

# Symptom Distress in Patients With Hepatocellular Carcinoma Toward the End of Life

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The study was funded by grant (119477-PEP-10-173-01-PCSM, principal investigator: Hansen) from the American Cancer Society. Hansen has previously consulted for Eli Lilly and Company and is supported by funding from the National Institute of Nursing Research of the National Institutes of Health. Kolbeck has previously received payment from Guerbet LLC for lectures and from Bayer for participation in advisory or review activities. This study is the result of work supported with resources from the VA Portland Health Care System in Oregon. The Department of Veterans Affairs did not have a role in the conduct of the study, in the collection, management, analysis, or interpretation of data, or in the preparation of the manuscript. The views expressed in this article are those of the authors and do not necessarily represent the views of the U.S. Department of Veterans Affairs or the U.S. government.

Hansen contributed to the conceptualization and design. Hansen and Kolbeck completed the data collection. Hansen, Dieckmann, Naugler, and Chang provided the analysis. Dieckmann provided statistical support. Hansen, Kolbeck, and Naugler contributed to the manuscript preparation.

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Submitted November 2016. Accepted for publication March 15, 2017.

**Keywords:** symptom distress; hepatocellular carcinoma; end of life; psychological distress; physical distress

ONF, 44(6), 665–673.

doi: 10.1188/17.ONF.665-673

**Purpose/Objectives:** To describe the presence, frequency, severity, and distress of symptoms in outpatients with advanced hepatocellular carcinoma toward the end of life, and the variability in psychological and physical symptom distress between and within patients over time.

**Design:** A prospective, longitudinal, descriptive design.

**Setting:** Outpatient clinics at two healthcare institutions.

**Sample:** 18 patients (15 men and 3 women) with hepatocellular carcinoma and a mean age of 63.3 years (range = 54–81 years).

**Methods:** Data were collected monthly for six months. Patients completed the Memorial Symptom Assessment Scale, which reports a total score, and three subscales that provide global distress, psychological distress, and physical distress scores.

**Main Research Variables:** Global, psychological, and physical distress.

**Findings:** Patients reported lack of energy and pain as the most frequent and distressing symptoms. Problems with sexual interest or activity was the fourth most present symptom after drowsiness. Global Distress Index mean scores had notable variability between and within patients over time. During data collection, six patients died. None were referred to palliative care.

**Conclusions:** Gaining knowledge about symptom distress and prevalent symptoms experienced by patients with advanced hepatocellular carcinoma is critical for designing symptom management strategies that are comprehensive and tailored to patients to optimize their quality of life as they approach death.

**Implications for Nursing:** Nurses play a vital role in advocating for, initiating, and providing comprehensive holistic care based on individual patient needs by facilitating discussions about apparent and less apparent distressing symptoms, including those related to sexuality.

About 75% of all liver cancers are hepatocellular carcinomas (HCCs) (American Cancer Society [ACS], 2017b; International Agency for Research on Cancer, 2012), and the mortality rate for HCC is increasing in the United States (ACS, 2016). In 2017, an estimated 28,920 people will die from liver and intrahepatic bile duct cancers (ACS, 2017a). HCC is the fifth estimated cause of death in men and the eighth in women (ACS, 2017a). Its primary etiologies are chronic hepatitis from hepatitis C and B viruses and alcoholic cirrhosis. Despite the new antiviral agents available to treat hepatitis C, the incidence of HCC will continue to be a challenge because of the increase in obesity, type 2 diabetes, and nonalcoholic fatty liver disease (Mittal & El-Serag, 2013). Many patients are diagnosed with HCC at an advanced stage, and the five-year relative survival rate is 17% (ACS, 2016).