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FAMILY PERCEPTION OF LIFE-SUSTAINING TREATMENT WITHDRAWAL IN PATIENT WITH SEVERE BRAIN INJURY: A QUALITATIVE STUDY IN BANDUNG-INDONESIA

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Abstract

Background: The decision-making process for withdrawing life-sustaining treatment (LST) in patients with severe brain injury can potentially become a problem between doctor and family because of different opinions.

Objective: Explore the family consideration in withdrawing LST in patients with severe brain injury.

Methods: This qualitative descriptive study with phenomenological approach conducted using semi-structured in-depth interview. Subjects were family members of coma patients due to severe brain injury and were admitted to the Intensive Care Unit in Hasan Sadikin General Hospital during January 2019 - December 2020.

Results: The results of the five-participant interview showed that the considerations for withdrawing LST include: (1) the patient's condition, (2) family psychology, (3) resources, and (4) family beliefs.

Conclusion: Doctors need to understand the family's considerations in terminating LST to bridge the inner conflicts that occur in the patient's family.

Keyword: *Family perception, brain injury, life-sustaining treatment withdrawal, Indonesia*

Introduction

Brain injury is the leading cause of death and disability in the world. (1) The mortality rate of traumatic brain injury ranges from 30% to 60% and approximately 15.4% in stroke. (2,3) The cognitive, physical, behavioural, emotional, and social impairment in brain injury patients could impact the health, life, and economy of the patient's family and relatives. (1,4) A study in Canada showed that 45% to 86.8% of deaths in severe traumatic brain injury patients were due to

withdrawal of life-sustaining treatment (LST), and no patient survived after removal of the device. (2)

The continuation of LST in patients with severe acute brain injury often allows patients to live for months or years but at the cost of being left in a state of disability that might be against their wishes. (5) Turgeon et al. noted variability in the timing of the withdrawal of life- sustaining therapy between trauma centres. Early withdrawal raises the concern of not only hastening death but increasing mortality for patients who might recover if given longer periods, whereas allowing patients to linger for extended periods may only result in prolonged suffering or patients and their relatives. (6,7)

Decisions about goals of care, treatment options, including withdrawal or withholding LST in severe brain injury patients need to be made by the family and doctors because the patients cannot make decisions by themselves. (2) The issue of LST withdrawal first addressed by the Supreme Court in Cruzan case in the United States, which involved different arguments between parents and doctors. (8) One of the main factors in deciding LST withdrawal is the patients' prognosis for recovery. Nevertheless, only a few reliable tools to inform prognosis of severe brain injury patients; therefore, prognostication is often based on clinicians' subjective judgment and experiences. (2) Furthermore, Kuehlmeyer et al. revealed other factors, namely the patients' aforementioned wishes, family expectations of the patient's recovery, family's definition of life-sustaining treatments, and the assumed moral obligation not to harm the patient. (9)

Indonesia is a country that has a variety of cultures and ethnicities, which generally are known as polite and tolerant people. (10) More than 70% of Indonesian people are Muslims. (11) Although there has been an increase in the middle-class group in the early Millenium, many Indonesians still have a relatively low level of education, with a high unemployment rate. (12,13) The country undergoes a shifting from rural to urban economy, with 56% living in urban area in 2019. (14) These characteristics of society may influence the view of an individual on an issue. In this study, the authors would like to explore the patient's family considerations in the withdrawal of life-sustaining treatments in severe brain injury patients in Indonesia. Although the process of end-of-life decision making in patients with severe brain injury is a routine in clinical practice, it has received little attention in the published medical work, especially when compared with similar decisions in patients with more gradually progressive severe illness. (5)

Methods

This research was an observational study with a qualitative descriptive method through a phenomenological approach. The aim is to explore how individuals perceive an issue based on their subjective experience. The subjects were selected through criterion sampling with inclusion criteria were family members who were surrogates of patients who had coma due to severe brain injury and were treated at the Intensive Care Unit (ICU) of Hasan Sadikin General Hospital (RSHS) and had been using at least one life-sustaining treatment during the period January 2019-December 2020. The criteria for subjects are adults (age>18 years old) with the closest family relationship with the patients (husband/wife, son/daughter, siblings) who had been taking care of patients while the patient was hospitalized, and residents of Bandung City.

Data were collected through semi-structured in-depth interviews of the patient's family members. Interviews are conducted verbally via telephone or other devices that the patient's family prefers in 30-60 minutes. The questions were about the patient's family considerations in determining the withdrawal of life-sustaining treatment. Interview recordings were then

transcribed verbatim, then analyzed by categorizing and compiling data. The credibility test of the results was done by member-check.

