Research Paper:
The Perceptions of Families of Comatose Patients in the Intensive Care Unit: A Qualitative Study

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ABSTRACT

Background: There are specific challenges regarding the perceptions of families of comatose patients in Intensive Care Units (ICUs). Identifying these perceptions may attract the cooperation of families with nurses and provide better care for patients. This study aimed to explore the perceptions of families of comatose patients in ICUs.

Methods: This was a qualitative content-analysis study. Seventeen families with comatose patients were recruited by the purposive sampling technique. The necessary data were generated by semi-structured interviews, continued until data saturation, and concurrently analyzed by an inductive content analysis method.

Results: Four main categories were manifested, including shock and disbelief, the effort for adaptation, exhaustion, and burnout as well as hope and support.

Conclusion: The obtained results signified the importance of nurses' awareness concerning the family members' perceptions of their comatose patient status in ICUs. The relevant findings reflected the need for nurses to pay attention to the feelings and emotions of the families of these patients.

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Highlights

- There are specific challenges regarding the perceptions of families of patients affected with coma in intensive care units.
- Identifying these perceptions may attract the cooperation of families with nurses and providing better care for patients.
- The present study findings led to the formation of 4 categories; shock and disbelief, the effort for adaptation, exhaustion, and burnout and hope and support.
- According to the study findings, patients' families should be supported by the intensive care team.

Plain Language Summary

Many people annually go into a coma all over the world and most of them are admitted to intensive care units. The hospitalization of a family member in a critical care unit is a very bitter and special experience. This study explored the perceptions of the families of comatose patients in intensive care units. The related findings suggested that the families are in shock and disbelief, and try to adapt to the situation, feel exhausted and burnt-out, and need hope and support. The findings reflected the need for nurses to pay attention to the feelings and emotions of the families of these patients.

1. Introduction

More than millions of individuals worldwide experience coma annually (Weiss et al. 2012). Besides, most of them are admitted to the Intensive Care Unit (ICU) (Peeters et al. 2015). The prediction of these patients' recovery trends is highly complicated (Chookalayia et al. 2018; Horsting et al. 2015; Stevens, Cadena & Pineda 2015). Accordingly, the patients' families play a key role in their care and are recognized as a member of the healthcare team (Wetzig & Mitchell 2017). The families of patients hospitalized in ICU may encounter frustration and a high level of emotional and mental stress (Mitchell et al. 2016). Emotional disturbance, role conflict, variable responsibilities, interference in daily routines, and changes in familial relationships make caring for comatose patients more difficult. Furthermore, regulations on limited visits and technical equipment of critical care units hinder the family from providing care to the patient (McDonald et al. 2017); consequently, exploring families' challenges and perceptions may help with better care planning and the cooperation of the families with the ICU staff.

Three-quarter of patients admitted to ICU are unable to remark on their treatment decisions; thus, physicians and nurses should refer to their families to decide on treatment procedures (Mattar, Liaw & Chan 2013). Such conditions aggravate the pressure on their families and their emotional distress (Gorji et al. 2014). However, these families may be unable to characterize their needs in the early stages of crisis (Kirshbaum-Moriah et al. 2018). Accordingly, ICU nurses are in an ideal position to address the families' needs and help them to face stressful conditions due to close interaction with patients (Lam & Beaulieu 2004; Leon & Knapp 2008).

Nevertheless, because of concentrating on providing care to patients, nurses may unintentionally ignore the emotions and needs of patients' families and rank them as their second priority (Azoulay et al. 2000; Wetzig & Mitchell 2017). Thus, such studies can increase the awareness of physicians and nurses about the family members of these patients.

In Iran, few researchers have addressed the experiences of the family members of comatose patients affected in ICU; previous studies investigated the condition of comatose patients and how to help their family so that their patient regains consciousness sooner. Some studies argued that cultural issues strongly influence the perception of these families (Leon & Knapp 2008; McDonald et al. 2017). The concept of providing care to patients in a coma and their families remains undiscovered in our culture, i.e. special challenges in this area (Lam & Beaulieu 2004); thus, it is necessary to explore this issue to understand the problems of these families and present a solution to reduce families' worries and improve the condition of patients in coma admitted to ICU. Accord-

ingly, this study aimed to investigate the perceptions of the families of comatose patients in the ICU.

