relationship is a lot closer to that of our concept of professional relationship.

This is exactly how we can understand a nurse’s presence more than only on physical level – the “Me and You” level, not the “Me and It” level. The absence of such presence can then be understood as uncaring attitude (Rehnsfeldt & Eriksson, 2004; Stasková, 2015). Referring to M. Heidegger, Šimek (2016) classifies care as a meaningful component of our existence while pointing out two principally differing methods of caring for another person, perceivable in Heidegger’s *Being and Time* – in the one we control another person and make them dependent, in the other one we develop their own abilities to care. Exactly these two different methods of care are reflected in the research by A. Björkdahl et al. (2010).

Most researches focused on suffering due to care deal with specific behaviours that can be classified as uncaring interaction. Quirk, Mazor, Haley, Philbin, Fischer, Sullivan, and Hatem (2008) however point out that in abstract meaning, there exists a group of behaviours representing (un)caring but the assessment whether or not an interaction is caring or uncaring consists “in the observer’s eye” and rather depends on the caretaker’s hidden abilities than on the specific behaviour. A certain behaviour may appear both caring and uncaring.

Researches concerning suffering related to care typically take the form of qualitative studies, which makes it important to pay attention to the effort by Nordmann et al. (2008) to create a standardized tool. Last but not least, attention must be paid also to the reasons for neglecting patients. It may be due to tiredness, exhaustion, overwork or insufficient motivation (Ptáček & Bartůněk, 2014) Distant attitude is also caused by phenomena mentioned in the literature as *moral distress* and *compassion fatigue* (Sabo, 2006).

Reflecting on the fact that something like this may and does occur and considering the causes of the phenomenon, we can also find a way to improvement.

Conclusion

Suffering related to care represents an acute ethical issue because human dignity is being trampled on and patients’ lives and health are being threatened. It occurs when the patient, as a unique human being, no longer represents the meaning and aim of care. However, such

suffering is not indispensable. Reflection on this phenomenon may lead us to a change in attitude.

Ethical aspects and conflict of interest

Authors declare that they are not aware of any conflict of interest concerning the present study.

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