The Lived Experience of Iranian Caregivers of Comatose Patients

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Abstract: It was to examine the lived experience of caregivers of comatose patients. Van Manen's conception of hermeneutic phenomenology with convenience or purposeful sampling of nurses and family members of teaching hospitals was used in Tehran in 2011. The data were collected through interviews. The gathered data were analyzed using Van Manen's phenomenology. The participants were 5 males and 5 females and working in critical care units between 6 and 23 years. 19 essential subthemes were elicited, were classified into 2 themes: Holistic care and Caregiver's characteristics. Therefore, caring experience of comatose patient was scientifically defined: Caring for a Comatose Patient is a holistic care that depends on caregiver's Characteristics. The trustworthiness of sub themes and themes were achieved in our study. ***Conclusion:*** Our findings will enable nurses to know what patients have experienced in coma, to give greater insight to what is the issue of being faced by the caregiver, to enhance insight can lead to improved practice through more sensitive relationship with the patients and more focused assessment of their needs, to achieve and create an assessment tool based on the findings of our study; it seems that the results can be used in this regard.

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1. Introduction

Coma comes from the Greek word, ***Kuma*** that means deep sleep, with prolonged unconsciousness (Menck, 1998). There are 8 million head injuries in the USA yearly, which 700 thousands of the victims are hospitalized mostly in critical care units with intensive nursing care (Villanueva, 1999).

The novice nurses encounter with especial problems and challenges in caring of these patients with no previous experience. 73% of these nurses cannot communicate with comatose patients and feel unsafe and disappointed (Villanueva, 1997). On the other hand, 69% of them pay more attention to physiological and pathological aspects of these patients (Menck, 1998).

Novice nurses do not have the opportunity to practice the care giving role in comatose patient until it is upon them. In addition to the physical and emotional of caring for comatose patients, is very difficult. A nurse led support group focused on these aspects would give participants the opportunity to understand the transition and learn coping skills that would enable others to more successfully navigate their way through it.

The most important note is that the quality of care in comatose patients is the most significant criteria for evaluation of nursing care quality because this caring is long and very burdensome. This criterion is covered with transferring of nurse's experiences to other novice nurses.

Literature review

Two qualitative studies have been conducted regarding the experience of caring of comatose patients. Hence, the lack of qualitative study and a standard definition and research instrument for experience of caring of comatose patients, long and various research time periods, possible bias in data gathering or analysis, conducting studies in same research sites have resulted in in confidentiality of the studies' findings. Nevertheless, our findings have proved very helpful in improving nurses' quality care in comatose patients.

Villanueva (1999) studied on experience of critical care nurses who caring for patients in traumatic coma or pharmacological paralysis in university of Miami. Using grounded theory methodology to explore the experience registered nurses. After 16 interviews, data saturation was achieved. The core category was giving the patient a chance.

On the other study, (Menck, 1998) studied on the experience of caring when the patient is comatose in New Yourk University. The 5 registered nurses were interviewed. The nurse's experiences were dynamic and rewarding.

However; they, in their dissertation, worked on caring experience in critical care unit by grounded theory and case study which is very different from phenomenology. We used hermeneutic

phenomenology in our study and we think it is more specific than others.

Background in Iran

All teaching hospitals in Iran have only registered nurse, from novice to expert, according to the Iranian ministry of health, even in critical care units specially in caring of comatose patients; in addition, many patients have nursing care from the teaching health care facilities. On the one hand, hard working conditions and units overcrowding result in nurses' lack of experience in comatose caring patients. On the other hand, expert nurses who cannot transfer any caring experiences to novice nurses are employed in critical care units.

Regarding studies about coma in Iran, we don't have any qualitative study specially phenomenology design. Thus, in this study we aimed to examine the lived experience of caregivers of comatose patients and finally to define and transfer it to other nurses in Iran.