2. Materials and Methods

This was a qualitative study. To achieve the study's objective, a conventional content analysis method was used. This method is recommended for phenomena about which little is known (Elo & Kyngäs 2008). The family members of hospitalized comatose patients who were regularly present at the hospital and met them if necessary (N=17) were requested to participate in the present study. The setting was Fatemi educational hospital affiliated with Ardabil University of Medical Sciences. To recruit the study participants, the purposive sampling method was used; then, the purpose of the study was explained and a written informed consent form was obtained. Moreover, semi-structured interviews were used to obtain the necessary data. Interviews were conducted in the nurses' restroom in Azeri. Interviews were conducted from August 2015 to June 2017 until the data was saturated. The interviews were conducted according to a prepared guide. Some examples of the questions were as follows: "How did you feel when you were informed she/he has gone into a coma and been admitted to ICU?" "How did you spend your days in this time?" "How do you describe ICU?" Following the responses of the study participants, more follow-up questions were probed, e.g. "Can you explain more?" or "What do you mean exactly?".

During the interviews, feedback and oral consent were received from the study subjects to continue the discussion. Eventually, 17 interviews, each lasting 45-60-min were performed, recorded, transcribed verbatim, coded, and analyzed. Besides, voice recording was conducted under the permission of the study participants.

In qualitative studies, analysis of data is conducted simultaneously with data collection, so both inform each other. To analyze the qualitative data, conventional qualitative content analysis was applied. First, the content of the interviews was transcribed word by word; the research participants' words and signifying codes (researcher's inference) were used for initial coding. To specify semantic units, every interview was reviewed several times; subsequently, the codes were categorized based on similarities and differences by coding the semantic units of the study participants' expressions, indicating their perceptions. Then, the categories and subcategories were compared and the analysis of these data led to extracting themes and further abstract concepts (Elo & Kyngäs 2008).

To evaluate the rigor of data, the criteria of credibility, transferability, conformability, and dependability suggested by Guba and Lincoln were used (Hsieh & Shannon 2005). The interviews and associated analyses were shared with the study participants and their opinions were considered (member checks). To ensure credibility, i.e. equivalent to the reliability, the codes were given to external experts to confirm the process of coding. Prolonged engagement (around 19 months) led to the researcher being deeply immersed in the data. Furthermore, for transferability, i.e. equivalent to generalizability (suggesting that the findings have applicability in other contexts), the researchers attempted thick describing the context of the study. To ensure the confirmability of the research results, the transcription of some interviews was delivered to two professors mastering qualitative research; they were requested to evaluate the accuracy of the data coding process. Maximum variation sampling was performed through interviews with different individuals, including those with experiences of working in ICU (Table 1). Eventually, to ensure dependability, an inquiry audit approach was used. The interviews and the process of analysis were shared with a professor (not involved in the study project); she was requested to examine the process and product of the study.

3. Results

Seventeen family members of patients in a coma (age range: 15-52 years) participated in this study. The study participants' mean age was 36 years (Table 1). The findings on the perceptions of families of comatose patients admitted to ICU led to 870 initial codes, 10 subcategories, and 4 themes, including shock and disbelief, the effort for adaptation, 'exhaustion and burnout, as well as hope and support (Table 2).

Based on the present research findings, when the participants realize that their patients have been admitted to the ICU, they experienced fear resulting from unknown environment and equipment, as well as the lack of awareness and support by personnel and other family members. Besides, they experienced a range of feelings from sadness and frustration to effort, adaptation, and hopefulness through praying.

Shock and disbelief was the first category, i.e. frequently mentioned by the patients' families. This category has 3 subcategories, including denial, sorrow, and feeling guilty. Numerous participants stated that as soon as they were informed about their loved one being admitted to the ICU, they have experienced severe denial, sadness, and grief. Some participants also blamed themselves for what

Table 1. Demographic characteristics of the study participants and the patients

Code	Age (Year)	Education	Gender	Marital Status	Job	Relationship With the Patient	Patients' Gender	Patients' Age (Year)	The Duration of Stay in the ICU (Day)
1	36	High school	Female	Married	Housekeeper	Sister	Female	40	8
2	22	Associate degree	Female	Married	University student	Child	Female	50	4
3	34	High school	Male	Married	Self-employed	Father	Male	15	14
4	47	High school	Female	Married	Barber	Mother	Female	30	12
5	38	BA	Female	Married	Nurse	Child	Male	50	26
6	30	MA	Male	Married	University student	Son-in-law	Male	52	20
7	28	Associate degree	Female	Married	Housekeeper	Wife	Male	32	5
8	43	MA	Female	Married	Teacher	Mother	Female	26	7
9	34	High school	Female	Married	Housekeeper	Wife	Male	43	13
10	23	High school	Male	Single	Self-employed	Brother	Male	30	3
11	38	Primary school	Male	Married	Self- employed	Child	Male	51	8
12	35	Associate degree	Female	Married	Housekeeper	Wife	Male	42	12
13	47	High school	Female	Married	Housekeeper	Mother	Male	20	15
14	46	Primary school	Male	Married	Self-employed	Father	Female	20	30
15	41	BA	Female	Married	Clerk	Mother	Male	20	16
16	31	High school	Female	Married	Housekeeper	Mother	Female	15	10
17	51	High school	Female	Married	Construction worker	Wife	Male	43	14

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has happened to their loved ones and felt guilty for causing it. A young father stated: "The words coma and ICU are annoying. It is highly unexpected and terrible to hear that your child is in a coma in ICU…" (Participant no. 3).

