# **ORIGINAL ARTICLE**

# Evaluation of a Home-Based Hospice and Palliative Care Program in a Community **Health Center in Korea**

Su Hyun Kim<sup>1</sup>, Bok Yae Chung<sup>1</sup>\*, Yu Xu<sup>2</sup>

<sup>1</sup>The Institute of Nursing Science, College of Nursing, Kyungpook National University, Daegu, Republic of Korea <sup>2</sup>School of Nursing, University of Nevada, Los Angeles, USA

To evaluate the effects of a home-based palliative care program, delivered by a community health center in Korea, in terms of quality of life and health care utilization.

A cross-sectional comparative study was utilized. Data were collected from 30 terminally ill cancer patients who had received palliative care from the community health center and 46 terminally ill cancer patients not receiving palliative care from the center. The measurements used in the study were a Revised Korean version of Quality of Life at the End of Life survey, self-reports on days of hospital admission and the frequency of outpatient care and ER visits during the past 6 months.

**Results** The palliative care group had a higher quality of life only in a physical aspect. The palliative care group had a lower frequency of outpatient visits and ER visits in the last 6 months than the nonpalliative group, but no significant statistical differences were found.

A home-based palliative service program delivered by the community health center appears to be an appropriate care model for managing physical symptoms. Reinforcing services for psychosocial and spiritual counseling and encouraging affiliation with free-standing inpatient healthcare providers are warranted. [Asian Nursing Research 2009;3(1):24-30]

> **Key Words** home-based palliative care, quality of life, terminally ill patients

# INTRODUCTION

For decades, the Korean health care system has been unable to meet the needs of dying patients because it has focused on rapid rescue from acute illnesses and cure of diseases. Most patients with terminal illnesses diagnosed as "hopeless" cannot afford expensive hospital care and are discharged home. As a result, many home-bound terminally ill patients are often neglected without formal services. In studies of home-based cancer patients, 71% complained of ineffective pain control (Kim, Yang, Jeong, Park, Lee, & Lee, 1999) and 74% of family caregivers wanted to receive assistance with symptom control at home (Yun et al., 2001). Patients had to visit the emergency room (ER) or be admitted to hospitals



\*Correspondence to: Professor Bok Yae Chung, College of Nursing, Kyungpook National University, 101 Dongin-dong, Jung-gu, Daegu 700 422, Republic of Korea. E-mail: bychung@knu.ac.kr

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to manage their symptoms. Consequently, inappropriate patterns of health care utilization have led to increased health care expenditure for end-of-life treatment and care. The expenses were so high that health care utilization in the last 2 months of life accounted for 40–50% of total health care expenditures (Youn, 2002; Youn, Huh, Jin, You, Kim, & Huh, 1998).

In this context, investigators and policy makers have made efforts to develop palliative care models for patients with terminal illnesses, which are deemed best suited for the health care environment in Korea. This environment includes home care hospices, hospices in independent institutions and hospices in tertiary hospitals (Cho, 1993; Lee, 2002; Ro, Han, Kim, Yoo, Yong, & June, 2001). One visible outcome is the development of a home-based palliative care program implemented by some government-run community health centers. In fact, community health centers are being established in each part of the administrative districts in Korea. The goal is to promote residents' health by providing primary care, prevention and tailored programs for health problems in the community. Palliative care delivered by community health centers has the advantage of providing better access to the free-of-charge service from proximal locations, and efficiency by utilizing existing structured systems and services.

Evaluating the effects of existing hospice and palliative care models can guide the development of appropriate delivery of treatment and standardization of care of terminal cancer patients in Korea. However, to the authors' knowledge, no study has been done on the effectiveness of palliative care provided by community health centers in Korea. Furthermore, although palliative care development has been driven by the need to improve quality of life and cost-effective treatment (Lee, 2002), evidence of its effects is very limited (So & Cho, 1991; Sun, 2003; Yoo, 2001). This study evaluated the outcomes of home-based palliative care delivered by a community health center in terms of quality of life and health care utilization by comparing patients who received home-based palliative care with those who did not.

