

REVIEW

Hepatocellular carcinoma and its impact on quality of life: A review of the qualitative literature

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Abstract

Introduction: Hepatocellular carcinoma (HCC) carries significant burden of disease, with high mortality rates and poor prognosis. It is therefore important to consider quality of life (QoL) for patients with HCC. Quantitative research assesses HCC and QoL via standardised measurement tools, but these do not capture the full scope of patient experiences. This review examines the body of qualitative research on this topic, to develop a comprehensive understanding of QoL for this population.

Methods: Medline, EMBASE and PsycINFO were systematically searched with keywords relating to HCC, QoL and patient experience. After applying inclusion and exclusion criteria, key findings of included studies were extracted and analysed for themes.

Results: Eleven studies were included for thematic analysis, with five themes identified as central to QoL: (1) burden of physical symptoms and treatment side effects; (2) psychological impact and coping strategies; (3) social function and stigma; (4) spiritual wellbeing, sense of self and meaning of illness and (5) pervasive uncertainty.

Conclusion: HCC profoundly impacted patients' lives, spanning physical, psychological, social and spiritual QoL domains. While QoL was reduced overall, some features of patient experiences that enhanced QoL were noted. The findings complement data from quantitative studies, helping to build a richer understanding of QoL.

KEYWORDS

hepatocellular carcinoma (one key word preferably), liver neoplasms, palliative care, qualitative research, quality of life

1 | INTRODUCTION

Hepatocellular carcinoma (HCC) is the main form of primary liver cancer and one of the most common malignancies worldwide (Bray et al., 2018; McGlynn et al., 2021). Aetiology of HCC varies, but

Hepatitis B virus (HBV), Hepatitis C virus (HCV) and high alcohol consumption are all important risk factors (Singal et al., 2020). Liver cirrhosis is a primary risk factor for HCC regardless of underlying cause (Singal et al., 2020). HCC also carries a high mortality rate and is the fourth leading cause of cancer-related deaths (Bray et al., 2018; Singal et al., 2020). Five-year survival rates are globally less than 20%, in part because the absence of symptoms in early stages leads to delayed diagnosis (Laube et al., 2021). By the time of diagnosis, most patients

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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are not eligible for curative treatments such as liver resection or transplantation (Fan et al., 2010; Firkins et al., 2021). Other treatment options include transarterial chemoembolisation, radiotherapy and chemotherapy; these can prolong survival but are ultimately noncurative (Laube et al., 2021).

Poor prognosis, underlying chronic liver disease (CLD) and significant symptom burden in later stages, means that HCC can have a considerable impact on patient quality of life (QoL) (Fan et al., 2010). Many frameworks have been designed to define QoL, but Ferrell's model is useful to consider as it is specific to cancer patients (Ferrell et al., 1995). The model defines four domains that contribute to overall QoL, which are physical, psychological, social and spiritual well-being (Ferrell et al., 1995). Health-related quality of life (HRQoL) is a similar, albeit narrower, concept and is defined as QoL in relation to health and disease status (Fan et al., 2010). HRQoL is frequently used as an outcome measure in research, and for the purposes of this review, the terms QoL and HRQoL will be used interchangeably.

QoL outcomes are increasingly recognised as an important measure of the effectiveness of healthcare, particularly when a cure is not possible (Firkins et al., 2021). They are highly relevant in the context of HCC. First, it has been shown that QoL has independent prognostic value in predicting survival outcomes for HCC patients (Bonnetain et al., 2008). In addition, given that HCC is often a terminal illness, making global assessments of QoL becomes more important than focusing entirely on treatment outcomes and overall survival (Laube et al., 2021). Understanding disease-specific effects on QoL should therefore be a priority for all healthcare professionals caring for patients with HCC.

Quantitative research has examined HCC and HRQoL via general HRQoL measurement instruments, as well as cancer- and HCC-patient-specific instruments (Fan et al., 2010; Firkins et al., 2021; Kang et al., 2020). These instruments include items that assess physical, psychological and social domains of QoL to variable degrees (Fan et al., 2010; Kang et al., 2020). However, a systematic review by Firkins et al. (2021) found almost no assessment of spiritual QoL in the quantitative research on HCC, as the most common HRQoL instruments do not assess this domain. In addition, the conclusions of these studies predominantly focus on the impacts of HCC on physical well-being and comparatively less on psychosocial QoL (Fan et al., 2010; Firkins et al., 2021). This raises the issue that the existing body of quantitative research may not comprehensively capture the patient experience of HCC.