Furthermore, a 47-year-old hairstylist mother mentioned: "When I was told my daughter is in a coma, the shock left me numb. I could not accept at all that my daughter is in a coma" (Participant no. 4).

Concerning sorrow and feeling guilty, a participant stated: "I had not been answering my son's calls for a while, I had abandoned him … He mingled with bad friends and drove recklessly, like them. One day, he was driving fast, the tire burst, and the car plunged into the valley. If I had not disregarded him, he would not have been socialized with gangs; I feel guilty" (participant no. 15).

Another participant (patient's spouse) referred to a similar point: "Before my spouse's accident, we argued over title deed and I had told him that he could not transfer my share in the property to our son because he is not old enough. He left the house furiously. I got shocked hearing the accident news" (participant no. 12).

The category of effort for adaptation has two subcategories, including a search for information and adaptation with the fear of unknown environment and equipment. According to a majority of the research participants, an essential problem they had faced in ICU was the fear of unknown environment and equipment and inadequate information about the patient's condition. They believed that receiving enough information about the patient's condition and equipment functions can help and causes adaptation with the existing condition.

A 47-year-old mother mentioned: "I had already heard about ICU, but being involved is only when you know how difficult it is and you find that you have no information … I do not understand its' devices and medications.

Table 2. Summary of the categories and subcategories extracted in this study

Categories	Subcategories
Shock and disbelief	Denial
	Sorrow
	Feeling guilty
Effort for adaptation	Search for information
	Adaptation with the fear of unknown environment and equipment
Exhaustion and burnout	Responsibility
	Physical and mental burnout in the whole family
Hope and support	Effects on family's togetherness and support
	Praying
	Personnel's support

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I searched on the internet for hours and asked others, but my information was not enough to take care of the patient; however, reading helped me to cope with the situation" (Participant no. 13).

A 30-year-old participant who was the son-in-law of the patient argued: "ICU seems a strange place. I have no information about the treatment of my patient, and I keep asking questions from physicians and nurses while caring for my patient" (Participant no. 6).

Another participant (patient's spouse) stated: "My fear and anxiety increased when I saw the tubes, i.e. connected to my spouse's throat and mouth. How should I take care of my husband at home? … I tried to look carefully at what nurses do or ask other patients' companions to find out the strange environment of ICU and how the devices work".

Concerning exhaustion and burnout, one of the issues that all participants referred to was the difficulty of taking care of comatose patients in ICU. They believed that this responsibility can lead to physical and mental burnout of the whole family. A continuous attendance of a family member, disturbance in their roles at home and workplace, treatment expenses, long-term hospitalization, and the inability of other family members to care for the patient caused biopsychological burnout in the whole family.

A participant who was under the burden after his brother's going into coma mentioned: "I am under pressure. I cannot stand this burdensome responsibility. May God heal him or grant a merciful release. I have sold all my properties for his treatment, but he does not get better and there is no decrease in the expenses. I am really tired" (Participant no. 10).

Another participant stated: "Everybody expects me to take care of my father because I am a nurse, but I am fed up and my life is being ruined" (Participant no. 5).

Another participant stated: "I have sleeping disorder now. I have lost weight. My life is about to ruin" (participant no. 14).

Another category was hope and support. Most of the research participants expressed a similar perception of the importance and effect of support and praying. Besides, they identified family, praying, and staff support as the main elements of stability and treatment continuation. Most study participants believed that religious belief and praying were very effective for their peace and the patient's recovery, and others' support, especially by the staff, generated assurance and hope.

The study participant no. 3 claimed: "When everybody helps, you do not get tired soon, and you have more energy and eagerness to take care of the patient". Another research participant stated: "When I see my sister taking care of my dad heartedly, I eagerly do the same, and in this way, it is more rewarding" (Participant no. 11).

Almost all study participants stated in different words that they request God to bless their patients through praying and mercy. Study participant no. 2 (patient's child) declared: "I tell myself I did not suffer more than

Hazrat-e Zeinab. Lady Zeinab, please ask God to bless my patient".

The research participant no. 3 mentioned: "I have offered God a lot. I have prayed in all shrines. In this way, I feel more peaceful too".

