

RESEARCH ARTICLE

Understanding Hope and Spiritual Wellbeing of Filipino Caregivers of Terminally-Ill Cancer Patients

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Abstract

This descriptive correlational study determined the level of hope and spiritual wellbeing among Filipino caregivers of terminally-ill cancer patients, and the relationship of hope and spiritual wellbeing to various patient and caregiver characteristics. The study involved 50 caregivers of terminally-ill-cancer patients, mostly belonging to 51-60 age group (42%) with mean age of 44 years (SD=15), mostly females (72%), married (62%), Roman Catholic (90%), high school graduates (50%), spouses of patients (28%), with an average of 18.36 hours of caregiving in a day for an average duration of 21.4 months. The hope and spirituality scores of caregivers were 3.24 (SD=0.28) and 3.25 (SD=0.46) respectively. Caregivers had high self-efficacy (3.29) but low social support (1.72). Patient's age was moderately correlated with caregiver's hope ($r=0.3$; $p=0.03$). Caregiver's educational attainment was significantly associated with hope ($p<0.01$) and spiritual wellbeing ($p<0.01$). Caregiver's self-efficacy was moderately correlated with their spiritual wellbeing ($r=0.46$, $p<0.01$). Caregiver's hopes were (1) for their patients to get well and recover from their illness, (2) to have strong spiritual faith and be healed with God's help (3) to be hopeful and positive, (4) hope for longer life, (5) resumption of family relations, and (6) free of pain and other discomforts. Caregivers' thoughts on spiritual wellbeing were to have: (1) stronger faith, (2) being prayerful, and (3) being positive. Compared to other studies, Filipino caregivers had lower hope scores, but higher spiritual wellbeing scores. Nursing interventions promoting hope and spiritual wellbeing should be conducted in patients' room, clinic appointments, or during home visits. Nursing care promoting hope and spiritual wellbeing should be part of patients' activities for daily living.

Introduction

Many cancer patients today receive part of their care at home. Hospital stays are shorter than they used to be, and there are now more treatments that do not need an overnight hospital stay or can be given outside of the hospital. Terminally-ill patients prefer to stay home with their loved ones and in doing so caregivers are subjected to emotional and psychological stress. Caring for terminally-ill loved one has been described as work that is exhausting and difficult (Holtslander, Duggleby & Williams, 2005 in Revier, Meiers & Herth, 2012). Cancer is experienced not only by the patient, but also by the whole family who may act as caregivers. Caregivers may be spouses, partners, children, relatives or friends who help the patient with activities of daily living and health care needs at home.

Hope allows family members to cope with the illness experience and the terminally-ill persons to have quality of life in their final days (Paiva et al., 2015). Hope among Filipinos is rooted in spiritual wellbeing emanating from belief in God as shown by the expression, "*Bahala na ang Diyos*" (It is up to God). The Filipinos are known to be spiritual, often getting their strength in facing problems from a Supreme Being and resorting to their spiritual practices in asking for help and guidance.

Despite the large burden of cancer in the Philippines, there is still paucity of research on hope and spiritual wellbeing among Filipino caregivers of terminally ill patients. Therefore, this study aimed to describe hope and spiritual wellbeing of caregivers of

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terminally ill cancer patients, determine the relationship between hope and spiritual wellbeing to various patient and caregiver characteristics, and explore the caregivers' experience of hope and spiritual wellbeing.

METHODOLOGY

A descriptive-correlational study was conducted in a private tertiary-level hospital in the National Capital Region of the Philippines, which has an oncology unit providing cancer services such as consultations, out-patient chemotherapy treatment, blood transfusion and bone marrow biopsy and also pastoral care services extending healing ministry. Taking into consideration a power of 0.80, alpha of 0.05 and a moderate effect size of 0.40, a sample of 50 caregivers were selected based on the following criteria: primary caregiver of a patient with advanced cancer, terminally-ill or receiving palliative care, age older than 18 years and can read English/ Filipino. Exclusion criteria included cognitive impairment and inability to read or write responses. The study sought ethical review and clearance from the hospital and appropriate endorsements from the hospital director and nursing service administrator prior to data collection.

Research Instruments.

The independent variables were measured using the following research instruments: General Questionnaire on socio-demographic profile, patient and caregiver characteristics, General Self-Efficacy Scale, and Interpersonal Support Evaluation List-12 for social support. The dependent variables were measured using the following tools: Herth's Hope Index and Functional Assessment of Chronic Illness Therapy – Spiritual Well-being Scale.

General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995) was used to assess the perceived self-efficacy with the aim in mind to predict coping with daily hassles as well as adaptation after experiencing all kinds of stressful life events.

Interpersonal Support Evaluation List-12 (ISEL-12) was used to measure social support of caregiver.

The *Herth Hope Index (HHI)* was used to determine the definition of hope of Filipino caregivers with subscale scores also computed for (1) temporality and future, (2) positive readiness and expectancy, and (3) interconnectedness.

