First days in intensive care units: A tragedy for families

Primeros días en unidades de cuidados intensivos: una tragedia para las familias

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Abstract

The first days of patients' hospitalization in intensive care units are very important for their family members. Therefore, it is necessary to explore the families' perceived experiences in order to adopt appropriate nursing care. This qualitative study aimed to explore the perceptions of families in the first days of hospitalization of their loved ones in intensive care units. This is a conventional qualitative content analysis study. Unstructured interviews were conducted on 26 family members of patients hospitalized in the first five days of hospitalization in intensive care units in two private and two public hospitals in the Karaj, Iran. The data analysis led to the formation of three categories: "Overwhelming turmoil", "Scary events" and "Acute psychosomatic tensions". The results indicated that the first days of hospitalization of patients in the intensive care units encompass a painful tragedy. Findings can be applied as a guide for the nursing assessment of families to help them for a healthy transition of this stressful situation.

Keywords: Qualitative Study; Critical Care Unit; Family; Hospitalization.

Resumen

Los primeros días de hospitalización de los pacientes en unidades de cuidados intensivos son muy importantes para sus familiares. Por lo tanto, es necesario explorar las experiencias percibidas de las familias para adoptar la atención de enfermería adecuada. Este estudio cualitativo tuvo como objetivo explorar las percepciones de las familias en los primeros días de hospitalización de sus seres queridos en unidades de cuidados intensivos. Este es un estudio de análisis de contenido cualitativo convencional. Se realizaron entrevistas no estructuradas a 26 familiares de pacientes hospitalizados en los primeros cinco días de hospitalización en unidades de cuidados intensivos en dos hospitales privados y dos hospitales públicos en Karaj, Irán. El análisis de los datos condujo a la formación de tres categorías: "Agitación abrumadora", "Eventos de miedo" y "Tensiones psicosomáticas agudas". Los resultados indicaron que los primeros días de hospitalización de pacientes en las unidades de cuidados intensivos abarcan una tragedia dolorosa. Se aplicará como una guía para la evaluación de enfermería de las familias para ayudarles a lograr una transición saludable de esta situación estresante.

Palabras clave: Estudio cualitativo; Unidad de Cuidados Críticos; Familia; Hospitalización.

Acknowledgments: This article is a part of a Ph.D. dissertation in Nursing which was approved by the Medical Ethics Committee of Tarbiat Modares University, Tehran, Iran. Besides, we thank all participants who shared their valuable experiences with us.

Conflict of interest the author(s): declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding: We are heartily grateful to the Research Council of the university for financially supporting the study

Introduction

Hospitalization in Intensive Care Units (ICUs) is usually felt like a catastrophic event and is accompanied by a psychological crisis in the patients' family members[1-5]. This emotional and physical disturbance persists even after the patient is discharged from ICUs[6,7]. Emotional instability results from the sudden confrontation of families with life-threatening and aggressive treatments applied to manage it[8]. These families need to deal with a wide variety of duties and experience different negative psychological problems while their patients are in ICUs[1-5]. In such a tense situation, nurses should support the family emotionally and physically[9,10]. However, due to the critical conditions of patients admitted in the ICUs, the main concern of ICUs nurses seems to be patient management and hence, the patients' family members and their needs are usually taken for granted[6,11].

A study showed that family members experience a growing crisis in the first six days of a patient's hospitalization, which peaks on the fifth day[12]. A number of previous studies on the family members of ICUs patients have mainly focused on family members' needs, coping strategies and psychological conditions during a long hospital stay, disabled elderly, chronic illness or after hospital discharge[13-17]. Some studies have also focused on specific topics such as long-term psychological consequences, severity, and frequency of emotional problems and post-intensive care syndrome in families[18,19]. However, despite the fact that the first days of ICUs admission are very distressful for their families[6,20,21], no study is available about families' experiences and perceptions during these critical days, and therefore, the question still remained that 'what happens to families in the first days of the patients' hospitalization in the ICUs?

Due to the gap regarding family members' perceptions and experiences during the first days of ICUs admission of their loved one[6,20,21], the present study was conducted to fill this gap.

Aim: This study aimed to explore the perceptions of families in the first days of ICUs admission of their own loved ones.

Methods

Design

This conventional qualitative content analysis was conducted from March 2017 to June 2018 in Karaj, Iran. This approach is useful for exploring people's perceptions and interpretations of life experiences[22].