In addition to our professional grounding; Approximately, I spent 1 month in caring for my terminally ill wife and my father until they died of traumatic coma in 2008 and 2009. I also have experience in caring for comatose patients at ICUs for 4 years between 2003 and 2007. This interest eventually led to my doctoral studies and to my choice for the topic of study.

2. Material and Methods

Our worldview was reciprocal interaction. This worldview can better respond to questions of the nursing discipline (Fawcett 2005).

My interest in comatose patients' care giving began in 2008 during the process of caring for my father and in 2009 for my wife as they died of traumatic coma. The events and emotions encountered during those years of care giving had a deep and lasting effect on me and eventually led to my choice of this care giving as my phenomenon of interest while in postgraduate level. When I spoke with caregivers, I came from the perspective of one who had done care giving. Although my own care giving experiences would not be included in the data analysis process or results of the study, the existence of those experiences would be present in my ability to relate to the caregivers and in my thinking as I analyzed their interviews. In an attempt to identify my pre-existing ideas about my care giving for both my wife and my father, I kept fifty three pages of writing were produced between July 20, 2009 and April 10, 2010.

First of all, for orienting to the phenomenon, the phenomenological questions were formulated Working from a phenomenological perspective, the research question became "What is the lived experience of caring comatose patients?" For examining the lived experience, by continually searching for ways to deepen his or her understanding of the phenomenon, we tried to deepen our standing of the phenomenon by probing questions and field notes and certain observations.

Table 1: six themes of Van Manen hermeneutic phenomenology

Theme	Activities
1. Turning to the nature of lived experience	1. Orienting to the phenomenon 2. Formulating the phenomenological question 3. Explicating assumptions and pre-understandings
2. The existential investigation	4. Exploring the phenomenon: generating data a. Using personal experience as a starting point b. Tracing etymological sources c. Searching idiomatic phrases d. Obtaining experiential descriptions from subjects e. Locating experiential descriptions in literature, art, etc. 5. Consulting phenomenological literature
3. Phenomenological reflection	6. Conducting thematic analysis a. Uncovering thematic aspects in life world descriptions b. Isolating thematic statements c. Composing linguistic transformations d. Gleaning thematic descriptions from artistic sources 7. Determining essential themes
4. Phenomenological writing	8. Attending to the speaking of language 9. Varying the examples 10. Writing 11. Rewriting
5. Maintaining a strong and oriented relation	
6. Balancing the research context by considering parts and whole	

Table adapted from "Practicing Phenomenological Writing", Van Mannen, (1984)

We followed Van Manen's hermeneutic phenomenology (Van Mannen 1997):

Table 2: Participant's Characteristics changes or revisions, and to elicit any additional data the participant wished to contribute. This process continued with all 10 participants; data analysis was ongoing as the interview process progressed confidentiality.

Participants	Numbers	Sex	Marital Status	Age	Location of Living	Period of Caring	Educational Level	Occupation
Nurses	8	5 Males	7 Married	26-42	Tehran	6- 23 years	6 Bsc	6 Staff Nurse
		3 Femals	1 Single				2 Msc	2 Head Nurse
Family Members	2	Females	Single	40-42	Tehran	2- 7 months	Bsc	Teacher

For tracing the etymological source of the words associated with caring for a comatose, we follow and examine the etymology of "coma," "patient," "caregiver," "cares," and "experience" for creation of useful and obvious narratives. Then for having arisen from the lived experiences of people, we were searching idiomatic phrases for the informative nature of idiomatic.

In order to achieve experiential descriptions from participants, a convenience or purposeful sampling was used. The goal in sampling was to have a nurse and family member who were currently living the experience of caring for a comatose patient in hospital or home and who had done so for at least one time. Inclusion criterions were caregivers who had Persian language, had a communication with patient directly or indirectly and were volunteer and informed from critical wards or homes in Tehran hospitals.

An initial sample of 14 participants had been anticipated, however this number decreased throughout the research process. Data saturation was recognized when after interviewing 10 participants. Table 2 shows participant's characteristics.

