Disciplined Care for Disciplined Patients

Experience of Hospitalized Blind Patients

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Blindness is a permanent condition that alters daily life of blind people. Interpretive phenomenology was used to understand lived experiences of the hospitalized blind people. "Disciplined care for disciplined patients" was one of the themes that emerged from the data. Provision of disciplined care can help health care professionals provide a holistic and comprehensive competent care for blind patients. **KEY WORDS:** *blind people, disciplined care, disciplined people, lived experience* *Holist Nurs Pract* 2013;27(6):344–348

While visual sensation is the primary means by which human beings understand the world,[1] visual impairment is one of the common causes of disability around the world.[2,3] There is no doubt about the importance of eyesight in daily life among people. In many societies, people acknowledge eyesight as the best gift of God to human beings.[4,5] According to a report of the World Health Organization, "Every five seconds one person in the world goes blind. One child goes blind every minute."[6] In 2010, the World Health Organization announced that there are about 285 million visually impaired people (39 million blind and 246 million low vision) worldwide[7] and estimated that the number of people with visual impairment would double by the mid-2020s.[2] Approximately 90% of visually impaired people live in developing countries.[8] In Iran, there are no national statistical data on the prevalence of blindness and low vision. On the basis of studies conducted in some provinces in Iran, the prevalence of bilateral blindness is 1.09% in an urban population of Tehran[9] and 1.3% in Khuzestan Province.[10]

Basically, blindness is the inability to see. According to the World Health Organization, *blindness* is defined as "visual acuity of less than 3/60, or corresponding visual field loss to less than 10 degrees in the better eye with best possible correction."[11] Although blindness is usually preventable, it affects many people around the world. Vision impairment changes the daily life style of the affected people,[12] as it is associated with falls risk, injury due to falling, decrease in health-related quality of life, mortality risk, less social activity,[13,14] and difficulty performing most of vision-related daily tasks.[15,16]

Blind people are hospitalized for different health issues. Nurses and other health care professionals who provide care for this group of patients need to have better understanding of patients' need and expectations.[17] Nurses are the first-line practitioners for caring of patients, and they spend considerable time with them.[18] Although nurses try to provide a holistic care for every patient in hospitals and in the communities,[19] caring for blind patients usually is not the same as caring for sighted people.[17,20] In addition, a review in the medical and nursing literature reveals that there is limited knowledge in terms of caring of

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This article is based on PhD dissertation of the first author. The research has been accomplished in the Faculty of Nursing and Midwifery, Tehran University of Medical Sciences.

We are thankful to the participants who shared their lived experience with us. In addition, we thank Tehran University of Medical Sciences for financial support of the research project.

The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

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DOI: 10.1097/HNP.0b013e3182a72bcd

this specific group of patients and their diverse needs.[2,17] Understanding the lived experience of blind people helps nurses expand their knowledge regarding blind patients to provide a holistic care and improve the quality of care for blind patients.[17,21] This article aims to describe one of the themes that emerged from the lived experience of blind patients in the hospital.

METHODS

This article is a part of an interpretive phenomenological inquiry. While the interpretive phenomenology played an umbrella-like role in the overall purpose of the study, the 6 methodical activities that were introduced by van Manen[22] (Table) helped the researchers to conduct the study.

Participants and setting

Participants were recruited to this study by a purposeful sampling method, from January 2011 to February 2013, in a general teaching hospital in Tehran. The sampling process took a long time because of the small number of blind inpatients. To recruit informed participants, the admission staff in the hospital were asked to inform the researchers when blind patients were hospitalized. Potential participants were assessed by the researchers for their eligibility in an introductory meeting. They were fully informed about the research purpose and invited to participate in the study in the introductory session. They were allowed enough time to make decision for their participation.

Finally, 10 adult patients with total blindness were recruited to the study. There were 6 male and four female participants, aged 28 to 60 years, with a mean age of 48.50 years. According to the medical documents, 3 participants were congenitally blind and 7 of them became blind during the childhood. All participants spoke Persian language, and they lived within the geographical border of Tehran. On the basis of participants' self-report, they had a normal hearing ability without any severe disturbing physical or psychological problems, which may affect their daily lived experience. The reasons of their admission were as follows: diabetes (n = 3), hypertension (n = 2), ischemic heart disease (2), renal failure (n = 1), and orthopedic surgery (n = 2).

Data collection

Data were collected through in-depth semistructured interviews with participants, and the length of interview sessions ranged from 45 to 70 minutes. Interview sessions were organized to collect the data in a quiet room in the ward. The commencing question was "Would you please talk a little bit about your daily activities in the hospital?" Dialogical interviews were conducted, with special concentration on activities of daily in the caring environment. All interviews were recorded on audiotape in a MP3 file format. The files were transcribed to the plain text verbatim. The first author (the interviewer) was engaged in the process of thematic reflection.

