

# **The Need of Palliative Care for Javanese People Living with Life-Threatening Illness: A Qualitative Study**

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## **Abstract**

**Objectives:** As the result of illness trajectories, people with advanced chronic diseases are living with inability to perform major activities, often with pain, or other uncomfortable symptoms. Therefore, integrated life-threatening care, consequently, is very necessary to relieve suffering, implement life-prolonging treatments when possible and appropriate, improve quality of life, support the caregivers, and apply rehabilitation process. This research conducted qualitative method in order to investigate the people living with life-threatening illness and the caregivers' perspectives toward health and sick, death and the dying process, also the need of palliative care services. **Method:** Data collections were conducted through in-depth interviews explored the perspective of the participants about the need of palliative care service. Three informants living with life-threatening disease (stroke, cancer, and lung disease) and two caregivers participated into this research. Data were analyzed with thematic content analysis and resulted 51 codes and 11 categorizations. **Results:** There are four main themes retrieved from this study stated that sick condition influences others, family as a part of the patients' caring, death and dying is necessary to be discussed and prepared, also that end-of-life care should be provided for all. **Conclusion:** It is recommended that nurses should understand the competencies of palliative care. The skills will be important to deliver nursing care for patients and families living with life-threatening diseases. Nurses should also improve their knowledge and skills of end-of-life communication and pain management for the patients' quality of life.

## **Keywords**

Qualitative, Palliative Care Need, Patient, Caregiver, Life-Threatening Illness, Yogyakarta, Indonesia

## **1. Introduction**

Nowadays, more people worldwide die from advanced chronic illnesses rather than infectious diseases. World Health Organization (WHO, 2010) asserts that cancers, diabetes, cardiovascular, and chronic lung diseases are the leading Non-Communicable Diseases (NCDs) causes of disability and death. As the result of illness trajectories, people with advanced chronic diseases are living with inability to perform major activities and often with pain, or other uncomfortable symptoms (Bacon, 2013). Integrated life-threatening care, consequently, is very necessary to relieve suffering, implement life-prolonging treatments when possible and appropriate, improve quality of life (QoL),

support the caregivers, and apply rehabilitation process (Morrison, 2004) through specific knowledge and skills as in palliative care settings (Phillips, 2011).

Unfortunately, the attention to palliative care in developing countries remains at a low level due to the infectious diseases and malnutrition problems which have a higher health care priority (Crane, 2010). Whereas, approximately 80% of the global NCDs deaths were in low- and middle-income countries (WHO, 2008). The lack of palliative care services in developing countries has also been associated with the lack of trained staffs, funding, infrastructure, research, academic links, and misunderstanding regarding health issues

(Clemens, 2007). Indeed, palliative care has been recognized as a fundamental human right (Brennan, 2007) so every-single-person has right to have the provision of good health care at the-end of life.

Indonesia, one of developing countries, started the Palliative Care movement in the early 1990s (Al-Shahri, 2002). Generally, Indonesians tend to avoid terminal illness discussions and that only God can determine time of death (Chaplaincy, 2013). Besides that, death is seen as the beginning of spiritual life and grief can be very emotional (Chaplaincy, 2013). Each religion also has different death-special needs, for example, post mortem care of a Moslem should be delivered by persons of the same sex (Chaplaincy, 2013).

Therefore, due to the various cultures and religions background, the attitude towards health, sick, dying, and death could also be very different. With this broad range of populations with a mix of religions, cultures, traditions, histories, and languages, palliative care services also require a culturally-sensitive-comprehensive care from healthcare practitioners to patients and families in the most difficult times of their lives (Roth, 2010).

## 2. Methods

### 2.1. Study Design

This study investigated the need of palliative care service among Javanese people with life-threatening illness and their perspectives toward the discussions of health and sick, also death and dying process. From this research, it is hoped that health care providers may have an overview in delivering palliative communication with the respect of the patient and family's culture and beliefs. This research conducted qualitative method in order to investigate the perspectives toward health and sick, death and the dying process, also the need of palliative care services.