Qualitative research is a valuable lens to support a rich understanding of illness experience through the patient viewpoint. To date, there are small numbers of qualitative studies that explore the illness course of patients with HCC, but no review has collectively examined their findings. These studies may provide deeper insight into the effects of HCC on all domains of QoL, as well as how measurement tools could be improved to better capture QoL concerns relevant to this patient population. This narrative review therefore aimed to systematically search the qualitative literature and draw together the results to examine how the patient experience of HCC impacts on QoL.

2 | METHODS

2.1 | Search strategy

A preliminary search was first performed to identify key terminology used in the literature on HCC, QoL and the patient experience. This informed the search strategy, which is shown in Tables 1–3. On 30 July 2021, three electronic databases were systematically searched via the Ovid interface: Medline, EMBASE and PsycINFO. The databases were selected for coverage of biomedical, psychology and psychiatry literature.

A combination of key words and Medical Subject Headings (MeSH) was used when building the search in Medline. Equivalent subject headings were identified on EMBASE and PsycINFO by comparing definitions on the respective databases. Where no equivalent subject heading existed, the term was omitted from the search. Boolean operators 'AND' and 'OR' were used to combine terms.

2.2 | Inclusion and exclusion criteria

Citations were screened using EndNote X9 software, and inclusion and exclusion criteria were applied. Titles and abstracts were screened first, followed by a full text review. Reference lists of studies that met all the inclusion/exclusion criteria were also screened for additional relevant publications.

TABLE 1 Search strategy on MEDLINE (Ovid)

MEDLINE (Ovid)		
Search number	Search term	Number of results
1	exp Carcinoma, Hepatocellular/	90,837
2	exp Carcinoma, Hepatocellular/px [Psychology]	107
3	exp Liver Neoplasms/px [Psychology]	213
4	hepatocellular carcinoma.m_titl.	60,414
5	1 OR 4	103,780
6	exp 'Quality of Life'/	217,580
7	exp Adaptation, Psychological/	132,296
8	exp Stress, Psychological/	140,349
9	(Illness experience* OR illness perception* OR patient concern* OR patient experience* OR patient journey or patient narrative* OR patient perspective* OR patient-reported outcome* OR patient survey*).ti,ab.	57,496
10	6 OR 7 OR 8 OR 9	500,071
11	5 AND 10	493
12	2 OR 3 OR 11	637
13	Limit 12 to (English language and yr = '2011-Current')	381

TABLE 2 Search strategy on EMBASE (Ovid)

EMBASE (Ovid)		
Search number	Search term	Number of results
1	exp liver cell carcinoma/	174,882
2	hepatocellular carcinoma.m_titl.	84,585
3	1 or 2	178,952
4	exp 'quality of life' /	541,071
5	exp psychological adjustment/	6,373
6	exp mental stress/	91,592
7	(Illness experience* OR illness perception* OR patient concern* OR patient experience* OR patient journey or patient narrative* OR patient perspective* OR patient-reported outcome* OR patient survey*).ti,ab.	92,899
8	4 OR 5 OR 6 OR 7	705,690
9	3 AND 8	2,682
10	limit 9 to (English language and yr = '2011 -Current')	2010

TABLE 3 Search strategy on PsycINFO (Ovid)

PsycINFO (Ovid)		
Search number	Search term	Number of results
1	hepatocellular carcinoma.m_titl.	103
2	exp 'Quality of Life' /	45,975
3	exp Adjustment/	53,305
4	exp Psychological Stress/OR exp Distress/	32,606
5	(Illness experience* OR illness perception* OR patient concern* OR patient experience* OR patient journey or patient narrative* OR patient perspective* OR patient-reported outcome* OR patient survey*).ti,ab.	9,530

To find contemporary studies relevant to this review, inclusion criteria required that papers were published in a peer-reviewed journal, in English, within the last 10 years and followed qualitative methodology or mixed-methods with a qualitative component. Studies were only included if they assessed patient QoL and/or patient experience in the context of HCC and/or CLD and/or gastrointestinal cancer. Studies focusing on patients with CLD or gastrointestinal cancer needed to have patients with HCC form part of their sample. The justification for including studies on CLD is that over 90% of patients with HCC have underlying liver disease (Laube et al., 2021).

