

Original Article

Comfort Assessment of Cancer Patient in Palliative Care: A Nursing Perspective

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Abstract

Background: Comfort is a basic and essential need in palliative nursing care. Patients in palliative care often experience physical, psycho-spiritual, socio-cultural, and environmental discomfort. However, comfort has not been the focus of attention of health care professionals in Indonesia.

Objective: This study aimed to describe the nursing perspectives about the patient's comfort in palliative care.

Methodology: This study used qualitative study in which the data collected through a focus group discussion.

Results: Four themes were obtained: 1) several issues of comfort experienced by patients with advanced cancer, 2) nurses need an easy and valid instrument to assess patient's comfort, 3) approaching patients is not easy, and 4) not all of the patient's expectations can be met.

Conclusion: Patients with advanced cancer experienced various comfort problems, but the nurses had difficulties to approach and assess the patient to fulfil the patients' needs. The study entails the need to develop a practical yet valid and reliable comfort assessment tool.

Key words: assessment instrument; cancer patient; comfort; palliative care.

Introduction

Comfort is a substantive need in palliative care. Patients and their family also express that comfort is an essential part in palliative care (Carrow, Ward, Plummer, Bruera, & Abernethy, 2008). Patients in palliative care frequently experience physical, psycho-spiritual, socio-cultural, and environmental discomfort (Kolcaba & DiMarco, 2005). However, comfort issue is commonly overlooked by the health care professionals, including nurses. Instead of helping the patients to achieve their optimal comfort at the end of life, health care professionals often focus giving aggressive anticancer treatments although

evidences showed no association of such interventions with the patient survival (Nevadunsky et al., 2014). Neglecting comfort issue may affect the patient's psychological condition, even lead to prolonged depression. It is important to note that depression was found as the most significant factor which may cause hopelessness among patients, apart from pain and lack of family support (Hack, 2012).

Nurses, when dealing with comfort issues, mostly focus on pain which is one of the physical discomforts. Other areas of comfort are still poorly addressed. In fact, patients with advanced cancer also have psychological, social, cultural and

spiritual needs which should be met in palliative care (Breitbart, 2008) Palliative care is a comprehensive care to release discomfort, symptoms and stress of the life-threatening and chronic diseases to prevent and reduce morbidity and to promote the quality of life of the patients.

Oncology nurse has the responsibility to promote the comfort of the patients during the therapy and in their daily activities. Patients expect the nurses to be caring in helping them fulfilling their needs of comfort. However, this patient expectation cannot be accomplished yet. Study found that nurses regarded their caring behavior lower than patients and caregivers (Karlou, Papathanassoglou, & Patiraki, 2015).

Studies pertinent to comfort in patients with cancer commonly focused on the data from patients and families, while data from nurses is still limited. Study on the nursing perspective is of high importance to balance the information source, thus enriching the knowledge to promote comfort. This study aimed to describe the information from the oncology nurses with regards to patient's comfort need, the barriers in addressing the comfort problems and the expectation to increase the patient's comfort.

Methods

This study was a qualitative study using focus group discussion data collection method. Eight oncology nurses from palliative care unit in Jakarta, Indonesia, participated in this study. The inclusion criteria were having minimum qualification of diploma in general nursing and having oncology care training. We used a pre-prepared discussion guide consisted of open-ended questions to explore the opinion of the nurses with regards to the comfort assessment of patients with cancer, attempts of the nurses to assess comfort, nurses' perspective on the importance of comfort assessment of patients with cancer, nurses' suggestion about the form of the comfort instrument and another attempts to be done for assessing comfort in patients with cancer.

The descriptive qualitative method of this study emphasized on the deeper exploration of the nurses' perspectives regarding the discomfort experienced by cancer patients in palliative care. The data were analyzed with Colaizzi's descriptive

data analysis (Speziale, H. J. & Carpenter, 2007). This technique was started with listening the verbal description of the participants from the tape recording. The transcript was carefully read and reread to get the general sense of the entire content of the participants' perspectives. Afterwards, we searched, underlined and extracted the significant statements to formulate meanings which were sorted into categories, clusters of themes and themes. The themes were incorporated into an extensive description of the nurses' perspective on comfort measurement for cancer patients in palliative care. We sought the validation from the participants to match the research findings with their perspectives.

Ethical clearance was obtained from the Research Ethics Committee, Faculty of Nursing, Universitas Indonesia. All participants received thorough information regarding the study, their rights and privacy before signing the informed consent.

Results

The participants involved in this study were nurses who give palliative nursing care to patients with cancer. Table 1 summarized the characteristics of the participants.

The majority of participants were female (87,5%) and of middle-aged (62,5%). Most of the participants hold bachelor of nursing degree (75%) and worked at the adult ward for patients with cancer (75%). Four themes emerged in this study.

Discomforts experienced by the patients with advanced cancer

The discomforts experienced by the patients with advanced cancer were physical, psycho-spiritual, sociocultural, and environmental discomforts.