Participants

The participants were selected purposefully from two private and two public teaching hospitals in Karaj, Iran. Family members were included if[1] their patients were in the first five days of hospitalization in an adult coronary care or intensive care unit for an acute critical illness, and[2] had no similar experience in the past (Table1).

Table1. Demographic characteristics of participant 1. Demographic

Participant Number	Gender	Age	Relationship to Patient	Educational Level	Types of hospital and unit
1	Male	37	Husband	Elementary school	Teaching CCU
2	Male	33	Husband	University	Private CCU
3	Male	42	Child	Diploma	Teaching CCU& ICU
4	Male	39	Child	Diploma	Teaching CCU
5	Male	34	Brother	Elementary school	Teaching ICU
6	Male	37	Brother	Elementary school	Teaching ICU
7	Female	30	Brother	Diploma	Private ICU
8	Female	36	Mother	Elementary school	Teaching CCU& ICU
9	Female	38	Spouse	University	Teaching CCU
10	Female	19	Child	Diploma	Teaching CCU
11	Male	44	Father	Diploma	Teaching ICU
12	Male	36	Child	Diploma	Private CCU
13	Female	40	Spouse	Elementary school	Teaching CCU
14	Male	21	Child	University	Teaching CCU
15	Female	28	Child	University	Private ICU
16	Male	47	Child	Elementary school	Teaching ICU
17	Female	32	Father	University	Private ICU
18	Female	27	Father	Diploma	Private ICU
19	Male	32	Child	University	Private ICU
20	Female	35	Child	University	Private ICU
21	Male	28	Mother	Diploma	Private ICU
22	Male	42	Husband	University	Teaching ICU
23	Female	24	Child	Diploma	Teaching ICU
24	Female	50	Child	University	Teaching ICU
25	Female	22	Spouse	Diploma	Teaching ICU
26	Female	34	Sister	University	Teaching ICU

Data collection

Data were collected through face to face in-depth unstructured interviews. The time and place of the interview were scheduled with each participant. Interviews began with a general question: "Please tell me about your feelings after hearing about your family member's hospitalization in the ICUs, "may you please tell me about the difficult situations you experienced in the first few days of hospitalization of your loved one in the ICUs?" Probing questions were then asked to collect more in-depth data. These questions included "What do you mean by this?",

"Could you explain more about this?", "Please tell me more about difficult moments you experienced after ICUs admission your loved one" Data collection was stopped after 26 interviews, where the data seemed saturated and no new conceptual code or subcategory emerged[23]. Interviews with family members were conducted during hospitalization days of their loved one in the ICUs. All interviews were conducted by the first author in the Persian language, and each lasted thirty minutes, on average.

Data analysis: Data analysis was performed using Zhang's eight-step method simultaneously with data collection. To this end, 1) all interviews were transcribed verbatim. 2) After reading each interview transcript for several times and grasping its main ideas, semantic units relevant to the study aim were identified and coded. 3) The codes were then categorized according to their similarities and differences into subcategories and categories. 4) All extracted codes, subcategories and categories were checked by the research team and another expert in nursing and qualitative study outside the research team in order to check the data stability and credibility. 5) The data gathering and analyzing were continued till the data saturation occurred 6) and the data stability, 7) and properties, dimensions and the relations between categories were frequently rechecked by the research team. 8) All the steps were fully reported.

Trustworthiness

Data trustworthiness was evaluated by credibility, transferability, and confirmability. Credibility was confirmed using peer checking (re-analyzing some data by a nursing professor with experience in qualitative research), allocating enough time for each interview and prolonged engagement with the data. Transferability was applied through maximum variation sampling (Table1). Confirmability was also examined by member check[24].

Ethical considerations

This study was approved by the Ethics Committee of Tarbiat Modares University (grant No. D52/3060). Verbal informed consent was obtained from all participants. The participants were also informed about the aim of the study, voluntary participation, anonymity, data confidentiality, and the right to withdraw from the study at any time.

Findings: The data analysis revealed three categories, "Overwhelming turmoil", "Scary events "and "Acute psychosomatic tensions" (Table 2).