Review papers were excluded to reduce bias when drawing conclusions from original study findings. Single case-reports were excluded, as it is recommended that sample size in qualitative research should be a minimum of 6–12 to reach data saturation

(Fush & Ness, 2015). Conference abstracts and other publication formats that did not provide access to the full set of findings were also excluded.

2.3 | Data synthesis

The 11 studies that satisfied all inclusion criteria were tabulated, and the following data were extracted: aims, study setting, sample, methodology and key findings. A hermeneutic phenomenological framework was drawn upon to extract a central set of themes from the data (Jones et al., 2012). This involved reading, reviewing, creating initial codes, discussing with the research team and combining the data into cohesive themes. Twenty-five per cent of the included papers were independently coded by another researcher and discussed with the primary author, to support credibility.

3 | RESULTS AND DISCUSSION

The process of study identification, screening and selection is detailed in a PRISMA flowchart in Figure 1. The search yielded 2,080 non-duplicate citations from the three databases. After inclusion/exclusion criteria were applied in a title screen and subsequent abstract screen, 19 papers were selected for full text review, and a final total of 11 studies were included for analysis. The aims, methodology and key findings of these studies are summarised in Table 4.

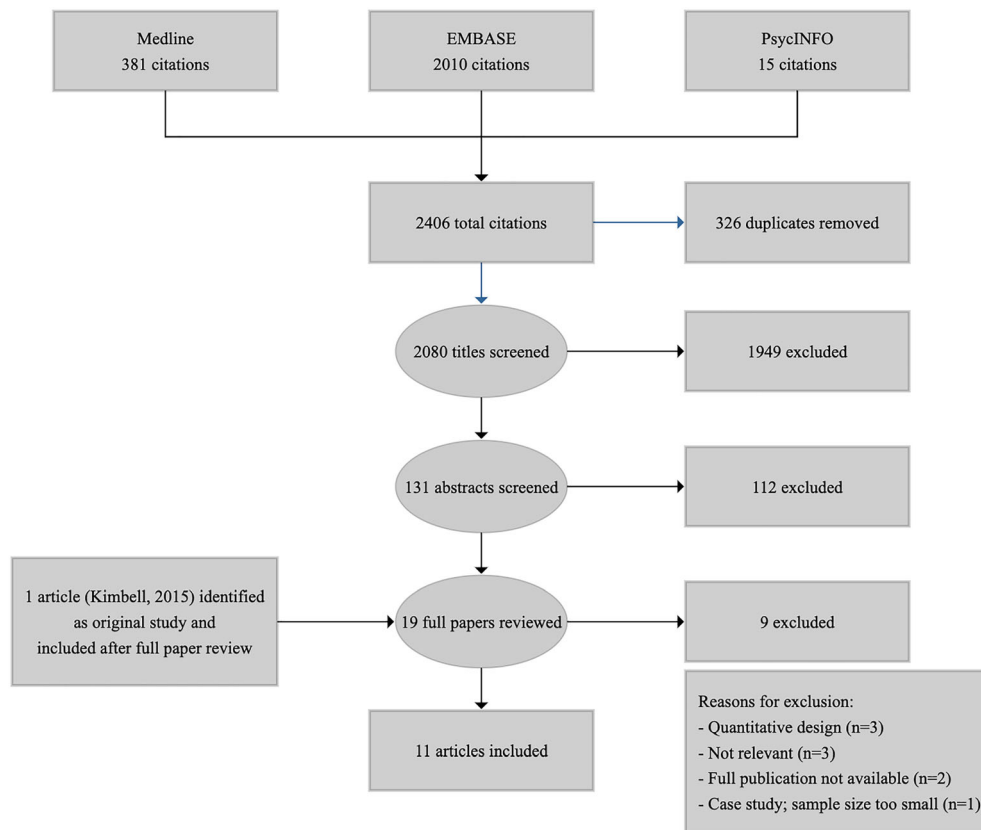
3.1 | Summary of themes

Five key themes were identified in relation to QoL and the patient experience of HCC. These were (1) burden of physical symptoms and treatment side effects; (2) psychological impact and coping strategies; (3) social function and stigma; (4) spiritual wellbeing, sense of self and meaning of illness and (5) pervasive uncertainty. Table 5 provides a summary of themes and includes representative patient quotes.