Physical discomforts perceived by nurses are illustrated below:

"They felt discomforts because they had a pain. Sometimes their pain was resulted from their cancer, the presence of painful lump or swelling, insufficient dose of medications, or different types of medication administered". (N1)

"Patient's discomforts were observable from their facial expressions". (N3)

“Palliative patients commonly complained of discomforts associated with loss of appetite, insomnia. Everything they did was not inconvenient for them, they could not sleep, nor could get alert. Also, despite of the absence of respiratory problems, they easily had fatigue”. (N2)

Psycho-spiritual discomforts perceived by nurses are described as follows:

“Palliative patients surely needed adequate attention, mam. Nonetheless, their family was never there, or hardly present. They, furthermore, didn’t give moral support, as stated by another staff, their family didn’t care about the patient’s condition”. (N6)

“Our patients had no substantial problems associated with spiritual needs fulfillment. Nonetheless, patients had physical limitations,

and could not do worshipping activities since they considered their body was soiled or worn diapers or had catheter installed. Thus, some might have discomforts due to unable to perform worshipping activities”. (N9)

“There was a critical patient who requested going to the church, expecting prayers from the worshipers, yet he was not allowed to do so on account of the hospital regulations”. (N6)

Socio-cultural discomforts perceived by nurses are explained as follows:

“Most people in our culture conceal the unpleasant information to patients. Families usually know earlier about the patient’s health conditions and requested nurses to keep it from the patient. It, for the most part, occurred”. (N3)

Table 1. The characteristics of the participants (n=8)

Characteristics	(n)	(%)
Gender		
Male	1	12,5
Female	7	87,5
Age		
Young adult (21-35 y.o.)	3	37,5
Middle adult (35-55 y.o.)	5	62,5
Unit		
Radiotherapy	1	12,5
Pediatric ward	1	12,5
Adult ward	5	62,5
Private adult ward	1	12,5
Education		
Diploma in general nursing	2	25
Bachelor in nursing	6	75

“Once, the doctor visited my patient and had a talk with her about her/ actual health conditions. However, the information from the doctor depressed my patient and irritated her family. Thereafter, the patient’s family shunned the doctor”. (N2)

Environmental discomforts perceived by nurses are described as follows:

“Patients’ rooms were inconvenient. In one patients’ room, we might have a patient with odorous cancer wound, whilst other patients would be disturbed with the odor. Or, we might find a very talkative patient whereas other patients needed to rest”. (N1)

“Patients had to stay in a patient room, where they were unfamiliar with. Moreover, they had to share the rest room with other patients with various characteristics and habits. Some might use dry toilet, while others might use wet toilet. In addition, they shared the room with other patients for sleeping while they used to sleep with their spouse. They were strange to the physicians and nurses as well, and thereby making them feel discomfort”. (N3)

There was an urgent need of valid and user-friendly assessment tools of advanced cancer patient’s discomforts

“There was an urgent need of discomfort assessment tools as a guideline for nurses who are lacking of skills in evaluating patient’s discomfort”. (N8)

“The assessment tools may contain pictures, checklist forms, or spaces for narrative descriptions. I imagined that it would be better if the patient can easily select the picture on the tool that may represent their discomforts or how they feel”. (N8)

Patient’s expectations could not be fully met

Patients certainly expected excellent services. Nonetheless, their expectations may vary according to in which room’s class are they staying. Generally, patients in class 3-inpatient unit (economical class) expect less. Thus, nurses will feel less- stressful.

“Patients in class 3- room were generally not demanding, they respected us better”. (N4)

“We avoided asking their (patients) expectations”. (N3)

“Newly hospitalized patients were commonly more demanding, asking lots, and should be responded quickly. After they stayed longer, they eventually understood, and were adaptable”. (N4)

Patients in private room (the most expensive type of hospital room service) expected fast responses from nurses, demonstrated on the statements below:

“Patients in private room could not wait, they demanded fast services. When they rang the bell, they wanted nurses to come in seconds”. (N3)

Patient’s expectations frequently differed from family expectations. Family would expect the patient to live in any ways. On contrary, the patient wearied of various procedures.

“Patients were coerced by their family into some medical procedures, despite no progresses were made. We, medical and healthcare team, tried convincing the patients to follow their family suggestions through some approaches. The patients, initially refused, but then they did so. In my view, education for family about palliative care is of importance, and is ideally started when the patients are in stable conditions. As a matter of fact, we educated them when the patients were dying, and therefore, the family was unable to cope with grieving and we did not know what were the patient expectations”. (N8)

Approaches to the patients did not prove to be easy

Nurses believed that patients with low and middle socio-economical status are more approachable than those with higher socio-economical status. In addition, patients with higher socio- economical status are more dependable to physicians than to nurses.

