Needs of patient with advanced stages of cancer in a Thai community

Mixed method approach

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Abstract

Purpose – The purpose of this paper is to explore the needs of people with cancer in advanced stages and to analyze factors that influence them.

Design/methodology/approach – A concurrent mixed-method design was used. Descriptive design was conducted in Ubon Ratchathani Province, Thailand. Data were collected from a convenience sample of patients with advanced cancer of any tissue or organ. Questionnaires were completed by 110 patients aged 60 years and above (response rate 110/130 = 84.6 percent). In-depth interviews were conducted with a total of eight patients. Content analysis of semi-structured interviews of a sub-sample was subsequently performed to better understand the real needs of patients with advanced stages of cancer at home setting.

Findings – The majority (77.5 percent) reported a preference to spend their final days at home. The four most common palliative care needs were more information about disease and medical treatment (98.2 percent), more treatment for pain (97.3 percent), health education for family caregivers (95.5 percent) and health volunteers visit at home (95.5 percent). Content analysis of the qualitative data suggested that patient needs health care providers to deliver open communication, pain management and provide psychosocial supports.

Originality/value – The result showed that patients-related variables are associated with the palliative care needs in patients with advanced stages of cancer. Communication skills and pain management are the key components to support the need for palliative care at home and to benefit the quality of life in terminally ill patients.

Keywords Palliative care, Cancer patients

Paper type Research paper

Introduction

Cancer is a potential life-threatening disease. In 2014, the World Health Organization (WHO) projected that the number of annual new cancer cases will rise from 14m in 2012 to 22m within the next two decades[1]. In high-income countries, such as the United States, an estimated 1,688,780 new cancer cases are expected to be diagnosed in 2017 and 600,920 are expected to die of cancer or about 1,650 people per day[2]. In England, 356,860 new cases of cancer were registered in 2014. Data from the Office of National Statistics (ONS) revealed that cancer was the leading cause of death in England, accounting for 29 percent of all deaths in 2014[3]. In Thailand, data from the Health Information Unit, Bureau of Health Policy and Strategy revealed that cancer is the first leading cause of death in adults. The mortality rate per 100,000 populations from cancer has increased from 95.2 in 2011 to 113.7 in 2015[4]. In 2011, the WHO
has reported that over 29m (29,063,194) people have died from diseases requiring palliative care at the end of life[5]. Most patients with advanced stages of cancer suffer from pain, fatigue, anxiety, depression, dyspnea and other symptoms[6, 7]. Moreover, when confronting death at the end of life, patients may suffer certain phobias, i.e. fear of pain, lack of all control, loss of dignity and fear of dying alone[8]. As a result, holistic palliative care plays an important role not only in controlling symptoms but also maintaining or improving patient quality of life (QOL). Palliative care focuses on the relief of suffering and supports for the best possible QOL for patients facing serious life-threatening disease and for their families regardless of whether the final outcome is death or cure of the illness[9, 10].

Palliative care is an approach to care for patients with potentially life-threatening disease and their families, focusing on all aspects of holistic health care such as pain treatment, advising family members, referring to social services. The ultimate goal is to provide patients and families with the best QOL during the trajectory of diseases[11]. The data from previous studies showed that many terminally ill patients would prefer to stay and die in their own homes, but unfortunately some of patients may not be able to do so[11–14]. Evidence has presented many benefits of home care for palliative care patients. These are, for example, relieving the symptom burden, increasing the patients’ self-management of the illness, increased receipt of sufficient information to handle an illness emergency, relieving the caregivers’ burden, and the positive effects on the satisfaction of care[15]. Despite the fact that many studies have also demonstrated that palliative home-based care by physicians or nurses supports patients to die at home, most were performed in countries where palliative is integrated into mainstream medicine. Regarding the latest report from the Worldwide Palliative Care Alliance in 2014, Thailand is classified as a country where palliative care is only provided in some areas[4].

Palliative care services delivery was the highlighted national policy in Thailand[16]. Palliative care services in Thailand are mainly delivered in hospital settings; integrative palliative care from hospitals has not been effectively linked with community settings[17, 18]. Wright et al.[19] classified palliative care activity across the globe, and countries were allocated to one of four categories: no known palliative care activity, capacity building activity, localized care provision, and palliative care services integrated in the health system. Thailand is classified as a nation in category 3 because localized palliative care provision is available in hospital. The improvement of community and home-based palliative care programs is needed to increase the coverage of palliative care services[20]. Moreover, costs of medical care in home programs are less than those in acute services care used in emergency departments and hospital wards[21, 22]. No national statistics in Thailand are available on the rate of death at home or are related directly to the place of death. It differs from western countries such as in the UK, where the rate of death at home increased from 18.3 percent in 2004 to 20.8 percent in 2010[23].