3.1.1 | Burden of physical symptoms and treatment side effects

Patients experienced substantial symptom burden due to underlying HCC and CLD (Ellis et al., 2013; Fan & Eiser, 2012; Gill et al., 2018; Hansen et al., 2015; Kaiser et al., 2014; Kimbell et al., 2015; Patel et al., 2022; Speck et al., 2018; Valery et al., 2017). Fatigue was universally reported, with other salient symptoms being abdominal pain (Ellis et al., 2013; Gill et al., 2018; Hansen et al., 2015; Kaiser et al., 2014; Patel et al., 2022), loss of appetite (Fan & Eiser, 2012; Gill et al., 2018; Kaiser et al., 2014; Patel et al., 2022; Speck et al., 2018), weight loss (Ellis et al., 2013; Gill et al., 2018; Patel et al., 2022), disturbed sleep (Fan & Eiser, 2012; Kaiser et al., 2014; Patel et al., 2022),

FIGURE 1 PRISMA flowchart of study selection



dizziness (Ellis et al., 2013; Fan & Eiser, 2012; Kimbell et al., 2015; Patel et al., 2022) and gastrointestinal issues including nausea, vomiting, altered bowel function and jaundice (Ellis et al., 2013; Fan & Eiser, 2012; Gill et al., 2018; Hansen et al., 2015; Kaiser et al., 2014; Patel et al., 2022; Valery et al., 2017). These results are consistent with the quantitative literature, which show that patients with HCC experience a range of symptoms and have reduced physical health compared to the general population (Fan et al., 2010; Kang et al., 2020).

Side effects of treatment for HCC independently influenced QoL (Ellis et al., 2013; Gill et al., 2018; Hansen et al., 2015; Kaiser et al., 2014; Speck et al., 2018). Speck et al. (2018) noted that fatigue, loss of appetite, pain and hair loss were the most reported side effects across various HCC treatments. Gill et al. (2018) found that all treatments were challenging for patients but transarterial chemoembolisation and radiotherapy tended to improve QoL, while the palliative chemotherapy agent Sorafenib had an extensive side effect profile and a largely negative effect on QoL. The significant burden of Sorafenib was consistent across studies, with an emphasis on skin toxicity as a unique complication of this agent (Gill et al., 2018; Hansen et al., 2015; Kaiser et al., 2014; Speck et al., 2018). Hansen et al. (2015) found that some patients regretted starting Sorafenib in the first place and others decided to cease this treatment to focus on QoL. While side effects of Sorafenib have been previously documented (Aly et al., 2020; Fan et al., 2010; Kang et al., 2020), the finding that these were severe enough to influence treatment decisions

provides important insight into the value that preserving QoL holds for patients.

The studies also linked symptom burden to functional impacts on patients' lives. Pain, fatigue and dizziness were cited as symptoms causing the most functional limitation (Kaiser et al., 2014; Kimbell et al., 2015; Patel et al., 2022). As a result, many patients were no longer able to do normal activities of daily living (Gill et al., 2018; Patel et al., 2022), had to quit their jobs (Fan & Eiser, 2012; Gill et al., 2018; Kimbell et al., 2015) and spent more time confined to bed (Kaiser et al., 2014; Patel et al., 2022). Conversely, when patients had better physical health, they fared better overall (Fan & Eiser, 2012; Kaiser et al., 2014; Patel et al., 2022). Collectively, these results highlight the crucial role that physical health plays in determining patients' ability to function and adjust to HCC.

