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Life Quality of End of Life Patient's Family in Intensive Care Units

Noor Fitriyani[1], Achmad Zulfa Juniarto[2], Reni Sulung Utami[3]

[1]STIKes Kusuma Husada Surakarta, Mahasiswa Magister Keperawatan FK UNDIP Semarang
Jl. Jaya Wijaya No 11, kadipiro, Surakarta, Jawa Tengah, Indonesia
[2]Fakultas Kedokteran UNDIP Semarang
Jl. Prof Soedarto SH, Tembalang, Semarang, Jawa Tengah Indonesia
[3]Departemen Ilmu Keperawatan Fakultas Kedokteran UNDIP Semarang
Korespodensi *author*:
Email: pipitnizam87@gmail.com

Abstrak

Lima puluh persen pasien akhir hayat menghabiskan waktu terakhir hidupnya di Unit Perawatan Intensif (ICU). Kondisi akhir kehidupan berdampak pada lingkungan psikologis, fisik, sosial, dan keluarga yang memengaruhi kualitas hidup keluarga lain. Kesejahteraan keluarga akan berdampak pada hasil perawatan, waktu rawat inap, dan tingkat stresor pasien. Tujuan dari penelitian ini adalah untuk mengeksplorasi kualitas hidup keluarga pasien akhir hidup di ICU. Penelitian ini menggunakan metode kualitatif dengan pendekatan fenomenologi deskriptif. Pengambilan sampel dilakukan dengan teknik purposive sampling dengan 9 peserta. data dikumpulkan melalui wawancara mendalam dan dianalisis menggunakan metode Colaizzi. Validitas data dirancang untuk memenuhi prinsip triangulasi peneliti dan teori. Hasil penelitian menunjukkan 7 dimensi kualitas hidup keluarga fisik pasien akhir hidup (kelelahan, gangguan tidur, sakit kepala, nafsu makan menurun), kesehatan mental (kecemasan, kesedihan, harapan peningkatan kondisi kesehatan keluarga), kesehatan spiritual (penerimaan), kesehatan sosial (dukungan sosial), kehidupan sehari-hari (penyesuaian kehidupan sehari-hari), kesehatan keuangan (beban keuangan), dan lingkungan (kesempatan untuk mendapatkan informasi, infrastruktur keluarga). Studi ini menyimpulkan bahwa kondisi akhir hidup pasien kritis berdampak pada 7 dimensi kualitas hidup keluarga. Perawat harus memperhatikan kualitas hidup keluarga karena mempengaruhi kondisi pasien dan keluarga sebagai unit layanan perawatan.

Kata Kunci *: Kualitas Hidup, Keluarga, Akhir Hidup, Unit Perawatan Intensif*

Abstract

Fifty percent of end-of-life patients spend the last time of their life in the Intensive Care Unit (ICU). End of life conditions have an impact on the psychological, physical, social, and family environment that affect the quality of life of other families. Family welfare will have an impact on care outcomes, hospitalization time, and patient stressor levels. The purpose of this study was to explore the life quality of end of life patient's family in ICU. This research used qualitative method with descriptive phenomenology approach. Sampling was done by purposive sampling technique with 9 participants. data were collected through in-depth interviews and analyzed using the Colaizzi method. The data validity was designed to meet the principle of triangulation of researchers and theory. The results showed 7 dimensions of life quality of end of life patient's family of physical health (fatigue, sleep disorder, headache, decreased appetite), mental health (anxiety, sadness, hope of improved family health condition), spiritual health (acceptance), health social (social support), daily life (daily life adjustment), financial health (financial burden), and *environment (opportunity to get information, family infrastructure). This study concludes that end of life condition of critical patients impacts on the 7 dimensions of family life quality. Nurses should pay attention to the family life quality because it affected the condition of the patient and family as the care service unit.*

Keywords*: Life Quality, Family, End Of Life, Intensive Care Unit*

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INTRODUCTION

The *end of life* patient is a condition in which a person experiences the final period of life. Medically, he/she is close to death, and the medical treatment process can not be done (1,2). The condition will create great suffering for *end of life* patients physically, psychologically, socially, and spiritually (3,5). The hospital as a place of end-life patients spends the last 90% of its life and 50% in the Intensive Care Unit (ICU) (6).

End Of Life care services is not only focus on the needs of patients, but also their families (7). The family plays an important role as a major provider of health care, support system, emotional bonding, and proximity for *end of life* patients (8 –11).

Research by Nakken N et al (12) showed that the family prosperity will impact on the family members and length of hospitalization. The application of positive coping by the family will affect the outcome of care for the better patient (13). Another impact on patients is the increased of stressor as a result of psychological disorders that occur in families (14).

