Living With Hepatocellular Carcinoma Near the End of Life: Family Caregivers’ Perspectives

Lissi Hansen, PhD, RN, Susan J. Rosenkranz, MA, Kathleen Wherity, RN, BSN, and Anna Sasaki, MD, PhD

Purpose/Objectives: To explore family caregivers’ perspectives of caring for patients with terminal hepatocellular carcinoma (HCC) as patients approached the end of life.

Research Approach: Longitudinal, qualitative descriptive design.

Setting: Oregon Health and Science University in Portland and Veterans Affairs Portland Health Care System in Oregon.

Participants: 13 family caregivers with a mean age of 56 years (range = 22–68 years). The majority of family caregivers were female (n = 10) and identified as White (n = 11).

Methodologic Approach: Interview data were collected from family caregivers once a month for as many as six months, for a total of 39 interviews. Data were analyzed using conventional content analysis.

Findings: Five core categories and nine subcategories were identified. From the time of the terminal diagnosis to the end of life, family caregivers felt unprepared, uncertain, and in need of information. They struggled with whether symptoms were HCC- or cirrhosis-related.

Interpretation: Nurses can support family caregivers by eliciting their knowledge and concerns, and attending to symptom presentation and interpretation and to treatment challenges. Understanding challenges caregivers experience is crucial for developing interventions that address their desire for information, support, and help along the HCC disease trajectory.

Implications for Nursing: Nurses play a critical role in preparing caregivers to understand the importance of pain assessment and management and early referral to palliative care.

According to a National Alliance for Caregiving (2015) report, cancer was reported by 7% of caregivers as the main condition for which their recipient needed care. The experience of caregivers who provide care for patients with brain, breast, gynecologic, colorectal, and prostate cancer has been described in the literature (Fletcher, Miaskowski, for patients with brain, breast, gynecologic, colorectal, and prostate cancer has been described in the literature (Fletcher, Miaskowski, Baranova, & Younossi, 2011). According to a National Alliance for Caregiving (2015) report, cancer was reported by 7% of caregivers as the main condition for which their recipient needed care. The experience of caregivers who provide care for patients with brain, breast, gynecologic, colorectal, and prostate cancer has been described in the literature (Fletcher, Miaskowski, Baranova, & Younossi, 2011). According to a National Alliance for Caregiving (2015) report, cancer was reported by 7% of caregivers as the main condition for which their recipient needed care. The experience of caregivers who provide care for patients with brain, breast, gynecologic, colorectal, and prostate cancer has been described in the literature (Fletcher, Miaskowski, Baranova, & Younossi, 2011). According to a National Alliance for Caregiving (2015) report, cancer was reported by 7% of caregivers as the main condition for which their recipient needed care. The experience of caregivers who provide care for patients with brain, breast, gynecologic, colorectal, and prostate cancer has been described in the literature (Fletcher, Miaskowski, Baranova, & Younossi, 2011).