## **METHODS**

# Study design and procedure

The study design was a cross-sectional evaluation study, which compared quality of life and health care utilization between patients who received homebased palliative care and those who did not. This study was conducted in a community care center in Goryeong, a small rural town in southeastern Korea. The home-based palliative care team at the community health center was established in 2003 to meet the growing needs of palliative care in the rural community, where the death rate from cancer was estimated to be very high (27.5%). The community health center has developed a cancer database to manage cancer patients in the community. Those who have less than 6 months life expectancy are approached by the palliative care team established by the community health center and asked if they would like to receive palliative care from the center. For those who requested palliative care, the team, consisting of two nurses and one physician on an 8-hour-per-day basis and 82 trained volunteers, provided management of symptoms and psychological and spiritual counseling via home visits. They also offered bereavement services for families. Nurses visited the hospice patients on a regular basis and upon their request. After assessing patients' symptoms and needs, nurses provided palliative care services such as pain and symptom management, medication, wound care, comfort care, psychological support and counseling, and education of family caregivers on how to care for patients at home. For those with very severe pain and symptoms, nurses administered narcotic analgesics or other medications after obtaining prescriptions from the physician. Community volunteers helped with household chores and clergy volunteers visited and prayed for the patients on request. The frequencies of home visits by the team depended on the clinical conditions and needs of the patients.

#### Sample

In December 2006, the investigators collected data from 30 terminally ill cancer patients registered in the cancer database who had received the palliative service from the community health center. As for the control group, we approached 65 home-bound, terminally ill cancer patients in the cancer database who had less than 6 months of life expectancy and had refused the offer of the home palliative care service from the community health center. We collected data from 46 patients among them who agreed to participate in the study. The inclusion criteria for the study included being 18 years of age or over, a diagnosis of being in a terminal stage of cancer with a predicted life expectancy of less than 6 months, and having no difficulty with communication. Before data collection, the local Institutional Review Board approved the study, and research assistants explained the study purposes to the participants and received their written, informed consent.

## Measurements and analyses

Patients' quality of life was measured by the Revised Korean version of the Quality of Life at the End of Life survey, which was revised from the Quality of Life at the End of Life survey (QUAL-E; Kim, Chung, & Suh, 2007; Steinhauser et al., 2002). The Korean version of the Quality of Life at the End of Life survey was mostly translated from the QUAL-E survey and partly rewritten in Korean to adapt to the Korean culture. The QUAL-E survey consisted of 20 items on a 5-point Likert scale. It has five subscales: physical symptoms, social relationships, preparation, control and completion. Scoring of the scale was performed by summing the indicated points of each subscale and then dividing by the number of the items; each subscale ranged from 1 to 5, with higher values indicating higher quality of life. Validity and reliability of the scale for terminally ill patients has been demonstrated (Kim et al.). Factor analysis demonstrated a four-factor structure, which explained 68% of variance. Cronbach's alpha for the subscales ranged from 0.72 to 0.84 (Kim et al.). The tool was administered at an interview with each participant. The research assistants were trained in interviewing weak and fragile terminally ill patients and the administration of the questionnaire. Health care utilization was measured by self-reports on the days of hospital admissions and the frequencies of outpatient unit and ER visits during the past 6 months.

Following data collection, data were entered into SPSS version 13.0 and a Chi-square and *t*-test were conducted to compare the general characteristics, quality of life, admission days, frequencies of outpatient unit visits and ER visits for the last 6 months between the two groups of patients.

#### **RESULTS**

Table 1 reports the profile of the two groups of participants. The sample consisted of 30 participants in the palliative care groups and 46 participants in the nonpalliative care group. Most of the participants in both groups had less than 6 years of education and were married. The prevalent types of primary tumor that the participants had in both groups were stomach cancer, colorectal cancer and breast cancer, consecutively. The mean ages were 65 years (SD 10.67) in the palliative care group and 67 years (SD 10.59) in the nonpalliative care group. There were no significant statistical differences in the demographical characteristics between the palliative care and the nonpalliative care patients. In the palliative care group, 35% received the palliative care service for less than 1 month, 38% for 1 to 6 months, and 27% for more than 6 months. As for the frequency of the palliative care service, 18% had more than two visits per week, 19% had one visit per week, 15% had two to three visits per month, and 48% had less than one visit per month.

Table 2 presents data on the quality of life perceived by the two groups. Several observations stand out from this comparison. First, the palliative care group scored higher across four out of the five subscales except on "Preparation," indicating a higher quality of life than the nonpalliative care group. However, significant statistical difference was found only in "Physical Symptoms" but not in psychosocial or spiritual aspects of "Social Relationships," "Preparation," "Control" or "Completion." Second, the palliative care group scored highest on "Physical Symptoms" (t=2.33, df=74; p<.05), suggesting that

