



The Dignity of Middle Adult Palliative Patients at Home in Bantul

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Abstract

BACKGROUND: The condition of middle adult patients with palliative disease is prone to experiencing physical weakness and psychological suffering, disrupting dignity. As a caregiver at home, the family plays an essential role in providing support to maintain patient dignity.

AIM: This study aims to determine the image of the dignity of the middle adult patient with palliative care needs by family at home.

METHODS: This research is a qualitative study with a phenomenological approach. Participants were seven people with the purposive sampling method. Data collection methods were conducted using in-depth interviews and semi-structured observation. Research instruments included interview guidelines, field notes, and an observation form. Data validity used reference material, rich and thick description, and peer debriefing. Data analysis included data collection, data reduction, data presentation, and conclusion.

RESULTS: The results showed that the dignity of patients was considered by six themes; self-esteem went up and down, the meaning of illness and death, family response to the patient, sources of decision-making, an image of the quality of life, and future wishes.

CONCLUSION: This study had six themes depicting the dignity of patients that consisted of subthemes. The themes included self-esteem went up and down, the meaning of illness and death, family response to the patient, sources of decision-making, an image of the quality of life, and future wishes.

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Introduction

Palliative care is an approach to improve the quality of life of patients and families in dealing with problems related to life-threatening diseases, through prevention and recovery of suffering from early identification, and treatment of pain and other problems, physical, psychosocial, and spiritual (World Health Organization [WHO], 2018) [1], [2]. Furthermore, the WHO (2018) [3] stated that palliative care is needed, especially for people with non-communicable diseases such as heart disease, stroke, cancer, chronic respiratory disease, and diabetes, leading to global mortality. Other diseases that require palliative care are life-threatening diseases with a chronic progression such as chronic cardiovascular disease, Alzheimer disease, multiple sclerosis, chronic liver disease, neurological diseases, chronic kidney failure, resistant tuberculosis, and HIV/AIDS (Matzo and Sherman, 2019) [4].

The WHO (2016) [1] reported that the phenomenon of cases of non-communicable diseases affects many adults. Moreover, the WHO (2018) found that non-communicable diseases caused 15 million deaths with an age range of 30–69 years old in recent years [2]. According to Erikson's theory, this age was a middle adult age range (40–65 years).

Disease conditions with the need for palliative care suffered will hamper the patient's ability to carry out activities in accordance with their developmental tasks. Suffering in palliative patients is physical and psychological, spiritual, cultural, and social aspects (Lamrous, 2018) [5]. End-of-life conditions with physical weakness become one of the factors that reduce the dignity aspect of the patient.

Research by Nur Hasanah and Arianti (2018) [6] on palliative patients showed that the majority of patients had a good intact dignity, but some patients had fractured or disturbed dignity. Complete dignity is when there are no problems that occur with the patient's dignity, while patients who have a fractured dignity experience symptoms that make physical distress (pain, difficult breathing, and nausea). They are unable to carry out routine activities as usual and feel a burden. Another study by Rodriguez-Prat *et al.* (2016) [7] showed that most patients became dependent and unable to do activities, causing them to lose dignity, self-identity, inability to control circumstances, lose self-esteem, and feel useless.

Preliminary survey results through Yogyakarta Government Health Office (2018) [8] showed that Yogyakarta Province was an area with a high number of life-threatening diseases such as cancer, stroke, chronic heart disease, diabetes, chronic kidney failure,

acute respiratory disease, and hypertension. Bantul Regency is an area with a high incidence of non-communicable diseases. The observational survey of researchers showed that patients with palliative needs showed symptoms in their illness. They were rarely or even excluded from treatment decisions. A lack of support and motivation from family is the basis of a form of patient dignity. Based on the description above, the researcher attempts to examine the dignity of middle adult patients with the need for palliative care at home by families in Bantul Regency.

This study aims to describe the needs and availability of dignity aspects of middle adult patients with palliative care provided by the family at home.

Methods

This study is qualitative research, which used a phenomenological approach. Seven participants were included who were selected using purposive sampling technique with specific criteria. The inclusion criteria should be met in the participants, such as (a) palliative patients at home who had been diagnosed in the past 2–3 months; (b) aged between 40 and 65 years old; (c) palliative patients who were good in verbal communication; (d) participants should show normal vital signs before and after the interview session; and (e) the primary family caregiver of the palliative patients.