### 2.2. Setting and Sample

The participants were purposively selected from Javanese people living with life-threatening illness and the caregivers in Yogyakarta district. The potential participants with life-threatening illness (include cancers, stroke, and respiratory diseases) and caregivers, with good mental status and communication skills were contacted to take a part into the study. They agreed to be interviewed and recorded in their convenient time and place. People under active treatments from medical doctor were excluded from the study.

### 2.3. Data Collection

Data collections were conducted through in-depth interviews explored the perspective of the participants about the need of palliative care service. Nine potential participants were called but only seven of them agreed to be interviewed. Finally, three informants living with life-threatening diseases (stroke, cancer, and lung disease) and two caregivers participated into this research and signed the consent form. The approximate length of the each interview was 35 to 60 minutes.

### 2.4. Data Analysis

All of the interviews data were transcribed using the name of P1, P2, etc. for each participant. The verbatim transcription were analyzed with thematic content analysis and resulted 51 codes and 11 categorizations.

### 2.5. Ethical Consideration

The research ethics board of each participating institution and the provincial research department provided ethical approval for the study. The researcher has explained the aim, risks, and benefits of the study to all participants. All participants have read and signed the informed consent. The researcher provided a souvenir as the incentive.

## 3. Results and Discussion

Four themes retrieved from the study will be described below:

### 3.1. Sick Condition Influences the Families

Healthy can be defined as three dimensions of traditional, ecological, or WHO concept (Boruchovitch & Mednick, 2002). From the traditional perspectives, health is a free condition from disease, while WHO stated that health is a comprehensive situation include psychology, social, and cultural.

Most of the participants stated that health is free from disease and affect to the daily activities of the person. Participant 1 (P1, woman, 61 year) said:

*"Sick made people weak, can't work at all. I got the disease because I fell down, then I realized that I got hypertension. At the same time, I also knew that I got diabetes. I felt so sad, I can't do my daily activities properly like before. Surely better when we were healthy and active".*

The first participant gave emphasis of sick on physical problem that affected to the daily activities. Participant 2 also stated that sick may have effect on activity problems although P2 (woman, 62 year) added that the effect could influence others:

*"Healthy means I feel comfortable with myself, do whatever I want to do freely, and no tiredness. Just like now, Ms, I can't do any work. So many disadvantages when we got sick. Many years ago I could do and go as I please. But now... I am so dependent".*

As P1, the second participant believed that health means an independent state when a person can do any activity without tiredness or other problems. Despite physical problems, sick can also make psychic problems as stated by P5 (woman living with breast cancer, 52 year):

*"Well...Of course I felt so sad. Sad like... I don't know... I got sick... a serious disease.... How my children will be?"*

*What about my shop? [Bitter smile]"*

P2 explained that sick can influence other people's live, particularly the family. When a family member experienced health problems, they will need other member's help to fulfill some needs that could not be done by the sick person. Javanese have also been known as shy and more introvert people. It will need very hard efforts to dig information from them. Most of Javanese will prefer to hide their condition from other ears as described by P4 (caregiver, male, 44 year):

*"[My father] had an accident, but he kept his condition for himself. When we asked him, he just said that he was fine. I think he did not want to be a burden of us. My father do not want his life as a burden for his children. Maybe... hiding... like he just wanted to keep it for himself only".*

Moreover, the same participant also exclaimed that the effect of the disease to relatives can be traumatic.

*"I don't know, Ms. My father has been trying hard to be healthy all the time. He seems afraid to go for seeking a doctor. I don't know why.... Maybe he is afraid because when my mother died in a hospital, she got a chronic disease and treated in that hospital for a long period of time. He felt uncomfortable about that".*

Additionally, most of the diagnosis will be explained first to the family in order to protect the patient's condition. In this study, it is found that actually they want the patient can be explained about the condition, because it is hard for the family to keep it from the patient:

*"I think it is very important for someone to understand their condition. If the family hide it from them, it means that we lied. Someday they will find it out when the condition is getting weaker and they will ask "why I feel so bad? What is actually happened to me?" contrary to what everybody said that they were just fine" (P3, caregiver, male, 25 year)*

From all of these perspectives, it is known that from both patients and their relatives agreed that sick condition may change their daily activities and other people's life. Compared to the definition of health by WHO, participants also stated that sick can influence physical, social, and psychic. Sick is not only affect the patient, but also people around them because of the weaknesses of the patient impacted they cannot fulfill the basic human needs or other daily activities.

