

Caring relationship: the core component of patients' rights practice as experienced by patients and their companions

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Abstract

The aim of this article is to describe how Iranian patients and their companions explain their lived experiences with caring relationships in a central teaching hospital in Tehran, Iran.

Despite a large number of theoretical articles on this topic, the meaning of caring is still ambiguous, particularly in specific cultures. In Iran, there is not enough qualitative evidence on this topic to indicate what patients actually mean when they refer to caring relationship. This article explores how Iranian patients and their companions perceive and describe caring relationships as an element of patients' rights practice.

This is part of a phenomenological research on patients' rights practice in Iran conducted during 2003-2006. Semi-structured interviews were conducted with 16 patients/companions, and van Mannen's approach was used for thematic analysis.

The ethics committee of Tehran University of Medical Sciences approved the study.

Patient-centered care, compassion, effective communication, support/advocacy, informed participation and meeting patients' basic needs were found to be the key elements in defining caring relationships. These themes were all described as elements of patients' rights practice issues.

The results indicated that it is necessary for care givers/nurses to understand the person who will receive care in order to provide zealous and authentic care, because feeling "to be cared for" is even more important than providing the "care" itself.

Keywords: Caring relationship, Lived experiences, Patient's companion, Patients' rights.

Introduction

"Caring is not unique to nursing, but is unique in nursing. Caring is something done with people,

for people, to people and as people and this is what makes it unique" (1). "Caring is considered to be a

universal and culturally derived phenomenon (2, 3).”It has mostly been seen as a nursing term, including all aspects of delivering nursing care to patients (4). Despite a large number of theoretical papers (5, 6) and some impressive literature reviews (7-11), the meaning of caring is still ambiguous because of its complex nature.

Some nursing theories believe that caring is the essence of nursing practice (12-16). According to Nightingale, it is one of the most familiar nursing roles and the most important work in nursing (17). Boff states that originally providing care to a person in a situation of disease reveals the meaning of the existence of nursing itself. The care provided to these patients’ beings maintains nursing as a profession. By giving care, nursing creates and re-creates the culture of care itself, which is essentially ethical.

Caring is more than an act, it is an attitude. Therefore, it covers more than a moment of attention, zeal and unveiling. It represents an attitude of occupation, concern, responsibility and affective involvement with the other (18).

Since the 1990s, a considerable amount of research has been conducted dedicated to explaining what caring practices are from the nurses’ perspective (19-21). However, in studying caring issues, exploring the patients’ perception of the concept is as important as exploring the nurses’ views. It is necessary to understand the person who will receive care in order to provide zealous and authentic care. This requires the caregiver to carefully research the existential experience of the being who needs care (18).

Many studies used qualitative approaches to investigate nurses’ perceptions of what constitutes ‘caring for patients’ and patients’ perceptions of what is important in making them feel cared for (8, 9, 22-24). Despite an increasing focus on patients’ rights by Iranian researchers and policy-makers (25-28), there is not enough evidence that the concept of caring is discussed and understood in Iran.

In an extensive phenomenological study by Joolae et al. in 2006 in Iran, caring relationship was found to be one of the sub-themes of patients’ rights practice (29). The aim of this article is to describe how Iranian patients and their companions (each patient is expected to have a ‘companion’ constantly at the bedside) perceive and describe their lived experiences with caring relationships as a component of patients’ rights practice. This may help to highlight probable similarities and differences between Iranian /Muslim patients and patients of other cultures in a multi-cultural era.

Method

This is part of a phenomenological study of patients and their companions’ lived experiences

with patients’ rights, which was conducted as the first author’s PhD dissertation during 2003-2006 in Tehran, Iran.

Purposeful sampling method was used and semi-structured interviews were conducted with patients and their companions in a central teaching hospital in Tehran. The interviews were continued until data saturation (16 interviews were conducted). Each interview lasted an average of 30-60 minutes and was done by the first author in a time and place appropriate for the participants (mainly in their bedside or the hospital’s yard).

