

Jenny Drott, PhD, RN
 Bergthor Björnsson, PhD, MD
 Per Sandström, MD
 Carina Berterö, RN

Experiences of Symptoms and Impact on Daily Life and Health in Hepatocellular Carcinoma Patients

A Meta-synthesis of Qualitative Research

KEY WORDS

Daily life
 Experiences
 Health
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 Meta-synthesis
 Symptoms

Background: The incidence of hepatocellular cancer (HCC) has continually increased. To achieve optimal supportive cancer care for HCC patients, it is important to consider patients' experiences and preferences. **Objective:** This meta-synthesis aims to critically interpret how patients with HCC experience symptoms and the impact of the disease on daily life and health. **Methods:** Searches were performed in the following bibliographic databases: PubMed, CINAHL, Web of Science, Scopus, PsycINFO, and Cochrane Library. In addition, searches were performed using Open Gray to identify relevant studies in the gray literature. The search was limited to studies published in English from 2009 to 2019. Five studies (124 participants) were identified, appraised, and ultimately interpreted and synthesized. **Results:** Receiving an HCC diagnosis was overwhelming and affected the patients' entire lives. Three themes were identified based on the meta-synthesis: (1) disrupted life, (2) living with uncertainty, and (3) a changed body. Patients with HCC experience disrupted lives because of the cancer's effect on health and multidimensional symptoms. **Conclusion:** Available research on the experiences of HCC patients is limited. This meta-synthesis of available studies shows that being given a diagnosis of HCC is an overwhelming event. Our study findings show that an HCC diagnosis affected the individual's entire life. **Implications for Practice:** It is important

Author Affiliations: Division of Nursing Science, Department of Health, Medicine and Caring Sciences (Dr Drott and Prof Berterö), and Departments of Surgery and of Biomedicine and Clinical Sciences (Dr Björnsson and Prof Sandström), Linköping University, Sweden.

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Correspondence: Jenny Drott, PhD, RN, Division of Nursing Science, Department of Health, Medicine and Caring Sciences, Linköping University, House 001, Entrance 5/76/78, Floor 13, Campus US, 581 83 Linköping, Sweden (Jenny.Drott@liu.se).

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Jenny Drott: <https://orcid.org/0000-0002-7601-6450>

Bergthor Björnsson: <https://orcid.org/0000-0001-9704-1260>

Per Sandström: <https://orcid.org/0000-0002-8078-9528>

Carina Berterö: <https://orcid.org/0000-0003-1588-135x>

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to identify the patients' physical, psychological, social, and existential needs during the investigation of their condition, during any curative treatment, and at the palliative stage of the disease.

The incidence of hepatocellular cancer (HCC) has continued to increase for the past several years, and HCC is one of the leading causes of cancer-specific deaths worldwide.¹ Promoting health-related quality of life and providing good symptom relief is important when caring for patients with HCC. Symptoms caused by the disease and by treatment-related adverse effects are common, and patients with HCC reported worse physical, functional, and emotional health-related quality of life compared with the general population. Compromised physical health may be a consequence of severe HCC symptoms or treatment adverse effects, especially pain, loss of appetite, and fatigue.² Multidisciplinary teamwork can mitigate both general cancer-related symptoms as well as more specific HCC symptoms such as ascites and encephalopathy. Through effective symptom relief and psychosocial interventions to reduce negative feelings, patients' health-related quality of life may increase.² Health-related quality of life is a prognostic factor for survival in patients with HCC.³ It is important to pay attention to symptoms for optimal and individualized support for HCC patients.^{4,5}

