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The Patient's Family Experience Accompanying Patients In The Intensive Care Unit (ICU) Of Imelda Pekerja Indonesia General Hospital

[1]Nixson Manurung, [2]Ododo Hondro,
[1,2]S-1 Keperawatan Universitas Imelda Medan

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ABSTRACT
Critical patients are patients who experience critical pain due to physiological, psychosocial, developmental, and spiritual changes. Patients who suffer from critical illness will experience hospitalization that requires the role of the family as a family support system. The role of the family in dealing with critical patients can have physical impacts, such as fatigue, sleep disturbances, and health problems. Psychological impacts such as anxiety, fear, sadness and depression and social impacts in the form of reduced communication and social isolation. The purpose of this study is to find out the patient's family experience while accompanying the patient in the ICU room of the Imelda Pekerja Indonesia General Hospital. This study uses a qualitative type of research with a phenomenological approach. The sample in this study consisted of 6 participants with nuclear family inclusion criteria, over 18 years old who had waited for more than 3 days in the ICU Room. Data collection techniques with in-depth interviews. The results of this study obtained 4 themes that describe this family experience, namely fear of not being able to see patients again, pity to see patients with many tools, abandoning the routine of seeing patients, and relying on God. Further research suggestions should provide interventions related to the impact that arises when families face critical patients.

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Corresponding Author:
Nixson Manurung
Universitas Imelda Medan
Jl. Bilal Ujung No.24,52, Pulo Brayan Darat I, Kec. Medan Timur, Kota Medan, Sumatera Utara
nixsonmanurung@gmail.com

INTRODUCTION

Intensive Care Unit (ICU) treatment is a treatment that can cause feelings of stress, anxiety, fear not only in patients but also in patients' families. Unfamiliar environments, intensive room regulations, changes in emotional status, and changes in daily activities are some of the factors that cause stress in ICU patients' families (Farhan, 2014). The family cannot be separated from the ICU care process, where in the scope of critical care the family has the role of active presence, protector, facilitator, historian and coaching (McAdam, 2008).

Studies in American hospitals show that the symptoms of anxiety in patients' families are 10-42% (Kulkarni, et al, 2011). Based on the results of the study (Bayu Ambarwati, 2013) at PKU Muhammadiyah Hospital Yogyakarta, 1 family member said that he had given up on

the patient's condition, and 1 family member said that he was uncomfortable in the hospital and when he remembered his sick family members, he suddenly felt sad. From the results of the survey conducted in the Intensive Care Unit (ICU) of H. Adam Malik Hospital Medan. The total number of ICU patients treated was 114 pediatric patients, 201 adult patients, and 137 postoperative patients with a total of 452 patients treated in the ICU room in 2018, based on a preliminary survey, where patients treated in the intensive care room amounted to 137 patients. This is due to the lack of care, attention, and information from nurses because when nurses provide nursing care with a touch of affection, care, kindness, presence, and listening to patients and families, the patient's family feels less comfortable and trusts nurses (Indonesian Journal of Nursing Science an d Practice, 2020). In a survey in early June 2022, in the ICU room of the Imelda Pekerja Indonesia General Hospital, researchers found that 1 family member showed dissatisfaction with the scheduled visit time.

Based on the researcher's experience during his service in the ICU room, families faced various difficult situations and conditions such as shock and fear when they received a call from the ICU room, fear of equipment in the ICU room, feelings of uncertainty about the patient's condition, and so on. Anxiety, depression, and stress experienced by families arise from the first day of treatment in the ICU (Azoulay, Chaize, and Kentish Barnesh, 2014; McAdam Jl, Dracup KA, White DB, Fontaine DK, 2010; Plaszewska-zywko & Gazda, 2012; Turner-Cobb et al., 2016). Strict visiting regulations, lack of communication from the ICU team, lack of comprehensive information regarding the patient's condition and the instability of the patient's condition make the family feel even more depressed and sad (Maite, Antoine, Philippe, at al, 2014). Stressful conditions make families unable to make decisions independently so families seek help from health professionals in making decisions for patients (Schmidt, Azolay, & Syndrome, 2012). Another experience that families feel is a change in the quantity and quality of sleep. Choi et al,. (2013) and Kao et al,. (2016) in his research showed that families experience sleep disturbances which according to Day, Haz-Bakri, Lubchansky, and Mehta (2013) are caused by anxiety, pressure and feelings of fear. This decrease in quantity and quality can lead to disruption of the functional status of the family (Corwin, 2015; Jiyeon, 2016). Providing information related to ICU treatment procedures that are different from other units (Wigert, Dellenmark Blom, & Bry, 2014) and information related to the development of the patient's condition (Day et al, 2013) can reduce family stress levels and if added with relaxation techniques can improve the quality of family sleep.