The main research question was “what is the meaning of patients’ rights for the patients and their companions?” and since “caring relationship” was one of the captured themes, participants were asked to talk about caring relationship and their experience with the feeling of being cared for, during their hospitalization. More specific questions such as “when do you feel that a nurse is caring for you?” and “would you please explain a situation in which you felt non-caring behaviors of a nurse?” They were also asked to focus on the specific behaviors of nurses that could make them to feel they have or have not been cared for. The interviews were tape-recorded and transcribed verbatim for further analyzing.

van Mannen’s holistic and selective thematic analysis was utilized to analyze the transcripts. van Mannen stated that ‘the purpose of phenomenological reflection is to try to grasp the essential meaning of something. This process is considered a thoughtful attempt to discover, or reach the essence of the phenomenon. To follow van Mannen’s approach, the researchers read and re-read the transcribed interviews to achieve a holistic meaning of what participants stated. This is called “holistic thematic reflection” (30). The next stage was reading the texts, line by line and highlighting the meaningful parts to capture the essence of the lived experience. The researchers then returned to the whole meaning they captured and this cycle was repeated constantly during data gathering and analyzing.

This final step of hermeneutic phenomenology requires ‘creating a state of homogeneity between the research sections by considering the whole and relevant parts’ (31). This process of continuous attempt to create a balance and congruence among research units by moving from the whole to the parts and *vice versa* makes the themes meaningful as they gradually emerge until no new themes can be captured.

To ensure trustworthiness of the data, the transcribed texts were analyzed by the research team to achieve consensus on each theme and then these were returned to some participants for confirming or revising. Some slices of texts were also given to external readers to see whether the process of analysis makes sense or needs more

clarification. Revisions in each stage of data analysis were carried out by the research team.

Ethical Considerations

Study was approved was by the ethics committee of Tehran University of Medical Sciences. Participants were fully informed about the study purpose and oral informed consent was obtained for participation. They were also assured regarding anonymity and their right to withdraw from the study at any time without recrimination.

Results

In the context of nursing, caring involves a personal relationship. The interpersonal process of caring is based on an exchange of energy and information between the one providing care and the one being cared for (32). In this research, a caring relationship (as one of the elements of patients' rights practice) was perceived by patients and their companions as: receiving comprehensive patient-centered care together with compassion, support, and effective communication by health care providers; it was also seen as involving them in their care process and meeting their basic needs (Table 1)

Patient-Centered Care

The participants reported a negative experience as a feeling of being treated as an object. They indicated that they need to feel a whole person and at the centre of the activities undertaken by the care providers, rather than merely as an entry on their task list. [*Nobody sees you...but rather they see your illness, your body, your wound, your cannula...; you are nothing more than the sum of your parts...*] stated a participant while his companion declared [*the one being forgotten is the patient...; everyone is just trying to finish his/her tasks and does nothing more!*]

Compassion

The need to sense that someone understands and cares about them was an important subtheme of a caring relationship from the patients' perspective. A lack of such a compassionate approach was a source of distress and anguish. [*... She was giving me an IV injection, I was experiencing great pain, but she was still carrying on, she didn't even glance at me to see my pain. I don't know if she couldn't see my agony or was pretending not to see it*]. In sharp contrast, another patient referred to a positive experience that had made a lasting impact. [*One of the junior doctors, who realized none of my family and friends was available to buy my medications,*

took my prescription and brought in the medications the following morning. I shall never forget his understanding and kindness. I was really impressed by his caring manner....]

Effective Communication

Effective communication was found to be an important element of caring relationships. The participants indicated that good communication is sometimes more significant than the physical care they receive.

Nurses were perceived as being very busy people, without time to talk to patients. One patient stated that: [*talking with and listening to patients is not always time consuming if they want to see us...*]; and an elderly participant said: [*...she (the nurse) didn't even look at me...; I tried to look at her eyes...; I needed just a short eye contact. I wanted to say hello..., to thank her for all she was doing..., but she didn't look at me. Instead, she looked carefully after my IV and did something for it...; I, as a person, was not as important as any problems that my IV might present. She needed no more time to look at me than checking my IV line*]. A patient's companion, helping his father to get out of bed, stated: [*Sometimes, patients are just looking for a facial expression for feeling to be seen... or to be cared for; ...sometimes, they need a moment of silence to feel they have been heard...and, when this occurs, there is a sense of being cared for, a caring relationship is established.*]