The major risk factors for HCC include liver cirrhosis and hepatitis B virus infection.⁶ The complexities of the treatments administered to this group of patients can be challenging for both professionals and patients. Improvements in medical and surgical treatment options have been made in the past decade. Therefore, the treatment of HCC patients is complex, and multidisciplinary cooperation is important.^{1,5,7} Liver resection, liver ablation, and liver transplantation are curative surgical treatments for eligible patients. The presence of liver cirrhosis, localization of the tumor(s), and the patient's performance status often limit the possibility of a curative approach. Hepatocellular cancer treatment algorithms recommend alternative treatments, for example, transarterial chemoembolization and palliative thermal ablation.⁸ Effective adjuvant treatment has recently been suggested to significantly improve the 5-year relapse-free survival of HCC patients after hepatectomy.⁹

Unfortunately, many patients with HCC do not meet the criteria for curative treatment. Therefore, optimal supportive cancer care for patients with HCC is very important. However, during the last year, research often focus on tumor response or survival time. Although patients' experiences and preferences are important in a holistic care approach, and HCC has a great impact on the patients' health and well-being, physical, psychological, social, and existential needs should be identified during the investigation period, during any curative treatment, and at the palliative stage of the disease.¹⁰ There is little research that investigates the patient's perspective, and no existing reviews have been identified on this topic. This meta-synthesis aimed to critically interpret how HCC patients experience symptoms and to determine how HCC impacts daily life and health.

■ Methods

Meta-synthesis is a generic term for a study in which qualitative studies are analyzed and synthesized.¹¹ This method of integration offers more than the sum of the individual data sets. In general, 10 to 12 articles are sufficient for a meta-synthesis, but fewer may be sufficient.¹² This meta-synthesis followed the procedures outlined by Paterson et al.¹³ Through this synthesis, we examined multiple accounts of a phenomenon and identified similarities and discrepancies among reports on relevant primary qualitative studies, thereby gathering an integrated perspective on HCC patients and their health-related experiences. In addition, we aimed to clarify aspects of the experiences of HCC patients in different clinical settings, at different disease stages, and during different treatments.

Search Strategy and Screening

This qualitative meta-synthesis aims to bring together research evidence on HCC patients' health-related experiences. Searches, screening, and qualitative synthesis are applied to reported research relevant to the topic and to the research question with the aim of contributing to our current knowledge, providing new insights and documenting this information in an easily accessible format. Searches of PROSPERO and the Cochrane Database of Systematic Reviews were initially conducted, and no ongoing qualitative meta-syntheses on the topic were identified. To identify studies that could be included in the meta-synthesis, a thorough search for relevant articles was performed using the following bibliographic databases: PubMed, CINAHL, Web of Science, Scopus, PsycINFO, and the Cochrane Library. In addition, a search was performed using Open Gray to identify gray literature. Searches for studies to be included were conducted based on the following concepts: HCC, liver cancer, experiences, symptoms, health, daily life, quality of life, and qualitative research. The key terms used included "hepatocellular carcinoma" and "qualitative research." More specifically, the medical subject heading (MeSH) terms used in the PubMed database search included "hepatocellular carcinoma," "hepatic carcinoma," "liver neoplasms," and "qualitative research." Searches were performed using Boolean operators and truncation symbols, and the search terms were combined and applied across all databases. The inclusion criteria for this meta-synthesis were as follows: (1) qualitative research studies that focused on the experiences of adult patients (>18 years old) with HCC at different disease stages who were undergoing different treatments and (2) studies published in English between January 2009 and December 2019.

The following is an example of electronic search strategy, PubMed:

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((hepatocellular carcinoma) AND ("Qualitative Research"[MeSH] OR "Focus Groups"[MeSH] OR "Nursing Methodology Research"[MeSH] OR qualitative[Title/Abstract] OR "grounded theory"[Title/Abstract] OR ethnogra*[Title/Abstract] OR ethnolog*[Title/Abstract] OR phenomenogra*[Title/Abstract])
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Abstract] OR *phenomenolog**[*Title/Abstract*] OR *hermeneutic**[*Title/Abstract*] OR *focus group**[*Title/Abstract*] OR *field study*[*Title/Abstract*] OR *narrativ**[*Title/Abstract*] OR *lived experience** [*Title/Abstract*] OR *life experience**[*Title/Abstract*])) AND *interviews*