3.1.2 | Psychological impact and coping strategies

The studies showed that HCC profoundly affects psychological QoL. Psychological impacts were both common and highly disturbing to patients (Patel et al., 2022). Consistent across the literature on HCC and CLD, the categories of emotion most frequently reported were anxiety/fear (Ellis et al., 2013; Fan & Eiser, 2012; Gill et al., 2018; Gray-Renfrew et al., 2020; Patel et al., 2022; Valery et al., 2017), anger/frustration (Ellis et al., 2013; Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Patel et al., 2022), sadness/depression (Fan &

TABLE 4 Summary of the included qualitative studies, including key characteristics and findings

Author, title, publication and year	Aim(s)	Setting	Sample size	Methodology	Key findings
Ellis et al. Understanding the symptom experience of patients with gastrointestinal cancers in the first year following diagnosis, and diagnosis: findings from a qualitative longitudinal study. <i>Journal of Gastrointestinal Cancer</i> (2013)	To contextualise and map the experiences of people with GI cancer within the first year following diagnosis, and to identify how and when these patients can be best supported	Single tertiary specialist centre in North England	19 patients with GI cancer; 2 had HCC	Participants were identified during outpatient visits. Semi-structured interviews were conducted at 4 time points. Final set of 60 interview transcripts were analysed using content/framework analysis based on Leventhal's theory	5 themes were central to the patient experience across the sample: <ol style="list-style-type: none"> 1. Symptoms experienced 2. Impact of symptoms on everyday life 3. Return to work & survivorship 4. Impact on sense of self 5. Fear & uncertainty
Fan & Eiser. Illness experience in patients with hepatocellular carcinoma: An interpretive phenomenological analysis study. <i>European Journal of Gastroenterology & Hepatology</i> (2012)	To explore how patients perceived the impact of HCC on their lives, and how they coped with the demands of HCC, as a preliminary step towards developing a formal measure of HRQOL appropriate to the cultural setting in Taiwan	2 participating hospitals in Taiwan	33 patients with HCC	Purposive sampling was undertaken. Semi-structured interviews were organised around pre-prepared themes. Interpretive phenomenological analysis was performed on transcripts	3 themes contributed to disease adjustment: <ol style="list-style-type: none"> 1. Impact of HCC on patient's lives (physical symptoms, psychological symptoms, social disruption) 2. Illness perceptions (including association of HCC with death, and unmet information needs) 3. Coping strategies
Gill et al. Insights into the hepatocellular carcinoma patient journey: Results of the first global quality of life survey. <i>Future Oncology</i> (2018)	To better understand the hepatocellular carcinoma patient journey, and to compare the effects of later-stage treatment of QoL	Participants were recruited across 13 countries in Europe, the Americas, and Asia-Pacific	256 patients with HCC	The survey was developed via an iterative process between medical charities and centres across 13 countries. Participants could self-select or were recruited at their specialist clinic. Data generated was processed in excel and used to build word clouds	<ul style="list-style-type: none"> • Feelings at diagnosis were 'fear', 'worry', 'anxiety', 'scared', 'shock' • Significant side effects from treatment impacted on function, relationships, life outlook and overall mental condition • Patients wanted more information, comfort, and support at diagnosis
Gray-Renfrew, Kimbell & Finucane. Emotional experience of people with advanced liver disease: Secondary data analysis. <i>Chronic Illness</i> (2020)	To explore the basic emotions experienced by people with advanced liver disease in the context of their illness, and to consider how these emotions might influence illness behaviours	Primary and secondary care in south-East Scotland	15 patients with advanced liver disease; some of whom had HCC	This paper is a secondary data analysis of the original qualitative study by Kimbell et al. (2015); see below. Interview transcripts were analysed, and emergent themes were categorised based on Ekman's five basic emotions	<ul style="list-style-type: none"> • Fear was linked to diagnosis, prognosis, loss of control, and lack of employment • Anger was directed at loss of physical health • Sadness was linked to depressive disorders and poor overall QoL

(Continues)

TABLE 4 (Continued)

