

## Conference Paper

# Terminal Cancer Patient's Experience in Decision Making of Palliative Care at Home

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## Abstract

**Background:** Increased cancer prevalence, especially in terminal condition, needs a comprehensive management approach through a palliative care. Cancer patient is very encouraged to be involved in an independent decision making especially palliative care at home. **Objective:** This study aimed to explore the experience of terminal cancer patients in their decision - making process of palliative care at home.

**Method:** This study was a qualitative study using descriptive phenomenological approach. The data were obtained through in-depth interview technique for 40 – 60 minutes with 10 palliative cancer patients with the focus of the question exploring the experience of terminal cancer patients decision making for home-based palliative care.

Analyzed by using Colaizzi method. **Results:** The results obtained 2 themes which significantly describe the dynamic of patients with cancer from medication process to decision making of palliative care at home. Two themes emerged in this study were (1) patient wish to stay treated in the hospital and (2) the influence of family dominance in making palliative care decision. **Conclusions:** The study was expected to be a reference for nurses in conducting therapeutic approach by considering participant's characteristics. It was also expected to improve nurses' knowledge and communication skills in advocating and clearly informing palliative care purposes and program at home. Thus, patients do not have doubt to receive discharge from hospital and palliative care at home. In addition, a strategy from government is needed to optimize palliative programs through palliative care based on home care in various regions in Indonesia.

**Keywords:** terminal cancer patient, decision making, palliative care

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## 1. Introduction

Cancer has become one of the leading causes of death in the world with an incidence of 18,1 million new cases and 9.6 million patients died in 2018 (Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A., 2018). Based on a latest national health survey in 2018, the incidence of cancer has increased in 1,8 per 1,000 people and reported cancer to be the seventh ranking of the causes of death in Indonesia (Risquesdas, 2018). The increasing prevalence of cancer requires comprehensive management. One of the problems that occur in Indonesia is the limitations of the aspect of resources

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and priority handling. The obstacle of handling cancer causes 70% of cancer patients detected in terminal stage conditions (Kemenkes RI, 2013; Gulia, A., Byregowda, S., & Panda, P. K, 2016).

Advanced cancer patients do not only experience various physical problems such as pain, shortness of breath, weight loss, and disruption of activity but also experience psychosocial and spiritual disorders that affect their life quality and their families. The poor prognosis of cancer is potential to add the mental burden of the sufferer then triggers the emergence of feelings of despair, loss of enthusiasm for life, being isolated, and anger. It also affects the treatment result they are undergoing (Susanto, P., Sari, S. M., & Suprobo, F. P, 2016). Therefore, patient handling is certainly not only curative but also needs a holistic support to the end of a patient's life with focus on symptom control that carried out through an interdisciplinary approach, namely palliative care (Cimino, N. M., & McPherson, M. L, 2014).

Palliative care is a comprehensive approach that aims to improve the life quality of patients and families who experience terminal or life-threatening disease problems through prevention and pain discharge by conducting early identification and good evaluation. In addition, controlling physical symptoms that often indicate local recurrence with curative treatment progression is not able to provide the expected cure and to deal with psychosocial and spiritual problems. Palliative care should be optimally done since the diagnosis until the end of patient's life and given at each care level (Gulia, A., Byregowda, S., & Panda, P. K, 2016; World Health Organization, 2016).

The peaceful end of life theory is one of theory related to palliative nursing. The theory is in line with the principle of palliative care which must respect individual's autonomy or patient's right in making decisions and realize the end of his life peacefully. It can be obtained by involving patients in making decisions on palliative care and always providing patient care with respect and adjusting to their needs and their families as care giver (Alligood, M., & Tomey, A, 2014).

Patients with cancer and needing palliative care are strongly encouraged to be involved in decision making, one of which is making home care decisions. It increase s human dignity and patient satisfaction. In this case nurses have an important role in improving effective communication to encourage patient involvement in decision-making on palliative care at home (Bélanger, E., Rodríguez, C., Groleau, D., Légaré, F., Macdonald, M. E., & Marchand, R. (2014); Fauzan, A (2016)).