The essence of palliative care is that the holistic care includes the psychological, social, and spiritual needs of the patients[24]. Thus, the needs of patients with advanced stages of cancer become a healthcare issue. However, the literature reveals that most of research studies were conducted to assess needs of palliative care among patient in hospital[25–28]. The result of this study will inform professional nurses and guide policies on how to provide appropriate health care services for patients with advanced stages of cancer. Moreover, an expected outcome of this study could guide care at home aiming to improve patients’ QOL and place when the end of life comes. Therefore, the objective of this study aimed to explore the needs of patients with advanced stages of cancer in home setting.

**Methods**

*Design*

The concurrent mixed-method design, combining a major quantitative and minor qualitative, was used[29]. First, descriptive design was conducted to explore specific needs and problems among elderly patients. The study populations included 110 patients who enrolled in
palliative care program at Sapprasitthiprasong Hospital from January 2014 to March 2014. Inclusion criteria comprised of patients 60 years who were diagnosed cancer stage 4 by the oncologist and were receiving treatment to alleviate symptoms and promote their comfort rather than cure their illness. Patients were excluded if they had a problem with cognitive impairment or a health status that did not allow them to comprehend interview questions.

Second, semi-structure interview was conducted to explore specific needs and problems among elderly patients focusing on home-based care. The interview was constructed on the bases of the item of the questionnaire choosing those considered less deep in the evidence base. A purposive sample of 8 patients was subsequently selected for the interviews. Participants who enrolled in home-based palliative care for at least 1 month were identified by an oncologist nurse. Interviews were taped on tape recording machines and transcribed verbatim. Each participant was given a code number for identification purposes to maintain their anonymity. New participants were added until saturation of the data was reached[30].

Measurement
A self-report questionnaire was developed by the researcher based on literature reviews aimed to explore patients' needs in the study. The general characteristics were created for the collection of basic demographic and clinical data.

The palliative care needs were developed by the research based on literature reviews consisting of 13 items. It asks about different of needs: information (item 1–3), physical (item 4–7), emotional/spiritual (items 8–10) and social supports (item 11–13). Each item represents one need of cancer patients and scale was rated on a scale from 1 (not importance) to 5 (very importance). Five experts were invited to assess content validity index and the questionnaire was revised according to their comment. Afterwards, the reliability was tested by a pilot test on a convenience sample of 30 patients with advanced stages of cancer at the OPD/IPD and returned to the researcher. The reliability of the questionnaire, as well as the reliability of the questions of each dimension, was measured with Cronbach’s α coefficient. Results showed that the Cronbach’s α coefficient for the overall questionnaire was 0.852.

The semi-structure interview is presented in Table II. All interviews were conducted at patient’s home. Individual oral interviews were conducted in the Thai language.

Data analysis
The characteristics of the participants were presented in terms of frequency and percentage for categorical data and mean with standard deviation for continuous data. The relationship between individual variables was assessed with Spearman’s correlation coefficient. Significance was set at $p < 0.05$. Regarding the qualitative data, we used it to confirm the quantitative findings by examining the coded units of meaning in each narrative content and then recorded to identify the emerging themes. Content analysis was used to explore the needs of home-based palliative care[31]. This study used data triangulation through data collection to identify major issues. The data that were derived from the interviews reached a saturation point when no new information emerged from the interviews. All the transcriptions were read and analyzed by the researcher. The analysis proceeded by defining codes that were derived from the data. The combination of larger thematic categories was used, which were coded and linked using notes and interview summaries[32].

Ethical considerations
Approval was obtained for conducting research with human subjects through the Institutional Review Board (IRB), Faculty of Public Health, Mahidol University (MUPH 2013-142) and the approval from the Health Research Ethics Committees of Sapprasitthiprasong Hospital (Code No. 003/2557).
Results of the quantitative study

Sample characteristics
A total of 111 patients participated in this phase. The majority of the participants were female (64.0 percent), with mean age 66.16 years (SD = 6.73) ranged from 60 to 84 years, living with spouse (71.2 percent), Buddhist (93.7 percent), and attained primary school grade (82.0 percent). The health care costs were mostly covered by universal coverage scheme (94.6 percent). Most of them preferred home as a place for caring (77.5 percent). In this sample, the most common cancers in male were liver (32.5 percent) and lung (27.5 percent). The most common cancers in female were breast (29.6 percent) and cervical (11.3 percent) (Table I).

