

Family Experience In Decision Making Regarding Medical Treatment In Terminal Disease Patients: A Phenomenological Study

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Abstract:

Background: Making decisions about medical procedures can cause psychological stress and confusion in family members. Family members of critically ill patients are routinely asked to participate in medical decision making. In such conditions, nurses must be able to control the situation, especially towards families in crisis who require attention because someone's death can occur suddenly. The aim of this study was to explore family experiences in making decisions regarding medical treatment for terminally ill patients.

Materials and Methods: This research used a qualitative method with a Focus Group Discussion (FGD) approach on 5 family members with critically ill patients being treated in the ICU. Data analysis was carried out using the Collaizi method.

Results: The results of this research found 5 themes, namely 1) Nurses' attitudes in caring for patients, 2) Seeking information before making decisions, 3) Role and function of decision makers. 4) The patient's right to get the best service, and 5) Evaluate every action taken. Evaluation of decision making must be carried out with good communication and clarification by the nurse. Continuous monitoring of the patient's condition requires adjustments to the implementation plan, evaluating suggestions from others, admitting mistakes, reversing poor choices, and ultimately sticking with the right decision. Decision making regarding medical procedures is important during the care of terminally ill patients, so a nurse's attitude is needed that fosters calm in family members.

Key words: Decision making, medical procedures, family.

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I. Introduction

The increasing number of patients with terminal illnesses in both adults and children such as cancer, degenerative diseases, lung diseases, cystic fibrosis, stroke, Parkinson's, heart failure, genetic diseases and other infectious diseases require palliative care, in addition to promotive, preventive, curative and rehabilitative [3].

Palliative care is needed for various diseases, especially chronic diseases such as cardiovascular disease (38.5%), cancer (34%), chronic respiratory disease (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological diseases, dementia, congenital anomalies and drug-resistant tuberculosis [18].

Riskesdas data shows the prevalence of cardiovascular diseases such as hypertension increased from 25.8% in 2013 to 34.1% in 2018, stroke from 12.1 in 2013 to 10.9 in 2018, coronary heart disease remained at 1.5% in 2013-2018, chronic kidney failure, from 0.2% in 2013 to 0.38% in 2018 [6]. Cardiovascular diseases such as heart disease, cancer, stroke, kidney failure continue to increase every year and rank as the highest cause of death in Indonesia, especially in the productive ages [5].

The number of diseases that cannot be cured for both adult and pediatric patients is increasing, terminal diseases are diseases that cannot be medically cured, this disease occurs at an advanced stage [13]. Terminal illness is a condition experienced by individuals who undergo a medical condition and ultimately end in death within a very limited time [15]. Treatment for terminal patients aims to reduce pain, by preventing the patient from suffering due to an illness they are experiencing that can no longer be treated [19]. In this case, the orientation of the services provided to patients is not only healing, but also care that enables patients to achieve the best quality of life for themselves and their families [13].

The patient was treated at *Intensive Care Unit* (ICU) for several reasons, namely: level of ICU monitoring, intensive nursing care, special procedures, and therapy with special requirements or risks. At the time of ICU

admission, patients have specific needs related to their diagnosis such as gastrointestinal bleeding, septic shock, or acute renal failure. In addition, all patients require special attention to some universal needs [7]. Family members of critically ill patients are routinely asked to participate in medical decision making, they adopt the role of substitute decision maker in patients who are unable to make decisions. Families are responsible for complex medical decisions with uncertain risks, benefits, and outcomes [10]. ICU physicians look for one person to be the primary decision maker, a family role that physicians view as central to end-of-life decision making when the patient is incapacitated [12].

Critical illness and treatment in the ICU creating a stressful experience for patients and their families [10]. The results of research conducted by Quinn [12] show that families have many decision makers, differences of opinion between families hinder the decision-making process, apart from that there are families who use their own opinions in the decision-making process.

Decision making causes psychological pressure on family members, families experience difficulty in making decisions and feel anxious about mistakes in making the best decisions [10]. The results of research conducted by Iverson [2] stated that some people experience more doubt or regret in decision making. Apart from that, families also experience confusion about disease treatment or treatment plans. Families experience psychological burdens in making choices [16].