Experience based on ICU care time is described by Gill et al (2016) in three phases. The admitted phase of the patient provides an experience of shock and disbelief that then continues to become disoriented and difficult to adjust to the medical interventions, equipment and culture of "aliens" in the ICU in the second phase. In the treatment phase, the experience felt by the family includes knowing and appreciating the patient's wishes, the desire to know more about the patient's condition, the culture that exists in the ICU and decision-making. Different specific discussions were carried out by Orgaes (2014) where experiences were divided according to the type of communication experience (communication with health workers, between patients' families), emotional experiences

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(feelings of love) and humanitarian experiences (changes in the family's perspective on health workers and patients).

It can be concluded that patient care in the ICU provides a different experience or impression at each phase from the patient's admission to the discharge process. The lack of studies in Indonesia that delve into family experiences makes health workers or the public in general have a limited picture of the conditions faced by families while accompanying patients in the ICU. Based on the description above, the researcher is then interested in conducting research on family experiences during the patient mentoring process. The purpose of the study is to get an in-depth picture of what the family sees, feels, and perceives during the process of accompanying patients in the ICU room.

METHODS

This study uses a qualitative method with a phenomenological approach to describe the family's experience while accompanying patients in the ICU room. Participants were selected using purposive sampling by looking at the participants' experiences and relationships with patients. Participants received an explanation of the purpose of the research and read informed consent, were given the opportunity to ask questions and make choices related to involvement in the research. Participant recruitment was carried out until data saturation was obtained, in this study saturation was obtained in the 6th participant. Ethical approval is obtained from the ethics committee of the hospital where the research was conducted. This research was conducted in the Intensive Care Unit (ICU) room of Imelda Pekerja Indonesia General Hospital.

The data collection method uses in-depth interview open-ended questions with an average interview duration of 60 minutes. Open-ended questions were chosen by the researcher so that participants could express what they felt freely in their own language. The researcher listened to and recorded what the participants said during the interview process (Hooloway & Galvin, 2016). The interview began with the question "Can you tell me about the experience you felt while accompanying patients in the ICU room" and to dig into more in-depth information, the researcher used probing questions. Participants were interviewed until no new information was obtained, data saturation had been reached and data were sufficient to describe the family's experiences during their stay in the ICU.

The population in this study is family members of patients who are treated in the Intensive Care Unit (ICU) room of Imelda Pekerja Indonesia General Hospital. The sample used in this study was as many as 6 participants. The selected participants are family members of patients who are treated in the Intensive Care Unit (ICU) room of Imelda Pekerja Indonesia General Hospital.

RESULTS AND DISCUSSION

The researcher took 6 participants who met the inclusion criteria as a sample. Participants who accompanied their families for more than 3 days. The characteristics of the sample consisted of participant code number, participant initials, age, occupation, gender,

relationship status with the patient, domicile and length of time accompanying the patient. The characteristics of the sample obtained from the results of the study are as follows:

1. The first participant with the code P-1, the initials Mrs. MR is a 29-year-old woman domiciled in Medan Helvetia. The relationship between the participant and the patient was as a wife who worked as a trader and had been waiting for her husband for 7 days in the ICU room.
2. The second participant with the code P-2, the initials Mrs. L is a 27-year-old woman domiciled in Tanjung Mulia. The relationship between the participant and the patient is as a child who works as a housewife and has been waiting for his father for 5 days in the ICU room.
3. The third participant with the code P-3, the initials of Mr. M is a 41-year-old man domiciled in Pematang Siantar. The relationship between the participant and the patient is as a child who works as a self-employed person and has been waiting for his mother for 8 days in the ICU room.
4. The fourth participant with the code P-4, the initials Mr. S is a 40-year-old man domiciled in Rantau Prapat. The relationship between the participant and the patient is as a younger brother and his employment status as a farmer. The participant had been waiting for his brother for 6 days in the ICU room.
5. The fifth participant with the code P-5, the initials Mr. R is a 35-year-old man who lives in Batang Kuis. The relationship between the participant and the patient was as a husband with self-employed employment status, and the participant had been waiting for his wife for 10 days in the ICU room.
6. The sixth participant with the code P-6, initials Mrs. T is a 30-year-old woman domiciled in Medan Perjuangan. The relationship between the participant and the patient was as a child with a job status as a teacher, the participant had been waiting for his mother for 7 days in the ICU room.

All participants interviewed were 3 women and 3 men. The researchers took the samples between 25-45 years old because the researchers hoped that the participants' experiences as families accompanying patients in the ICU room could be explored a lot. The number of participants in this study was taken as many as six participants, because the researcher adjusted the achievement of data saturation from each data that had been obtained from all participants. Participants tried their best to get information from the six participants so that data that was in accordance with the research objectives were obtained.

Presentation of Research Results Data

The results of this study were obtained from the family's experience while accompanying the patient in the ICU room, which will be described in 4 themes from the thematic analysis process of the participant's narrative.