Houses of the palliative patients located around the Bantul district area were chosen as comfortable places to collect data using a depth interview. The data collection was taken between January until March 2020.

This study used semi-structured observation as a method of obtaining data. Sugiyono (2015) [9] stated that semi-structured observation is an observation of an object in a participant and its environment with an observation guide without reducing the researcher's freedom to develop components that must be observed. Researchers observed the participants' condition and their environment, the patients' non-verbal attitudes, and the families' attitudes toward the patients during the interview. Observations were carried out for 50–60 min at the participants' homes along with the ongoing interview process. The researcher recorded and described the observation results of each of the related components in detail.

The validity test used in this study was to use the data credibility to show the validity of the data obtained. The data credibility method used in this study was based on Sugiyono, 2016 [10]; Afyanti and Rachmawati, 2014 [11], including:

Reference material

Using reference materials are to prove that the researcher has found the data; for example, data are supported by the presence of voice recordings of interviews. Researchers' interaction with participants is evidenced by photos/pictures as authentic documents so that the research is more reliable.

Rich and thick description

Researchers make detailed, complete, clear, and concise descriptions of the research results to describe the informants' knowledge during the research process.

Peer debriefing

Peer debriefing is a discussion process conducted by researchers to review research results to minimize the researcher's subjectivity in the data processing. This peer debriefing is conducted to increase the accuracy of the research data.

Results

We found seven participants who were palliative patients in Bantul Region, Yogyakarta, and also their families. The finding of this study emerged in the characteristic of the participants and six themes.

Characteristics of participants

In this study, we had seven participants consisting of six palliative patients and one palliative patient family. The characteristics of the participants are shown in Tables 1 and 2.

Table 1: Participant's characteristics (palliative patients)

Participant code	Age	Gender	Education level	Length of illness	Chronic Illness	Dependent level
P1	52	M	Primary school	9 years	Stroke	Total care
P2	47	F	Primary school	± 5 years	Chronic kidney disease	Minimal care
P3	44	M	Secondary school	7 years	Brain tumor	Minimal care
P4	46	M	Primary school	8 years	Chronic kidney disease	Minimal care
P5	47	F	Primary school	7 years	Diabetes mellitus	Total care
P6	47	M	Primary school	10 years	Heart failure	Minimal care

The first table shows that most of the participants were male, educated in primary school

Table 2: Participant's characteristics (family caregiver)

Participant code	Age	Gender	Education level	Length of care	Relation	Patient condition
P7	63	M	Primary school	5 years	Father	Chronic kidney disease with minimal care

level, had experienced illnesses more than 5 years, and needed minimal care. On the other hand, there were two participants who needed total care. The next table explains about participant that came from the family caregiver.

The finding themes

Six themes were found regarding the dignity in middle adult age palliative patients. These are the following themes:

Self-esteem that goes up and down

The first theme was told us about self-esteem that sometimes went up and down, consisting of two subthemes. The subthemes were a support from the health-care teams in the hospital and negative views of society about the patient's condition of illness. These findings came from the statement of one participant that, "...doctors and nurses are very familiar with me, they are very friendly speaking, I am comfortable with the nurses at Y Hospital, so it adds to my enthusiasm, who has been sick for a long time." (Participant 2)

There was one participant who said:

"Wow, suppose the attitude of the nurses and staff at X Hospital is very good at serving patients, from doctors to nurses. In that case, all are friendly; there is no difference between patients; I am also not neglected even though I often seek treatment there. I am very happy to be treated with medical officers like that." (Participant 6)

The two participants told us how their feelings were when they were hospitalized and health workers' response, especially nurses. Most of the medical personnel were friendly and communicative, so they made patients excited and felt happy during their treatment. It showed that the patient's experiences while in the hospital made his self-esteem good and increased.

Negative views from society were obtained when the patient was at home. Participants found that the community response was not good enough, so it had an impact on the feelings of patients who felt neglected by the surrounding environment. Patients also received adverse verdicts from residents related to their illness. The following participant statements evidenced this, "...I really feel the changes of the gentlemen around here. They underestimate me, sometimes they argued with me, yeah. I used to be underestimated, maybe because I am sick (shaking his head)." (Participant 3)

Well, things that annoyed me and made me bad were the responses of the neighbors around here. These people acted like they were knowledgeable when they knew nothing.