Needs of palliative care among patients with advanced stages of cancer
The participants had high levels of needs for all 13 items, and the four most important needs among cancer patients for palliative care included information needs (98.2 percent), patients needed more treatment for pain (97.3 percent), needed more information for caregiver (95.5 percent) and health volunteers visit at home (95.5 percent) (Table II). There was no correlation between patients’ higher age, income, duration of being diagnosis and patients’ needs (Table III).

Results of the qualitative study

Based on content analysis, we found three core needs of patients with advanced stages. First, our interviews revealed the issue of type of information needs, pain management, and social support.

Type of information needs. Type of information, the first core quality of palliative care, was described by participants. The participants were described as being ill-informed regarding a chance to ask about cancer treatment and care. First, patients needed information about diseases and treatment:

When doctors said I have cancer stages 4. I don’t want to listen any things. I only needs to know the chance of cure and spread of disease. I need to know how long I can live. (P2)

One participants confirmed:

I preferred full treatment (at initially time); I think I can cure and I don’t think that I will die. Doctors should told me what I have to do […] medicine, surgery […][…] (P10)

Participants required discussion together about therapeutic options. As participants described:

I want to talk with my family before make decision for surgery. (P1)

My family more worries and suffered after they know I have to operate. They don’t want I do. Doctor have to talk with me and family about this […] (P2)

As the time passes and symptoms get worst, the participants need information about chances of cure and progressive of disease. As participants described:

I needed to know how long that I can live […] I can cured […] If not I don’t needed any aggressive treatment. (P8)

I want to finish every things house, land […] before I gone. I needed to know how long […]. (P5)

The last, patient needs times to talk about peaceful death:

I have to go soon. I know about diseases and […] How I can go with peaceful mind and no worries. (P9)
Pain management. All of them experienced moderated to severe pain on a daily basis. The participants described their experience by pain and its consequence as below:

I do not want to have pain again. The pain disturbed me and also made sleepless night. I don’t want to talk to anyone, I don’t want to make them upset. I actually felt regret for my husband and families. When I was not pain, I feel so good. When I was in pain, I want to gone. The pain scared me. I have no fear for dying when I still suffered with the same pain. I thought that if I die soon, it better. (P6)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<td></td>
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<tr>
<td>Male</td>
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<td>36</td>
</tr>
<tr>
<td>Female</td>
<td>71</td>
<td>64</td>
</tr>
<tr>
<td>Age (years)</td>
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<td></td>
</tr>
<tr>
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<tr>
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<tr>
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<tr>
<td>Couple</td>
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<td>Separated/Divorced/Widowed</td>
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<td>20.7</td>
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<tr>
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<tr>
<td>Health payment</td>
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<td>Universal coverage</td>
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<td>1.8</td>
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<tr>
<td>Social insurance</td>
<td>4</td>
<td>3.6</td>
</tr>
<tr>
<td>Choose place for caring</td>
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<td></td>
</tr>
<tr>
<td>Home</td>
<td>86</td>
<td>77.5</td>
</tr>
<tr>
<td>Hospital</td>
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<td>22.5</td>
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<tr>
<td>Type of cancer</td>
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<td></td>
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<tr>
<td>Hepato-biliary cancer</td>
<td>20</td>
<td>18.0</td>
</tr>
<tr>
<td>Lung</td>
<td>24</td>
<td>21.6</td>
</tr>
<tr>
<td>Colon</td>
<td>18</td>
<td>16.2</td>
</tr>
<tr>
<td>Breast</td>
<td>21</td>
<td>18.9</td>
</tr>
<tr>
<td>Cervical</td>
<td>8</td>
<td>7.2</td>
</tr>
<tr>
<td>Head and neck</td>
<td>6</td>
<td>5.4</td>
</tr>
<tr>
<td>Others</td>
<td>14</td>
<td>12.6</td>
</tr>
</tbody>
</table>

Table I. Demographic characteristic of patients with advanced stages of cancer.

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<th>Duration of being (diagnosis, months)</th>
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<tr>
<td>Range</td>
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<tr>
<td>Mean</td>
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<td></td>
</tr>
<tr>
<td>SD</td>
<td>5.62</td>
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</tbody>
</table>

Note: n = 111
I was really uncomfortable [...] My family bring me to hospital in night time. It difficult when they move me. I thought it would be better I die. I would no longer be pain. (P1)

Two essential needs for an effective pain management were identified by cancer patients. The first need was for 24 hours palliative care cover and medication:

I think night times are long. I want to talk with palliative care team, when pain increase. (P9)

Patients expressed a need for pain relieve medication:

My son take me to take injection when I have severe pain. I want doctors come to give me injection or educate my family to help me. (P5)

Why doctor don’t educate my family to help me for pain relief continuously [...] injection morphine. (P7)