Theme 1: Unable to meet patients

This theme was expressed by all participants because of the assumption that patients treated in the ICU room had a large percentage of deaths. This theme was expressed by the participants in various forms of expression such as fear of the patient dying or not being

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saved, very afraid of losing the patient, afraid of the patient dropping or deteriorating and afraid of getting bad information such as the following participants:

"...khawatirnya masalah umur kan kita nggak tau ya kan pak,, takutnya nggak ketemu lagi,, itu yang paling dikhawatirkan,, takut nggak ketemu lagi (meninggal)..." (P-6).

In addition, the frequent news of deaths from other waiting families made participants feel that their family members also had a great chance of dying. This is as expressed by the following participant 1:

"...apalagi di sini ada yang meninggal, terus tetangga ada yang meninggal, aduh pikiran ibu, hati ibu,, sempat berpikir begini dek "Ya Allah saya pulang jangan sama ambulance ya Allah..." (P-1).

Theme 2: Pity to see patients with many tools installed

Intensive care requires a variety of care aids, even though they know the function of these tools for the patient's recovery, but the family feels sorry if the patient is installed with many tools. The following is the expression of the 2nd participant when he saw the patient with many tools installed:

"...saya sempat berpikir kalau ini jalan terbaik ya nggak apa-apa, tapi hati kecil pengennya...yaah janganlah (jangan dipasang alat), kasihan..." (P-2).

The perception that the installed medical device indicates that the patient's condition is getting worse, the use of this device also hurts the patient, making the family feel sorry for the patient, as the following participant said:

"...iya, ibu nggak tega gitu kan, jantung pake alat deteksi..,semua pake alat...(P-6).

Theme 3: Leaving the routine to accompany the patient

The family said they left their jobs and daily routines such as housewives, employees and students/students to be able to accompany patients. Leaving this routine was expressed by all participants as follows:

"...kalau anaknya alhamdullilah ninggalin semua aktivitasnya, kerja dia tinggalin, dia ngerti keadaan mamaknya begitu...(P-4).

Leaving this routine was also expressed by the family because it was a pity if they left the patient in the hospital alone. The family feels that they have to be on standby because at any time the doctor or nurse needs the family to help treat the patient. Standby in the hospital also allows families to know the latest developments in the patient's condition, help treat patients and actualize their role as a family who is always present next to the patient. This was expressed by the following 2 participants:

"...belum pernah pulang, karena saya takut kalau ada apa-apa dari istri saya, nanti dokter memerlukan saya, saya nggak ada..."(P-5).

"...takutnya kalau ditinggal...takut dipanggil...makanya yang dekat-dekat aja, jadi sewaktu-waktu dipanggil saya ada..."(P-3).

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Theme 4: Hanging on to hope

This theme is the theme that appears in all participants. Participants said that this life has been regulated, humans are only able to try and pray. The critical condition of the patient that has the potential to cause death, even though the treatment uses sophisticated equipment and a competent medical team, the healing still comes from God, only the power of God is able to save the patient. This can be seen from the following expressions of participants 2 and 3:

"...saya tetap tenang dan berdoa kepada Allah. Insyaallah Allah akan menolongnya asal kita yakin bahwa yang menyembuhkan semuanya dari Allah". (P-2).

"...kalau Allah berkehendak belum waktunya insyaallah sembuh lagi, itu yang saya harapkan semua saya berserah kepada Allah..."(P-4).

Discussion

Family is a person who has close relationships or emotional bonds between family members. During patient hospitalization, the family plays a role in providing attention, compassion, creating security and privacy, advocating and ensuring patients receive good care (Mcgraw et al., 2013). This closeness of family members makes the entire family in this study feel afraid if their loved one dies. Participants said fear arose because their families thought all patients in the ICU had unstable health conditions that could deteriorate at any time and lead to death. A study showed that 91.38% of patients' families in the ICU said they were afraid if their loved one (patient) died (Oktavia, 2014). The fear of death is related to the prognosis of the disease, the instability of the condition and the chronic diseases suffered by the patient (Płaszewska-żywko & Gazda, 2012; Schmidt, Azoulay, & Syndrome-, 2012).

The fear of death was also expressed by Oktavia (2004) and Urizi (2007) in their qualitative research where most families (91.38%) expressed fear if their loved one (patient) died. This fear of death is related to the perception that patients admitted to the ICU have a poor condition and are at high risk of dying (Urizzi, 2007) where this poor condition is related to the prognosis of the disease, the instability of the condition and the chronic diseases suffered (Płaszewska-żywko & Gazda, 2012; Schmidt, Azoulay, & Syndrome-, 2012).