|                                                    | Table 1                        |                                 |                                         |  |  |
|----------------------------------------------------|--------------------------------|---------------------------------|-----------------------------------------|--|--|
| Characteristics of Study Participants ( $N = 76$ ) |                                |                                 |                                         |  |  |
| Characteristics                                    | Palliative care group (n = 30) | Nonpalliative care group (n=46) | р                                       |  |  |
|                                                    | Freque                         | ncy (percent)                   |                                         |  |  |
| Gender                                             |                                |                                 | .21                                     |  |  |
| Male                                               | 15 (50)                        | 28 (62.2)                       |                                         |  |  |
| Female                                             | 15 (50)                        | 17 (37.8)                       |                                         |  |  |
| Religion                                           |                                |                                 | .59                                     |  |  |
| Protestant                                         | 5 (16.7)                       | 6 (13.6)                        |                                         |  |  |
| Buddhist                                           | 17 (56.7)                      | 27 (61.4)                       |                                         |  |  |
| None                                               | 5 (16.7)                       | 10 (22.7)                       |                                         |  |  |
| Other                                              | 3 (10)                         | 1 (2.3)                         |                                         |  |  |
| Education (years)                                  |                                |                                 | .42                                     |  |  |
| None                                               | 8 (27.6)                       | 18 (39.1)                       |                                         |  |  |
| <6                                                 | 13 (44.8)                      | 19 (41.3)                       |                                         |  |  |
| 7–9                                                | 4 (13.8)                       | 6 (13.0)                        |                                         |  |  |
| > 10                                               | 4 (13.8)                       | 3 (6.5)                         |                                         |  |  |
| Marital status                                     |                                |                                 | .77                                     |  |  |
| Married                                            | 22 (75.9)                      | 31 (68.9)                       | • • • • • • • • • • • • • • • • • • • • |  |  |
| Single                                             | 1 (3.4)                        | 2 (4.4)                         |                                         |  |  |
| Widowed                                            | 6 (20.7)                       | 12 (26.7)                       |                                         |  |  |
| Primary tumor                                      |                                |                                 | .32                                     |  |  |
| Stomach                                            | 8 (27.6)                       | 13 (28.2)                       | .52                                     |  |  |
| Colorectal                                         | 4 (13.4)                       | 7 (14.4)                        |                                         |  |  |
| Breast                                             | 3 (10.3)                       | 5 (11.1)                        |                                         |  |  |
| Liver                                              | 2 (6.9)                        | 4 (7.8)                         |                                         |  |  |
| Lung                                               | 2 (6.9)                        | 3 (7.3)                         |                                         |  |  |
| Thyroid                                            | 2 (6.9)                        | 3 (7.3)                         |                                         |  |  |
| Others                                             | 6 (28)                         | 11 (23.9)                       |                                         |  |  |
| Length in cancer database                          | - \/                           | (,                              |                                         |  |  |
| <1 month                                           | 7 (23.3)                       | 10 (21.7)                       | .99                                     |  |  |
| 1–3 months                                         | 8 (26.7)                       | 13 (28.3)                       | •//                                     |  |  |
| 3–6 months                                         | 8 (26.7)                       | 12 (26.1)                       |                                         |  |  |
| >6 months                                          | 7 (23.3)                       | 11 (23.9)                       |                                         |  |  |
|                                                    |                                |                                 | EO                                      |  |  |
| Age mean (SD)                                      | 65.7 (10.67)                   | 67.1 (10.59)                    | .58                                     |  |  |

this was the most effectively delivered service by the palliative care team. Third, both groups scored lowest on "Preparation" ( $2.37\pm0.82~vs.~2.49\pm0.82$ ), indicating that this was an area that needed improvement. This meant that both groups felt that they were least prepared to deal with financial strain and

being a burden to family. Regarding health care utilization in the last 6 months (Table 3), the palliative care group had a lower frequency of outpatient visits  $(5.69\pm7.24~vs.~8.33\pm30.49)$  and ER visits  $(0.11\pm0.32~vs.~0.25\pm0.53)$  than the nonpalliative group; however, no significant statistical differences were

|                                                                                                                            | 1a                             | ble 2                             |                |
|----------------------------------------------------------------------------------------------------------------------------|--------------------------------|-----------------------------------|----------------|
| Comparisons of Quality of Life Between Patients Who Received Home-based Palliative Care and Those Who Did Not <sup>†</sup> |                                |                                   | ative Care and |
|                                                                                                                            | Palliative care group $(n=30)$ | Nonpalliative care group $(n=46)$ | t              |

|                      | Palliative care group $(n=30)$ | Nonpalliative care group $(n=46)$ | t     | р   |
|----------------------|--------------------------------|-----------------------------------|-------|-----|
|                      | Mean $\pm SD$                  |                                   |       |     |
| Physical symptoms*   | $3.89 \pm 1.00$                | $3.37 \pm 0.92$                   | 2.33  | .02 |
| Social relationships | $3.72 \pm 0.64$                | $3.53 \pm 0.89$                   | 0.98  | .33 |
| Preparation          | $2.37 \pm 0.82$                | $2.49 \pm 0.82$                   | -0.64 | .53 |
| Control              | $3.74 \pm 0.54$                | $3.73 \pm 0.54$                   | 0.06  | .95 |
| Completion           | $3.48 \pm 0.64$                | $3.31 \pm 0.77$                   | 1.01  | .31 |

