

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

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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, Given, & Schumacher, 2012; Li, Mak, & Loke, 2013; Stamataki et al., 2014). Little is known about caregivers of patients with hepatocellular carcinoma (HCC). In the United States, HCC (about 75% of all primary liver cancers) can be defined as a rare cancer, with an estimated 30,000 new cases and 21,000 deaths each year (American Cancer Society [ACS], 2017; Cancer Treatment Centers of America, 2017; Centers for Disease Control and Prevention [CDC], 2016b; Houlihan, 2015). It is the fifth estimated cause of death in men and the eighth in women (ACS, 2017). The overall five-year survival is about 17.5% (National Cancer Institute, 2016). A major contributing factor to HCC is liver cirrhosis caused by hepatitis C virus infection (CDC, 2016a, 2016b). During the next two decades, HCC mortality is predicted to increase due to nonalcoholic fatty liver disease (Vernon, Baranova, & Younossi, 2011).