Some considerations of the importance of patient decision-making switching from hospital care to palliative care at home are based on the benefits which patients and families will get from palliative care at home. Home palliative therapy is proven to

improve patient welfare, manage physical symptoms, give patients the opportunity to stay at home as long as they desire, and reduce health expenses to a minimum for the treatment process in hospital (Delgado-Guay, M. O., Hui, D., Parsons, H. A., Govan, K., De la Cruz, M., Thorney, S., & Bruera, E, 2011).

However, the polemic in Indonesia, especially in making decisions for palliative care, is still a problem in several big hospitals that have palliative care programs at home. Indonesia is a developing country in Southeast Asia with a population of around 260 million and more than 200 ethnic groups. Indonesia experiences a transition in terms of perceptions of disease and death patterns, including the decision making of palliative care place for patients. Some obstacles in making palliative care decisions for patients include the lack of desire to reveal the prognosis of the disease, taboo perceptions of death at home. In addition, the lack of information and awareness about palliative care make patients and family to continue the curative treatment even though medical intervention cannot be maximally carried out (Witjaksono MA, Sutandiyo N, Suardi D, 2014).

Another obstacle in the selection of palliative care is the professional staff who will provide health care. Palliative care is still considered as the last option when medical treatment cannot be continued. Psychological, social and spiritual problems of patients is not seen as important aspects of health care for patients who will face the end of their lives. It happens due to unevenness distribution of palliative care development in several regions of Indonesia. The human resources (medical personnel) who have attended palliative care training, are certified and skilled in conducting therapeutic communication in the provision of end of life nursing care are still limited. Moreover, unavailability of module and clear standards of palliative care is a challenge in developing palliative care in Indonesia. It impacts on the lack of public confidence to make home care decisions and many cancer patients die at home with unfulfilled holistic needs due to their unwillingness to do palliative care especially home care (Witjaksono MA, Sutandiyo N, & Suardi, D 2014).

Based on a polemic regarding barriers to the application of palliative care in Indonesia, due to several obstacles as the physical and psychological problems of the patient, the inadequate phase of educating the patient, the lack of knowledge of the patient and family about palliative care at home, related to the values and cultural norms prevailing in society, financial factors and being studied by nurses in relationships that must be improved, so researcher feel the important to reveal in depth the experiences of cancer patients in palliative care at home. Although there are several studies in other countries that reveal the experiences of cancer patients in palliative care, the studies in Indonesia

context which is culturally and situationally different will provide a different experience. The researchers have not yet found the relevant studies that focus on the exploration of the experiences of patients who refuse to be discharged from hospital to perform palliative care. This study uses a qualitative approach which is expected to explore more detailed information about decision making in palliative care at home.

## 2. Methods

**Study design.** This study used a qualitative method with descriptive phenomenological approach, which aims to explore the experiences of terminal cancer patients in making palliative care decisions at home.

**Participants.** In this study, the researchers conducted data collection on ten participants of advanced stadium cancer who were included in the specified inclusion criteria. The participants' inclusion criteria are as follows: (1) advanced cancer patients (stage III A to IV) planned for palliative care, (2) willing to be the participant of the study and signing informed consent, (3) having compos mentis and knowing the condition of the disease, (4) good general conditions (no nausea, no pain, no tightness, no weakness and others), and (5) able to communicate well and cooperatively (not in meta brain condition). The participants were selected by using purposive sampling technique, whose number was determined based on data saturation in this study.

**Data collection.** The number of participants of the study were 10 cancer patients based on the inclusion criteria and treated at Cipto Mangunkusumo General Hospital. Staff nurses at the wards of the hospital helped researcher to identified and initially approach about the study, and gave informed consent. We collected the data used in-depth interview technique for 40 - 60 minutes. Interviews were tape recorded and used field noted to observation non verbal respond of the participants. In this study, data reached saturation after the interview with the 10<sup>th</sup> participant. The participants' identity used a P code to ensure anonymity and the records obtained were destroyed after five years from the research process.