Some neighbors said that I have this illness due to my bad attitude, like to be drunk and stubborn. (Participant 4)

Based on the data, there are several categories of the two subthemes, including medical personnel being informative, maximum medical service, adverse changes in residents, inadequate environmental responses, and adverse verdicts by the surrounding environment.

The meaning of sickness and death

The participants felt that their sickness made them closer to God. These findings were supported by the participants' statement:

The meaning of this pain, Ma'am, I believe there is a lesson from God from this test. I feel this pain made me draw closer to God again; this test makes me believe I have to increase my faith and thoughts. It might also be a premonition of my past mistakes. InsyaAllah, there is wisdom behind this test. Every time I feel I want to go up to a faith class, I have to feel the test first. So this is the test I have to feel (crying and frowning). (Participant 3)

For me, the meaning of this disease is a form of reprimand because I do not get closer to Allah. I rarely prayed, and I rarely worshiped because I was always working day and night in the past. I feel now closer to God, with a robust power since I was sick. (Participant 4)

Two participants said that their illness had meaning for themselves. The ill condition made the patient realizes that it was a form of test and rebuke to raise their faith and correct their thinking. Patients admitted that the meaning of pain was a way of approaching God and had its own wisdom.

Based on the data found, there were several categories of these subthemes, including believing that pain brings wisdom, pain is a warning from God, and pain is for raising faith.

Family's response to the patient

This theme consisted of two subthemes, namely, family supports patient care and changes in family attitudes toward patients. The existence of family support in patient care was obtained from the following statement:

Yes, my father never complained. For example, when I have feelings of annoyance, the spirit of the father asked me to be patient and keep me to continue the dialysis therapy. Whatever the condition was, my father always took me to dialysis. (Participant 7)

Anyway, when I was sick in early 2014, my wife and my mother took care of me. They showered

me and kept me clean. My mother bought me "Minowell drink" whose price was 450 thousand rupiahs, which was so expensive, but they did the best for me. (Participant 3)

Participants shared that their families always provided support during their treatment. The form of support was an uplifting attitude shown by the family, caring without complaining, and encouraging patients to continue to carry out treatment optimally.

A brain tumor participant explained that his family cared for him at the beginning of his diagnosis. Taking care of the patient's bath and giving herbal medicinal products were a form of care and support that the family provided.

On the other hand, as the disease became chronic, both participants said a change in the caring family's attitude. The indifferent attitude of other family members, such as children, was a form of attitude change that the participants felt. This attitude was indicated by an attitude of indifference to the status of the disease and the form of care the patient was undergoing.

The change in attitude from the family made the patient feel that his self-esteem had been damaged. The family attitude that did not respect the patient's existence also created the perception that the patient felt unloved. It is based on the following statement, "... Now, my first child ignored me. He neither asked me about dialysis, nor made me some food or drink. Only my husband continued to take care of me." (Participant 2)

Honestly, Ma'am, I don't think it's appreciated anymore. People often complain about my sick condition; I feel that their love must have faded. My wife shouted at me once, in front of my friend, and I felt that my pride was trampled on; I finally went to the mosque to calm down. (Participant 3)

Based on the data found, there were several categories of the two subthemes, including family support in the form of enthusiasm, informative family related to treatment, family facilitating basic needs, negative family responses to the patient's chronic condition, and the family's irrespective behavior toward the patient.

The source of decision-making

This theme had two subthemes: The patient decides on self-medication, and the patient is not involved in family decisions. The decision-making regarding treatment rested with the participants. It is based on the following statements from participants:

"I choose all the treatment, Ma'am. I wanted surgery, I asked for the tumor treatment. Alternative treatment is all I want, even though I am advised here and there, but I want it myself.