<sup>\*</sup>p<.05; †based on the range of 1–5: Higher values indicate higher quality of life.

|                                    | Table 3                                                     |                                                     |        |     |
|------------------------------------|-------------------------------------------------------------|-----------------------------------------------------|--------|-----|
| • '                                | are Utilization in Past 6 Mo<br>based Palliative Care and T | onths Between Patients Who Red<br>Those Who Did Not | ceived |     |
| Items                              | Palliative care group $(n=30)$                              | Nonpalliative care group (n=46)                     | t      | р   |
|                                    | Mean (SD)                                                   |                                                     |        |     |
| Admission days                     | 21.31 (50.14)                                               | 17.89 (49.99)                                       | 0.27   | .79 |
| Frequency of outpatient visits     | 5.69 (7.24)                                                 | 8.33 (30.49)                                        | -0.43  | .67 |
| Frequency of emergency room visits | 0.11 (0.32)                                                 | 0.25 (0.53)                                         | -1.43  | .16 |

found. The main reasons for outpatient clinic and ER visits in the nonpalliative care group were reported as pain and symptom control, disease management and consultation with physicians.

# **DISCUSSION**

Findings from this study appear to support the effectiveness of the home-based palliative care delivered by the community health center in improving quality of life regarding the physical aspect of palliative care. Compared with other studies that showed no improvement of physical symptoms of terminal cancer patients after being transferred from tertiary hospitals to hospice facilities in Korea (So & Cho, 1991; Yoo, 2001), this study indicated that home-bound terminally ill cancer patients with insufficient

symptom management, often being neglected by formal health services, would benefit from home-based palliative care provided by community health centers. The free services offered by community health centers appear to be particularly beneficial for those with limited access to health care services, such as those with low income in rural areas. Thus, this finding indicates that a home-based hospice care model delivered by the community health center may be suitable for rural areas that have insufficient infrastructures for providing palliative care. To maximize their benefits, however, home hospices affiliated with community health centers need to be connected and coordinated with free-standing inpatient facilities such as hospitals and independent hospices to ensure the coordination and continuity of care.

However, the lack of positive outcomes in psychosocial and spiritual aspects of care indicates a

need to enhance comprehensive care at the end of life. Thus, palliative care services provided by community health centers are yet to be improved for those in need of assistance in managing symptoms and obtaining psychological, spiritual and social support. In making such improvements, it is essential to have interdisciplinary teams comprising nurses, physicians, social workers, clergy and volunteers working together as a team (Hong, 2002).

Regarding health care utilization, the study showed that the palliative care patients had lower frequency of outpatient and ER visits, but no statistical significance between the two groups of participants was observed. One tentative explanation is the potential selection bias that could not be ruled out because the nonpalliative group was not enrolled for palliative care, based solely on their subjectively judged less severity of illnesses. To accurately measure health care utilization at the end of life, not only admission days and outpatient and ER visits but also total expenditures spent on patient care should be calculated after patient's death or for a fixed period before death (Higginson et al., 2003). In addition, there were potential issues of subjectivity from retrospective self-reports. Future research can reduce or eliminate this subjectivity by collecting accurate and objective clinical data. Another limitation of the study is the voluntary nature of enrollment into the palliative care services. Terminally ill cancer patients who preferred to stay at home without rehospitalization may be more likely to choose to receive palliative care; thus, this factor could influence the outcomes in terms of quality of life or the utilization of health care resources. Because convenience sampling was used in this study, findings of the study cannot be generalized.

In conclusion, home-based palliative care services delivered by the community health center appear to be an appropriate care model for terminally ill cancer patients in Korea, especially for those with limited health care access. To enhance the quality of care, reinforcing services for psychosocial and spiritual counseling and encouraging affiliation with free-standing inpatient healthcare providers and independent hospices are warranted. At this stage of

the evolution and expansion of hospice and palliative care in Korea, more program evaluations of the diverse ways of providing palliative care are needed to find and design best service delivery models to serve the needs of patients and families requiring end-of-life care.

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