

## **Sigma's 30th International Nursing Research Congress**

### **Asian Family Caregivers Caring for Patients With Terminal Cancer**

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#### **Purpose:**

Culture can be an important factor in family caregiving for patients with terminal cancer. Asian family caregivers (FCs) have unique sociocultural values that can affect their end-of-life (EOL) caregiving and may have an impact on their terminal cancer caregiving. This literature review describes: 1) characteristics of Asian FCs of patients with terminal cancer; 2) the cultural context assumed through the experiences of Asian FCs in the end-of-life cancer care setting; 3) Suggestions to improve nursing practice to support Asian FCs.

#### **Methods:**

A systematic review was conducted from June 2018 to September 2018 using the following electronic databases: PubMed, CINAHL, and PsycINFO. Keywords of the study include: end-of-life care, terminal care, palliative care, advanced cancer, terminal cancer, metastatic cancer, life-limiting, life-threatening, terminally ill, advanced directives, advance care planning, grief, loss, death, bereavement, decision-making, communication, coping, Asians, and Asian Americans.

We included English-language primary articles published in the United States and Asian countries after January 2000. Eligible populations included Asian FCs or Asian American FCs of adult patients with terminal disease. We found 61 articles in PubMed, CINAHL, and PsycINFO: 26 more were retrieved from the reference lists of the articles. We excluded studies that covered the topics of professional caregivers, paid non-professional caregivers, patients with terminal disease other than cancer, or FCs of young patients with terminal disease. Fifty-one articles describing EOL care delivered by Asian FCs to patients with terminal cancer were selected from the 87 articles for this literature review.

#### **Results:**

We classified cancer care literature on Asian FCs' experiences into the following eight categories: quality of life, depression, burden, decision-making, coping and resilience, social support and religiosity, end-of-life experience, and bereaved caregivers' symptoms. Most articles were based on FCs in South Korea, Japan, Taiwan, China, and Singapore, but predominantly from South Korea, Japan, and Taiwan. Forty-two articles were observational quantitative studies, including cross-sectional, prospective, and longitudinal studies, with only four randomized controlled trial studies. Five articles were qualitative studies. Various patients' factors (age, symptoms, and functional status), FC factors (age, family budget, health condition, and self-efficacy), and environmental factors (social support and informational support) have impacts on the quality of life of Asian FCs. Asian FCs' depressed moods and sense of burden are negatively correlated with their quality of life. Asian FCs who consider caregiving a heavy burden are more likely to experience a severe depressive mood. Meanwhile, our review demonstrated that extent of religiosity, coping skills, resilience, and self-efficacy that Asian FCs have is positively correlated with their quality of life. Moreover, social support and psychological interventions could help Asian FCs deal with demanding EOL cancer care. Asian FCs initially feel conflicting negative and positive emotions when it comes to terminal cancer caregiving. By helping their loved ones, Asian FCs end up gaining a positive outlook. However, more social and educational support for them is required, especially for Asian FCs who care for patients with terminal cancer, because they are more likely to suffer from many negative emotions. Bereavement symptoms for Asian FCs tended to decrease when they expressed sound

understanding of the EOL care and terminal symptoms of patients, and when their loved one died at home instead of at an acute care hospital. This is because the quality of death at home is better than the quality of death at an acute care hospital. Quality of life of Asian FCs is also closely related with the duration and severity of bereavement. When it comes to decision-making, our review indicated that Asian terminal cancer patients and their FCs may differ in their preferences regarding some aspects of EOL care. Specific reported differences are related to the timing of the disclosure of terminal cancer diagnosis and the receptiveness to hospice care. The definition of a good death may be different between patients and FCs. For example, FCs want to have the time to say goodbye to patients, but they prefer to have a swift death without suffering.

### **Conclusion:**

More end-of-life care-based studies of Asian FCs, especially for Asian American FCs, are recommended. Various sociodemographic factors pose challenges to Asian family cancer caregiving, leaving needs of Asian FCs unmet. Culturally sensitive nursing care supporting Asian FCs at the EOL phase, such as culturally tailored social support and psychological interventions, could create positive outcomes for Asian FCs. Culturally competent, community-based interventions may bring positive outcomes for the Asian FCs who care for patients with terminal cancer by decreasing decisional conflicts between Asian FCs and their loved ones and also by helping increase their caregiving skills.

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### **Title:**

Asian Family Caregivers Caring for Patients With Terminal Cancer

### **Keywords:**

Asian Family Caregivers, Culturally Competent Care and End-of-Life Cancer Care

### **References:**

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### **Abstract Summary:**

Terminal cancer often advances rapidly, which makes it challenging for family caregivers to cope with end of life caregiving for their loved one. Asian family caregivers embrace unique sociocultural values, which could affect their terminal cancer caregiving. However, how the values of them affect terminal cancer caregiving isn't fully understood.

### **Content Outline:**

#### 1. Introduction

A. Culture in family caregiving for patients with terminal cancer can be an important factor.

B. Asian family caregivers embrace unique sociocultural values, which can affect their end-of-life caregiving.

#### 2. Body

A. Main Point

## #1 Characteristics of Asian family caregivers of patients with terminal cancer

- Asian family caregivers' experiences fall into the following eight topics: quality of life, depression, burden, decision-making, coping and resilience, social support and religiosity, end-of-life experience, and bereaved caregivers' symptoms.

### B. Main Point

#2 Quality of life for Asian family caregivers is interrelated with their depression and caregiver burden.

### C. Main Point

#3 Asian family caregiving is influenced by social support for Asian family caregivers and their coping skills, resilience, and extent of self-efficacy.

### D. Main Point

#4 Bereaved Asian family caregivers are affected by various factors.

- Bereavement symptoms for Asian family caregivers tended to decrease when they expressed a sound understanding of end-of-life care and terminal symptoms of patients, and when their loved one died at home instead of at an acute care hospital.

### E. Main Point

#5 Asian terminal cancer patients and their family caregivers may differ in their preferences of end-of-life care.

- Specific reported differences were related to the timing of the disclosure of terminal cancer diagnosis and to the receptiveness to hospice care.

## 3. Conclusion

a. More end-of-life care-based studies for Asian family caregivers who go through a transitional period are recommended.

b. Culturally sensitive nursing care supporting Asian family caregivers at the end-of-life phase could bring positive outcomes for the Asian family caregivers.

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**Author Summary:** Dr. Lee has studied Korean/Asian Americans' depression, caregiving, health promotion, disease prevention, and end-of-life care. Dr. Lee has served as PI and co-Investigator on several university and NIH-funded grants, and have successfully tested culturally appropriate interventions to improve cancer screening in Koreans as well as other minority populations.