Based on preliminary studies and interviews toward six families of *end of life* patients while waiting in the ICU room, they stated that their daily activities were disrupted, tired, uncomfortable, sleepless, occasionally taking medication, threatened with job loss, feeling confused, increasing financial burdens, non-fulfillment of sexual needs, and the limitations of interaction with others. When there was an explanation about the condition of the patient, the families felt anxious, sad, hopeless because of the length of hospitalization, and fear of lossing their family member.

The changes in these aspects will have an impact on the quality of family life. Research related to the life quality of *end of life* patient's family in ICU was needed to prevent of decreasing life quality of *end of life* patient's family. The purpose of this study is to analyze the life quality of the *end of life* patient's family in Intensive Care Unit (ICU).

MATERIALS AND METHODS

The research design was qualitative method with descriptive phenomenology approach. This method focused on the life quality of *end of life* patient's family. The underlying phenomenon was the physical, psychological, social, and environmental changed that occur in the *end of life* patient's family based on the experienced while waiting in the ICU room.

This research used purposive sampling technique. This technique was better to obtain of completeness, the depth of data which direct to important data sources and related to problems study (15–17). There were 9 persons as participants based on some criterias; length of hospitalization > 48 hours, main family member of *end of life* patient, more than 18 years old, and had been waiting for the patients for ≥ 9 hours.

Data collection was conducted in May - June 2017. The implementation of the research was in ICU RSUD Dr. Moewardi Surakarta and Dr. Soeradji Tirtonegoro Klaten. The instruments of data collection were medical status, interview guides, stationery, and voice recorder. Colaizzi method was used to conduct data analysis. The data validity was used some criteria; creadibility, dependability, comfirmability, and tranferability (15). The technique of triangulation was used to make the result valid.

The result of interview transcripts was done by *member checking data* according to the information provided by the participants. The auditing involves mentors, palliative and intensive care experts. The observation methods were conducted to confirm what participants said and how non-verbal participants' responses being interviewed, then discussed the results with the mentors to determine the theme. In order to maintain the objectivity, it can re-contact participants related to the interview's conclusions. The next stages were creating the complete explanation, clear, and systematic so that can be understood by the reader to obtain descriptions about life quality of the *end of life* patient's family in Intensive Care Unit (ICU).

RESULTS AND DISCUSSION

The Result of Thematic Data Analysis

The results of this study obtained 7 dimensions of the *end of life* patient's family in ICU, namely physical health, mental health, spiritual health, social health, daily life, financial health, and environment.

1. Physical Health Dimensions

The physical health dimension influenced the ability of individuals to perform activities. This was experienced by participants when waiting for their family member in ICU. It included four themes, namely fatigue, sleep disorders, headache, and decreased appetite.

There were 4th and 9th participants' statements with fatigue:

> “I feel tired and exhausted because the lack of rest. I waited for 24 hours. My husband has been in ICU room since 7 days ago. There was no family member can replace me waiting for my husband. Sometimes my children accompanied me, except my son who's in elementary school. "(P-4)
>
> "My experienced while waiting for my wife was tired ... after finishing my job, taking a shower, resting at home less than 30 minutes then came to hospital to keep my wife in here, as it continued." (P-9)

1st and 3rd participants' statements with sleep disorders:

> “I often woke up at 2 o'clock. I slept on 12 o'clock at night because of thinking her condition which was getting worse. I couldn't sleep well waiting for my wife in ICU."(P-1)
>
> "I just slept for 1 hour because of thinking her condition. Here, I can slept on the floor sleep, but cold because the wind from outside of the window went inside. "(P-3)

4th and 8th participants' statements with headache:

> "Sometimes, I got dizzy because of waking up irregularly." (P-4)
> "I felt dizzy, but healing by itself. My sleep wasn't comfy ." (P-8)

6th participant's statements with decreased appetite:

> "My appetite diminished, I was thinking of my husband health condition" (P-6)

Fatigue was felt by participants due to length of waiting for the patients during the treatment in the ICU. Fatigue was experienced by the patient's family in ICU as a result of limited time to have time off (18,19).

Sleeping disorders experienced by participants due to the deterioration of the patient's condition, the responsibilities that must be fulfilled in accordance with its role, inadequate environmental conditions, thinking about abandoned families, and bad premonitions. Most of families wanted to wait and take care of the patient, consequently they did not get enough time to take a rest and keep their own health. Environmental factors made the patient's family experienced sleeping disorders due to the unfamiliar environment (21).