So, although it is an alternative medicine, I still believe that it must be treated medically." (Male patient, 44 years old, 7-year brain tumor, minimum care)

"I have continued to seek treatment from the start until now, yes, that is my decision, Ma'am, I want to seek treatment so that I can recover. My family also recommended buying insulin injections, but I still asked myself first, is that what I want? I chose to go to the hospital." (Female patient, 47 years old, 7-year Diabetes Mellitus, total care)

Participants shared that their current treatment options were the result of their own desires and decisions. The participants themselves made decisions regarding medical and alternative treatments by seeking advice from other family members. The illness condition did not hinder the participants' ability as a source of decision-making regarding treatment

Although the participants chose and determined treatment options according to their wishes, it was related to their family decision-making roles, and the patients were not involved. Family decision-making was shaped like an internal problem in the family. Families often did not ask participants for their opinions on decisions made. The absence of this participation made the patient feel disrespected for his existence. It is based on the following participant statements:

"Honestly, Ma'am, I don't think it is appreciated anymore. I have been sick, I feel sometimes there is something, but I go ahead without asking my opinion, without asking me." (Male patient, 44 years old, 7-year Brain Tumor, minimum care)

Based on the data found, there were several categories of these subthemes, including choosing alternative treatment, choosing medical treatment, determining the desired treatment, and not being asked for opinions, no longer being involved in family discussions.

Quality of life description

This theme consists of two subthemes, namely, the patient's gratitude for his current condition and the patient's feelings of hopelessness toward the sick condition. Some participants showed a picture of a good quality of life with feelings of remaining gratitude for their current state. One of the participants gave the following statement:

"I am grateful, Ma'am, I am always grateful even though I received a lot of pressure, I am still happy and grateful that my family is willing to take care of me and still accept me as I am." (Male patient, 44 years old, 7-year Brain Tumor, minimum care)

Participants shared that, with the illness, they suffered from their pressure, and the spirit to be grateful did not disappear. Feelings of gratitude were also based on the existence of a family who continued to take care of the participants. The presence of the family fostered feelings of pleasure and supported a better quality of life for participants.

Several other participants showed a picture of low quality of life. One participant who suffered from a stroke for 9 years showed feelings of hopelessness. The chronic illness suffered was the reason for the participants to feel hopeless. Participants did not even take medication for their disease as they believed that it would not make any difference to their condition. It is based on the following patient's statement:

"(Looking away from the face) It is useless, Ma'am. getting treatment or not did not make any difference to my condition, there is no significant change to my illness, it cannot be healed, my foot is painful." (a 52-year-old male patient, 9-year stroke, total care)

Based on the data found, there were several categories of these subthemes, including feeling grateful amidst ill condition, feeling grateful amidst pressure, thinking that treatment is not useful, not wanting to continue treatment, thinking that life is useless.

Hope

This theme has a subtheme, namely, the patient expects the family to accept the sick condition. Two participants with chronic kidney failure and heart disease shared that their hope was that their family could take full care of them. Suffering chronic disease certainly required the support of care from the family.

Participants said that their most basic wish was to be accepted by families with many of their deficiencies. Acceptance, care, and fulfillment of needs provided by the family would create a feeling of pleasure in the participants. It showed from the following participant statements:

"I also hope that I will always be given health, even though I have to have routine dialysis, the family has fully cared about my lack of condition (smile)." (Male patient, 46 years old, 8-year Chronic Kidney Failure, minimum care)

"I do not need to be cared for; as long as my wife and children take care of me, accept my condition, and fulfill my needs, I am happy." (a 47-year-old male patient, 10-year heart disease, minimum care)

Based on the data found, there were several categories of these subthemes, including hoping that the family can accept the patient's condition and hoping that the family can take care of them.

Discussion

The results showed that participants aged 40–65 years old had different disease status, duration of illness, length of care, and different levels of dependence. Diseases experienced included stroke, chronic kidney disease, heart, brain tumors, and diabetes mellitus. The length of illness experienced also varied from 5 years to 10 years. The chronic condition of the disease could have an effect on the dignity of the patient. In general, problems that can reduce the patient's sense of dignity are the behavior of family members who care for them and the quality of life during illness (Donato *et al.*, 2016) [12].

The attitude of the caring family members has an influence on the patient's comfort. Based on the results of research from Klinken *et al.* (2020) [13], it showed that the expectations and comfort of patients with palliative care conditions at home in going through the disease process were influenced by how caring caregiver's attitude was, trust in the caregiver, and feelings of being supported. Patients need caring family members to be around at all times and be able to discuss the patient's hopes and desires. Empathy and respect must be prioritized when treating palliative patients.

When associated with the length of time chronic illness, the patient's health condition and quality of life can influence future health plans and treatment needs. The disease's long-term duration is related to the quality of life conditions that worsen overtime, especially for stroke and diabetes mellitus (Busija *et al.*, 2017) [14]. The effects of dependence and length of treatment and a longer disease diagnosis duration affect patients' deteriorating quality of life (Li *et al.*, 2016) [15].