Critical Appraisal

The initial search across the databases yielded 459 articles; after removal of duplicates, 450 articles were screened for relevance based on their titles and abstracts. After exclusion based on the inclusion criteria, the remaining 14 articles were appraised for eligibility and quality (see Figure). To fulfill the aim of conducting a high-quality qualitative meta-synthesis, the articles were critically appraised by 4 independent researchers (J.D., B.B., P.S., and C.B.). Each primary research study was evaluated with an emphasis on research design, data collection methods, and analysis to ensure that the article met the inclusion criteria.¹³ This process also illustrated how the methodology used had shaped the researcher's knowledge of the phenomenon being examined.¹³ This critical appraisal was not used to critique the quality of the studies. Instead, the research designs of primary research articles were scrutinized to identify assumptions, preconceptions, and presuppositions associated with the research methodologies

The exclusion criteria included research conducted using quantitative paradigms, literature reviews, editorials, and conference abstracts. Studies focusing on healthcare professionals or family/next-of-kin perspectives were also excluded. Studies using different qualitative research methods and various data collection techniques were included; these studies could use individual interviews, focus groups, or qualitative observations. Only reported qualitative research data were used. Qualitative data were generated exclusively from qualitative design studies or as part of a mixed-methods study.

This systematic review was registered in the PROSPERO database under registration number PROSPERO 2020 CRD42020160720. The Figure presents a PRISMA flow diagram of the article selection process (<http://www.prisma-statement.org/>).