From 62 medical records of patients with severe brain injury treated in the ICU RSHS from January 2019 to December 2020, 42 were excluded because there was no clear family identity. The remaining 17 medical records met the inclusion criteria. A total of five family members of patients could be contacted and were willing to participate in the study.

Results

The participants were two males and three females with mean was 38 years, and all of them in the 30-49 age group. The participants' educational backgrounds varied from elementary school, high school, vocational college, and bachelor graduates. All participants were Muslim. Participants' occupations were employees, civil servants, and housewives. The participant and patient demographics are shown in tables 1 and 2. There are four considerations of the patient's family in terminating the life support system, namely (1) the patient's condition factor, (2) family psychological factors, (3) resource factors, and (4) family belief factors.

Tabel 1. Participants Characteristics

Code	Gender	Age (yrs)	Educational background	Occupation	Religion	Relation with patient
P1	Male	37	Diploma	Employees	Islam	Son
P2	Male	42	Undergraduate	Civil servants	Islam	Sibling
P3	Female	39	Undergraduate	Housewife	Islam	Son
P4	Female	36	Elementary school	Housewife	Islam	Sibling
P5	Female	34	High school	Housewife	Islam	Wife

Tabel 2. Patients Characteristic

Participants code	Gender	Age (yrs)	ICU length of stay (days)	Outcome
P1	Male	60	12	Ceased
P2	Male	43	8	Ceased
P3	Male	66	34	Ceased
P4	Male	16	9	Ceased
P5	Male	32	6	Ceased

ICU: Intensive Care Unit

Patient's condition

The patient's condition was the main consideration in determining the patient's termination of life. The absence of signs of improvement in the patient's condition, especially awareness, and the low probability of patient recovery made the family more likely to choose to end the patient's life.

> "From the time of hospital admission, surgery, till the D day I decided to bring him home in my eye, my brother's condition showed no progress. There was a suggestion from a relative that if we see this kind of situation we better take it off, we just bring him home. […] If he looked better I might have kept it maintained, because we wanted to do it maximally right, he was healthy before wished him to became healthy again" (P2)

Family Psychological Conditions

The death of a close family member can lead to stress. When the family decides to end the patient's life, mental readiness for loss becomes very important.

> "So if we were asked what's our feeling when the equipment was withdrawn, we ourselves because we have prepared mentally, even he was supported by equipment we've already known his condition was like that, […] well we were *ikhlas* (accepting) as if he was already gone since the beginning of the accident […] So well *alhamdulillah* (praise to God) we found it mentally that this life is not eternal one day we are going to be like that" (P3)

Most of the participants were afraid that the patient would only live because they were supported by life-sustaining treatment. They thought that patients who survive only because of that might not be fully alive.

> "[we] fear – what was the word – he was hanging there because of the equipment that was. […] fear that he was actually already not there, but because of the equipment the days were added, trapped." (P2)

> "Even the doctor said mam his life was depending on the ventilator and medicine. […] If for example he was not given any medicine or if for instance the ventilator was withdrawn it's over, (well it's) over mam he was not going to survive. Well, what the doctor's said we discussed it again, we as his children agreed that was not necessarily that what we thought was the best would become the best thing including for my mother too" (P1)

Participants in this study had the same view that they felt the process of receiving life- sustaining treatments for a long time would increase a patient's suffering.

> "It would be exhausting right to keep wearing that equipment, […] I didn't want to hurt his body any longer, just stop […]" (P3)

Resources

Based on interviews, the ICU could costs tens to hundreds of millions of rupiah (equal to thousands to tenths of thousand US dollars). For families with a low socioeconomic level who are not registered with health insurance, this was one of the considerations in maintaining the LST. In this study, three patients were fully covered by health insurance, one patient was partially covered, and the other did not have health insurance. Participants whose patient did not have health insurance felt that the costs incurred were burdensome and highly considered in ending the life support, coupled with seeing the patient's unpredictable condition.

> "[…] a lot of consideration, from our time, our energy, our financial too. […] Because

the cost had been increased by day it's just swollen swollen, it's quite (high)" (P2)

Q: "Why did it withdrawn?"
A: "Well pity, the first was pity, the second well there was no fund anymore. But (I) don't know if (we) had large fund maybe he could survive for several days longer." (P4)

Apart from costs, the energy spent in caring for patients is also a consideration. In one case, the patient was an unmarried man, 43 years old, orphaned, then all matters related to the patient were taken care of by his siblings. Apart from caring for patients, their younger siblings also have a responsibility to care for their own families; therefore, they could not treat patients optimally**.**

"By chance, my brother didn't have family (unmarried), our parents had passed away, it's like – what's the word – the siblings like older and younger siblings took all the responsibility, like that. If only he had children or wife, maybe his children and wife could (take care of him) more maximal." (P2)

Family belief

All participants were Muslim, and two of them considered themselves as observant ones. Both participants felt apprehension that to depend the patient's life on tools, such as LST, could be considered as against the provisions set by the Almighty.