Author, title, publication and year	Aim(s)	Setting	Sample size	Methodology	Key findings
Hansen et al. Patients with hepatocellular carcinoma near the end of life. <i>Cancer Nursing</i> (2015)	To explore the illness experiences of patients with terminal HCC as they approach the end of life	2 healthcare institutions in the Pacific northwest	14 patients with HCC	Convenience sampling was undertaken at liver clinic appointments. Semi-structured interviews were conducted monthly for up to 6 months, with 45 interviews total. Conventional content analysis was performed	<ul style="list-style-type: none"> Guilt/shame was linked to stigma around liver disease Some used humour to cope Symptoms, treatment decisions and unmet information needs all impacted on QoL Unifying all patient's experiences was the desire to control how HCC impacted their lives
Ibrahim et al. 'I want to know why and need to be involved in my own care ...': A qualitative interview study with liver, bile duct or pancreatic cancer patients about their experiences with involvement in care. <i>Supportive Care in Cancer</i> (2019)	To explore patient experiences of involvement in fast-track care programme services after receiving surgery for upper abdominal tumours	Single university hospital in Sweden	20 patients with upper GI cancer; 7 had liver cancer	Purposive sampling was done to recruit patients from a surgery clinic. Semi-structured interviews were conducted, and transcripts were processed following the 6 phases of thematic analysis according to Braun and Clarke	<ul style="list-style-type: none"> Patients prioritised individualised care, clear communication, and active dialogue with healthcare providers Cognitive symptoms meant patients needed clear communication and reminders Poor information provision led to uncertainty, while good communication mitigated uncertainty
Kaiser et al. Important and relevant symptoms including pain concerns in hepatocellular carcinoma (HCC): A patient interview study. <i>Supportive Care in Cancer</i> (2014)	To identify the symptoms and pain concerns considered most important and relevant by patients undergoing systemic treatment for HCC	Single cancer Centre in Illinois, USA	10 patients with HCC	Mixed methods approach. Patients were recruited at clinic appointments. Semi-structured interviews were conducted, and participants completed 2 standardised QoL questionnaires; the FACT-Hep and the EORTC. Data were tabulated, summarised, and qualitative data mapped to questionnaire results	<ul style="list-style-type: none"> A range of symptoms impacted on QoL: The most common were diarrhoea, fatigue, skin toxicity, and loss of appetite Almost all patients reported pain as a significant concern that had functional impact

TABLE 4 (Continued)

Author, title, publication and year	Aim(s)	Setting	Sample size	Methodology	Key findings
Kimbell et al. Managing uncertainty in advanced liver disease: A qualitative, multiperspective serial interview study. <i>BMJ Open</i> (2015)	To understand the experiences, needs and priorities of patients and their lay and professional carers towards the end of life, to propose effective models of care in advanced liver disease	Primary and secondary care in South-East Scotland	15 patients with advanced liver disease, some of whom had HCC	Patients were recruited from an inpatient liver unit. Purposive sampling was undertaken. Interviews were conducted up to 3 times over 12 months. Data analysis drew on constructivist grounded theory	Uncertainty defined the experience of all patients and impacted ability to cope. There were 4 subcategories of uncertainty: <ol style="list-style-type: none"> 1. Ambiguous onset and confused understanding of disease 2. Uncertainty as a feature of everyday life 3. Inadequate patient-doctor communication and discontinuity of care 4. Uncertainty as a barrier to talking about/planning for deteriorating health and dying
Patel et al. Understanding the patient experience of hepatocellular carcinoma: A qualitative patient interview study. <i>Quality of Life Research</i> (2022)	To understand the patient experience of HCC to guide patient-centred outcome measurement in drug development	Patients contacted across the USA via telephone	25 patients with HCC	Recruitment was via advocacy groups/research organisations/recruitment agencies. Concept elicitation interviews were held via phone. Concept analysis and concept saturation were performed. Salient concepts were mapped to common outcome instruments used in other studies on HCC	<ul style="list-style-type: none"> • Salient symptoms/signs included: Loss of appetite, weight loss, fatigue, diarrhoea, nausea, vomiting, abdominal pain, cognitive issues, dizziness, and weakness • Salient impacts included emotional impacts, impact on family/friends, frequent bed rest, impact on ADLs, disturbed sleep, and impact on social life
Speck, Lenderking & Shaw Integrating the patient voice with clinician reports to identify a hepatocellular carcinoma-specific subset of treatment-related symptomatic adverse events. <i>Journal of Patient-Reported Outcomes</i> (2018)	To identify, based on oncologist and patient interviews, a relevant subset of symptomatic adverse events from the PRO-CTCAE (a PRO tool used in cancer trials) that can be used to optimise patient reporting of symptomatic adverse events in HCC clinical trials	5 clinical sites across the USA	17 patients with HCC	A cross sectional, mixed-methods approach was used. Patients were recruited from third-party contracted sites. Semi-structured interviews were conducted. Content analysis was performed using ATLAS.ti software. Content saturation was assessed	<ul style="list-style-type: none"> • The treatment adverse effects which were the most common and most impactful on QoL were fatigue, loss of appetite, nausea, pain at injection/insertion site, and hair loss