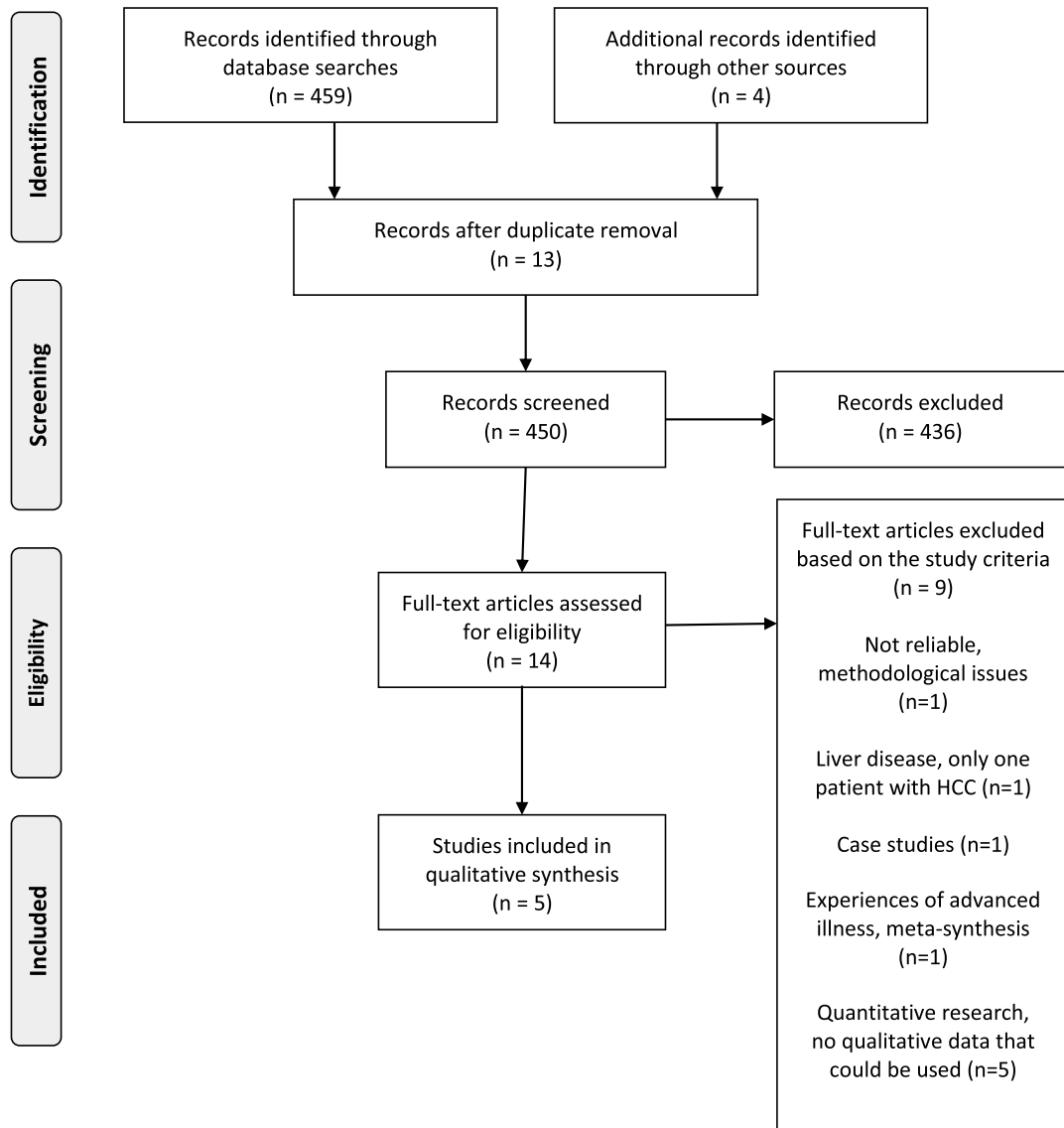


Figure ■ Flow diagram showing the article selection process.

as well as the rigor and soundness of the research methods used and to determine the appropriateness of the methods and how they influenced the reported findings.^{12,13} This appraisal process required the researchers to scrutinize the underlying theoretical perspectives of each study that met the criteria to ensure that the findings were interpreted appropriately (see Table). The Table presents the included and excluded studies.

Data Interpretation and Synthesis

Hermeneutics was used to interpret data in this meta-synthesis.¹⁹ A meta-synthesis is an interpretive integration

of qualitative findings that offers more than the sum of the individual data sets because it provides an innovative interpretation of the separate findings that answers “new” research questions.^{12,13,20} All 4 researchers (J.D., B.B., P.S., and C.B.) independently interpreted the data. The new findings and conclusions are derived from examination of all the articles in the sample as a collective group and present interpretations that are representative because the analysis is based on several articles.¹² Qualitative meta-synthesis allows a broader approach to evidence-based research and practice by expanding how knowledge can be generated and used in the researched area.²¹

Table • Demographic Information, Methodology, and Take-home Messages of Studies Included in the Meta-synthesis

Study (Year) Country	Sample Size, Age Range, Average Age, Cancer ^a	Objectives	Theoretical Orientation	Methodological Orientation	Major Findings (Take-home Message)
Fan and Eiser ¹⁴ (2012) Taiwan	Sample size, 33 31–76 y Average age, 54.2 y 22♂, 11♀ HCC	To explore the impact of HCC on patients' lives and the adjustment process	Illness experiences	Face-to-face interviews Interpretative phenomenological analysis	Patients' physical conditions and their illness perception and coping strategies contributed to their adjustment to their disease.
Lee ¹⁵ (2012) South Korea	Sample size, 40 34–89 y Average age, 60.9 y 26♂, 14♀ HCC	To examine the lived experiences of patients with primary liver cancer	Life Perspective Rhythm Model	Face-to-face interviews Giorgi phenomenology	More qualitative research is needed to understand the experience of living with liver cancer to further define the concept of stigma or spiritual distress.
Hansen et al ¹⁶ (2015) United States	Sample size, 14 54–68 y Average age, 61.5 y 11♂, 3♀ HCC	To explore the illness experiences of patients with terminal HCC as they approached the end of life	Illness experiences	Longitudinal interviews Conventional content analysis	A need to broaden studies including families and healthcare professionals to fully understand patients' illness
Speck et al ¹⁷ (2018) United States	Sample size, 17 54–84 y Average age, 68.8 y 15♂, 2♀ HCC	To identify, based on oncologist and patient interviews, a relevant subset of symptoms from the PRO-CTCAE that can be used to optimize patient reporting of symptoms in HCC	Reports from patients regarding treatment-related symptoms	One-to-one telephone interviews Content analysis	Identifying relevant clinical symptoms may support treatment safety and tolerability in HCC.
Ibrahim et al ¹⁸ (2019) Sweden	Sample size, 20 54–78 y Average age, 67.9 y 10♂, 10♀ Liver, bile duct, and pancreatic cancer	To explore patient experiences of involvement after surgery for upper abdominal tumors	Involvement in care when treated in a fast-track program	In-depth interviews Thematic analysis	Individualized care and continuous information about treatment and care goals increase safety and involvement.

