



Experiences of palliative care nurses in providing home-based care for patient with advanced cancer[☆]



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Abstract

Objective: The main concern of caring for an advanced cancer patient is to fulfill the physical, psychological, social, and spiritual needs to reduce the patient's suffering for a dignified death. The purpose of palliative care is to provide comfort and appropriate palliative care nursing. The courage and dedication to fulfill the complex needs for a dying patient become a unique experience for palliative care nurses.

Method: Such experience was explored by using a descriptive phenomenological approach. Eight palliative care nurses were involved as the participants. The findings from the interview were analyzed by using Colaizzi method.

Results: The analysis resulted six themes: palliative care given after the primary job in hospital, family's assumption of palliative care nurse as a caregiver, palliative care nurse concerned more on patient's physical needs, palliative care nurse more dominant in collaborating to overcome the pain, providing care for imminent death in accordance with predefined standards, and challenges in decision making regarding to palliative care.

Conclusions: It is suggested to improve the services to become a palliative care nurse specialist, to improve knowledge and training of palliative care nurse, and to manage the policy of palliative care nurse in National Health Service system.

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Introduction

Palliative care is a multidisciplinary approach of philosophy and organization to improve the quality of life of the patient and the family in dealing with life-threatening disease.^{1,2} Palliative care nursing is professionally provided by an oncology nurse, palliative care nurse, and a specially trained nurse.³ The focus of palliative care comprises pain and

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symptom management, as well as psychosocial and spiritual support for the patient and the family in order to prevent and reduce the suffering.⁴

Palliative care is given to a disease that is incurable with medication, commonly provided in a hospital, hospice, and patient's home. Home-based palliative care is a follow-up treatment from hospital and accounted to a nurse coordinator.⁵

One of the diseases that requires palliative care and preferably to be provided at home is advanced/terminal cancer.^{3,6,7} Home is chosen as a place of care due to the reason that home could provide comfort and support the patient for a dignified death since it is close to the family and the love ones,⁸ and because the family wish to take care of their dying family member at home.⁹

The vital role of nurses in home-based care for advanced cancer is to provide comfort by applying clinical competence and nursing science.^{4,10} Nurse is required to present physically, emotionally, and spiritually while taking care of the patient since dying until the imminent death.¹⁰ Emotional readiness becomes an important part of a nurse because s/he would witness the patient's suffering from dying to death.

According to National Institute for Clinical Excellence,¹¹ assisting an end-stage patient in remaining active is often considered impossible to achieve. Nurses are challenged to actualize this need. Some nursing strategies should be skillfully provided to achieve the purpose of nursing care and improve the quality of life of the patient. A nurse should be competent and confident in implementing clinical nursing care for a dying.^{12,13}

Competent nurse works in accordance with the standard of practice of providing nursing care. While in fact, the standard and manuals for palliative care in Indonesia are limited and highly depend on each institution, there is no national standard of the medical service system for palliative care.^{14,15} The existing manuals are still global and not specified to particular diseases. Therefore, it could affect the care quality for the patient and the family, and also could lead to a discrepancy of implementation of nursing management concept in real practice.

However, the challenge above did not hinder the palliative care nurses from remaining to provide their best palliative care. Experiences during taking care of dying patient have never been well identified. The researcher is interested in identifying such experiences and the reasons of their dedication in providing home-based care for a patient with advanced cancer. The researcher intends to identify the professional work of palliative care nurses that committed as a home caregiver. Such experiences were identified through this research question, "what and how is the experience of palliative care nurses in providing home-based palliative care to patients with advanced cancer?"

Method

This research employed a descriptive phenomenological approach by exploring the experiences of palliative care nurses who gave home-based palliative care in person. This research involved eight palliative care nurses as the participants in order to attain data saturation. Participants were

selected by using purposive sampling method. Those who met the criteria directly became the participants.

The criteria of participants for this research was based on the palliative care nurse criteria of the Ministry of Health 2012,^{5,16} i.e. working as a palliative care nurse, obtaining minimum D3 Nursing, possessing palliative certificate, having at least 3 years' experience of palliative care nursing, and able to articulate any experience related to home-based care for patient with advanced cancer.

This research has obtained approval from Ethic Committee, Faculty of Nursing, Universitas Indonesia, with reference number 240/UN2.F12.D/HKP.02.04/2017 and Ethic Committee of Dharmas National Cancer Hospital, with reference number 064/KEPK/IX/2017. Data were collected through in-depth interview with the participants by using the mp3 recorder, interview guidelines, and field notes, which subsequently analyzed by using Colaizzi method. The participants and two supervisors were tested for their credibility by comparing the findings to the previous findings (transferability), performing objectivity test (confirmability), and data consistency (dependability) by involving two supervisors as the external reviewers of this research.