Another symptom of a physical disorder was headache and decreased appetite. Some of the problems arised in the physical health dimensions which experienced by participants were pain, appetite and weight loss(20,22,23)

2. Mental Health Dimensions

The mental health dimension related to the individual mental which leads a person's ability to adapt. There were 3 identified themes on mental health dimensions, namely anxiety, sadness and expectations of improving patient's health conditions. There were the 3rd, 4th and 6th participant statements with anxiety and the taken actions:

> "Anxious, restless, and thought. If my wife has to go back to God ...... then if there was a call from ICU officer, felt anxiously. "(P-1)

> "I felt anxious because the illness was serious. Hearing the doctor said that his opportunity to save was difficult .... the percentage to death was closed .... My heart was beating so fast, *deg-degan* "(P-3)

> "When thinking about my husband's current health condition, It's better for me to silent, praying as much as I could, Allah SWT may be given strength for my husband, me and family." (P-6)

The following 6th and 7th participants' statements which expressed sad:

> " I'm sad because of my husband's condition, didn't improve." (P-6)

> "Here, I'm sad, crying, thinking of my husband. Hoping and asking Allah, my husband doesn't die. "(P-7)

The following 6th participant's statements which improved patient health conditions:

> "I hoped my husband's health improves. The worst thing was losing my husband. I always pray and pray. Sometimes, I do *Tahajud*, praying constantly, sitting with *dhikr* and *shalawat*. I begged a miracle of health for my husband. I also tried to give holy water from *Ustadz*, smeared on his lips, rubbed on his face and his body. We pray together with *Ustadz* (Spritual Teacher). "(P-6)

Anxiety and sadness experienced by participants due to patient's health conditions. Emotional changed was fear of losing, after getting explanation from the doctor about the condition of patient who was near from death.

The families felt anxiety and sadness because they had not been able to accept the patient's health condition and they were not ready to lose their family's member (20). The life quality will be decreased if they felt anxiety and sadness continuously(24).

In this study, the participants' relationship was a couple (husband/wife) and child. The life partner was the closest person, act as the primary caretaker for the patient and having affective function in fulfilling the psychological needs so that it had a big effect on the life quality for the family and patient (25).

All participants said there was a hope that the patient's health condition could be improved through the prayed or died in good condition. Most families believed that pray can change the situation and God will deliver miracles by changing the whole situation (26). The appearance of the family's expectations of a good death to the patient and the togetherness of the family members at the end of patient's life will provide the best possible care assessment so that patients will be happy (26,27).

3. Spiritual Health Dimensions

The spiritual health dimension was one's experience with the *acceptance* of life. *Acceptance* theme appears on the spiritual health dimension. Feelings of *acceptance* by participants were conditions of surrender, heartfelt, mentally prepared and believe in healing. The following 1st, 5th and 6th participant statements with *Acceptance*:

> "Because of age factor, surgical action was not necessarily cured her condition ..... After surgery, it could be possible of an infection." (P-1)

> "Belief, calm, and eager in life." (P-5)

> "I also tried to give holy water from Ustadz, smeared on his lips, rubbed on his face and his body. We pray together with Ustadz (Spritual Teacher). "(P-6)

The participants showed resignation to the *end of life* patient's condition and the their's trust level to the patient's healing efforts other than medical according to their belief. There was a change of self by the participants through his expression which shows the increased activity of worship.

According to Pilger C, Molzahn AE, Oliveira MP, Kusumota L(28) on the religious and spiritual dimension related to life satisfaction thus affecting the quality of one's life. Spiritual need is an important component of quality health care for patients and families, It impacts on positive thinking, loving each others, finding a meaning in life, and connecting to God (29).

4. Social Health Dimension

The social health dimension was the relationship between two or more individuals. social support appears in the social health dimension. The following to 1st, 4th and 6th participants' expressions with *social support*:

> "Alhamdulillah, until now there were some families' member want to take turns on waiting my wife. My co-worker understood my current position. There was'nt problem if I took time off..... friends and neighbors came to visit my wife. They wanted to know the progress of my wife's condition, pray, give money or food. .... my wife was active in mosque and often participated in social activities, her spiritial teacher and friends also prayed together for my wife's health. "(P-1)

> "My family supported my husband's got health treatment in here. His family came here for praying and giving support to be patient and strong. Giving money, sometimes they gave 200 thousand rupiahs, sometimes more or less than its. They showed me their love. "(P-4)
> "... my neighbors also had time to visit and give support." (P-6)

All participants in this study received support from their family, friends, or religious groups, and found the family relationships quality improved. Social support was provided by the nearest person, so it affected the comfortable in hospital and had positive effect on *end of life* care (30,31).

