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On home-based care decision making: The will of the family of palliative cancer patients $^{\stackrel{\wedge}{}}$



Boby Febri Krisdiyanto^{a,b}, Debie Dahlia^{a,*}, Agung Waluyo^a

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KEYWORDS

Decision making; Family; Home care; Palliative care

Abstract

Objective: Home-based palliative care has been suggested to be a beneficial model of care. Whether it is a desirable option of the family and patients is arguable. This study, therefore, aimed to explore the experience of the family the palliative cancer patients in their decision-making process of taking care of the patients at home.

Methods: This study was a qualitative study using descriptive phenomenology approach. Data were obtained through in-depth interviews with 10 family member of the palliative cancer patients.

Results: Three themes emerged in this study: (1) family's limited knowledge and skill to take care of the palliative cancer patients at home, (2) family wish the patients to stay being treated in the hospitals, (3) family depends on the hospital for palliative cancer patients.

Conclusions: Nurses should evaluate family preference, readiness, and capabilities in taking care of palliative cancer patients at home. Nurses should collaborate with the health care providers in assisting the family in their decision making to keep the palliative care patients at the hospital or take them home.

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E-mail address: debie@ui.ac.id (D. Dahlia).

^a Faculty of Nursing, Universitas Indonesia, Depok, West Java, Indonesia

^b Institute of Health Sciences Budi Luhur, Cimahi, West Java, Indonesia

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^{*} Corresponding author.

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Introduction

Cancer is the second most leading death cause in the world after cardiovascular disease. Cancer is also highly prevalent in Indonesia, in which it occurs in 1.8 per 1000 people. The latest national health survey in 2018 also reported that cancer ranked 7th of the mortality cause of Indonesian people.

The majority of the cancer patients in Indonesia come to the health care services at the advanced stage.² The care of the advanced-staged cancer patients primarily aims at palliative care, while palliative care has been advocated to be performed at home.³ Studies suggest that home-based palliative care has several benefits, e.g., to reduce health-care cost efficiency compared to hospitalization, to reduce the hospital-acquired infection, to increase patient quality of life, and to lead to more convenience for family and patients.^{4,5}

Woodman and colleagues asserted that the family of the palliative cancer patients would prefer to take care of the patients at homes. However, the decision to bring the patients home could be very problematic for the family. It is one of the nurse's roles and responsibilities to assist family and provide relevant information for the family to decide about where is the best place for the palliative cancer patients. The family should be given adequate information including the benefits and risks of extended hospitalization.

That some families refuse to take the palliative care patients home may impact the quality of life of the patients. Formal rules of the hospital may unintentionally restrict the patient's freedom and convenience to spend quality time with the family. The hospitalized palliative cancer patients may, therefore, experience distress, loneliness, and depression, or even severe anxiety before their death. Studies also found that 47% of a family of the hospitalized patients may also feel intense distress during patients' end of life. Therefore, nurses should be aware of the information and guidance to be provided for the family to decide home-based palliative care. 11

There is no study to date which explores the experience of palliative cancer patients' family in deciding for home-based palliative care in Indonesia, hence the objective of this study. It is deemed necessary to conduct this study to design effective intervention for assisting family decision making the process for home-based palliative care.

Method

Study design

This qualitative study used descriptive phenomenology design. This approach allows the researched to gain valuable insights into the family regarding their decision-making process about home-based palliative care.

Participants

Participants of this study were family of the palliative cancer patients who had been hospitalized a national referral hospital and had experience in deciding on taking care of the palliative patient at home. The family that decided to keep the palliative cancer patients at the hospital and those who decided otherwise (took the patient home) were included in this study. We used purposive sampling to recruit the participants. A number of 10 participants agreed to take part in the study, of which 6 participants refused home-based palliative cancer care and 4 participants did the home-based palliative care for their severely ill family members with cancer. The details of the participant characteristics are summarized in Table 1.

Data collection

We recruited 10 family members of the palliative cancer patients who had experience in the decision-making process for home-based palliative care. The criteria inclusion were a close family member (could be the father, mother, husband, wife, son or daughter) of a patient with palliative cancer at a top referral hospital in Jakarta, had to experience in deciding on taking care of the patient at home or in the hospital. Staff nurses at the wards of the hospital we used in the study setting helped identified and initially approach the potential participants. We contacted the potential participants, gave further explanation about the study, and obtained informed consent. Data were collected through in-depth interviews lasted for 40–60 min. The first author carried out the interviews at the participants' houses, as chosen by the participants. Interviews were tape recorded.