The time and location of the interviews were determined at the convenience of the participants. Two of the interviews in the participants' homes and 8 were conducted in intensive care units. Only one interview with the one participant was conducted in the same location again. Informed consent was obtained after the participants were given time to carefully read the consent form and to ask any questions they had before signing it

The interviews were conducted face-to-face and were audio-tape recorded. Most of the interviews lasted 47 to 98 minutes. After each interview, I took notes in order to document my impressions of the meeting and to record non-verbal cues the participant demonstrated. Each audio-tape was transcribed verbatim by a paid transcriptionist (The transcriptionist signed a confidentiality statement and each transcription was checked for accuracy by me against the original audio-tape. For analysis, I read and listened to tape more and more, to make any

Table 2: Participant's Characteristics changes or revisions, and to elicit any additional data the participant wished to contribute. This process continued with all 10 participants; data analysis was ongoing as the interview process progressed confidentiality. Appropriate measures were taken to ensure the confidentiality of the participants and included the following steps. All audio-tapes, field notes, and typed transcriptions wrote and rewrote times by times, were identified only by use of codes.
For descriptions from artistic sources; the Brook's book "Comatose patient" and comatose patient films were included with the data analysis.

The process of uncovering thematic aspects began in the current research study when the interviews were conducted with caregivers having the experience of caring for comatose patients. Questions used on the interview guide were formulated to enable the participant to facilitate the participants' movement away from their preconceived notions of care giving to what presented itself to them on an intuitive and visceral level. When the interviews were completed, we wrote memos in which my impressions and thoughts about the interview were recorded. We referred to these memos periodically during the data analysis process to refresh my memory of the particular interview.

The selective or highlighting approach was implemented in this study so each transcription was then read carefully and all phrases and sentences relevant to the phenomenon were highlighted for further consideration. The highlighted parts of the interview were examined for the sub themes contained within them.
Through sensitivity to the lived experience of the participant as reported in the transcripts, I developed a dialogue with what was being said. The resulting sub themes were the interpretive product of that interaction. The sub themes were what were revealed to me in my interaction with the transcript.

Once the sub themes of the various transcripts were identified, we composed linguistic transformations of them. In this hermeneutic activity, we attempted to interpret the text and to move the language to a more universal level of abstraction while at the same time remaining faithful to the participant's lived experience.

In order to increase our understanding of a lived experience and that as such, it is an appropriate resource for phenomenological reflection. We argued each subtheme with all participants and validate them word by word in several sessions. The responses of each participant within an interview were examined for commonalities pointing at a sub theme for that participant. This process continued until all of the interviews had been analyzed and a list of sub themes from all of the participants had been elicited.

Ethical issues

The Research Council of Shahid Beheshti University of Medical Sciences that supervised and corroborated its ethical considerations approved the study. Before data collection was commenced, Entrance permission to critical care units was obtained from the hospital managers. A covering letter to all of the participants informed them regarding the study aim. They were assured of the authors' commitment to their anonymity and confidentiality from the data gathering to publication of results. Informed consent was obtained from the participants who agreed to participate in the research.

3. Results

At first; 53 sub themes were elicited and after 8 scientific sessions with the expert academic professors and 10 sessions with our 10 participants until only those that are 19 essential sub themes to the understanding of the phenomenon remain. These 19 sub themes are shown in table 3.

After elicitation of 19 sub themes, we find two themes after research team sessions: Holistic Care and Caregiver's Characteristics.

The *"Holistic care"* is one of our themes. This theme was consisted of 12 sub themes;

(1) Complete care: it is all of physiological cal, social and psychological of care. *Routine Job:* it refers to all of routines and works in wards and homes.

(2) Resuscitation effort: it contains of all attempts that participants do for return of patients to life like CPR.…

(3) Effective and Successful of job: our participants said that their caring is some time successful and effective and occasionally it is non useful and effective.