Most patients became dependent and unable to do activities, which caused them to lose their dignity, which was their identity, inability to control the situation, losing self-esteem, and feeling useless (Rodriguez-Prat *et al.*, 2016) [7]. Patients' dependence is one of the factors that have a negative effect on family function as it increases the family's psychosocial suffering as a caregiver. Although the level of dependence of patients, whether mild, moderate, severe, or total dependence, does not have a significant effect on the stress level of the caring family, the length of care and chronic illness can also reduce the quality of life of the caregiver (Tavares *et al.*, 2019) [16] which triggers a change in the attitude of the family in caring.

Chronic disease conditions requiring treatment in the long term will physically impact the patient's palliative ability and impact psychological, spiritual, cultural, and social aspects (Lamrous, 2018) [5]. The influence in the social field is the occurrence of changes in the family structure. Chronic illness and length of treatment can threaten changes in family attitudes as they must be able to adapt to changing roles and impact

the patient's dignity. It can lead to stressful situations, and tension in care due to fatigue or loss of positive results from the treatment carried out.

Self-esteem that sometimes rises or falls reflects the patient's mental state since the illness. The absence of family support and a negative view of the environment make the patient mentally fall. Mental breakdown occurs due to increased stress. One of the stressors is feeling angry and unsupported due to lifestyle changes and feeling that they are not understood by friends and family members who do not feel the same limitations as patients (Canadian Mental Health Association, 2018) [17]. Disease conditions with long-term care cannot be cured, only managed. However, patients are at risk of social isolation, low self-esteem, and stigma and discrimination (Mental Health Foundation, 2020) [18].

Acceptance of death in patients with palliative conditions or terminal illness becomes an active process in which patients become more open and acknowledge all aspects of their current situation, both physically and emotionally, to make the most of their remaining time (Hulbert *et al.*, 2015) [19]. This acceptance of death is also affected as the patient views his condition as a destiny of life, and that, to them, death is indisputable. This statement is supported by qualitative research conducted by Kyota and Kanda (2019) [20] regarding the acceptance of death in cancer patients that they accept their condition and future death as the destiny and purpose of life. Patients understand that they can do little to fight disease or deny death. Patients ultimately avoid things that can trigger the stress of death. The patient accepts death because life and death are part of nature. They cannot fight this and prefer to think that life is a gift and then use the remaining life to do what they can for others.

Family support needs to be carried out to develop maximum care for these patients. The family also has significant potential to influence patients in managing their disease. The existence of family support plays a role in managing the condition of family members suffering from chronic diseases. Family care support can also be assessed by how often the family becomes the primary observer of patients' physical symptoms (Rosland, 2009) [21]. The best care given must develop an attitude of respect for the patient's autonomy and be loved by the family during the treatment. Active listening to patients is also an essential action in supporting dignity and respect for patients. Active listening means that as a caregiver, they really have to understand the patient's needs (Hsu, 2019) [22]. Respecting patient's rights also includes making decisions and the right to obtain information related to the disease experienced and the benefits and risks of the treatment carried out (Sedig, 2016) [23].

Participants hoped that they could recover from their illness, return to work, be accepted by the family, be maximally cared for, and be active again in

community activities. If the patient died, he would be prayed to by his family. The hope within the patient showed that aspects of the patient's dignity were still good. Hope becomes a positive concept, indicating that patients were still aware of their existence and became the value of the patient's moral strength to prevent feelings of hopelessness or helplessness (Bakan and Ozdemir, 2017) [24]. Patients' expectations have a role in increasing the patient's sense of dignity (Donato, Matuoka, Yamashita, Salvetti, 2016) [12]. Maintaining hope for the palliative patient is an essential element during treatment. There is hope that it can improve the patient's welfare and quality of life (Yadav and Jhamb, 2015) [25].

Conclusion

In a nutshell, the dignity of the palliative patient in middle adulthood is described as the self-esteem that sometimes rises and falls, the meaning of illness and death, the response of the family to the patient, the source of decision-making, the description of the quality of life, and hope. Attitudes and support from family, neighbors, community, and health workers significantly determine the patient's dignity.

Therefore, further research is recommended to find indicators of dignity in Indonesian palliative patients and makes a dignity assessment scale.

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