Participant	Gender	Age	Religion	Education	Relation to patient	Occupation	Patient's diagnosis
P1	Female	36	Islam	University	Daughter	Housewife	Stage IV liver cancer
P2	Male	30	Islam	University	Son	Student	Stage IV skin cancer
P3	Female	42	Islam	High school	Daughter	Housewife	Stage IV breast cancer
P4	Male	54	Islam	Primary school	Husband	Cleaner	Stage IV breast cancer
P5	Female	32	Islam	College	Daughter	Employee	Stage IV lung cancer
P6	Male	46	Islam	University	Husband	Driver	Stage IV breast cancer
P7	Female	57	Islam	Primary school	Wife	Housewife	SOL (Space of Lesion)
P8	Male	25	Islam	University	Son	Operator	Pancreatic cancer
P9	Female	48	Islam	High school	Wife	Housewife	Bone cancer
P10	Female	25	Islam	College	Daughter	Voluntary worker	Stage IV lung cancer

In this study, data reached saturation after the interview with the 10th participant.

Data analysis

We used phenomenological data analysis with Colaizzi's approach to describing the experience of the family of the palliative cancer patients in deciding for home-based palliative care. We started with the repeated line-by-line reading of the interview transcripts to get a general sense of the content and to obtain significant statements. The significant statements were then sorted into categories and themes. We continued with describing the themes and integrating the entire themes to achieve an exhaustive description of the family decision making the process for home-based palliative cancer care. Lastly, we sought for validation of the findings to the participants which was conducted by phone.

Measures were taken to ensure the trustworthiness of the study, its credibility, transferability, confirmability, and dependability. Data analysis was mainly conducted by the first author, and its rigour was enhanced by the collective process with the second and third authors who are experienced researchers in qualitative studies.

Ethical consideration

The ethical clearance of this study was issued by the Ethical Committee Faculty of Nursing Universitas Indonesia (No. 99/UN2.F12.D/HKP.02.04/2017). All participants voluntarily participated in the study and signed informed consent. We kept the confidentiality of the participants in the research process, including anonymization.

Results

The data analysis revealed the following themes:

Theme 1: Family's limited knowledge and skill to take care of palliative cancer patients at home

Nearly all participants described that they only had limited knowledge and skills to perform care for their family members with life-threatening cancer at their homes. They barely received adequate education about caring for the cancer patient at home. They also mentioned that they had no one in the family who was competent to take care of the patients. As a consequence, the participants felt far from ready to bring the cancer patient home and continue the care. For instance, a participant experienced trouble in giving the oxygen for the cancer patients because the family did not know how to use the oxygen cannula and container.

"... Since our knowledge is limited, so is our capability. The only mother took care of the father (the cancer patient), while the mother was also very old. We hardly knew about the care devices, even the oxygen devices; none of us had a medical background. So, we fully entrust the hospital to take care of our father (P1 line 108–111)..."

This excerpt shows that the participant had inadequate knowledge, and thus capability, to perform care for the father who had palliative cancer. This issue was the main reason for the family to keep their severely ill family member at the hospital.

Theme 2: Family wish the patients to stay being treated in the hospitals

This study finds that the family is willing to keep the palliative cancer patients hospitalized for care, despite many advantages of the home-based palliative cancer care. There are eight factors contributing to this family decision. First, the family is not ready to take care of the palliative cancer patient at home. Such unreadiness of the family makes them feel not confident to provide sufficient care for the patient. Second, the patient may have some unresolved problems which need to be treated by the health care professionals. Third, there is a national health coverage system to financially support the hospitalized patients. Fourth, the family expects the patient to gain some recovery from hospital treatments. Sending the patient home is perceived by the family as the give up a sign of the health care providers to take care of the patients towards recovery. Fifth, the family are reluctant to bring the palliative cancer patients home even though the request is coming from the patients. It is because the family considers that the decision to be treated at home is a stupid decision. Sixth, the family refuses the palliative cancer patient to be sent off home. Seventh, the family will make a special extra effort, approaching the hospital staffs or the person in charge to keep their family member with palliative cancer hospitalized. Eighth, the family only want to accept the discharge upon the patient's recovery. Here is one participant statement:

"... We want to keep our mother at the hospital – until all the treatment is concluded. Because we cannot take care of the mother if we follow her request to go home, that is an unlikely request. So, we keep mother being treated at the hospital for her best and her recovery." (P8 line 145–148)"

Participant 8 thought that the patient was on an ongoing treatment that required hospitalization. The participant also declined the patient's wish to bring her home because no one would be able to take care of the patient at home. This excerpt represents the theme of the family wishes to keep the patient at the hospital.