Table2. Category and subcategories

subcategory	category
Consternation	Overwhelming turmoil
intolerable first days	
inexpressible worries	
Uncontrollable worries	
Frightening name of the unit	Scary events
Stressfulness environment	
Fear of deterioration of the patient's condition	
Psychological tensions	Acute psychosomatic tensions

Overwhelming turmoil

This category contains subcategories of "consternation", "intolerable first days", "inexpressible worries" and "uncontrollable worries". After dealing with the process of acute illness and subsequent hospitalization of a patient, families were overwhelmed with emotional disorganization which expressed in words such as being shocked, feeling of falling into a coma, feeling ambiguity, and disbelief of the reality of patient hospitalization in the ICUs. Families faced unexpected and severe stress during the initial admission period, which made it very difficult and painful to tolerate these first days. Referring to the patient's critical conditions and fear of terrible events for the patient, two participants said:

"When the doctor said that blood is not reaching the patient's brain, it was deadly for me; I was dumbstruck and unable to talk for a while" (P1), "… It was a horrible moment when my husband's eyes and nose were getting bloody. I was frightened and very scared. I will never forget those moments" (P12).

The first days after ICUs admission of a loved one were very terrible, worrisome and uncomfortable for the families, and its memories were difficult for some of them to be articulated. Families were unable to control their increasing and indescribable worries. With tears in her eyes, a mother said:

"… I cannot describe those days; words cannot describe my concerns. My worries are so hard for me that it's unthinkable. It was very hard and worrying when my son admitted to the CCU, then ICU, and again to the CCU. It cannot be expressed at all" (P8).

In this regard another participant stated: ''I usually try not to show my worry; but when I came to see my dad in the ICU, I could not control myself, I cried a lot, I knew I should control myself, but I could not control my worries" (P9).

Scary events

This category includes three subcategories of "frightening name of the unit", "stressful environment" and "fear of deterioration of patient's condition".

In addition to being worried about the critical condition of the patient, the names of the ICU and CCU wards were frightening for families and admission of a loved one in these units made them afraid and very anxious. Advanced equipment, invasive procedures, noises from alarms, and restricted visiting hours made the family frightened and worried. Referring to such an anxious situation, two participants said:

"Facing the name of the hospital is quite worrying; especially if it is in the CCU. When I heard the name of CCU, I felt we were in danger and became worried" (P14). "…this environment, devices, and their alarms make people worry. Those devices connected to my child are very distressing for me; the environment of this unit makes me worried " (P19).

The invasive diagnostic and therapeutic interventions were stressful for the families. Families were always afraid of the harmful consequences of these invasive interventions for their patients. They were worried about the deterioration of their own patients after an invasive intervention. A male participant said about his worry when her husband has been sent for a CT scan:

"I was stressed when my husband was transported for a brain CT scan and was injected a drug, I was worried about the harmful effects of drugs and scans on her brain" (P10).

A female participant was also very anxious when her husband was sent to the angiography unit. She said: "… I'm worried that angiography will not work well for my husband and his heart vessels will be torn, I'm worried now that this minor disease will become a big problem" (P11).

Acute psychosomatic tensions

The category of psychosomatic tensions also consisted of two subcategories of "psychological tensions" and "physical tensions".

In the first days of hospitalization, the patients' family members showed signs of severe mental and physical stress. Psychological symptoms such as distraction, confusion, nervousness, persistent restlessness, and impatience caused families to experience decreased cognitive function. Because of this emotional stress, they were confused. The brother of a patient said:

"My brother is so bad now, I'm so worried that I'm confused (pauses a little bit) ... I cannot focus at all" (P6). Another participant also said: "I do not know what to do, I cannot concentrate at all" (P7).

In addition to psychological problems, most family members suffered from physical problems such as body trembling, headache, weakness, anorexia, sleep disturbance, impulsive behaviors, and feelings of being disintegrated after the hospitalization of their loved ones. Physical tensions caused problems in handling family and work-related tasks and in the following-up the medical needs of their own patients such as purchasing certain drugs. In this regard a participant said:

"Anxiety and trembling bothered me during days. My hands and feet are shaking constantly and did not allow me to stand over my dad "(P23). Complaining of the sleep disturbance, another participant commented: "I have not slept properly these days…, I cannot sleep at nights, I am awake all night and then I am sleepy during the day" (P6)

High levels of psychological pressure in the first days after the ICUs admission caused family members to ignore their health status, as a participant said:

"I am suffering from gastric ulcer, but since my father is admitted to ICU, I discontinued my treatment I have severe stomach pain" (P13).