**Data Analysis.** We used phenomenological data analysis with Collaizi's approach, which aims to look the overview of terminal cancer patient experiences in making palliative care decisions at home. The process begun by reading the transcript repeatedly to find some significant statements then to process the coding of the significant statements for preparing the categories. Furthermore, from the categories that have similar meanings, research themes were formed. The final process was to describe the

TABLE 1: The characteristics of the participants.

Code	Gender	Age	Religion	Ethnic group	Last Education	Occupation	Cancer Diagnosis	Stage	Long suffering from Cancer
P1	Female	31 years	Islam	Sundanese	Senior High School	Housewife	Pancreatic Caput Cancer	IV A	1 year
P2	Male	65 years	Islam	Sundanese	Elementary School	Laborer	Rectal Cancer	III B	2 years
P3	Female	48 years	Islam	Javanese	Junior High School	Housewife	Cervical Cancer	III A	2 years
P4	Female	45 years	Christian	Papua	Elementary School	Farmer	Cervical Cancer	III B	2 years
P5	Male	56 years	Islam	Sundanese	Diploma	Entrepreneur	Brain Cancer	II B	1 year
P6	Female	54 years	Christian	Javanese	Bachelor	Coop Employee	Ovarian Cancer	III C	2 years
P7	Male	36 years	Islam	Javanese	Vocational School	Private employee	Pancreatic Caput Cancer	IV B	2 years
P8	Male	46 years	Islam	Lampung	Senior High School	Farmer	Gastric Cancer	III B	2 months
P9	Female	31 years	Islam	Lampung	Elementary School	Brick Maker	Oxyphilic Carcinoma	III C	10 years
P10	Female	56 years	Islam	Javanese	Senior High School	Housewife	Recidivated Cervical Cancer, Post Ileostomy	III B	10 years

themes created and integrate them into a comprehensive description of the results to be revalidated by the participants.

**Ethical Consideration.** The research obtained ethical permits and passed the ethical test from the ethics committee of Nursing faculty of University of Indonesia. The researcher applied the ethical principles in the form of Respect for Autonomy and self-determination, Confidentiality and anonymity, and Protection from discomfort and harm.

### 3. Results

The data analysis revealed the following themes:

#### Theme 1: Patient wish to stay treated in hospital

In this theme, there were two opinions regarding the reasons for choosing the dominant treatment place. The participants chose to be hospitalized for several reasons including: the existence of national health insurance (Ina. BPJS) that covers the cost of care, the availability of complete facilities and professional health personnel in hospital, and the inability to do home care. The following is an excerpt from a participant:

*"The reason is because here are many doctors. Doctors are more aware of checking everything..... how should handle the patient they know more... the medical staffs and the nursing staffs are ready..." (P7)*

*"I'm afraid that my condition will suddenly deteriorate at home, I'm worried that I will drop at night and no one can overcome it..." (P10)*

*"I do not have competent family members to take care of me at home, so I feel afraid if at any time when I was dropped out there was no one able to handle it, I feel more comfortable in the hospital because there are health insurance facilities and professional health workers..." (P6)*

Based on the excerpt, all participants described that they had no one in the family member who was have competent knowledge, inadequate capability and patience to take care of terminal cancer patient at their homes. The impact, participants felt far from ready to continue the care at home. Beside that, one participant described that could benefit the most from the continuous treatment at the hospital using the health care coverage scheme.

### **Theme 2: The Influence of Family Dominance in Making Palliative Care Decision**

In this theme, the biggest decision makers are family and spouse (husband). Meanwhile, there are also male participants who are not able to make decisions and hand them over to their partner (wife).