Theme 3: Family depends on the hospital for palliative cancer patients

The family was dependent on the hospital for taking care of their family member with palliative cancer; in terms of trying to avoid the hassle of patient care at home. Family perceived that they their severely ill family member could benefit the most from the continuous treatment at the hospital using the health care coverage scheme. There were five participants conveying this inclination, for example:

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"It is very fussy of course to take care of such gruelling illness.... We cannot do much at home, so we just rely (on the hospital)..." (P5)

Participant 5 expressed his concern regarding the many demands of home-based care since the patient was suffering from plenty of unresolved symptoms while the family members had no time to take care of the patient. The participant, therefore, decided to depend on the hospital for the palliative cancer care of his family member.

Discussion

The ability and readiness of the family are the two most important factors to determine the family decision making for home-based palliative care. 12 Consequently, the health care providers should assess if the caregiver in the family is ready and able to perform care for the palliative cancer at home. 13 The study results of Damanhuri research show that not every palliative cancer patients can be home-treated. Some patients and families in other countries such as the United Kingdom and Australia choose to remain hospitalized for various reasons. 14 The main reason is the incapability of the family and patients to control pain and other symptoms at home. Some other factors include the absence of 24-hour care as in-hospital treatment and the patient's deteriorating condition. Family's deliberate choice, unavailability of palliative care service and access, and inability to provide palliative care at home are also identified to determine the family decision making for home-based palliative care.

Palliative care service in Indonesia is still facing the major problem of access. 15 Serving more than 265 million people of which 50% live in the rural area is a rough description on how providing accessible care remains a prominent issue in Indonesia. 16 Palliative care service is mostly available only in the cities in Indonesia. Effendy et al. assert that despite having been introduced as a national programme since 1989, palliative care in Indonesia has not established sufficient access. 17 The latest data reports there are only 10 big hospitals providing palliative care; all of them are assigned by the government. These hospitals are situated in seven cities in three main islands in Indonesia while Indonesia is an archipelago country consisting of over 17,000 islands. 18 This issue was also recognized by the participants in this study. Nine out of ten participants mentioned their need for accessible palliative cancer care.

This study reveals the lack of ability and aptitude of the family to take care of their family member with palliative cancer so that they keep the patient at the hospital. Five participants stated that home treatment would not allow recovery and healing of the patients since they still had some physical complaints due to cancer and its treatment side effects upon the discharge. The family, on the other hand, were not able to manage such problems at home. The caregiver in the family who was unable to do palliative care at home experienced high levels of stress that is disruptive for health. ¹⁹

Six out of ten participants in this study expressed their inability to perform care for palliative cancer patients at home. They believed that cancer patients should only get adequate care and treatment at the big hospitals. Effendy and colleagues' study results (2015)¹⁷ also found that

palliative cancer patients in Indonesia had more physical problems and unmet needs. This may be caused by a lack of supporting facilities, competent health care providers, and access to palliative care service, especially access from home.

Indonesian government initiated the universal health coverage system in 2014, which integrated several facets of prior government-funded health care insurance. The universal health coverage system in Indonesia is run by the Healthcare and Social Security Agency (known as BPJS in Indonesia). 20 There were five participants in this study mentioned their intention to keep the palliative cancer patients at the hospital was due to the healthcare insurance scheme. The patients had already paid for the insurance, so they deserved to get the health care service at the hospital. Patients with cancer receive excellent health care service at the government hospital using BPJS health care insurance, so the families rely on the hospital to carry on the patient care. However, the health care coverage system would not cope efficiently if this is routine practice. The health care insurance system (Medicaid) in the United States, for instance, can save up to \$6900 and \$252 million every year by reinforcing the home-based palliative care. Hospital-based treatment requires significantly higher operational costs compared to home-based care. In the Medicaid scheme, however, patients are also financially supported for being taken care at home.21

The present study found that the family expected early information and education regarding the patient condition and possible home-based care. The participants in this study reported that when deciding on taking the patient home, they were not ready to carry on patient care. Lack of readiness resulted fear, feeling shocked when they felt being compelled to take care of the patients at home, or in other cases, the family would go against patient discharge. A participant had a tense argument with the head of the nurse refusing to take the patient home. According to Seal et al. research, the main causes of family unreadiness for homebased care are the difficulty of hospital readmission when the patient is experiencing detrimental condition, tiredness to perform daily care at home, and concern about the other family members' wellbeing, particularly children, since the most energy would be directed for the severely ill patient.²¹ Woodman et al. assert that overloaded burden of the caregiver in the family is also the reason why a family is reluctant to take care of the patient at home.

