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Determinants of a hopeful attitude among family caregivers in a palliative care setting☆

Seon-Young Kim, M.D., Ph.D. [a,b], Jae-Min Kim, M.D., Ph.D. [b,*], Sung-Wan Kim, M.D., Ph.D. [b], Hee-Ju Kang, M.D., MSc. [b], Il-Seon Shin, M.D., Ph.D. [b], Hyun-Jeong Shim, M.D., Ph.D. [c], Sang-Hee Cho, M.D., Ph.D. [c], Ik-Joo Chung, M.D., Ph.D. [c], Jin-Sang Yoon, M.D., Ph.D. [b]

[a] Mental Health Clinic, Chonnam National University Hwasun Hospital, Hwasun 519-763, Korea
[b] Departments of Psychiatry, Chonnam National University Medical School, and Depression Clinical Research Center, Chonnam National University Hospital, Gwangju 501-757, Korea
[c] Department of Hemato-Oncology, Chonnam National University Medical School, Gwangju 501-757, Korea

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ABSTRACT

Objective: This study investigated the determinants of a hopeful attitude among family caregivers involved with palliative care.
Method: We investigated a broad range of factors for the patient–family dyad in a palliative care setting using a cross-sectional design. The patients' sociodemographic, clinical and psychological factors were evaluated, as well as caregiver-related sociodemographic and psychological factors, including depressive symptoms, burden, coping style and religiosity. Caregivers were divided into two groups based on a hopeful or nonhopeful attitude and assessed using the abbreviated version of the seven-item Beck Hopelessness Scale (BHS-7).
Results: Of 304 analyzed dyads, 210 (69.1%) caregivers showed a hopeful attitude, with a BHS-7 score of 0. The adjusted logistic regression analyses showed that caregivers' hopeful attitude was determined by only their psychological status: less depressive symptoms [odds ratio (OR), 0.86; 95% confidence interval (CI), 0.83–0.90], active coping strategy (OR, 1.12; 95% CI, 1.07–1.18) and lower burden (OR, 0.93; 95% CI, 0.88–0.99). In a subpopulation analysis ($n=200$), higher religiosity was a significantly associated factor.
Conclusion: Healthcare providers need to pay attention to the psychological vulnerability of caregivers to encourage a hopeful attitude. Additional studies of longitudinal design for hopeful attitude throughout the trajectory of palliative care are necessary.

1. Introduction

The impact of a terminal illness may have significant and enduring effects on the physical and mental well-being of family caregivers [1]. Compared to caring for a surviving patient, caring for a family member close to death contributes to increased depressive symptoms and an increased burden for caregivers [2]. Because the caregiver's psychological distress is closely associated with the patient's psychological distress [3], a palliative approach generally considers the family to be the "unit of care" [1].

Hope is a major theme for families of cancer patients in end-of-life care [4]. Family members of terminally ill patients with cancer suggest that hope is important in helping them deal with the caregiving experience [5]. Hope may decrease the vulnerability of family caregivers and protect against fatigue and burnout during palliative care [6]. Hope among family caregivers appears to have a reciprocal role in the maintenance of a patient's hope [7]. The depressive scores of both caregivers and patients were mutually related to caregiver and patient hopelessness [8]. Additionally, there were significant associations among caregivers' level of hope, burden and strain [9,10]. A strong overall feeling of hope leads to increased feelings of control, decreased feelings of loss and grief, and improved physical and psychosocial well-being within the context of uncertainty [11]. Thus, hope is an important mediator of personal, social and familial characteristics of mental quality of life for family members of patients with cancer [12].

Assessing factors related to family caregivers' hope in the palliative care setting is important for fostering caregivers' hope and managing vulnerability. Several sociodemographic, psychological and clinical factors influencing hope among caregivers have been reported for cancer patients, including caregivers' age and income (sociodemographic) and caregivers' anxiety, depressive symptoms, low self-efficacy and current concerns (psychological) [8,10,13,14]. Patient-related psychological and clinical factors include the number of patient hospitalizations, depressive symptoms, hopelessness, courage and general symptoms [8,13,15]. However, these results were not based on palliative care settings.

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* Corresponding author. Tel.: +82 62 220 6143; fax: +82 62 225 2351.
E-mail address: jmkim@chonnam.ac.kr (J.-M. Kim).

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Because caregivers of patients with advanced cancer in palliative care may be more hopeless than caregivers of patients with a newly diagnosed disease [16], studies focusing on palliative care would be valuable. However, limited data are available on factors associated with hope among family caregivers in a palliative care setting. Herth (1993) interviewed 25 family caregivers of terminally ill patients and identified isolation, concurrent loss, poorly controlled symptoms, fatigue and sleep disturbances as factors influencing hope [5]. Other studies reported that faith or spirituality and supportive relationships fostered hope, whereas fatigue, anxiety, anger, despair, the patient's physical symptoms, financial difficulties and communication problems eroded caregiver hope [17–19]. In terms of coping strategy, emotional coping by family members was significantly related to despair [20], and cognitive reframing was suggested as a caregiver's hope-fostering strategy [5]. However, those studies were limited by small sample sizes and psychological status, except for the hope level and coping strategy, which were determined by interview rather than by using validated scales.

In a cross-sectional study, caregiver hopelessness was predicted by the patient's marital status, radiotherapy [21], education level, family hardiness and self-efficacy [12], although these results were not adjusted for the caregiver's psychological characteristics [21], or the subjects were limited to only breast cancer dyads [12].