Data analysis

The data analysis process was guided by 6 interplay activities introduced by van Manen.[22] In fact, data

TABLE. van Manen's Method of Doing Phenomenological Study and Its Use in the Current Study

Six Methodical Activities Proposed by van Manen[22]	The Researcher's Activities in the Current Study
Turning to the nature of lived experience	Thinking and sensitizing on blind patients and formulating the phenomenological question: How the caring environment is experienced by blind people?
Investigating experience as we live it	Thinking on preunderstandings, prolonged engagement with blind patients, conducting in-depth interviews
Reflecting on essential themes	Listening the audios, reading the transcripts, immersing in the data, and conducting thematic analysis
Hermeneutic phenomenological writing	Writing the transcripts, writing about themes, and writing to create a phenomenological text
Maintaining a strong and oriented nursing relation to the phenomenon	Discussing the themes in relation to caring science
Balancing the research context by considering parts and whole	Moving between transcripts and themes in relation to caring environment

analysis commenced from preliminary engagement with the participants and continued throughout the study. However, the formal data analysis process used thematic analysis to obtain emerged themes inherent in the data. Themes are structural meaning units of data or meaning of the lived experience of participants.[23] All transcripts were read by the first author at least twice to make a phenomenological connection with the data and to ensure that there was no mistake in the transcripts. To manage these transcripts, the text files were imported to the MAXQDA program, the professional software for qualitative data analysis. The authors used all detailed, selective, and holistic strategies proposed by van Manen[22] to isolate themes. Through these strategies, the fundamental meanings of the words, sentences, and whole of conversational text were stated in thematic expressions. The main themes and subthemes were discussed in relation to the transcripts and other subthemes. During discussion on the themes and subthemes by the research group, some of the subthemes were modified or restated.

Rigor

Context-based validity or trustworthiness is an integral part of conducting qualitative research.[24] Strategies that helped the researchers to improve the quality of research include in-depth interviewing, constant review of the records, data immersion, collaborating data analysis, writing reflectively, turning to the research question at any point of the study, and attempt to generate a rich description of the phenomenon.[22,23] Besides the main theme and its structure explained for 3 of the participants, they confirmed that these appropriately reflected their experience.[25]

Ethical considerations

Ethical approval was obtained from the Ethics Committee of the Research Deputy in Tehran University of Medical Sciences. Participants were fully informed about the study purpose prior to the data collection. They were assured that the study would not influence their care process. To protect participants and anonymity, a pseudo name was used for each participant in the report of findings. A written informed consent form in Braille was signed by each participant before the interviews.

FINDINGS

"Disciplined care for disciplined patients" was one of the main themes that emerged from the dialogues of blind patients about their daily life in the hospital. Almost all of the participants called themselves as disciplined people. The theme "disciplined care for disciplined patients" emerged from 5 subthemes, including discipline through careful touching and listening, discipline as the ideal way of existence, discipline the preferred way of being independent, desire to take disciplined and detailed care, and reactions to the undisciplined caring culture.

Discipline through careful touching and listening

Careful touching and complete listening were the primary structures discerned from the conversation of blind people in the hospital. Blind patients use these alternatives to manage the environment in daily life. Nazila, a 28-year-old female patient, said:

> When I want to walk in my room [in the hospital], I am sliding my legs on the floor to see the footpath and make sure the footpath is clear. Then I remember the detail which is on the footpath. So it is not difficult for me to walk in the room.

Davood, a 60-years-old man who was admitted for the treatment of ischemic heart disease, said: "I see through touching . . . in fact, my touch is my eyes." Ali, a 36-year-old patient, said: "I can touch the objects around me while I am hearing all little events around me, Thank God I am not deaf!"

Discipline as the ideal way of existence

One emphasized meaning in the blind people's stories in the hospital was that being disciplined is an indispensable part of their life. The participants believed that discipline not only helps them adapt themselves in daily activities but also is the best way to help them feel their life is going like others. Being a disciplined person for most of the participants was not a selective experience. They believed that discipline is necessary when people see their surrounding through touching and hearing. Abdollah, a 52-year-old man who was admitted for the treatment of hypertension, said in this relation:

> You know I've lost my sight, I have to be disciplined. I am not same as other patients in this room; I have no other way to organize myself . . . . Just being disciplined can help me to be sure that everything is in its right place.

Another participant said in the interview: "I try to keep my room organized and tidy. If anybody pick up any object must turn it to its place . . . . If they [nurses] put everything in its own place, I can find it easily."