Providing psychosocial support. Psychosocial support involves psychosocial-spiritual comfort. Patients expressed their need of psychosocial support. The first need was patients needed friends and did not want to be alone. As participants described:

I am happy to spend my time at home. I sit here at the door, look at other people outside. I’m not strong to go out [...] (sign) and waiting who will come. I am waiting them for small talk. I enjoy to listen and answer their questions. (P3)

I want friends ['Moo-ma-ha’ in Thai language] come to see me and family around my home. (P8)

While being with friends and family, the participants expressed that touching helped them fell warmth:

Friends or family hold my hand. It was communicate of their affectionate feeling. I know, I am not alone. (P10)
The second requirement for social support is positive lasting memories for both of physician, patients and family. The patients reflected the activity of their feeling when oncologist said “No appointment.” As a participant expressed:

No appointments, it means my diseases going down. I still want to go hospital for checked up my diseases. It mean I still have hope to live longer. When doctors said no appointment, I told him, I can go hospital and happy to meet others cancer patients. (P1)

Another participant confirmed this:

When doctor said no appointment and don’t come. I felt so sad why doctor talk to me like this. Why he don’t like me so he don’t want I came. (P6)

In addition, some dissatisfaction was expressed about the last memories with their physician:

I felt unimpressed […]. I felt uncomfortable […] why told me no appointment (‘mai-nud’ in Thai language)? I know that they had many patients to care but why […] caring me. (P4)

The last requirement included patients being aware about their caregivers and family. Patients mentioned their concern of being a burden of their life:

I lost of myself as a mother, I feel regret for my daughter. I am sick and not having any others person to help me. Last night, I woke up my daughter because I was in pain and asking her to message my body […] asking her to do physical care. She looks so tried and needed longer rest. I really feel sorry to wake her up in midnight to take care me, but what I can do. I cannot control my body. I am suffering a lot. (P2)

Discussion

The quantitative results revealed that slightly more than half participants required caring at their home. The place of death is a major theme among patients in palliative care delivery research. Most patients at the end of life prefer dying at home[14]. The result demonstrated the greatest needs of a majority of patients that they require better understanding about their diseases, prognosis and medical treatment. This study is similar to the study of Morrison and colleagues[33] which indicated the top five needs concerning the treatment, care, and health information. A 2012 systematic review[34] aimed to explore unmet needs of palliative home care patients and caregivers, indicated that they need more information about diseases, in terms to manage their lives and make decisions. They also wanted a specific information regarding treatment, medication, and side effects. The core information-related need include listening actively and providing a safe space for conversation about peaceful death. Steele and Fitch’s [35] study revealed that eight of the top 10 most frequently reported needs were not physical, such as fears about the cancer returning or spreading. Moreover, the study in Denmark[36] indicated that women with pre-diagnosis period required an overview of the treatment process supplemented with information, involvement, and help to prepare themselves for treatment. Also, relatives need to be involved.

Effective pain management is the second greatest need among patients with advanced stages of cancer and the greatest need among caregivers. Most of the evidence indicated that pain was a common and devastating symptom of cancer-affected patients [37–39]. The 71 percent of patients in Indonesia and 67 percent of patients in Netherlands suffered from pain and pain-related difficulties with everyday activities[40].

Providing psychosocial support is the last need. Our finding appeared to be consistent with Yi et al.[41] that health professional was the most important needs category; information was next; and psychosocial needs were the most unmet needs. The psychosocial supports had the highest mean score in the unmet needs category. The strongest influencing factor was “no one to talk with.” Another aspect which emerged from the analysis of qualitative data is touching. The findings provide some relevant implications for nursing
practice, education and research. Nurses' roles in community health nursing should be to know the needs of their patient while caring at home setting. With this knowledge, nurses should be able to anticipate patients' needs, and enhance their experiences by providing appropriate interventions.

Regarding the strengths of our study, this is the first to provide an in-depth description of the needs of palliative care at home setting. The inclusion and exclusion criteria for participants contributed to population representatives, and the results may therefore be transferred to other similar contexts.

This study may provide only limited insight into the influence of patient’s experience on their palliative care services from one hospital. Since the data were collected in the end stages of patients, the interview was always terminated when patients had pain and others symptoms distress. Only some data related to research objectives were presented. We, therefore, acknowledge that future studies should attempt to know what is a need and barrier of palliative care among cancer patients and their families.

Conclusion
The current evidence suggests patients with advanced stages of cancer required home as the best place for their end of life. Therefore, home-based care supports patients to relieve suffering from symptom distress, and also helps them in improving QOL in their environment with their loved ones.

References

Needs of patient with advanced stages of cancer


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