Abbreviations: HCC, hepatocellular cancer; PRO-CTCAE, Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events.

The ♂ symbol indicates male, whereas the ♀ symbol indicates female.

^aTotal sample size, 124 participants (mean, n = 24.8).

■ Findings

Five studies met the inclusion criteria.^{14–18} All of the included studies were qualitative interview studies that used different approaches to qualitative data analysis. The included studies represented a variety of disciplines, and the participants in the included studies represented various countries: Sweden (1), South Korea (1), Taiwan (1), and the United States (2). The size of the research samples reported in the articles ranged from 14 to 40; the total sample size was 124 (mean sample size, 24.8) (see Table).

Receiving an HCC diagnosis was considered overwhelming and affected the entire life of the individual. Patients with HCC experience disrupted lives because of its effects on their health and its multidimensional symptoms. Living with a changed body and uncertainty related to the disease and its treatment affected the daily lives of a significant portion of the patients. Three themes were identified and interpreted from the meta-synthesis: (1) disrupted life, (2) living with uncertainty, and (3) a changed body.

Disrupted Life

It was especially difficult for patients to adjust to this disrupted life because HCC is an insidious disease with vague symptoms. Suddenly, the patients were hit by HCC, a severe disease that affected every aspect of their lives. Patients were forced to give up their ordinary lives and to change their goals and life directions. Hospital visits and treatments occasionally forced patients to give up work and social activities. The patients often looked back to life before the disease and compared it with life after the HCC diagnosis, noting that life had been disrupted. The disease and its treatment took over everything in life; ordinary life disappeared. The patients needed to manage this new disrupted life because it was still a life. Despite the numerous negative effects of the disease, the patients try to find positive aspects in their lives. The disease makes them realize what is important in life.

The disease affected individuals emotionally and caused psychological distress and numerous negative emotions. Downheartedness, anxiety, anger, initial shock and panic, feelings of inferiority, and difficulties in laughing and feeling happiness were common experiences. Patients reported using different methods to cope with the disease depending on whether they were dealing with disease-related stressors such as treatment and physical symptoms or life-related stressors.

Various coping strategies were used depending on the stressors and the stage of the HCC. When the patient was first given a diagnosis of HCC, the patient's immediate reaction was to seek out information, search for a good physician, and make contingency plans in case the disease worsened. Patients and their next of kin came across considerable information, including suggestions about treatments. Patients often tried formal treatments first. However, when their conditions worsened or during the palliative stage, patients were more open to alternative medicine. Considerable efforts were made to defeat the disease and to return to a normal life or at least to a "new normal" life. Even after they had struggled, endured treatment, and acted as prescribed,

some patients found their lives once again disrupted because of disease recurrence.