### 3.2. Family Leads the Patients' Caring

Family defined by USAID as "more than the sum of the personal health of individuals (including father) who form the family since it also takes in to consideration-interaction in terms of health (physical and psychological) between members of the family-relationships between the family and its social environmental stages of family life in its different structural types". In a short, family is not only a group of

people but there is also interactions between them includes physical and psychological, take care each other, particularly in health. This definition is also understood by all of the participants. P2 (female, 62 year, stroke patient) described:

*"I have a principle that I should treat others like I take care of myself. Don't hurt anyone else as you know that you don't want to feel the same".*

P2 wanted to say that as human has social needs so they should respect one to another. Our manner to others will reflect on what we will get. As a person who is very close to the patient, family should care and support the sick. P4 said (male, 52 year, caregiver):

*"I live together with him... he is my father so it is definitely my responsibility to take care of him. Yes... I am sure about this... my father don't like to be hospitalized. Never. If he got sick, he would keep it for himself".*

From the patient's side, the relationship between patient and their relatives describes as "try hard to be independent":

*"It's very hard, Ms... poor my husband... I got so many surgeries... it's too much [money]. If it is possible, I want to stay at home, they [the health care team] come to my house... but... it should be costly as well..." (P5, female, 52 year).*

From these various perceptions, both patient and their family try to help each other. Patient tries to keep independent and the family seek for the best treatment they can afford for the family member. The relationship between family members in Indonesia, specifically in Java are really close, so the family's role in the caring of the patient are also great. Javanese people have a very strong relationship with their family. In health problems, family have a strong power to decide the best treatments for the patients.

Currently, communication about patient's condition should be considered whether communicate directly to the patient or through the family members. Mostly, the communication will be delivered between the health care providers to the family first, then they will discuss the best way to deliver it to the patient or just keep it away from the patient.

### 3.3. No More Taboo for Death and Dying Discussions

Various researches have been done to explore the discussion about death and dying. The discussions about this topic are very sensitive and broad, include the aspects of religion, beliefs, habits, and cultures. A study in America found that beliefs factor (in this research was Hindus) related to another live after death are very strong and influence the health care service to the patients and their families through the difficult time (Gupta, 2011). Health care practitioners, particularly nurses, may also have difficulties to facilitate the dignity of the death as the enormous beliefs towards good death (Doorenbos, et al., 2006). From the caregiver's side, good death should include physic, psychic, also happiness in

soul and the provision of information about the condition and the care of the patients (Gennip, et al., 2013).

Discussions around death and dying is always difficult for health care team even though in developed countries where the people are more extrovert. This study tried to investigate the discussions about death and dying for Javanese. Generally, both patient and the caregiver are aware that death is a natural process.

*"It's natural that everybody will die. Sick or sudden death...." (P1, 61 year, stroke).*

*"But we should remember that all of us will be back to God...." (P2, 62 year, stroke).*

*"Well... may be some of us are not ready with the death, but will or not, we will...." (P3, 25 year, caregiver).*

Death is believed by the participants as a part of human life cycle. However, participants also belief that every single person has their own way to death.

*"Every person has their own way to die ... some are easier to death... Without sick, just like sleeping, while the others may have a very long period of sick before death..." (P2, 62 year, stroke).*

From that viewpoints, the health care team should also belief that people have individual attitude toward death and dying. The spiritual aspect and their beliefs may have impact on their end-of-life care. One of the caregiver felt afraid when his father asked about unreasonable topics or some people who already died.

*"I was so scare that my father were asking of our relatives... they died a couple years ago... why.... Or maybe he was thinking or missing them? Just now he asked about them... never discuss about it before... he said that he met them..." (P4, 44 year, caregiver).*

People may react toward death and dying depends on the cause of death which is suddenly or through a long way of sickness. Informants in this research explained that the general death response is sadness.