(Continues)

TABLE 4 (Continued)

Author, title, publication and year	Aim(s)	Setting	Sample size	Methodology	Key findings
Valery et al. Exploratory study into the unmet supportive needs of people diagnosed with cirrhosis in Queensland, Australia. <i>Internal Medicine Journal</i> (2017)	To explore the concerns and challenges of people with cirrhosis and their use of support services, and to describe health professionals' perspectives of patient concerns	Tertiary healthcare facility in Brisbane, Australia	53 patients with cirrhosis; 4 had HCC	Mixed methods approach. Patients were recruited via specialist clinics. Structured interviews were conducted with open- and closed-ended questions. Quantitative data was analysed using SPSS. Qualitative data was entered into excel and classified into meaningful categories	<ul style="list-style-type: none"> The most common patient-volunteered concerns that impacted QoL were: Symptom management, decreased mobility, ascites, fatigue, emotional issues, disease management, and stopping alcohol/substance use. A fear of dying and fear of the unknown were also highly prioritised concerns

Eiser, 2012; Gray-Renfrew et al., 2020; Patel et al., 2022; Valery et al., 2017) and guilt/shame (Ellis et al., 2013; Gray-Renfrew et al., 2020). Several patients also noted cognitive concerns, with memory and attention problems affecting daily activities and function (Ellis et al., 2013; Gill et al., 2018; Patel et al., 2022).

The qualitative data identified specific sources of salient emotions, adding depth to our understanding of the psychological domain. At diagnosis, patients predominantly felt scared (Gill et al., 2018; Gray-Renfrew et al., 2020), shocked (Fan & Eiser, 2012; Gill et al., 2018) and hopeless (Gill et al., 2018; Hansen et al., 2015), but there was a smaller pool who felt hopeful (Gill et al., 2018; Hansen et al., 2015) or accepting (Hansen et al., 2015). Over the course of illness, anxiety was linked specifically to financial issues and loss of work (Ellis et al., 2013; Gray-Renfrew et al., 2020; Patel et al., 2022), uncertainty (Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Hansen et al., 2015; Valery et al., 2017), body image (Patel et al., 2022) and fear of dying (Valery et al., 2017). Frustration revolved around ongoing symptoms and the inability to return to pre-illness functional status (Ellis et al., 2013; Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Patel et al., 2022). Depressive symptoms, including feelings of sadness and hopelessness, were linked to decreasing physical health (Gray-Renfrew et al., 2020; Patel et al., 2022), the terminal nature of the diagnosis (Gray-Renfrew et al., 2020; Hansen et al., 2015) and exacerbation of pre-existing depressive disorders (Gray-Renfrew et al., 2020). A loss of physical ability also led to feelings of guilt, as patients felt they were a burden to others (Ellis et al., 2013; Gray-Renfrew et al., 2020).