Family members often rely heavily on family health care professionals for guidance in the end-of-life decision-making process [7]. Shared decision making is one of the most important roles of family members treated in the ICU. In lieu of this, they are asked to understand treatment options that are often unknown to them, weigh complex risks and benefits, predict the patient's and their own responses to future health status [10]. Therefore, a related explanation is needed *informed consent* clear and complete information to the patient's family.

The decision-making process goes through several stages, namely identifying the need for a decision and collecting data, determining the goal or desired result, identifying alternatives, identifying the consequences of each alternative, identifying the benefits of each alternative, making a decision and acting and evaluating the decision [4].

The results of research conducted show that being part of decision making is a hope expressed by all families, which will help them understand what is happening to their sick family member. Families expressed a desire to be more actively involved in the decision-making process. The aim of this research is to explore family experiences in making decisions regarding medical treatment for terminally ill patients [3].

II. Material And Methods

This research is qualitative research with a phenomenological design which was conducted from August-September 2023 at one of the regional hospitals in Indonesia. *Key participants* in this study, the inclusion criteria were patient's family aged 21 years and above and 18 years and above for those who are married, able to communicate well, cooperative, willing to be an informant in this research. Whereas *Associate participant* in this study were nurses and room heads. The sample in this study was 5 participants. Data collection is carried out with *in-dept interview* and a semi-structured interview guide with open-ended questions developed by the researcher. Data analysis uses the collaizi method which has been arranged systematically.

III. Result

The results of this research found 5 themes, including nurses' attitudes in caring for patients, obstacles, looking for sources of information in making decisions, roles and functions of decision makers, the patient's right to get the best service, the patient's right to get the best service and evaluate every action taken. The following is an analysis of the data and themes obtained from the interview results with several questions described as follows:

Tabel-1: Data Analysis

Meaning Unit	Coding	Subcategory	Category	Theme
Nurses are friendly and polite. Nurses on duty 24 hours The nurse tells each patient's good and bad condition. The patient understands the family's feelings. Nurses as advocates	Friendly, polite, caring, 24-hour guard, explanation, empathy, advocate	Nurses' attitudes towards family presence	Good behavior shown by nurses while patients are being cared for	The attitude of nurses in caring for patients

Meaning Unit	Coding	Subcategory	Category	Theme
Family Hold discussions with the family Discussion to obtain information and make decisions. Discussion by consulting with siblings and family	Discussion, information, decision making, joint discussion	Decision making through a discussion process	Information gathering and decision making	Look for sources of information in making decisions
Ask the opinions of people around you. Seek better information from friends and relatives	Asking, Opinions of friends and relatives, very good information	Get better information		
Making decisions regarding medical procedures with family members The final decision on treatment is the parents. Treatment decisions are determined by men	Decision making, Final decision, Determinants of decision making	Determinants of decision and further treatment	Involvement of people in decision making	Roles and functions of decision makers
Sick people must have the best place. Placing patient health as a priority Families are given freedom in choosing services	The best place, The main thing, autonomy and priority	Patients have the right to get the best treatment and be free to choose	Healing is a priority and the family's right to know	The patient's right to get the best service
The most important action given is what is best for the patient's recovery. The family must know the explanation of the actions that will be given	Best action, healing, explanation to family	The best course of action should be known to the family		
The nurse evaluates the actions carried out in the hospital. The nurse asks how the family feels during the treatment. The nurse explains any changes in the patient's condition	Evaluation, Asking about family feelings, changes in the patient's condition	See the patient's progress after the procedure	Measuring the level of success of an action	Evaluate every action taken

The attitude of nurses in caring for patients

This theme explains that nurses provide good service while caring for patients. Some participants expressed their experiences as follows:

"The nurse is inside. Always on guard 24 hours" (P1)

"The nurse's attitude is good. friendly. Polite" (P2)

"In my opinion, thank God, the service here is good. The nurse's attitude. "Alhamdulillah, it's good too, friendly" (P3)

"Yes, including how you feel, whether there are complaints or not, you can still ask" (P4)

Look for sources of information in making decisions.

Before making a decision regarding medical treatment for a patient, the family seeks information regarding the action to be taken and the patient's condition. This is done so that the action taken is the right action. The information obtained starts from partners, parents, family, siblings and friends.