In addition to the feeling of fear if the patient dies, the use of various medical equipment also provides a unique experience for the family. The number of devices attached to patients makes the family feel sorry for the patient because the family feels that the device will hurt the patient. Urizzi (2007) said that the perception that the device can hurt the patient arises because the family tries to position themselves if they are a patient, so the family assumes that the patient is uncomfortable. The instability of health status makes patients need various treatment aids, but the advantages of using these tools are inversely proportional to the feelings felt by the family. The high percentage of ICU mortality that reaches 31% with a percentage of survival discharge of 69% (Jennifer L, K. Fontaine, Douglas B, A. Dracup, & A. Puntillo, 2014) makes the admission of patients to this unit will lead to a bad end. This picture makes the family always think negatively, and the use of a lot of tools on the patient's body indicates that the patient's condition is deteriorating and getting closer to death.

Feelings of shock on the first day of treatment and a feeling of not believing that their family members have to undergo ICU treatment is one of the factors that make families

distracted from the equipment in the ICU room (Gill et al., 2016). However, this negative experience will later help the family find effective coping to deal with the problem (J. M. Butler, Hirshberg, Hopkins, & Brown, 2016).

The implementation of family roles during the patient care process makes the intensity of family attendance in the hospital higher than outside the hospital. Some of the underlying reasons for the family to always be by the patient's side include feeling sorry for them, moral responsibility as a family and helping with care by being on standby if a room is needed. The same thing was stated by Gill et al., (2016) that it is important for families to always be present near patients, be friendly and be good informants for patients. In addition, the family said that being on standby at the hospital allows the family to quickly find out the development of the patient's condition and can immediately make a decision.

The meaning of being present next to the patient is interpreted differently in each family. In this study, being present next to the patient means being close to the space so that when at any time the family is needed can come immediately. This is different from the findings of other researchers where being present next to the patient is interpreted as always being next to the patient in the ICU room so that the family can listen to the patient's wishes, help treat the patient and advocate for the patient's needs (Jacob et al., 2016; Mcgraw et al., 2013). The same thing was expressed by Erickson (2010) that the family wants to comfort the patient, massage and clean the patient directly. This desire of the family is contrary to the desire of the nurse where 87.5% of the nurses said that family visits burden the nurse and interfere with the process of caring for the patient (Athanasiou, Papathanassoglou, Patiraki, & Mccarthy, 2014).

The patient's unstable health condition demands that the family play a greater role, so that the family is more often in the hospital than outside the hospital. Participants cited the underlying reasons for the family to always be by the patient's side, including feeling sorry, family moral responsibility and being on standby to help with care if a room is needed. Always being in the hospital allows families to ensure that patients get the best care, become patient advocates, always get the latest information on patient developments (Mcgraw et al., 2013) and be an informant for patients (Gill et al., 2016). Although it interferes with family routines, actively accompanying patients can be a source of coping for the family (Adams et al., 2014).

The pressure felt by the family during the patient's treatment, creates physical and psychological problems, so the family needs support to be able to survive. The source of psychological strength felt by the whole family is from God. This is in line with Nuraeni's (2013) research where surrender to God is found to be a source of strength for individuals. The spiritual approach is carried out by the family by praying, dhikr, praying and reading Quranic verses. Dhikr is part of non-pharmacological relaxation techniques that can reduce a person's anxiety level (Patimah, 2015). Families say relying on God according to the religion they believe in also makes God love and empower patients (Majdalani et al., 2014). The family is confident that with the miracle given by God, the patient can recover again (Majdalani et al., 2014). The family experienced hoping for a miracle from God to heal the patient even though according to the medical opinion the patient's condition was getting worse (Address et al., 2011).

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Fouka (2012) said that worship and prayer rituals carried out by families can also change negative emotional conditions into positive ones (Timmins, 2015). In addition to changing the emotional state, by praying, the family also believes that the prayers they pray can help the patient's healing because of God's help through miracles or miracles. The same thing was expressed by Mckiernan & Mccarthy (2010) that spirtual is a source of support for the family and for the patient. The results of the study showed that in addition to emotional support and a comfortable environment, the family also needed psycho-spiritual support (Al-mutair et al., 2013; Nolen & Warren, 2014). This spiritual support can come from the health team, family members and religious groups (Al-mutair et al., 2013). Families feel comfortable, guided and supported by the presence of religious leaders in hospitals where they are facing difficult times (A. E. Butler et al., 2015).

CONCLUSION

Treatment in the Intensive Care Unit room provides a different experience for each family. By using a phenomenological approach, family experiences during the process of assisting patients in the ICU room can be explored in depth and comprehensively. The results of this study obtained 4 themes that describe this family experience, namely fear of not being able to see patients again, pity to see patients with many tools, abandoning the routine of seeing patients, and relying on God. These themes emerged based on the situation and conditions felt by each participant by being influenced by experience or knowledge of care in the ICU room.

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