In the second category of the theme regarding involvement before decision making, the participants admitted that they were first asked by the family (husband) about the matter to be decided. It was revealed by the sixth and ninth participants who explained that they were invited to discuss what would be and what the participants wanted during the treatment and care process. If they were ready, their husband would support. However, the one who finally made the decision was their husband. The following are the excerpts from P6 and P9 interviews.

*"I firstly asked my mother. We talked then my husband decided." (P6)*

*"Well, it's my husband who finally made the decision." (P9)*

*"No.... because mama can't make decisions, it all depends on my families... well mamah leave it all to families..." (P4)*

*“My condition is sick and helpless, so the one who makes the decision is my wife...”*  
(P2)

This excerpt shows that nearly all participants described that in decision making, especially the choice of palliative care was dominated by the family (husband) of the female participant and the decision maker was the wife of the male participant. One factor that causes differences in decision making is motivated by cultural differences and the pattern of decision making relationships adopted by the family. This is also due to the helpless conditions experienced by respondents due to illness so they feel unable to use their autonomy in decisions making of palliative care

## 4. Discussion

The results of the study on the first theme described various expressions that some patients refused to be discharged from the hospital and to receive palliative care due to the high level of dependency on the hospital which was considered by Indonesian people able to cure the illness of their family members in addition to the unpreparedness of care giver to treat patients at home. Beside that, then the high level of trust in the services provided by medical personnel in the hospital, the existence of health insurance coverage to be some reason for refusing patients to do palliative care at home. Woodman C, Baillie J, Sivell, S study result (2016) which explains that the biggest reason for patients and families being very dependent on the hospital despite with the terminal patient's condition and recommendation for palliative care is their inability to listen to patient's complaints and groans at home due to the patient's unstable condition. Therefore, due to health insurance which can facilitate sick family members to be treated in hospital until they recover, their families or care givers tend to depend on the facility.

Thomas, T., Kuhn, I., & Barclay, S. (2017) asserted that the reasons for the refusal of patients and families to be resist bringing the patient home and to received palliative care because of the unpreparedness of the resources that become care givers to assume responsibility for caring for sick family members while at home, such as meeting basic needs in the form of hygiene, meeting financial needs, performing multiple roles at home and providing emotional support to patients. This creates a mental burden for families who care for patients at home. Meanwhile, the reason for patients to remain hospitalized is also related to the existence of expressions about health insurance coverage that can be utilized by them. BPJS or KJS health insurance makes the scourge of patients' problems to still want to be hospitalized. Because the free care guarantee provided by the health insurance provides a waiver of the full maintenance fee. So for

patients and families who have financial ability that is classified as middle to lower will think of loss if the insurance facility is not used for their treatment in the hospital to achieve recovery.

The majority of decision makers in this study were family (couples). There was a phenomenon in which male participants were unable to make decisions because of the female patient's role and gender transition that made women have the same role in making public decisions which one of them is to make a care decision for sick family members (Anggraeni, R. A., 2012). It causes wives to take over the husband's role in making care place decision.

The factors that cause differences in decision making are cultural differences and relation pattern of decision making adopted by the family. The third, sixth and eighth participants handed over the decision making to their family. They considered that their families were able to make the best decisions for them and it had become a habit for them that those who make decisions are their extended family. It is in line with the research of Effendy, C., Vissers, K., Tejawinata, S., Vernooij–Dassen, M., & Engels, Y. (2015) who conducted research on the role of families as patient care givers. The results revealed that families acting as caregivers of patients in hospitals were involved in all patient's symptoms and problems during hospitalization including being involved in decision making. It relates to the culture adopted by most Indonesian people who have a strong family bonding and love to "discuss", including family involvement in making decision of patient's care in hospital. The fact is also supported by the results of Kristanti, Setiyarini, and Effendy's study (2017) that states Indonesian people generally have strong family bonding and high family involvement during the process of patient care and hospitalization.