Patients made some efforts to change how they thought about their HCC diagnosis. They often knew they had HCC but did not label themselves as patients. They were ordinary people with a liver disease, and they reviewed their lives and searched for the meaning of life. Some sought religious beliefs, and some lost faith. The patients tried to make life go on, but relationships were disrupted because of the disease and treatments, and these patients were unable to fulfill normal family and work roles. The patients experienced psychological distress and withdrew of their own accord or unintentionally from social interactions. They did not wish to burden the people around them. Patients drew comparisons between other cancers or chronic diseases and HCC in their attempts to understand and describe their illness. A highlighted contrast between other "good" cancers and experiences of HCC was common. Hepatocellular cancer was experienced as a bad, cold, and isolating disease due in part to its negative associations with alcohol and drug abuse. It became a stigmatizing disease, and this increased the disruption of the patients' lives.

Over time, patients became more focused on their health-related quality of life. This change in attitude came in response to the adverse effects and the treatment burden, particularly given the impact of treatments on health and health-related quality of life. The treatment made life miserable over time, and patients experienced suffering. Thus, disrupted life could also mean no life. Having information about the disease and its symptoms and prognosis calmed the patients and made them feel safer. This information allowed patients not only to follow the course of the disease but also to face death with dignity. Disrupted life involved 2 components: adjusting to a new lifestyle and preparing to die.

Living With Uncertainty

When patients were initially given the diagnosis, they experienced feelings of fear. Patients realized that something was wrong and thought that their prognosis might have been better if they had sought treatment earlier. Patients were afraid and thought that HCC meant death for them. They were living with uncertainty and did not know how long they would live. Hepatocellular cancer was a death sentence for patients; they were left not knowing anything for certain and experiencing lots of thoughts.

The expectations of treatment outcomes varied from hope of remission to extending life or even being cured. Some patients who decided to start treatment found that having a treatment plan in place had a calming effect. Starting treatment provided a sense of control over the disease and offered a way to cope with the situation. Other patients felt uncertainty about the effects of the treatment and were unsure whether it was useful or worsened the situation. Several treatment-related adverse effects were perceived as symptoms of HCC and liver failure, making patients uncertain about the effect of treatment versus worsening HCC. Repeated treatments acted as reminders of disease and death, so patients experienced constant uncertainty. Patients felt fearful of relapses or other complications or consequences due to treatment.

Receiving too much information in a single meeting was problematic, and patients experienced trouble concentrating

and remembering all of the information that was delivered in a single session. It was difficult to remember the information about care and progress, and this brought forth uncertainty. Not knowing or a lack of information and not understanding the disease made the situation even more uncertain for patients. Patients felt unprepared. Knowing and being involved made the patients feel more secure and safe, and not knowing what would happen made it difficult for them to make decisions. Even so, well-informed patients could experience uncertainty about decisions.

Living with hope was a strong motivator for patients to cope with life after an HCC diagnosis. Treatment provided hope and could mean a new normal life because the patient was still alive. In the palliative situation when no cure was possible and treatment was only administered to prolong life, patients were hoping for a liver transplant. They thought of and wished for solutions. They were giving up but simultaneously hoping for a cure despite the palliative situation. Some even thought that perhaps there would be a miracle. Some patients noted that it was important to be hopeful because accepting the diagnosis and subsequent death was equivalent to giving up hope.

Other patients saw acceptance as a path to managing their emotions. Accepting the cancer diagnosis rather than holding out hope for recovery brought relief and allowed them to experience peace because they were able to accept the uncertainty. These patients said it was important to prepare oneself for the worst scenario or possibly the better scenario. For most patients, uncertainty about treatments increased over time. Feelings of uncertainty based on the decision to start and stop treatment, as well as uncertainty about treatment efficacy, were noted from the beginning. Some patients regretted ever starting treatment. They now looked for quality in life.