A number of family members also behaved unconventionally due to their excessive anxiety. A patient's wife said:

"… I'm so worried about my husband that I'm not calm at home, … I've bitten off all the nails in my hand, I've bitten my lips so much so that they are in pain now, I talk in my sleep and clench my teeth together" (P16).

The overwhelming psychosomatic pressures resulted from the acute illness and ICUs admission of a loved one made family members tired and exhausted. Participants used the term "disintegration" to describe their turmoil, which meant severe damage to the family in all respects. A patient's son said:

"I suffered from excessive worry in the days after my father was admitted in the ICU and then in the CCU. On day three I really felt disintegration, and then worried about myself, I had really bad days, I'm depleted because of great worries, I'm worn out and need a few days to rest and then to follow my own treatment…" (P6).

Discussion

This study showed that family members of patients admitted in ICUs perceived tragic days due to unexpected hospitalization of their loved ones. They described the first days of patient hospitalization as the most difficult days they ever experienced. A number of studies have reported that ICUs admission imposes much more tension and frustration to family members[2,25,26]. A critically ill patient brings a sudden shock to the family, and most families cannot easily adapt to the patient's ICUs admission. Consistent with our findings, studies showed that close relatives of patients admitted to ICUs perceive shock and disbelief[12,27]. The first days of ICUs admission of a loved one are so terrible for the families that they cannot easily describe it. Similarly, an earlier study reported that it is hard for the family members of ICUs patients to find a proper word to describe their painful feelings[28]. Our study showed that not only ICUs admission of a loved one, but also the name of these wards imposes lots of stress and worry on the family. The current study also showed that family members suffered from some emotional and physical health problems after the hospitalization of their loved ones. Similarly, a number of earlier studies in Iran and some other Middle Eastern countries showed that the families of patients admitted to ICUs suffer higher levels of anxiety and stress than the families of patients admitted to general care units[29,30]. As our results showed, in addition to the patient's critical condition, factors such as the types of equipment used, invasive procedures, and restricted visiting hours may contribute to the increased family concerns. In line with these findings, some of the previous studies have also confirmed

the impact of the hospital environment and invasive procedures on the unpleasant and frightening experiences of the patients' family members[28,31,32]. The current study revealed that the first days of ICUs admission of a loved one disrupts family members' mental and physical health. An earlier study also showed that the patients' family members are at high risk for mental and physical illnesses, especially when the pressure on them exceeds their capacity to adapt to critical conditions[33]. The findings of this study also revealed the fact that families were not only confronted with difficulties in addressing the patients' caring needs, but also had problems in doing their own daily life activities, addressing their own personal needs, and suffered from sleep and nutritional irregularities. Then, such self-neglect behaviors predisposed them to exacerbation of some emotional and physical disorders. Along with this finding, a study showed that families are less attentive to their health needs than the health of their patients[34]. Similarly, studies found that the patient's hospitalization in the ICUs is challenging for family caregivers in keeping their own personal health schedules, doctor appointments and even in their own routine rest, exercise and meals[35], and a majority of them suffer from high levels of stress, fatigue, sleep disturbances, and nutritional problems.

The finding of the present study revealed that family caregivers of patients admitted in ICUs confronted a complex of problems in the first days of ICUs admission of their loved ones. Such a complex of problems affects all aspects of their life and clearly manifested itself in the term "disintegration" which family caregivers used to describe their severely turbulent situation in the first days of ICUs admission of their loved ones. Although we only focused on the effects of the first few days of ICUs admission of patients, it has also been shown that the symptoms of anxiety and stress caused by ICUs admission of a patient disturb family caregivers' health and coping mechanisms even for longer periods[36-42].

Conclusions

The results of the present study indicated that the first days of ICUs admission of patients are a painful tragedy for their families. Due to the strong emotional bonds between family members in Iran, affliction with a critical condition and the consequent ICUs admission of a patient brings the family a real tragedy. The findings of this study can help nurses identify vulnerable families and help them relief in the first days of ICUs admission of their loved ones. Our findings can also be used in the nursing assessment of families to help them pass this stressful situation. Further researches are still needed to examine the family's emotional state in different cultures.

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