Results

Demography data shows that participants' age ranged from 29 to 61 years old. They have occupied Nurse Education (4 participants), D3 Nursing (3 participants), and Master of Nursing (1 participant), and been certified for palliative care. Participants consisted of 5 females and 3 males. They have experienced in providing home-based palliative care for 4–16 years. The analysis resulted in six themes, namely:

Theme 1. Palliative care was given after the primary job in a hospital

This theme was constructed from two subthemes. The first subtheme was that home-based palliative care became the additional work from the hospital. This subtheme was based on two categories, that is palliative care was given after the office hour and on holiday. The participants who expressed this statement were Pr2, Pr3, Pr5, Pr6, and Pr10. One of them stated that:

"...it should be off day here, so we use it (nurse off day)..." Pr5 line 322-323.

This statement could represent the subtheme because it expressed the use of off day to provide palliative care. The second subtheme was that palliative care nurses sacrificed their me- and family-time. This subtheme was based on two categories, i.e. family time was used for home care and the commitment to use a day off for home care. The participants who expressed this statement were Pr2, Pr3, Pr8, Pr9, and Pr10. Here is one of their statements:

"...I was about to come to my husband's office occasion, then I got a call for home care ... so, I cannot join (the occasion) ..." Pr10 line 53-56

This statement could represent the category because the participant expressed his/her commitment of being a home-based palliative care nurse.

Theme 2. Family's assumption of palliative care nurse as a caregiver

This theme was constructed from two subthemes. The first subtheme was that the family did not understand the job description and the function of a palliative care nurse. This subtheme was based on two categories, i.e. palliative care nurse was treated as a household assistant and assumed as a caregiver. Such a statement was expressed by participants Pr2, Pr4, Pr6, and Pr10. Here is one of their statements:

"...we are a professional worker. we're often assumed as a caregiver..." Pr10 line 159-162

This statement represents the subtheme as the participant showed their disappointments by taking a deep breath and fast releasing while lowering their both hands on the table. The second subtheme was that the family did not involve in taking care of the patients. This subtheme was based on two categories, i.e. nurse took the whole responsibility of providing care and the family did not understand their part in taking care of the patient at home. One of the statements that expressed this statement is:

"...there is some family...all give it up to us..." Pr4 line 153-155

Theme 3. Palliative care nurse concerned more on the patient's physical needs

This theme constructed from two subthemes. The first subtheme was that palliative care nurse more concerned to overcome pain and physical complaint. This subtheme was analyzed from two categories, i.e. comfort for pain and dealing with the physical problem. The statement that stated this condition is:

"...especially pain...wound, breathless, nausea, and vomiting..." Pr7 line 67-70

This statement could represent this subtheme because the participant stated it firmly that the main concerns were pain and some other physical symptoms. The second subtheme was that a palliative care nurse fulfills the basic human needs within two categories, such as personal hygiene, and elimination (defecate and urination).

"...surely, basic need like personal hygiene..." Pr9 line 141-143

Theme 4. Palliative care nurse more dominant in collaborating to overcome the pain

This theme was constructed from two subthemes. The first subtheme was that the pain of cancer could not be handled with nursing care. This subtheme was based on two categories that pain cannot be handled by nursing care, and non-pharmacological treatment does not affect it. One of the participants stated that:

"...to (overcome) pain needs only a little of nursing care, just collaborating in the end..." Pr4 line 384-386

The second subtheme was that nurse did collaborative action with the doctor when the patient suffered from pain. This subtheme was based on two categories that are a collaboration with the doctor to overcome the pain and 4-stage cancer pain can only be treated using some medication.

"...the point is that we'll still have to collaborate with the doctor... like pain relief medicine, such as morphine, codeine, coditam, etc..." Pr5 line 34-39

Theme 5. Providing care for imminent death in accordance with predefined standards

This theme was constructed from three subthemes. The first subtheme was the ability to assist the patient and family for the imminent death. This subtheme was based on two categories that are communication-related to patient's condition and preparing family psychological to deal with death. This statement was expressed by participant Pr4 and Pr9. The statement was as follows:

"...not only preparation for the patient, but also the family needs explanation..." Pr4 line 132-134

The second subtheme was about recognizing the end-of-life signs and symptoms. This subtheme was based on two categories that are physical recognition of imminent death and signs regarding to the patient's assumption in his near death. This statement was expressed by participant Pr2, Pr3, Pr4, Pr7, and Pr10. One of the statements was as follows:

"...they usually say something like, the nurse I want to meet my wife, that is not available theoretically..." Pr7 line 339-341

The second subtheme was the ability to provide care when death was coming. This subtheme was based on three categories regarding to corpse care, preparing the death certificate, and preparing for the family needs when their family member died. The statement that supported this subtheme is:

"... for Muslim family, usually like what mosque, where to sepulcher... bathing (corpse)..." Pr3 line 260-262

Theme 6. Challenges in decision-making regarding to palliative care

This theme was constructed from two subthemes. The first subtheme was the different decisions among doctor, nurse, and family. This statement was expressed by participant Pr3, Pr4, Pr7, and Pr10. The statement that supports this subtheme was as follows:

"...decision is not only made by family, but sometimes nurse also involved..." Pr9 line 154-156

The second subtheme was the different opinions about what information should be told to the patient. This subtheme was based on two categories regarding to the information that should be agreed by the family and should please the patient. The statement that represented this subtheme was as follows:

“...to the family first... some will say, don't ask something like this (about the patient), just make him happy instead...” Pr3 line 251-252

The participant showed his/her disagreement of the compulsion to explain to the family first, and then to the patient.

Discussion

The demography data analysis shows that all participants have met the criteria of palliative care nurse in accordance with the policy of palliative care nurse criteria from the Ministry of Health Republic Indonesia.¹⁶ However, the first theme which stated that home-based palliative care was conducted after office hours is not in line with the principle of home-based palliative care as it would be better if it is provided by special palliative care nurse who only serves for home-based palliative care as the quality of the palliative care could not be maximized due to the transition of role and the difference of care objectives.^{17,18} The role of palliative care nurse who works in the hospital concerns more on providing intervention to handle the disease, while home-based palliative care concerns more on preventing and reducing the suffering through the management of physical symptoms, psychological, social, and spiritual supports for the patient.^{4,19}

The demography data also shows that the education levels of the participants were varied from Diploma, Bachelor with Nurse, and Master of Nursing. The participants also have obtained a palliative certificate from education and training in their workplace. The topic of education and training was not distinguished based on the education level. This statement was in line with Payne, Ingleton, Sargeant, and Seymour¹² who stated that the different levels of education did not affect the palliative care competence because the requirement of being palliative care nurse is trained and obtained the certificate and there is no difference in topic of palliative care in terms of education level. It is suggested that in order to improve the quality of palliative care nurse, education and training for home-based palliative care should be given and supported by formal education of palliative care.¹⁷

Another analysis result from this research was that palliative care nurses were frequently assumed as a household assistant or caregiver. Such an assumption was possibly due to the absence of explanation regarding to home-based palliative care when the patient and family still in the hospital. The family should be trained and educated about palliative care before the discharge, and they should have been prepared the readiness of having home-based care. Therefore, when the care was moved to the home, family and nurse have already understood their roles, where the nurses only concern with the nursing care that cannot be handled by the family.^{4,20,21}

The analysis of the fourth theme resulted that palliative care nurses were more focused on the physical problem. Handling physical problem was required collaborative action, and all action should be consulted to the doctor in charge. This finding is different from the philosophy of comprehensive and holistic palliative care.⁴ Palliative care indeed involved multidiscipline, however in treating

the patient, the nurse should prioritize the nursing care before collaborating with the other palliative care team. According to Mehta et al.,²² non-pharmacological nursing care was effective to support handling the patient problem and could be combined with pharmacological therapy to support nursing care.^{22,23} This finding was because in providing home-based palliative care, the nurse only concern about the patient's physical inconvenience, and the treatment given was based on this consideration; therefore, they did not consider the appropriate holistic and comprehensive care.

The fifth theme shows that palliative care nurses were able to provide the appropriate palliative care in accordance with the standard operational procedure. Based on the principle of palliative care, palliative care nurse should be able to give information related to the end-of-life signs and symptom to the patient and the family.⁴ This statement has been implemented by palliative care nurses by giving education about death signs to the patient and family, providing psychological supports for the patient and family, and preparing the patient for a dignified death.^{24,25} Even though death is a sensitive issue to be discussed with the patient and family, some nurses think that the dying patient could take benefit from the education about death as it could help the patient be more ready compared to those who did not receive any education.²⁶ The other principle is an important action that should be done by the nurses, such as corpse care in regards to the patient's religion and belief as well as the culture. This principle should consider the culture of the patient and the family regarding to death.^{27,28}

Conclusions

Principally, home-based care should emphasize and believe in patients and family choice regarding all aspects of life, care, death, condolence, as well as where they will die and who they will die with.²⁹ The decision-making is given up to the patient and family. This statement is different from the statement of the finding in this research where the patient and family tend to give up all the care to the nurse. This principle is surely different from the principle that stated patient and family should be in charge of making a decision. This finding was because the patient and family were not well prepared and had no enough explanation in detail during their stay in the hospital.⁴

Conflict of interests

The authors declare no conflict of interest.

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