The Changed Body

A changed body was often the first symptom of the disease. The disease and the treatment produce different symptoms, and patients described how the disease and its treatment became the first and most important considerations in their lives. A wide range of physical symptoms such as jaundice, digestive problems, constipation, diarrhea, and flatulence, as well as more general symptoms such as sleep problems, fatigue, lack of physical vigor, dry mouth, itching, loss of appetite, hair falling out, and weakness, were experienced by the patients. Patients experienced adverse effects of treatments that were noted as bodily symptoms and found it difficult to determine whether or not these symptoms were caused by the disease. There was uncertainty about whether the changed body was due to treatment or to worsening of the disease.

The body was not responding as it typically did. Changes in physical conditions were noted, and it was difficult to understand what was happening to the body. The treatments caused bodily changes and reduced the patients' energy. Some patients were becoming increasingly weaker and simultaneously getting older dramatically faster. Some patients made comparisons about themselves. Before the disease, they were strong and healthy. Now, they were fragile and constantly tired. The patients were feeling more tired in both body and mind. Some patients felt

as if they had become someone else, that they were not the same person any longer. Not being able to manage simple things such as daily routines was frustrating. Their changed bodies hindered them in many ways by preventing them from managing various tasks and from eating what they wanted. The patients could not live as they previously had done. Patients experienced worsening pain, which made them feel closer to death. The symptoms and bodily changes were not the same for everyone, so patients experienced that they were not treated as unique individuals.

Discussion

To achieve optimal supportive cancer care for HCC patients, it is necessary to understand their experiences and preferences. To our knowledge, this is the first comprehensive meta-synthesis to interpret and synthesize qualitative studies on patients with HCC. Our study findings show that an HCC diagnosis affects an individual's entire life. Patients with HCC experience disrupted lives because of the effects of the disease on their health and its multidimensional symptoms. Living with a changed body and uncertainty related to the disease and treatments affected the patients' daily lives.

This meta-synthesis indicated that HCC patients experience disrupted lives. Their normal identity is threatened. All assumptions that were previously taken for granted were questioned. Normal life, including work and social activities, was disrupted. Now, the patients experienced pain, suffering, and death. They also felt that they were no longer the same person as before. Life was disrupted, and they had changed. This notion is confirmed by a study of patients with colorectal cancer.²² Similar findings are presented in a review and meta-synthesis of patients with lung cancer.²³ These patients try to reconnect with their everyday lives and to maintain their roles and routines.

Our findings show that patients are affected not only by the disease itself but also by the treatment. In a recent review of patient-specific outcomes of radiation for HCC that included overall survival, the effects of radiation dose and the toxicity burden were notable in patients. The researchers reported acceptable survival and low posttreatment morbidity. However, incomplete reporting of toxicities was noted, and a strong need for better reporting was identified.²⁴ That systematic review studied quantitative measures; it also confirmed that there are deficiencies in qualitative data and studies on symptoms and toxicity, and these findings are consistent with the availability of qualitative measures and data for patients with HCC during different phases of the disease. Most of the available published studies are of a quantitative nature, and few studies have assessed how patients with HCC experience symptoms and health conditions.

The findings in our review demonstrate that HCC and its treatment override everything else in patients' daily lives. A wide range of physical symptoms (eg, jaundice, digestive problems, sleep problems, fatigue, lack of physical vigor, itchiness, and other symptoms) were experienced by the patients. There was uncertainty about whether the changed body was due to treatment or to worsening of the disease. Research suggests that uncertainty in patients with cancer is associated with negative

consequences,²⁵ including more psychological distress, a sense of losing control, and reduced health-related quality of life.²⁶ The patients' relationships were disrupted because of the disease and its treatment, and the patients experienced psychological distress. Difficulties with social interactions may also have been interpreted as unmet needs, and more supportive care from healthcare professionals is needed to allow patients to cope with and achieve control of the situation. Over time, HCC patients became more focused on their health-related quality of life. Measurement of patient-reported outcomes may be one method that can be used to support HCC patients and follow the progress of their health.²⁷