"[…] even if there is a special room (to take care of the patient) till 20 years forward, I thought I meant is it contradictory with our religious teaching? We sustain a man's life which perhaps his time has already ended, maybe Allah had another willing. So just never mind" (P3)

Discussion

Most patients in a prolonged coma will eventually remain unconscious, survive disabled, or die. (15,16) Limiting LST in patients is often considered by the family. Families endure emotional burdens filled with sadness, fear, and even guilt. However, in the USA, the decision to remove the LST is the most common cause of death in comatose patients. (16) In our study, although the decision can be made collaboratively between the family and doctors, the doctors play an essential role in giving sufficient information regarding the disease and the suffering the patient might experience.

A number of studies showed that family as caregivers of long-term brain injury patients have high levels of anxiety, depression, family tension, and prolonged grief, a condition characterized by disturbing thoughts, guilt, dissatisfaction, empty and meaninglessness. (17) The family feels that their loved one is still alive but also has died simultaneously. The phenomenon experienced by the family is defined as an emotional paradox by Stern et al. (9,18) In this study, some participants afraid if the patient was dead, but was "forced" to survive by LST.

In a study in Italy by Cipolleta et al., five of the fourteen family members wanted the continuation of LST because they could not bear the loss of their loved one and could not imagine their life without the patient, although some said the patients might disagree. They considered themselves lucky enough to have patients with them. (19) Kuehlmeyer et al. found a contradiction

conveyed by one of the participants in Germany, that withdrawing the LST is inhumane to others, but for himself, he would choose to give up all the means of life support if one day he falls on that condition. But the Kuehlmeyer study also revealed that even though the family did not expect improvement in the patient's condition anymore, most of them still wanted to continue all therapeutic interventions. (9) Meanwhile, in our study, participants felt that if they let the patient live longer in that kind of condition, with all the life-supporting tools attached to his body, they will increase the patient's suffering. Considering the patient's possible feelings at that time, participants expressed that they did not want to impose the patient's life. The result is in line with Kitzinger et al. in the UK, which described a vegetative patient's family's experience when removing a nasogastric tube from the patient. The family revealed that they wanted the LST withdrawal because they believed that maintaining the patient in this state was morally wrong. (20)

Families play an essential role in patients' life, often at the expense of their health and well-being. (21) They hold a unique position of both providing and needing support for themselves. (22) In a study conducted by in Italy Leonardi et al., half of the patient's family spent more than 3 hours with the patient. (23) Not only lose time, but some also lose their jobs, interests, hobbies, friends, and feel socially isolated. (19)

Economic factor also triggers stress and anxiety in the family when patients are admitted to the ICU. It could be due to an ICU where patients are critically ill and receive intensive care and close monitoring, and it is the most expensive medical service. (24) In the USA, in 2005, critical care costs accounted for 13% of hospitalization costs. (25,26) Expensive treatment of critically ill patients may be ineffective and may cause discomfort, such as the insertion of devices that cause pain. (27) Expensive treatments at the end of a patient's life may also be incompatible with patient preferences and values, and impose an emotional, physical, and financial burden that unnecessary to the patient and the family. (28)

Another interesting consideration that emerges from our study is the principle of not wanting to impose destiny. This consideration is a novel category that emerges from this study that has not been found in the previous studies. All participants in this study were Muslim, which believes that death is a destiny that has been written. Two participants who considered themselves as observant Muslims believed that letting the patients live longer with LST seemed to be against a predetermined fate. This apprehension is somewhat consistent with some prominent Islamic legal scholars claimed. For example, Yusuf Qardhawi opined that if the patient's condition does not improve after treatment for a long time, continuing the treatment is neither mandatory nor sunna. (29)

This research has a limitation. Due to Covid-19 pandemic, the interview was not conducted face-to-face; therefore, facial expression or body language could be observed. The face-to-face interview may increase participants' trust to be more open and provide more in- depth data. Quantitative follow-up research should also be undertaken to provide data on what matters the most, particularly in various Indonesian contexts. This type of research is necessary to represent public opinion to be given special attention by healthcare professionals.

Conclusion

This study reveals several considerations that arise from the family regarding the termination of the LST in patients with severe brain injury, namely: (1) the patient's condition, (2) family psychology, (3) resources, (4) family beliefs. It is vital for healthcare professionals to understand these considerations, to take a better approach in collaborating with families in decision-making.

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