Not only Javanese ethnic community that have a culture of placing families as decision makers especially men who have a major role in making public decisions, but it is also Sundanese ethnic community (West Java) who have a very close family ties. Individual values are very dependent on community assessment. Thus, in making decisions, such as marriage, work, care of family members and so on, a person generally cannot escape from the decisions determined by his family (Lestari, T. R. P, 2010). Likewise, Lampung ethnicity have cultural diversity. They are pluralistic society consisting of various ethnic communities which each of them still has the existed strong cultural values as a reference for patterns of perception, attitudes and behaviors in their daily life both individually and in groups. Lampung women very maintain their honor in front of men (their husband) by never denying what their husband say, taking care of their children, and doing household chores well. Lampung women who live in villages are

very afraid of being considered defiant if they do not obey what men (husbands) say. In decision making in the public sphere, men always dominate women. It shows that women in Lampung villages had never been involved in public affairs since there is a relation between the kinship system and the degree of patriarchal ideology developing in the community.

Besides high dependency factor, the researchers found other factors that made participants unable to make decisions independently. One of them is a high psychological fear that the decision which the patients will take will be wrong and can have an impact on him and be troublesome for family who will take care of him. It parallels the research results of Hoerger, Perry, Gramling, Epstein & Duberstein (2017) that patient's fear and worry are existed in making certain decisions in palliative care. It can reduce the potential for patient's preference or opportunity to make decisions for palliative care, especially home care.

Whereas, patients who suffer from cancer and need palliative care are strongly encouraged to be involved in decision making. They have right to make decisions that we must respect and become an integral part of palliative care at home. Participation of patients who still can be involved in decision making of their care can improve human dignity and patient satisfaction. Decision making through family consideration without the patient's consent is a violation of the patient's rights (Belanger, et al., 2014; Fauzan and Kristanti, 2016). Other research confirms that patient participation in the treatment is important because patients have autonomy over themselves, including in making decisions in choosing a palliative care place. It can increase patient's satisfaction of the care he carries out, reduce the level of anxiety felt by patients and become an indicator to evaluate service quality (Langer, Guez, & Groleau, 2010).

In the treatment decision-making process, the participants said that they were invited to discuss what would be decided, but they were not given the opportunity to make decisions independently. It certainly violates the patients' right of autonomy in making decisions about themselves, including the place of care. The condition is not in accordance with one of the main concepts in Ruland & Moore's peaceful end of life theory in Alligood, M., & Tomey, A (2014), namely experience of dignity and respect which is interpreted as a process of respecting individual autonomy right, in this case cancer patients, in realizing the end of his life peacefully. A peaceful end of life can be obtained by involving patients in making palliative care decisions and always providing them the care they and their family as care giver need respectfully.

Seeing the description above it can be concluded that in palliative care, patients have the right to determine what actions will be undertaken or will not be undertaken and

participate in making decisions in the treatment plan. Thus, communication becomes very important. Communication with patients and families based on the principle of the patient has the right to know the actual condition, but also has the right to not know if desired. The information provided is expected so that patients are able to understand what conditions are happening, accept and adapt to all the limitations posed by existing conditions. If the patient's condition is no longer possible to make decisions because cognitive abilities decline, the family appointed by the patient will replace his role. This is often not easy for the family. Therefore, in palliative care, it is necessary to have Advanced Care Planning given before the patient's condition is unable to make a decision.

## 5. Conclusion

The changes physical, psychological, social and spiritual experienced of cancer patient can be affect patient's ability to make decisions. To facilitate successful decision - making of taking care of the palliative cancer patients at home, the patient need early information for preparation and to make the best decision for palliative care at home. Beside that, patient and family need support from the government as policy maker and health care professionals especially nurses to improve knowledge and communication skills in advocating and clearly informing palliative care purposes and program at home. Thus, patients do not have doubt to receive discharge from hospital and palliative care at home. In addition, the Indonesian national health insurance should support palliative cancer at home to increase the efficiency of care for palliative cancer patients.

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