(4) Giving Hope to Family: all of nurses implied that hoping and hopness of patient' family is an important goal for them.

(5) Effective Relationship: the relationship among caregivers, patients and family of patients is the most significant factor in knowing of patients and his or her return to life.

(11) Certain and Burdensome Job: all of participants believed that caring of comatose patients is very hard, exhausting and the other hand, very sensitive and certain.

(13) Spiritual and Moral perception: our participants were praying for patients like read of Quran, asking of God for return of patients.

(15) Attention to patient: all of caregivers told me that we didn't forget the patient.

(16) Living with Patient: our caregivers were belonged to their patients and followed them in whole times and places.

(17) *Calm Death:* all of nurses implied that while we can't help them, we have to give them opportunity to die calmly.

(18) Respect to Human Dignity: all of caregivers told us, all of human rights and dignity are significant and every patient has living right, moral rights and like these.

Therefore the "*holistic care"* is a complete care with routine works. Every caregiver wants to care in holistic manner, has to take an effective, certain and burdensome effort for patient resuscitation. Perception of spiritual and moral aspects in these patients is one of parts of complete care and it needs respect to patient's human rights and in fact you have to live with your patients and never miss her or him at all. If a caregiver will care her or his patient completely, he or she must care until end of the life even calm death.

Some of the relevant quotations of holistic care come below:

Participants 1; …*when I come back to ward, I look for and ask about my patients especially when he or she isn't in bed* (***Living with Patient***)…. *When I care from a comatose patient, I try to maintain relationship with him or her by speakin and, touching* (***Effective Relationship***)…. *When our attempt is not useful, we have to give him or her time to live without intensity and disappointment* (***Calm Death***)…. *Looking at her or his face is not forgetful* (***Attention to patient***)…. *I want to see her or his family in order to know her or him* (***Effective Relationship***)….

Participant 5; ….*happiness in caring, hope of family, it helps us, better care* (***Giving Hope to Family***)….*the patient require respect, advocacy, rights; these are important* (***Respect to Human***

Dignity) *…. I think about my patients and his or her care even in my home (**Living with Patient**)…. I care from my patients according to the physician's orders and schedule of ward (**Routine Job**)…. When I deliver the schedule of my ward to another staff, I imply that my patient has gavages, please check it significantly and tell to her or his family about progress of her or his level of consciousness (**Attention to patient**)….*

The *"Caregiver's Characteristics"* is another theme. This theme is consisted of 7 sub themes;

(6) Mutual Satisfaction: it refers to satisfaction of caregivers, patients and families.

(7) Caregiver's Depression and Disappointment: when the comatose patient dies after whole of effort, the caregivers have a sense like depression and disappointment.

(8) Caregiver's Hopefulness: the caregivers say that if all of patients die, we select comatose patient again because we are hopeful.

(9) Caregiver's Guilt: when the patient dies, caregivers accuse themselves and think that are guilty.

(12) Commitment and Responsibility to Care: in comatose patient it is very different because patient in coma can't percept anything and complain from any mistake so the caregiver's responsibility is a vital and crucial.

(14) Belief of Death:, some of them believe death is in God' hand and human is not able to return the patient if God won't.

(19) Compassion and Sympathetic sense: caregivers say that the comatose patients are very solely and they don't have anybody and nurse is just his or her relative.

On the other hand, *caregiver's characteristics,* in fact these are the most effective factors on holistic care. These are features of every caregiver and holistic care alters beneath of them. Some caregivers percept his or her patient's satisfaction when they are pleasant themselves. Some participants have compassion and sympathetic sense because the comatose patients are solely, without significant relative. Some caregivers believe that the death isn't in human scope and in fact God can return the patient and sometimes he won't and we can't do anything at all.