5. Daily Life Dimension

Daily life Dimensions was an activity that individuals do in daily activities. It identified a theme on the daily life dimensions, namely:

adjustment of daily life. The following were 1st, 4th and 8th participants' expressions with adjustment of daily life:

> "I never went home as long as my wife was in ICU. I went to hospital after finishing my work. I waited information from the inside, just sitting and lying in the waiting room, eating and bathing were done in here, and taking drugs at the pharmacy" (P-1)
>
> "I usually take care of my children because I'm a housewife but with this condition, I'm just waiting to hear about the condition of my husband, taking drugs, sitting praying, eating, and bathing in here." (P-4)
>
> ".... as long as my son is being sick in here, I stop working. Just sitting, sleeping, worshiping, and waiting for news in the waiting room "(P-8)

The participants stated that they had to leave their jobs since their family members were being hospitalized. In this study, most of their relationships was child or spouse.

The results of this study were supported by previous research by Yoon S et al(32) a change experienced by families of cancer patients with a terminal phase in Korea expressed thei inability to run activities as usual due to family social burden that has the responsibility of waiting for family members who were sick.

6. Financial Health Dimension

The financial health dimensions related to how individuals got financial problems. There was one theme on the financial health dimension that wass the current financial burden. The following were 4th, 6th and 8th participants' expressions:

> "When my son accompanied me in here, he lost his cell phone. This was a burden for me, my current economic condition is very heavy. The cost in this hospital is high enough. I do not participate BPJS so use the general cost. My husband as main worker in my family, while I am a housewife. I have 3 children, who are in college, Senior high school, and 5th grade elementary school. I have spent much money to pay a health care in this hospital. "(P-4)
>
> "Maybe, for entering school fee of my children, I will sell my motorcycles because it's the only one we have. If my husband dies, I wil be the head of my family. I have to work for family to live together. "(P-6)
>
> "During this time my husband and I did not work because my parents suggested to focus on our child. The most important thing is the health of our child. I use my saving money to pay a health care in this hospital and other needs. "(P-8)

The condition of the financial burden experienced by the participants due to the relatively high cost of care in ICU room, the treated patient is the only one who works in his family, and now both of them were not working, and then they should fulfill of other needs.

The patient's condition made 80% financial burden on the family economy due to the ICU's costs, lost income, and savings. It made the current financial burden, future financial worries, and financial constraints so it was necessary to make adjustments and limitations on spending money. Similar to the conducted survey in Nigeria, financial health dimension appears on the life quality of family which caused financial burden by the *end of life* patients' condition (34).

7. Environmental Dimensions

The environmental dimension was the individual's residence/place which included the circumstances, facilities and infrastructure that can support their life.

There were *opportunity to get information and health care* themes on the environmental dimension. The following were 2nd, 3rd, 7th and 8th participant's expressions:

> "The doctor did a good job. He explained that the patient's condition was already small chance for life. "(P-2).
>
> "Uncomfortable waiting room and jam. The toilet smelled too bad, queuing up. Many items were lost, such as money, cell phones and other goods. "(P-3)
>
> "The information related to the development of the patient's condition and the action to be taken in treatment was presented by nurse or doctor." (P-7)
>
> "We should ask information related to the development of the patient's condition. Sometimes the officer informs us about certain actions and not all medications should get family approval. "(P-8)

In this study, participants stated that sometimes they asked for information to the nurse / doctor related to the development or health condition of the patient. The nurse and doctor provided the same information as well as the family's approval to the treatment given to the patient, and the cost of patient's care.

Informations were needed to find out how the patient was treated medically, to know the specific facts about the progress of the patient's condition at least once. It was important to achieve the quality of service on *end of life* care (35,36).

In this study, care services provided not only for patients but also families, including the security and physical environment of hospitals. This was reinforced by Heidari MR's research; Norouzadeh R (37) from the experienced of Iranian nurses on the *end of life* patient's family in ICU, by facilitating the waiting room environment will provide comfortable sense for patient's family.

CONCLUSIONS AND SUGGESTIONS

There were Identified 7 dimensions of life quality of *end of life* patient's family, namely physical health, mental health, spiritual health, social health, daily life, financial health, and environmental.

It was important for families to be able to understand the impact of problems which arised when waiting for families with *end of life* phase in the ICU. There were the role of patient's waiting substitute, doing family health checked, and taking time to rest as an effort to overcome changes in physical health conditions. Family's awareness to increase religious activities and discuss with family or the closest people to solve the mental health problems. Participated in the health insurance program to solve the financial burden for the family. Providing moral support from the family's member or the nearest person, especially in the crucial time.

Hospitals as health care providers should facilitate the family's health checked that were comfortable to rest, close to the patient, and secure physically and psychologically. Nurses, spiritual teacher and psychologicst helped families to anticipate the effects of mental health problems. The hospital should provide information to the family regarding the patient's condition, approval and action treatment to the patient, and considering the needs of the family at least once a day.

It was suggested to conduct further research through measuring and analyzing of the life quality of *end of life* patient's family.

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