Discipline the preferred way of being independent

Participants believed that they were not persons with a disability. Participants liked to be independent patients, and discipline was the best way for them to be independent. For example, the following statement was taken from one of the participants. He pointed out: ". . . discipline . . . discipline [participant pause] . . . . Thank God, I am independent because everything in my life is based on discipline." For the participants, discipline helped them to be independent in their everyday life. Reza, a 55-year-old patient said: "I liked that my personal stuffs to be in a convenience and easy access place in my room, I don't need other people help to find my stuffs when I put everything in its own place."

Desire to take disciplined and detailed care

The participants expressed that discipline was not enough to be considered by them to make them independent, but individuals who work with visually impaired people should be disciplined. Enayat, a 55-year-old man who was admitted for the treatment of ischemic heart disease, said:

> One of the important priorities here [hospital] should be discipline. . . . they [hospital staffs] have to be disciplined. I expect my nurses, physicians, my family and anybody who are with me to be well organized. For example, yesterday my nurse cluttered my commode and it was difficult for me to find my clothes and medical documents. . . . nurses and other hospital staffs should consider that I cannot see!

Not only participants expected health care professionals to consider disciplined care but also almost all of them had experience of undisciplined caring among the staff. In fact, blind people need a reciprocal discipline in the caring relationship. As a typical example, Jasmine, a 42-year-old female patient who was admitted for treatment of diabetes, said: "I asked her [the nurse] where is toilet? She said it is over there. She didn't consider that I can't see."

Reactions to the undisciplined caring culture

Participants mentioned various reactions to the undisciplined caring culture, which could be classified into 2 main meaning units: worries about inappropriate caring culture and relating undisciplined caring culture to their blindness. Zahra, a 52-year-old patient, expressed: "Yesterday, I couldn't find my toothbrush and toothpaste in the place that I put them. It made me stressful and angry." In this regard, Abdollah said: "When the environment is cluttered, I am apt to be restless and anxious."

Some of participants relate the inappropriate and undisciplined caring culture to their disability (blindness). In other words, participants thought that the inappropriate caring by health care professionals originates in their disability. Nazila said: "I am not seeing so I must adapt myself by the situation. It is my problem any way!"

DISCUSSION

This study explored the structural meaning of discipline in daily life of the hospitalized blind people. The main theme extracted from the lived experience of blind patients was "disciplined care for disciplined patients." The study discerned that blind patients are disciplined people who prefer to have disciplined caring culture. This caring culture helps them to be independent during their hospitalization. The study uncovered that being disciplined primarily is attained through careful touching and listening. Likewise, almost all of the participants believed that they prefer to be disciplined and to be cared in a disciplined and detailed manner.

Visual sense is vitally important for daily life and object identification.[26] In this study, everyday experience of blind hospitalized people showed that they try to keep the surroundings disciplined. For participants, discipline predominantly comes from the primary ways of understanding the world. In fact, blind people use steady and careful touching and hearing to manage the physical obstacles in the environment. This findings are congruent with the study of Kells,[26] who found that blind people use slow movement, making a noise to detect obstacles in the unfamiliar environment. When blind patients come to the hospital, they are not familiar with the new situation and they start to understand the new situation with new obstacles and new people. In this situation, nurses play an important role to help these patients shape their new embodied world.

For the participants, being disciplined helps them to be more independent as well as help them to

understand the embodied world. This supporting link between disciplined caring culture and interdependence is a valuable principle in caring of visually impaired patients. As one of the participants pointed out: "I do my duties by myself if I get enough awareness to the surroundings. For an ideal awareness, I need an organized environment."

Blind people like to have a detailed and disciplined care. They prefer nurses who spend enough time in caring communications and provide full information about nursing implementations. The findings showed that present caring culture is not appropriate for blind patients and indirectly indicates that nurses and other health care professionals are not fully aware of blind people. While understanding of patients and their expectation of health care received is highlighted in caring discipline,[27] the lived experience of blind patients show that they do not receive a disciplined care that they are expecting. This is consistent with the findings of Sharts-Hopko and her colleagues[17] about health care experiences of visually impaired people.

CONCLUSION

Phenomenological inquiry of blind patients' experiences in the hospital revealed that they commonly are disciplined people and want to be cared in a well-organized and disciplined caring environment. Furthermore, they need to be familiar with the new caring environment. A well-disciplined and familiar environment helps blind patients to increase their level of independence. In addition, blind patients prefer a detailed, informed, and disciplined caring culture. Health care professionals should consider the concept of disciplined care to provide a holistic and comprehensive competent care for blind patients.

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