Some of the relevant quotations of caregiver's characteristics come below:

Participant 8; …. *When my patients die or heard about their deat, I depressed (**Caregiver's Depression and Disappointment**)…. After death of my patient, I have a sense like guilt sense or like (**Caregiver's Guilt**) …. When I visit my patient, I percept my duties and attempt to care carefully (**Commitment and Responsibility to Care**)…. My colleagues in the hospital and I try to understand the patient's satisfaction, it is very hard but it is fiseable (**Mutual Satisfaction**)…. Actually I find out the satisfaction in my heart when the patient is satisfied (**Mutual Satisfaction**)…. When my patient return alive and became conscious, I have satisfied more and more (**Mutual Satisfaction**)….I begin CPR but he or she dies and, and I know God carry him or her sole (**Belief of Death**)….*

Participant 10; …. *God acts like an angel, he can carry or take patient's sole (**Belief of Death**)… in fact comatose patient is very single, very solely and doesn't have anybody (**Compassion and Sympathetic sense**)…. If all of my patients die, I continue my care and attempt to rescue the rest of them (**Caregiver's Hopefulness**)…. When I came in nursing, I promised that will attempt and work in hard situation and coma is one of them (**Commitment and Responsibility to Care**)…. If my patient will be worst, I have been disappointing (**Caregiver's Depression and Disappointment**)…. I see my patient's sole in ward at nights and I believe there is (**Belief of Death**)…. My colleagues are satisfied from my care and I care better (**Mutual Satisfaction**)…. The patient's family asks about patient and the message of death, it is very bad and I will be depressed (**Caregiver's Depression and Disappointment**)….*

We consider these sub themes and two themes as a whole and define the caring experience of comatose patient. We know that without any sub theme, we can't define our lived experience and the other hand, every one of 19 sub themes, can't define lived experience solely. However, we define the caring experience of comatose patient with entire 19 sub themes and 2 themes in a scientific way: *The Caring of Comatose Patient is a Holistic care that is dependent to caregiver's Characteristics.*

4. Discussions

Villanueva (1997), in her dissertation, worked on caring experience in critical care unit by grounded theory which is very different from phenomenology. We used hermeneutic phenomenology in our study and we think it is more specific than grounded theory. In this study, participants included 16 nurses and we got saturation with 8 nurses and 2 family members.

Table 3: 19 essential subthemes in caring for comatose patients included

Themes	Sub Themes	Sub themes
Holistic care	(1) Complete Care (2) Routine Job (3) Resuscitation Effort (4) Effective and successful job (5) Giving Hope to Family (6) Effective Relationship	(11) Certain and Burdensome Job (13) Spiritual and Moral perception (15) Attention to patient (16) Living with Patient (17) Calm death (18) Respect to Human Dignity
Caregiver's characteristics	(7) Mutual Satisfaction (8) Caregiver's Depression and Disappointment (9) Caregiver's Hopefulness (10) Caregiver's Guilt	*(12) Commitment and Responsibility to Care (14) Belief of Death (19) Compassion and Sympathetic sense

( ) number of subthemes,
* Most frequent sub theme.

The her core category, giving the patient a chance and the subcategories were learning about the patient, maintaining and monitoring, talking to patient, working with families, struggling with dilemma and personalizing the experience. Factors influencing on them were identified such as the acuity of the patient, experience level of the nurse and the presence or absence of family member or significant others.

The subtheme of *Resuscitation Effort* was also found in Villanueva's study (Villanueva, 1997) as well as effective relationship and attention to the patient as themes. We found commitment and responsibility to care as a frequent subtheme.. She emphasized on the nurses' experience variations as the most effective factor on themes but we found effective and mutual relationship with comatose patients as the most significant factor.

In hence, the limitations of this study involved using registered nurses from one neuroscience intensive care unit; where the study was conducted there was no other level I trauma center with a neuroscience intensive care unit. The population for this study was limited to the unresponsive patient with the etiology of trauma. Race, gender and physical appearance did not emerge as factors that influenced on this experience. Villanueva only interviewed with nurses and didn't have any family member. In our study, there were not these limitations.