Stajduhar asserted that being not ready as the caregiver, the family may feel fear and incompetent in taking care of the palliative cancer patient at home. Furthermore, Carter et al. argued that the family's lack of readiness would result in negative emotion and outlook regarding the home-based palliative care so that they would resist bringing the patient home. The family who is unready and yet takes the family for home treatment are in high risk for having a traumatic experience of home-based care. Some family may take an uninformed decision about home-based palliative care and hardly realize the implication of the decision.

The results of this study highlight the necessity of early education and discharge planning for the family of the palliative cancer patients as reported by six out of 10 participants. Early education is essential to make a decision and prepare for the home-based patient care. As told by one

participant, education and discharge planning should be given at least two weeks before discharge. Topf et al.²⁴ suggested that the most troubling reason for the family to decide on home-based palliative cancer care was that they had not enough time to prepare themselves and the resources at home. They only had limited time to discuss with the other family member about getting more supporting resources. Early education and discharge planning should be given both to the patients and family. Patient involvement in decision making and treatment plan will have positive impacts on the patients. As the theory of the peaceful end of life posits, the experience of dignity/respect can be reached through the involvement of the patient and the family in the decision making of the treatment.²⁵ The issue of family's incapability to deliver daily care for the palliative cancer patients due to limited access to palliative care from home is well addressed in the developed countries by establishing the Specialist Palliative Care (SPC). World Health Organization strongly supports SPC in every hospital. SPC comprises several health care providers working at the hospitals as the consulting team and those working in the community to provide home care, nursing home, and hospice. SPC generally consists of physicians, experienced nurses, psychologists, and social workers. Since SPC has been put into practice in the past 10 years in the United States, the demand of palliative care has increased fivefold (15-75%). Hence, family tends to opt for home-based palliative care instead of prolonged hospitalization. SPC plays a key role in such decision making. It also emphasizes the patient quality of life as mainly indicated by the pain alleviation of the patients with life-threatening cancer. 26,27

SPC starts working early since a patient is admitted in the hospital. Cancer patient with the palliative condition will be referred to the SPC. SPC will carry out some discussions with the family about the palliative treatment plan. Following on the patient's readiness and autonomy, the palliative cancer patient care will be moved from the hospital to the community, as chosen by the patients. SPC has shown the impacts on improving the patient quality of life, reducing the stress of the patient and family, lowering the aggressive medical treatment and hence the hospital costs, and even on increasing patient life expectancy.²⁸

The United Kingdom (UK) is a good example of how SPC has been well developed and succeeded to improve access to quality palliative care service. In 2005, the UK had already had 361 hospitals with SPC and 277 community palliative care nurses. They then set up 263 hospice day care units in 2015 and 24-hour hospice home care for cancer patients. The UK's National Health Service (NHS) is responsible for the policy making of palliative care including its coordination and the provision of opioid for palliative cancer patients. For palliative care carried out by private health care providers, the NHS gave 32% subsidy of the operational cost.²⁹

The Indonesian government can learn and adopt the system of integrated palliative care service from developed countries. The remaining issues as identified in this study can be addressed by implementing the integrated palliative care. Ensuring access for opioid medication is also needed for palliative cancer patients. Nurses in the SPC have the role as the coordinator for service (home care, nursing home, and hospice) and human resources (including physicians, pharmacists, mental health workers, therapists, and other health

care providers). The essential entry point the nurse must assess is the family ability and readiness to provide daily palliative care at home. ¹⁹

The nurse is a key player in delivering home care service. However, as home care or home visit is not covered by the national health care insurance (known as BPJS), it is down to the family to use the service or not. The trend in many countries shows the shifting focus of chronic care from the hospital-based to home-based service. Home care services are unique to each country. For example, home care is mainly managed by the government via long-term insurance scheme in the UK and Sweden, social insurance programme in Germany and the Netherlands, and also Australia. Incorporating nursing home care service in the BPJS system in Indonesia could be a significant benefit for the palliative cancer patients and their family. 30,31

Conclusions

The experience of family decision making of home-based palliative cancer care can be described in five themes: (1) family's limited knowledge and skill to take care of the palliative cancer patients at home, (2) family wish the patients to stay being treated in the hospitals, (3) family depends on the hospital for palliative cancer patients. The decisionmaking process of palliative care is a meaningful experience for the family members of the palliative cancer patients in this study as it involves not only the family but most importantly the patient at the end of life. To facilitate successful decision making of taking care of the palliative cancer patients at home, the family needs support from the health care professionals and the government as the policy maker. The family also need early education and information to make the best decision and preparation for home-based palliative care. In addition, the Indonesian national health insurance should support home-based palliative cancer care to increase the efficiency of care for palliative cancer patients.

Conflict of interests

The authors declare no conflict of interest.

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