Functional Assessment of Chronic Illness Therapy – Spiritual Subscale (FACIT-Sp) measures the sense of meaning and peace, with faith's role in illness (Peterman et al., 2002 in Sessana et al., 2011).

Open-ended questions were adapted from Gebhardt et al. (2011) and Ebright and Lyon (2002) to explore the caregivers' experience of hope and spiritual wellbeing.

All research instruments were translated to Filipino by the UP *Sentro ng Wikang Filipino*.

Data Analysis.

Using SPSS version 23, correlational analyses among the factors that affect hope and spirituality were done using Pearson's r , while association with nominal data were determined using Chi square. For the open-ended questions, description and tallying of the responses were done based on categories arising from the responses.

FINDINGS

Demographic and Clinical Characteristics of Caregivers. The mean age of the caregivers was 44 years (SD=15). They were predominantly females (n=36, 72%), married (n=31, 62%), Roman Catholic (n=45, 90%), high school graduates (n=25, 50%), and spouses of the patients (n=14, 28%). The mean duration of caregiving for the patients was 21.4 months (SD = 28.8 months), spending an average of 18.36 hours (SD=8.48) each day.

Level of Hope and Spirituality of Caregivers. The mean score of caregivers in the HHS was 3.24 (SD=0.28), with the following scores on the subscales: (1) temporality and future (M=3.15, SD=0.38), (2) positive readiness and expectancy (M=3.40, SD=0.38), and (3) interconnectedness (M=3.18, SD=0.33). Meanwhile, the caregivers had a mean score of 3.24 (SD=0.46) in the FACIT-Sp, with the following scores on the subscales: (1) meaning (M=3.54, SD=0.44), (2) peace (M=2.66, SD=0.65) and (3) faith (M=3.24, SD=0.56).

Factors affecting Hope and Spirituality of Caregivers. For self-efficacy and social support, the caregivers had a mean score of 3.29 (SD=0.43) and 1.72 (SD=0.35) for the GSES and ISEL, respectively. Caregiver's hope was significantly correlated with patient's age ($r=0.30$, $p=.03$). Caregiver's spiritual wellbeing was significantly correlated with self-efficacy ($r=0.46$, $p<.01$). Finally, caregiver's educational attainment was also significantly associated with both hope ($\chi^2=10.49$, $p<0.01$) and spiritual wellbeing ($\chi^2=12.56$, $p<0.01$).

Experience of Hope and Spirituality of Caregivers. In the caregivers' responses to the open-ended questions about their hopes for their terminally-ill cancer patients, the most frequent response was for their patients to get well and recover from their illness (n=49, 98%), followed by their patients to have strong spiritual faith and be healed with God's help (n=14, 28%), being hopeful and positive (n=12, 24%), and longer life (n=11, 22%), resumption of family relations (n=6, 12%) and free of pain and other discomforts (n=3, 6%).

Regarding on caregiver's management of shattered hopes of their patients, the caregivers' most frequent responses were: (1) keeping faith in God (n=26, 52%), (2) enduring suffering and praying (n=25, 50%), (3) continuing the journey (n=9, 18%), (4) being uncertain, scared and having difficulty (n=8, 16%) and (5) being positive (n=5, 10%).

The caregivers' most frequent responses on their experience of spiritual wellbeing while caring for their family members were: (1) stronger faith in a higher being (n=33, 66%), (2) being prayerful (n=27, 54%) and being positive (n=16, 32%). Forty nine of the caregivers (98%) responded positively that they are indeed searching for help from a Higher Being while they are caring for their terminally-ill cancer patient.

DISCUSSION

The level of hope reported by the Filipino caregivers in this study (M=3.24, SD=0.28) was lower compared to other studies, such as Herth's (1993) longitudinal study involving 25 family caregivers of terminally-ill people (M=3.7, SD=4.11), Duggleby, et al's (2014) study of 122 rural women caregivers of persons with advanced cancer (M=3.8, SD=5.4), Benzein & Berg's (2005) study of family members of patients in palliative care (M=3.61, SD=6.2), Utne, Miaskowski, Paul & Rustoen, 2013 study of caregivers of patients with advanced cancer (M=3.68, SD=4.0). Meanwhile, the spiritual wellbeing of Filipino caregivers (M=3.24, SD=0.46) was found to be higher compared to a study involving family members of patients after two years of diagnosis (M=2.90, SD=0.76) (Kim & Spillers, 2010) and 252 female cancer caregivers (M=2.95, SD=0.73) (Kim, Wellisch, Spillers & Cramer, 2007). However, this mean score was lower than a study of spousal caregivers of cancer survivors (M=3.56, SD=8.77) (Colgrove, Kim and Thompson, 2007).

This study found that caregiver's hope was significantly correlated with patient's age, similar to the results of Benzein and Berg (2005) among patients and family members in palliative care. While Duggleby et al (2014) and Utne, Miaskowski, Paul and Rustoen (2013) found that hope scores were significantly influenced by self-efficacy and self-esteem scores, this study revealed that it was the caregiver's spirituality that was actually significantly correlated with self-efficacy, not their hope scores.