On the other study, (Menck, 1998) studied on caring experience of comatose patients with qualitative method along with case study. 5 nurses were interviewed and after data collection and analysis, the experience was found to be dynamic, energetic and holistic. We also found holistic care as a theme because the caring of comatose patient is complete and multidimensional and it is better to be called Holistic Care. One of the subcategories of holistic care was routine job consisting of physical and relationship aspects of patient according to caregiver's experience, Believed that this experience is not routine or mechanical but relevant to rigorous knowledge. In her study, role of palpation, conversation, mobility of limbs and certain attention to physical and psychological aspects of comatose patients were the most significant factors in caring and, in our study; caregiver's characteristics consisted of these aspects. Menck (1998) concluded that quality of care in comatose patients is the most significant criteria for evaluation of nursing care quality because caring is long and very burdensome. Our findings are in accordance with her because caring for comatose patients needs tactfulness, vigilance, high knowledge, excellent relationship and good perception. In this study, the participants did not find comatose persons very different from other patients but was invert in our study. In our study, the importance of touching, talking to, gently moving extremities, paying attention to minute details and finally knowing the patient was mentioned. In addition in our study, psychosomatosocial, spiritual and moral aspects of caring were important.

In her results; Technology and physical care were part of the job and not discussed as heavy or troublesome. Most participants said that this care for comatose patients took a long time like our participants.

In two studies; the goal of these caring experiences included being able to practice nursing at its full potential and we believed that novice nurses require them. The caring for the comatose patient was challenging, rewarding and an intensely rich and humanistic experience in these studies and in our study, it was hard and bothersome.

Their limitations consisted of: participants were 5 women who were similar in their cultural background, education, geographical location and experiences. No predictions or interventions, with only one investigator, unconscious biases were possible and little room for documenting the nurse's experiences. We didn't have these problems. These studies define the caring experience but we offered a certain and complete definition.

Finally; we assessed rigor of our data significantly. The second author observed the four interviews and supervised the transcribing process. The research nurses also recorded observational data for each participant and another person transcribed the interviews. The quality of interviews and transcriptions was ensured by the first author as author checked each transcribed interview for accuracy and integrated the observational data into final data files.

The first and second author completed the first draft of data analysis individually. To appraise the credibility of data analysis, numerous discussions continued until agreements were achieved about each aspect of the process. An expert in the phenomenological method reviewed the analysis of data and concluded that appropriate procedures had been followed. The researchers also discussed the final data analysis with two expert researchers who considered the data analysis valid. Finally, we compared the findings and integrated the bracketed knowledge and relevant literature.

Conclusion

Caring is an ancient and universal process that promotes the mutual growth of the participants. In everyday life in connotes a gentle concern and action taking place with and among living creatures, ideas, or objects. For centuries, there has been a caring relationship between caregivers and the suffering and the helpless. Caring begins when the caregivers and patients come together and, through communication, develops a relationship concerned with the patient's health experience.

We sought for the caregiver's perception of caring in one of the most challenging experiences caring for a comatose patient. It is a unique experience which presents caregivers with a number of challenges.

We meet these challenges in various ways and will put these experiences in an instrument for evaluation of caring in future research. As a result, it is very useful both for caregivers and patients.

The crucial point of this study was to uncover the caregiver's meaning of caring as an experience embedded in practice. The ability of our study to obtain meaning within context is essential in understanding the experience of comatose patient caring in its fullness.

Limitations and Implications

First of all, there is not new reference for qualitative research about comatose patient's care and we couldn't access to them.

We couldn't find more family member but we take saturation with these problems, interrupting of one interview by workload and the noise in the wards interfering with the participant's concentration. Designing a study with more family members and utilizing of grounded theory for explanation of caring process for these patients in Iran are highly recommended.

However; our results are useful for arising of ability of nurses to know what patients have experienced in coma and to give greater insight to caregivers. It results in improving practice through more sensitive relationship with the patients and more focused assessment of their needs.

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