The staff support and sympathy were very effective in the moral improvement and treatment follow-up of the patients.

Study participant no. 6 confirmed: "Several responsibilities demand support. You feel well when staff get along with you and support you. Accordingly, you can tolerate the difficulties more easily". Study participant no. 1, as the patient's sister declared: "When you realize that physicians and staff judge your patient's life and death and do not give you information and state that the patient will not recover, you feel bad".

4. Discussion

This study attempted to clarify the perceptions of families of comatose patients in ICU. The relevant findings indicated that the families' perceptions in the process of taking care of comatose patients included 4 main themes, namely shock, and disbelief, the effort for adaptation, 'exhaustion and burnout, as well as hope and support.

The shock and disbelief category included the subcategories of denial, sorrow, and feeling guilty. Ong et al. argued that the family members of such patients experience negative and unpleasant reactions when being informed that their patient is in a coma and admitted to the ICU (Ong, Dhand & Diringer 2016).

Effort for adaptation category included the following subcategories: search for information and adaptation with the fear of unknown environment and equipment. Search for information about treatment methods and care provided to the patient was among the most important concerns of comatose patients' families. Besides, they stated that physicians and nurses provide inadequate information, and in some cases, visiting the patient is restricted; however, some other studies indicated that informing families about medical-caring actions can lead to families' satisfaction and the cooperation and acceleration of patient recovery (Stutzman et al. 2017; Tan 2017).

The unknown and stressful environment and equipment of the ICU was another problem that caused stress in the families concerning providing care to their patients. Several studies supported this issue. Moreover, families are under pressure due to the unknown environment and equipment of ICU; they encounter stress and hesitation in taking care of the patient, especially during approaching death (Curtis, Downey & Engelberg 2016).

The exhaustion and burnout category included the subcategories of caring responsibility, as well as biopsychological burnout of the whole family. The burdensome responsibility of caring for patients was among the problems faced by families, i.e. supported by other studies. For example, a study concerning the perceptions of Singapore and Chinese companions reported similar results (Tan 2017).

The hope and support category was extracted from the subcategories of effect on family togetherness and supporting, praying, and personnel's support and sympathy was another category that resulted in the present study. Among the common and frequent remarks of the study participants were vows and families' hope on God's blessing. In other cultures, praying and staff support were suggested (Sutton & Macey 2017).

Family unity was among the positive perceptions of families. Recent studies indicated that family unity and task division improved the process of caring for comatose patients even in the case of those with a poor prognosis (Weinstein et al. 2017; Wetzig & Mitchell, 2017; Young 2009). Staff support and sympathy were other critical subcategories of this study. Different studies signified the role of nurses as the best and closest supporter of patients and families, particularly comatose patients; sharing stories of recovered patients helps the families to manage the patient more efficiently (Donaldson-Andersen 2017; Gerow et al. 2010). Another study indicated that appropriate support by the staff increases families' awareness of prognosis and decreases their stress after trauma (Mistraletti et al. 2017). Besides, care interventions for the family and staff could improve families' satisfaction of medical-caring trends leading to enhanced cooperation of family with the healthcare team (Stutzman et al. 2017).

The transferability of the findings of qualitative studies is limited (Kyngäs, Kääriäinen & Elo 2020; Slevin & Sines 1999); however, if the context is consistent with the socio-cultural context of the present study, the findings can be extended to other cultures to some extent.

5. Conclusion

The current study results emphasized the significance of providing support and information about the patient's condition; the equipment of ICU by healthcare workers; the supportive role of other family members caring for the

patient, and the effect of praying on the perceptions and adaptation of the family members of comatose patients admitted to ICU. According to these findings, family members would benefit from open visitation policies and providing the necessary information by nurses and physicians. The obtained data can help physicians and nurses to provide more effective care for such patients' families.

Ethical Considerations

Compliance with ethical guidelines

This research was approved by the Ethics Committee of Ardabil University of Medical Sciences (AUMS) (code: IR.ARUMS.REC.1394.59). The purpose of the study was explained to the participants and a written informed consent form was obtained from them.

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Authors' contributions

Conceptualization and supervision: Mansoureh Karimollahi and Zahra Tazakori; Methodology: Mansoureh Karimollahi, Mehdi Ajri; Investigation, writing – original draft, and writing – review & editing: All authors; Data collection: Zahra Tazakori, Roghieh Fallah- Tabar; Data analysis: Zahra Tazakori, Roghieh Fallah-Tabar, and Mehdi Ajri- Khameslou; Funding acquisition and resources: Mansoureh Karimollahi, Zahra Tazakori.

Conflict of interest

The authors declared no conflicts of interest.

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