*"Don't ask me how... definitely so sad. Not all of us will be ready for the death, but I know that we will..." (P3, 25 year, caregiver).*

*"Absolutely I was so sad, I felt that I have missed something. But we should remember that everybody will be back to God. I easily cried when I heard someone died" (P2, 62 year, stroke).*

*"Well, death it normal thing. All of us will die someday. But it's also normal when we feel sad or shock... my father condition dropped when my mother died. But then he was fine. So it's normal, but also normal if we felt sad. It's been a long time ago... never thought about it anymore..." (P4, 44 year, caregiver).*

Although death is a normal process, but death is still assumed as an abstract thing. Therefore, it is very difficult effort to start a conversation about death and dying. However, this study found that actually the discussion of it is necessary.

*"I think it's not taboo talking about death because it's a normal cycle. I am fine to talk about death and dying" (P1, 61 year, stroke).*

*"Talking about death is not taboo anymore. Everybody will die. But just we don't know how and when...." (P2, 62 year, stroke).*

*"There is no taboo about it, we all will die..." (P3, 25 yo, caregiver).*

From these interviews, both participants from patients and caregivers were open for the discussion of death and dying. In Indonesia practically, however, there are many health care providers who are not open with the communication around this topic.

In palliative care, patient and their relatives should be prepared in facing the dying process so that the pain and other complaints management can be well-planned and solve the unfinished business (PCSA, 2015). Family should be accompanied in starting the discussion about how and where the funeral is, also who are will be invited to the event. This study also investigated things that usually inheritance to the family before died. However, all of the participants assumed that wills are always around property, although a participant has started the discussions about the funeral.

*"I think it is fine to write a testament, for example: house, and other properties. It's important to be discussed, but with family only" (P1, 61 year, stroke).*

*"It's common to write a testament for the property or other business that unresolved yet. But I think it should be discussed with the family only. It can be also about the funeral, whether they want to have it at their own house or other services, or when they want a cremation" (P2, 62 year, stroke).*

*"Writing a testament is common thing for us when we have something to be shared to our family, but if we don't have anything to be shared, it's not necessary to write one" (P3, 25 year, caregiver).*

The participants clearly stated that usually a testament is about property and no need to write it when someone does not have anything to be shared. The role of nurses in palliative care includes communicate that death with dignity can be achieve by discussing death and dying process, also the funeral (PCSA, 2015). The testament about the dying process and funeral will be important to decide the best end-of-life care. One of the participant clarified:

*"Weew... [take a deep breath] he doesn't like to be in hospital. He want to stay at home when something*

*happened to him. Just at home. He doesn't want a hospital"* (P4, 44 year, caregiver).

With this testament, if the patient wants to stay at their house at the end of their life, the health care team can deliver some information and other basic treatments for the family.

### 3.4. Palliative Care Service for All

Palliative care in Indonesia has been started in 1992 and can be found in big cities as Jakarta, Bandung, Yogyakarta, Surabaya, Malang, and Makasar. Palliative volunteers are increasing and it is hoped that the palliative care service can be broader.

In this study, all patients and caregivers were not familiar yet with palliative care, but can be established that the roles of palliative care service are numerous. The participants expected that the role of health care providers in end-of-life care can be improved, importantly in the communication. Participants also understood that all of diseases can be cured, although in some stages the human capability can be limited.

*"The health care team are all good, all diseases can be cured by them, but it depends on the patients also"* (P1, 61 year, stroke).

*"They are [health care team] all good although in some part need to be improved. I think not all of the diseases can be cured, just like me, I should live with it for the rest of my life. I just need to make my body is well enough and the disease is not getting worse. I cannot imagine how about a person living with cancer... It will need more team to take care of them... [sigh]"* (P2, 62 year, stroke).

Therefore, participants actually realized that at the end, the capability of health care providers are limited and the next treatments will be futile.

*"Person like them [at the terminal stage], depends on the doctor's decision also, will be sent to home, or if it possible, can be treated in a special service if they can afford it"* (P1, 61 year, stroke).

*"Not all of the disease can be preserved I belief. When a patient did not respond to the treatment anymore, well, it means that the disease is very serious... just wait the miracle or just give it back to God"* (P2, 62 year, stroke).

*"Not all of the diseases can be cured, like my mother had"* (P3, 25 year, caregiver).