“Patients with higher socio-economical status frequently requested their physician to visit them whenever they had health complaints. They declined our (nurses) suggestions. All they wanted was only to talk with the

physician. They behaved that way because they had money, perhaps". (N3)

"Patients in the first- class room, who was staying in the not-so-high nor so low- class of patient room, relatively trusted us. They had been in a long line for patient admission and therefore they seemed grateful that they could be admitted". (N1)

"Approaches to the teenaged patients were difficult, they never talked to me". (N5)

Discussion

Palliative patients frequently have a great deal of physical, psycho-spiritual, socio-cultural, and environmental discomforts (Kim, Kwon, & Pcm, 2007; Kolcaba & DiMarco, 2005; Krinsky, Murillo, & Johnson, 2014). Our study revealed that physical discomforts were observable from the patient's facial and non- verbal expressions. A study conducted in Bangladesh used mobile phone devices to measure the level of physical discomforts (Haque, 2013). Another study showed psychological pain measurement with electro encephalograph (EEG) (Meerwijk, Weiss, Ford, & Chesla, 2013; Rissacher, 2011). On the other hand, most healthcare teams in Indonesia commonly use the pain scale 0-10 to measure patient's physical discomforts. This scale is considered to be highly subjective, depending on the patient's perception and mood. Pain level stated by the patient is often imprecise and thus, the scale is unable to represent the actual pain level experienced by the patient. The use of a tool or a device will certainly help nurses to be more objective in measuring the pain and discomfort level experienced by the patient.

Our study also demonstrated that psycho-spiritual discomforts occurred due to insufficient family supports. A study conducted in China showed that family members and peers or relatives are the major source of supports, particularly emotional and informational supports (Cheng et al., 2013). Along with the result of that study, another study revealed that cancer patients in Indonesia received better psychological supports than those in the European countries (Effendy, 2015). Correspondingly, family supports closely related to cultural value.

Spiritual comforts in our study could not be fully met due hospital regulations. Dying patients,

regardless of their spiritual beliefs and activities, were banned to leave the hospital. As a matter of fact, Indonesian people were considered having great spiritual value and activities. This restriction frequently led patients and family to a difficult position.

They preferred early discharge without the use of life- support machines, yet the family felt very remorseful after ending the treatment. In order to anticipate this issue, both hospitals and nurses must become more responsive to the patient's spiritual needs. A study conducted in Indonesia proved that spiritual ability amongst cervical cancer patients has changed them from living in a miserable life into a content one. (Susanti, Hamid, & Afyanti, 2007)

Our study found that environmental discomforts were resulted from lacking of privacy and patient's inability to adjust with a new environment. A study result acknowledged that individual's satisfaction to the environment is closely linked to comforts (Shin, 2015). He further stated that this satisfaction could be attained through modifications in individual active perception and interpretation as well as modifications in physical and social environment.

Pain assessment is the only tool available to assess patient's discomforts. Without the use of a suitable instrument, it would be difficult for nurses examining patient's discomforts. The use of an appropriate instrument would help nurses to correctly diagnose patients. There were various tools available to assess discomforts among cancer patients (Effendy, 2015; Kim et al., 2007; Moriber, 2009; Wilkinson, Slatyer, Mccullough, & Williams, 2014). Nevertheless, most of these instruments did not take patient's socio-cultural value and backgrounds into account. As a matter of fact, perception of discomforts among patients in Indonesia and other countries might differ, depending on their socio- cultural value and backgrounds. Therefore, these instruments might not fit with the characteristics of patients in Indonesia.

Results of our study showed that nurses were unable to meet patients' expectations concerning comforts. The study described that palliative nurses play tough roles, including roles in educating, caring, coordinating, and organizing

(Pavlish & Ceronsky, 2009). To perform these roles, a nurse should possess the following professional attributes: clinical expertise, honesty, family-like orientation, attentiveness, presence at patient's side, ability to collaborate, calmness and carefulness (Pavlish & Ceronsky, 2009). Nursing shortage in Indonesia, however, contributed to the unmet expectations. These can be minimized by good communications and cooperation between patients, family, nurses and other healthcare professionals.

Nurses were unsuccessful to win the trust of certain patients. The "have" patients would rather directly talk about their health issues to their physicians than to nurses. Notwithstanding, not all physicians were available or on duty. This study also revealed that it was difficult to approach adolescent patients, and therefore nurses had to put themselves in the patient's shoes. Apparently, the assessment tool must include the strategy to approach and to establish the trust with difficult patients.

Conclusion

Results of this qualitative study comprised four themes that explained physical, psycho-spiritual, socio-cultural, and environmental discomforts among palliative cancer patients. Nurses found difficulties in meeting their patient's expectations due to failure in identifying the actual patient's problems. Thus, it is imperative that the discomforts assessment tools for advanced cancer patients are developed. Results of our study suggested further studies regarding the development of a holistic, valid, reliable and user-friendly instrument to assess patient's discomforts. The instrument may be derived from the existing instrument, but is suitable and applicable to patients in Indonesia.

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