Patients drew comparisons between other cancers and chronic diseases and HCC and characterized their HCC diagnosis as a bad, cold, and isolating disease, given its negative associations with alcohol and drug abuse. Hepatocellular cancer became a stigmatizing disease, and this increased its disruption of the patients' lives. Stigma is associated with poor psychological outcomes and quality of life in patients with other cancers.^{28,29} To the best of the authors' knowledge, the issue of whether stigma influences symptom severity in patients with HCC has not been investigated, but the existing evidence on stigma, cancer, and cirrhosis might be applicable to this patient population. Patients with cirrhosis often perceived stigma related to their disease, and an increasing sense of stigma can lead to depression, decreased quality of life, and tendency to seek healthcare. Stigma is common among patients with liver cirrhosis and is related to a broad range of downstream effects, attitudes, and behaviors, such as decreased healthcare-seeking behaviors.³⁰

■ Implications for Practice

Professionals need to be aware of these experiences and their potential impact on patients' interaction with the healthcare system, especially because the results of our study show that the patients experienced psychological distress and withdrew of their own accord or unintentionally from social interactions. The patients did not want to burden the people around them; because of this, it is of great importance that cancer nurses ask for symptoms and experiences to a greater extent in this patient group. Given that these patients experienced their cancer diagnosis as "uglier" than other cancer diagnoses, and more stigmatized, it may be more important to consider the supportive care when meeting with this patient group. An important clinical implication for both new and experienced cancer nurses is that patients became more focused on their health-related quality of life over time. Navigating patients' experiences of different types of symptom burden can be challenging for nurses, and it is not always easy to map out whether it is caused by illness or treatment. However, it is an important clinical implication of the outcome that patients receive active interventions for their symptoms and person-centered and individualized information based on needs to obtain the best possible health and quality of life over time. Supportive patient-centered care is important to allow HCC patients to effectively identify their needs and the impact of the disease on daily life. Patient-reported outcome measures should be assessed in these patients both in the short term and in the long term and

may facilitate patient-centered care. These measurements can be used as a basis for nurses to focus on the symptoms that patients find troubling, thus adapting the specific cancer supportive care. Patient-reported outcome measures should be incorporated into the National Quality Register to facilitate evaluations of patients' symptoms and further development of healthcare interventions, and the use of patient-reported outcome measures has been shown to have several potential benefits.³¹

■ Limitations and Strengths

Our study has some limitations that should be considered. The small number of included studies is one limitation. However, qualitative studies of HCC patients' health and experiences are few. The summarized sample size of the participants in the included articles provides a robust basis of evidence. Through this synthesis, we aimed to search for homogeneity and discordance among qualitative studies, develop an integrated perspective on patients with HCC and their health experiences, and clarify aspects of the experiences of HCC patients in different clinical settings, at different disease stages, and under various treatments. In addition, studies that were not published in English were excluded because of problems with accuracy related to translation and validation of the results. However, the included studies were not exclusively conducted in Western countries. The strength of this review and meta-synthesis is that it encapsulates the patients' real-life experiences of HCC. Through this synthesis, it is also possible to clarify aspects of the experiences of HCC patients in different clinical settings, at different disease stages, and under different treatments.

■ Conclusion

Available qualitative research on the experiences of HCC patients is limited. This meta-synthesis of available studies shows that being given a diagnosis of HCC is an overwhelming event. Our study findings show that an HCC diagnosis affected the individual's entire life. Patients with HCC experience disruption of their lives because of the effects of the disease on their health and its multidimensional symptoms. Living with a changed body and uncertainty related to the disease and treatments affected large portions of the patients' daily lives. It may be important to take into account that these patients often do not want to burden the people around them, and this result interpreted that it is extra important as a cancer nurse to ask for symptoms and experiences to a greater extent in this patient group. The experiences of stigmatization are added to the symptom burden. Important clinical implications for nurses are active interventions for their symptoms and person-centered and individualized information based on needs to obtain the best possible health and quality of life over time.

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