"The two of us, the important thing is that we have shared it first, looking for information outside of what it is, how it is, ask the families" (P4)

"First of all, the parents, uncle, then the family, there are sisters, there are brothers (people who are asked for their opinion)" (P2)

"With the existing doctor, but I will consult again with my friend" (P4)

Roles and functions of decision makers

Decisions regarding medical procedures to be carried out on patients with this disease are taken through joint decisions with family members. However, there were also participants who said that the final decision was the decision of their parents and husband. The following is the participant's statement:

"Mother. After that, brother, because brother, he works at ZA Hospital" (P2)

"You're welcome too. "It's more the husband's responsibility, but my brother's husband also asks me as his younger brother" (P1)

The patient's right to get the best service.

When making a decision regarding the medical action to be given, the aim of the action is to achieve healing for the patient, where the patient's health is the main priority, therefore the patient has the right to receive the best service. However, apart from that, patients and families also have the right to choose the actions to be taken. The following is the participant's statement:

"Yes, freedom. But right... We are definitely the best choice. I told the doctor, right? How good is the doctor" (P1)

"Oh, at that time I had given up. Everyone has given up. Our family has given up. How is it good to continue" (P1)

"Yes, quickly, of course if there is a complaint from us, it will be immediately responded to by them, from the nurse" (P2)

The nurse also provides an explanation to the family regarding the actions that will be given to the patient. So that the family also knows about the actions that will be given to the patient. This is in accordance with what was conveyed by participants during the interview as follows:

"It's been said right down to the effects it's been said" (P3)

Evaluate every action taken.

After a decision is made, and after the action is taken, an evaluation is always carried out. Withsee the patient's development after the action is carried out, the extent to which the decision is the right thing to be successful, and what improvements need to be made. The following is the participant's statement:

"Yes, the nurse said earlier that this has progressed, thank God" (P1)

"Checking again. In fact, they are always monitoring" (P2)

Based on the results of the interview *on associate participant* namely carers and nurses, that the statements expressed by participants were in accordance with what had been done so far in the hospital regarding the implementation of services in the ICU.

IV. Discussion

This research is in line with research, families who refuse to provide treatment will be discussed with the family to make decisions related to signing *informed consent* or rejection form [8]. The findings in this research also explain that patients have the right to get the best service. research conducted shows that the implementation of quality of care in the ICU and meeting family needs is on average good. Patients and families are satisfied with nursing services, especially regarding responsiveness and empathy [11].

Research shows that the decision-making process for family members with terminal illnesses requires considerations to be able to make final decisions regarding treatment plans for their loved family members [1].

Patients in terminal situations are individuals who have autonomy or freedom. Autonomy emphasizes that the patient can determine decisions regarding himself. Patients also have the right to know the truth about their condition, including their death [11].

The actions taken are always evaluated, by carrying out evaluations the effectiveness of the actions to be taken can be measured, apart from that, to find out whether the objectives in making decisions have been achieved, evaluating the actions that have been taken can help in planning further actions. In this case the nurse also asks about the patient's progress. Apart from that, the nurse also explains any changes in the patient's condition.

Nurses carry out evaluations of nursing actions including compiling an evaluation of results based on the patient's progress, collaborating or involving the patient's family in the evaluation, planning and carrying out

reassessments on nursing problems that have not been resolved, evaluating whether the patient's needs are met, evaluating whether the goals of the nursing plan are achieved [17]. Evaluation is also part of correcting matters related to the positive and negative actions regarding the development and changes in the health of patients with terminal illnesses, so that it can be taken into consideration regarding evaluation in making decisions regarding the medical actions carried out.

Every decision requires us to interpret and evaluate [14]. Decision evaluation includes communication and clarification to conduct continuous analysis and monitoring of any circumstances that may require adjustments to the implementation plan, evaluating suggestions from others, admitting mistakes, withdrawing from bad choices, and ultimately sticking with the right decision [9].

V. Conclusion

Decision making in carrying out medical treatment for terminal illnesses based on information from informants consists of five themes, namely the attitude of nurses in caring for patients, looking for sources of information in making decisions, the role and function of decision makers, the patient's right to get the best service, evaluating every action taken. Evaluation of decision making must be carried out with good communication and clarification by the nurse. Continuous monitoring of the patient's condition requires adjustments to the implementation plan, evaluating suggestions from others, admitting mistakes, reversing poor choices, and ultimately sticking with the right decision. Decision making regarding medical procedures is important during the care of terminally ill patients, so a nurse's attitude is needed that fosters calm in family members.

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