In relation to the caregivers' responses on the open-ended questions on hope and spiritual wellbeing, majority mentioned the hope for their patients to get well and recover from their illness. This is similar to Taylor's (2006) "having hope that I/my loved one will get well" scored the highest under Needing Positive Perspective of the Spiritual Interests Related to Illness

Tool (SPiRIT). In another study, Borneman and Ferrell (2002) found from the content analysis of their study that for the majority of family caregivers interviewed, hope is very closely related to one's connection to God as well as their faith in God. This in turn gave them a purpose in life. In Pope Benedict XVI's "*Spe Salvi*" (2007) hope is "a key word in Biblical faith so much so that faith and hope seem interchangeable". Furthermore, the Letter to the Hebrews closely links the "fullness of faith" (10:22) to "the confession of our hope without wavering" (10:23). Likewise, when the First Letter of Peter exhorts Christians to be always ready to give an answer concerning the logos—the meaning and the reason—of their hope (cf. 3:15), "hope" is equivalent to "faith" (Pope Benedict XVI, 2007). Borneman, et al (2002) cited maintaining hope came through one's connection with God and/or taking one day at a time. Factors that interfered or hindered their hope involved their own physical and emotional wellbeing such as fatigue, anxiety, anger disappointment and despair.

On experience of spiritual wellbeing, the respondents experienced spiritual well-being other than what has been mentioned already by boosting self-esteem, easing worries, giving hope, giving knowledge and wisdom, and providing happiness for the patient. Regarding their spiritual practices, they pray often, sing songs of praise, attend Holy Mass and Novena, and ask God to ease suffering and to prolong life. Spiritual wellbeing is finding meaning, purpose and value in life, often relating to God. Maintaining an optimistic perspective remains the most common spiritual interest for both the family caregivers and terminally-ill patients. Having hope and faith that their patient gets well and generally keeping a positive outlook is an important matter for both caregivers and the patient.

CONCLUSION AND RECOMMENDATION

The definitions of hope of Filipino caregivers of terminally-ill cancer patients are about *life has value and worth, positive outlook toward life, faith gives comfort, and to give and receive love and care*. While the Filipino caregivers' spiritual wellbeing is about *reason for living, life has meaning and purpose, patient's illness strengthens faith or spiritual beliefs, and life is productive*.

There were significant relationships of hope and spiritual wellbeing of Filipino caregivers with the following patient and caregiver characteristics: (1) patient's age with hope ($r=0.30$; $p=0.03$); (2) caregiver's educational attainment with hope ($\chi^2=10.49$, $p<0.01$) and spiritual wellbeing ($\chi^2=12.56$, $p<0.01$); and (3) caregiver's self-efficacy with spiritual wellbeing ($r=0.46$).

Filipino caregivers' hope experience in caring for terminally-ill cancer patients were as follows: their patients get well and

recover from their illness, their patients to have strong spiritual faith and be healed with God's help, being hopeful and positive, have longer life, resumption of family relations, and free of pain and other discomforts. Filipino caregivers' thoughts on how to manage if their hopes on the terminally-ill cancer patients do not happen is by keeping faith, enduring suffering and keep praying, continuing the journey, and being positive despite being uncertain, scared, and having difficulty.

Filipino caregivers' experiences on spiritual wellbeing as they take care of their terminally-ill cancer patients included keeping a stronger faith, being prayerful and thinking positive. Caregivers experience spiritual wellbeing by boosting self-esteem, easing worries, giving hope, giving knowledge and wisdom, and providing happiness for the patient. Regarding their spiritual practices, they pray often, sing songs of praise, attend Holy Mass and Novena, and ask God to ease suffering and to prolong life. Filipino caregivers' spiritual wellbeing emanates from the following beliefs: (1) Caregivers experience spiritual well-being by boosting self-esteem, easing worries, giving hope, giving knowledge and wisdom, and providing happiness for the patient; (2) "Only God is enough" guiding the patient and family, and (3) God as the "Dakilang Manggagamot", Him as "My Savior", "God is always with us".

Nurses and other health professionals have an important role in clarifying the caregiver's expectations to improve their hopes on their family members. Nursing interventions are needed to enable hope and spiritual wellbeing promotion activities be conducted in patients' room, during home visit or at clinic appointments. There is a need to formulate nursing care guide and pattern for daily nursing practice essential to maintain hope and spiritual wellbeing or practices as part of daily living and to achieve short-term goals. It is also recommended that hospital administrators develop policies and procedures on hope enhancement programs and spiritual wellbeing interventions for all patients with different religion and culture.

Future nursing research on hope and spiritual well-being should focus on developing a well-defined nursing intervention program to promote hope and spiritual wellbeing both to patient and caregivers. Nurse researchers may try to close the gap by searching for other methods or develop different tools to assess hope and spiritual wellbeing in different dimensions of personal meaning.

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