Another participant with a language problem (from Azarbaijan, speaking Azari), explained how the nurse who admitted him to the ward tried to find another Azari nurse to facilitate communicating with him: [*I was so depressed. I could not clearly explain to them what I was suffering from. She (the nurse) was so alert. She didn't understand my language but tried to prepare my needs and requirements, and contacted the supervisor and asked for help from an Azari nurse. I couldn't believe this could be happening to me. My happiness didn't last long, though, because the nurse on the next shift was only concerned with the technical routines and not my feelings, and when I asked for an Azari nurse, she explained with her hands and face that there is no need for this as the tasks could be done without any need for words!*]

Support/Advocacy

Entering any health care delivery system makes patients and their families face a world of unknown events. Participants frequently stated that dealing with this perplexity and bureaucratic maze was not less vexing than their main health problem. A young woman explained this helplessness as follows: [*I couldn't understand the situation; I was admitted in this ward without being informed about*

what was going to happen...; the nurses asked my husband to leave the ward and I didn't know that just a minute later I would need a lot of things to do with the nursing or medical procedures planned. I really felt lost and there was nobody to support me in that situation of helplessness.]

However, a 76-years old man explained his positive experience regarding some nurses' behavior: *[they are God's hands...; when you are most helpless they are here to support you... to make you feel that someone is taking care of you... and this is on top of all the other things they have to do (with his eyes he pointed to the nurses moving around).]*

Informed Participation

Usually people do what health care professionals ask of them during illness and hospitalization. This stance, typical of traditional paternalism is dominant in many health care delivery systems, leaves patients unaware of what is going on, and unable to be involved in decision making regarding their health problems. One patient's companion expressed this as *unbelievable ignorance throughout the whole system*. She explained how the staff took her father for colostomy surgery without informing them about the detailed diagnosis, prognosis and alternative possibilities. She expressed with anger that: *[I couldn't believe what happened to my father. How could they do this without previous discussion? How can he now adapt with this (she referred to the colostomy bag on her father's abdomen) to the end of his life?]*. Another young man who was confused about his physician's behavior in not informing him about his diagnostic surgery and letting him suffer from pain and using self-prescribed sedatives for a long time, complained: *[I have been in pain for a long time taking sedatives. Nobody explained to me that I should have diagnostic surgery before any other pain management is decided. I had taken a lot of pain killers during this time and I didn't know how dangerous this could be for me.]*. All these behaviors make for a sense of mistrust between patients and care providers and make for feeling not being cared for.

Meeting patients' basic needs

Patients suggested that they expected caregivers to understand and satisfy their basic needs even without their request. They believed that meeting these basic needs is an important part of a caring job. One elderly male participant stated: *[I am ashamed to ask help with changing my position frequently. I wish I could do this myself, but unfortunately, I can't...; I wish someone could understand how difficult it is for me to ask for help and could help me without asking.]*. He continued after pointing to his full urine bag: *[I'm really sorry*

that, sometimes, I'm not seen as a person who needs to be helped in meeting very simple basic needs.] A man with a plaster on his fractured arm and an intravenous catheter in his other hand explained what an acrobatic and difficult procedure the eating could be, with both hands limited in function, and how nice it would be to feel that someone might help him with this simple act. *[I cannot do even basic things such as eating and personal hygiene. I feel somebody should see this....]*

Discussion

The findings of this study revealed some very important insights into the way that Iranian patients and their companions perceive the interpersonal caring relationship with health professionals. These findings coincide with other studies investigating caring in nursing and highlight how both physical and emotional aspects are essentials of caring. The participants frequently emphasized real or genuine care when explaining their experiences, indicating that they expected something beyond routine tasks that were labeled 'care'. They want to say that the word 'caring' has been misused and to demonstrate what it 'should really be'; more reflection is necessary both by the professionals engaged in providing and those who are receiving this care.

Nursing and caring are closely linked in the literature (33) and, sometimes, uncaring behaviors of a nurse may still be called 'caring'. This should make us as nurses to use this term with caution and accuracy. Because the process in which nurses demonstrate authentic caring is an intentional interactive communication that conveys physical care as well as emotional concerns and promotes a sense of security in another (23).

In this study, the participants' perception of receiving information and support in an effective communication supports the debate led by Kitson who believed the aims of caring in nursing is meeting patients' informational, emotional and physical needs and for nurses to have appropriate knowledge, attitudes and skills to meet these needs.