Some participants agreed that it is not good for the health care team to give up, because it can make the patients feel down.

*"Not good to say that there is no more response of the patient towards the treatments, it can make them depressed"* (P1, 61 year, stroke).

When there is no more active medications or treatments for the patients, the health care team should plan any other

option for the patient and family.

*"The caring depends on the patient and family. They feel more comfortable in their house or hospital, it can influence other decisions"* (P3, 25 year, caregiver).

*"The treatment will depend on the patient and family... their decision... well... some want to stay at home. Our own house is surely the best place for end-of-life"* (P2, 62 year, stroke).

*"For some patients, the doctor will offer to stay at home..."* (P1, 61 year, stroke).

In addition, communication is an important part of the patient's caring. The family expected that there is a good communication from the health care team, so that they can decide the form of treatment and other decisions. The information should also deliver to the patient proportionately.

*"There is nothing need to be hided if it about the health status. If the health care or family keep it as a secret, it will give more disadvantages. I mean, when the patient's condition is suddenly getting worse, both patient and family cannot prepare it and then all of us will be shock"* (P2, 62 year, stroke).

*"It is very common that we determine the person's condition before we decided to inform it or not. Are they ready enough to get the information? If it impossible, the team can deliver it to the relatives first. If it possible, we can give the information directly to the patient"* (P3, 25 year, caregiver).

Participants were happy with the form of health care which can help patient and family trough the difficult time of the patient's treatment. The patient's house feels as the best place for patient and family, so they think that palliative care will be a very good service to the caring of the patient.

*"Well... I think that is a very good service.... If they can prepare the patient and family in facing the death and dying. I think in Indonesia we have so many serious diseases which are difficult to be handled. Surely the family need accompany from the health care team until the funeral. Also the family will need to care after that [bereavement care]"* (P2, 62 year, stroke).

*"I think that will be a very good service because I am sure most of patients will prefer to be cared at their own house rather than in a hospital. There is a big demand for patient and the family to be guided by the health care professionals since the disease has been diagnosed until the period after the death of a sick person"* (P1, 61 year, stroke).

*"I want to stay at home. I can see my children back from school. When I was in hospital, they should take a public transport to go to the hospital to see me. Poor them. Also my mother. But I got breathing difficulties yesterday so I did not have any other option. Between I want to stay at*

*home but difficult to breath or stay at hospital but become a burden for my family” (P5, 52 year, breast cancer).*

One participant stated that palliative care will be a very good service for people living with life-threatening illness, but she felt that it probably for rich people only.

*“Patients like this [with life-threatening illness] will be sent home depends on the doctor decision, but they can also be sent to a special service when they are from rich family” (P1, 61 year, stroke).*

Because there is an opinion that palliative care may only for rich people, the health care team should be more active to promote this service and that this service care is for all patients who need this facility. The main goals of palliative care is improving the quality of life so that it will be necessary to provide the care with reasonable cost.

#### 4. Conclusions and Recommendations

Palliative care in several developing countries may not very popular yet. In fact, palliative care service tends to improve quality of life of people living with life-threatening illness. This study tried to explore the perspectives of people living with life-threatening illness and the caregivers about the need of palliative care, including the topics of health and sick, communication about death and dying, the role of health care providers, and the need of palliative care facilities. From three patients and two caregivers, there were 51 codes and 11 categories which were analyzed with thematic analysis supported by two independent coders. There are four main themes retrieved from this study stated that sick condition influences the family, family leads the patients' caring, no more taboo for the discussions of death and dying, also that palliative care should be provided for all.

The characteristic of Indonesian' families are very strong relation and cannot be apart from the care of the patients. Communication about the disease or condition should be well-provided between the health care team and the patients, also with the family. It is assumed that discussion about death and dying is a very sensitive topic but from this study it is found that this discussion is necessary. It is recommended that nurses should understand the competencies of palliative care. The skills will be important to deliver nursing care for patients and families living with life-threatening diseases. Nurses should improve their knowledge and skills of end-of-life communication and pain management for the patients' quality of life.

#### Conflict of Interest

No conflict of interest has been declared by the author.

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