Therefore, the present analysis was performed to determine the factors influencing a hopeful attitude among caregivers, especially in palliative care. Based on a literature review, we hypothesized that caregivers' hopeful attitude might be associated with both patients' and caregivers' psychological factors. To overcome the limitations of previous studies, we examined and analyzed using a multivariate method a broader range of sociodemographic, psychological and clinical factors of patient–family dyads in a palliative care setting using validated scales.

2. Methods

2.1. Study design and recruitment

This analysis was performed as a component of a larger study designed to investigate the mental health of both the patient and family caregiver in a palliative care unit (PCU). Family caregivers of patients with cancer who were admitted to the PCU of Chonnam National University Hwasun Hospital, Hwasun, South Korea, were enrolled consecutively from March 2009 to August 2011. Eligible patients were those who had been diagnosed with terminal cancer by an oncologist, had an estimated survival time of a few months and were admitted to the PCU for palliative care. Patients who had been admitted to the PCU before the study began and those who had been hospitalized in the PCU for less than 3 days were excluded. Eligible caregivers were family members (spouse, son, son-in-law, daughter, daughter-in-law, parent, brother, sister or other relative who provided direct assistance to the patient), 18 years of age or older, who served as a primary caregiver for a patient. Caregivers who were mentally incapable of understanding informed consent or the objective of the study were excluded. After the purpose and details of the study had been explained, informed consent was obtained from each patient (or familial surrogate, according to the patient's mental status) and caregivers. This study was approved by the Institutional Review Board of Chonnam National University Hwasun Hospital.

2.2. Caregiver's hopeful attitude as a dependent variable

In this study, hopeful attitude was the dependent variable measured by a seven-item abbreviated version of the Beck Hopelessness Scale (BHS-7), a self-reported instrument developed to assess 'expectations or attitude' or 'pessimistic or optimistic cognitive style' regarding the future. The BHS-7 contained three factors of the BHS: three items for feelings regarding the future; three items for loss of motivation, which was defined as giving up or deciding not to want anything; and one item for future expectation. The BHS-7 has proven reliable and valid in patients with terminal cancer [22,23] and has adequate construct validity and internal consistency for both patients and caregivers [24]. The BHS has been used in previous studies that investigated hopeful attitude among caregivers of advanced cancer patients [12,16,21]. It has also been validated in a Korean population [25]. The BHS-7 includes three positive and four negative true/false statements. After reverse scoring of the positively worded items, all items were summed to give a total score ranging from 0 to 7, with a higher score reflecting increased hopelessness.

2.3. Related factors and measurements as independent variables

For the independent variables, sociodemographic, psychological and clinical factors potentially associated with caregivers' hopeful attitude were selected based on previous research [5,11,17–20]. Selected variables of patients and their family caregiver dyads were investigated simultaneously. The patients were interviewed and assessed by a psychiatrist 4–7 days from the date of admission to the PCU. On the same day, the family caregivers were assessed by a clinical research coordinator. The research coordinator encouraged caregivers to complete the assessment to minimize incomplete data.

2.3.1. Patient-related factors

Data regarding age, gender, years of formal education, marital status, recipient of Medicare, primary cancer site, time since cancer diagnosis, recurrent cancer, current palliative radiotherapy and metastatic sites were collected from each patient's clinical chart. Because there were too many metastatic sites to permit an analysis of each one, we analyzed the two most common sites of metastasis: the liver and lung. The Richmond Agitation–Sedation Scale (RASS) was checked to determine the patient's mental status. RASS is a 10-point scale ranging from unarousable (−5 points) or calm (0 points) to combative (4 points). RASS has established reliability and validity for rating the level of consciousness [26]. We categorized patients into three groups by RASS score: drowsy to unarousable (scores of −1 to −5), calm (0) or restless to combative (1 to 4). To assess patient physical status, the Eastern Cooperative Oncology Group performance status, which ranges from 0 (fully active) to 4 (completely disabled), was measured [27]. Subjective pain was measured using a numeric rating scale (NRS) of 0 to 10, where a higher score denoted greater pain intensity [28]. Depressive symptoms in patients were measured using the Montgomery–Asberg Depression Rating Scale (MADRS) [29,30]. The MADRS is an objective 10-item questionnaire about the previous week; each item was scored from 1 to 6, with a maximum score of 60. Higher scores indicated more severe depressive symptoms. MADRS was used in a previous study to measure depression in cancer patients [31].

2.3.2. Caregiver-related factors

Data regarding age, gender, years of formal education, marital status, relationship to patient, whether the caregiver lived with the patient before admission, employment status, medical illnesses and caregiving situation were investigated in a face-to-face interview. The caregiver's depressive symptoms were measured using the MADRS [29,30]. Coping strategies were assessed using the Stress Coping Questionnaire (SCQ), consisting of 24 items selected from the Korean version of the Ways of Coping Questionnaire and graded on 5-point Likert scale [32]. The SCQ, which has been validated in a general Korean population, classifies coping strategies into active coping (SCQ-AC) and passive coping (SCQ-PC). Active coping strategies include problem-focused coping and seeking social support. Passive coping strategies include tension reduction and wishful thinking. Scores ranged from 24 to 120, and higher scores denoted more frequent use of that coping strategy [32].

Subjective burden was measured using the seven-item short version of the Zarit Burden Interview (ZBI-7), which was developed specifically for the burden of palliative care [33]. The overall burden is