The caring relationship described by Iranian patients and their companions is confirmed by the findings of nurse researchers in Hong Kong and Thailand who, by referring to patient-centered care as an important aspect of caring, explained this term as 'treating each patient as an individual who has his/her own needs'. This is also supported by Mc Cane et al, who found that patients believe that caring should be provided in a person-centered way. Other researchers emphasized the importance of families in helping patients to be cared for (34-36). Given the Iranian families' cultural attachment, we can justify our decision to interview both

patients and patients' companions regarding this issue.

A significant divergence of perceptions between patients and nurses regarding the priority of caring aspects is reported in Basset's findings in which the most highly valued aspect of care for nurses was creating a strong relationship with patients, whereas patients valued a high level of competency and skills in nurses (37). The incongruence between nurses and patients' perceptions of caring is also evident in this study. They found that professional competence and interpersonal skills as the main focus of nurses, but for patients, being involved in care and decision making were more important aspects of caring relationship (38). This differs from our findings, in which participants (both patients and their companions) showed great concern regarding nurses' attention and emotional support above skillful task performance. Basset claimed that, in reality, patients are unlikely to say that they are not concerned about their relationship with nurses. They would clearly want both aspects of care, as even the most skilled and competent nurses could not deliver care properly without the ability to comfort, and create strong relationship with, patients and their families (37).

Participants in this study explained how they were in constant need of communication with nurses and exchanging information in a friendly climate. Their need for eye contact, being seen or listened to, and receiving verbal and nonverbal caring signs is supported by many study findings that suggest patients and family members' intention and desire to share personal thoughts and feelings in an open and honest manner (39-42). These can sometimes be demonstrated by simple gestures such as attentive listening (33), making eye contact (15, 43), touching (35), and offering verbal reassurance (10, 35). Henderson et al. suggests that nurses should discuss with patients about appropriate times when they can interact with them, learn about their specific needs and inform them about the long-term management of their conditions. This could potentially contribute in trust and connection between patients and nurses (44).

Our participants revealed that they wish their basic needs to be seen and met by nurses. They explained that they are not comfortable to make frequent requests and prefer to be understood by the nurses spontaneously. This perhaps seems unrealistic in Western culture, in which a logical reciprocity is expected. However, special attention to a sick person is part of the Iranian Muslim culture in which this study was conducted. Cortis showed similar findings regarding caring expecta-

tions by Muslim Pakistani patients living in the UK. Those patients experienced incongruence between their expectations and the care received by nurses because of cultural differences that had not been taken into account (47).

Tschudin argued that caring is a response to someone who matters, simply because the person is there (1). We respond to each person and situation differently but, in order to be truly human, we need to respond. This response requires a comprehensive attention to patients and their context.

According to the first researcher's experience as a nurse and nursing educator, Iranian patients trust health professionals implicitly and do not like to complain. As shown in this study, they have clear expectations of being cared for what, in most cases, are not even verbally expressed. This indicates that nurses should be more sensitive to unexpressed needs of patients. It means that they should not wait for patients' request for care. However, this may seem not to be congruent with principles of medical ethics, in nurse-patients relationships, in which nurses are expected to be present whenever vulnerability is exposed, a simple human response is more frequently demanded than a technical or scientific approach (1).

Regarding the negative experiences of patients and their companions during hospitalization, the unexpressed considerations of them is one of our study's limitations. The other was related to the nature of the qualitative approaches. This was also a relatively small study in just one health care facility and the findings can not be generalized.

Conclusion

Caring is a mixture of physical and emotional attentive communication, which patients and their companions expect from health professionals particularly nurses. The study also revealed that the Iranian patients, sometimes, prefer their needs to be seen and heard by health professionals without asking. These types of unexpressed needs or feelings are familiar in Eastern cultures, but might be ambiguous in some Western, more 'rational', societies.

If nurses are to provide authentic care for patients, it is necessary for them to understand the person who will receive the care, because the feeling of "being cared for" is even more important than being "care-provided".

Nurses are expected to consider their clients as individuals and provide patient-centered care as one of the quality assurance indicators for caring.

Table 1. The captured themes

The main theme	Sub themes
Caring relationship	Receiving comprehensive patient-centered care
(as one of the elements of patients' rights practice)	Compassion
	Effective communication
	Support/advocacy
	Informed participation

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