Patients used a variety of coping strategies to help understand their disease and reduce stress (Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Hansen et al., 2015). These included cognitive strategies such as maintaining optimism (Ellis et al., 2013; Fan & Eiser, 2012), adopting a 'fighting' attitude (Hansen et al., 2015), pushing the disease out of mind (Fan & Eiser, 2012), facing reality (Fan & Eiser, 2012; Hansen et al., 2015) and using humour (Gray-Renfrew et al., 2020). Some patients also used behavioural strategies including seeking information, sharing experiences with others and incorporating healthy changes such as giving up drinking (Fan & Eiser, 2012). The latter is in contrast with Gray-Renfrew et al. (2020), who found that some patients with CLD relapsed into drinking alcohol to cope. Identifying both adaptive and maladaptive strategies helps build a more complete picture of patients' psychological wellbeing. It may also aid better care, as interventions can be used to target coping mechanisms and specific sources of psychological distress. Psychosocial interventions have been shown to reduce negative emotions and improve HRQoL for patients with HCC (Lin et al., 1998; Steel, Nadeau, et al., 2007). The findings from the qualitative literature could therefore be used to inform and improve such therapies for this population.

3.1.3 | Social function and stigma

The studies highlighted that HCC and CLD had a detrimental impact on social function (Ellis et al., 2013; Fan & Eiser, 2012; Gill

TABLE 5 Themes and key quotes identified from analysis of the qualitative literature

#	Theme	Summary of theme	Key quotes
1	Burden of physical symptoms and treatment side effects	Patients experienced a wide range of physical symptoms due to HCC and underlying CLD, as well as side effects from cancer treatment (predominantly chemotherapy). These caused suffering, impaired day-to-day function, and had an overall negative impact on QoL.	<p>'I've chosen not to take Sorafenib because it makes my life so miserable that I do not feel like I will even have a life. I feel like I'm just additionally suffering for no reason ...' (Hansen et al., 2015, p. E24)</p> <p>'I'm not taking that crap, because it has been nothing but the side effects and not the quality of life that I want'. (Hansen et al., 2015, p. E25)</p> <p>'Nothing but just like dog tired. I just thought it was normal [...] Just tired, exhausted'. (Patel et al., 2022, p. 6)</p>
2	Psychological impact and coping strategies	HCC negatively impacted psychological wellbeing, and brought up emotions such as anxiety, frustration, sadness, and guilt. Patients used both adaptive and maladaptive coping strategies to manage psychological stress.	<p>'I could not laugh at all, everyday I was depressed, and my temperament was bad, very bad' (Fan & Eiser, 2012, p. 205)</p> <p>'Coping with the disease? Only lifestyle, eat light food, go to bed early, regular life schedule'. (Fan & Eiser, 2012, p. 206)</p> <p>'The psychological aspect of the cancer has affected me more than anything else' (Patel et al., 2022, p. 9)</p>
3	Social function and stigma	Patients experienced strained relationships, decreased sexual function, and loss of social connections. Social QoL was further impacted by perceived stigma around liver diseases.	<p>'You just feel dirty. That's how I feel, I feel dirty' (Gray-Renfrew et al., 2020, p. 290)</p> <p>'There is no coffee pot, there is no free hats ... there is no camaraderie among the people that have it ... Liver cancer is cold. You're all by yourself' (Hansen et al., 2015, p. E23)</p> <p>'Their attitude is like, "you are a drunk," or "you are a druggie." I do not have the high tech, the good cancer, you know ... like leukaemia' (Hansen et al., 2015, p. E23)</p>
4	Spiritual wellbeing; sense of self and meaning of illness	Disruption to identity, coming to terms with mortality, and losing control and autonomy were all sources of spiritual distress. Although the impact was largely negative, a few patients experienced positive changes in this domain.	<p>'For someone who's used to bringing up your own child and paying your own bills and doing a full time job and everything and you are in control of everything and all of a sudden that control goes away'. (Ellis et al., 2013, p. 64)</p> <p>'In psychological terms, I do not treat myself as a patient' (Fan & Eiser, 2012, p. 206)</p> <p>'That's my identity now, is being a cancer patient versus being who I was before ...' (Patel et al., 2022, p. 9)</p>
5	Pervasive uncertainty	Uncertainty was experienced across all stages of disease. This was centred around the unpredictable course of HCC and was compounded by poor communication from healthcare professionals.	<p>'It's very hard living with it in your head, like constantly you just do not know what's around the corner' (Ellis et al., 2013, p. 65)</p> <p>'There was so much information at one time ... I had just received word that I had cancer and also about the poor prognosis, and I tried to concentrate on anything they said; it wasn't easy ...' (Ibrahim et al., 2019, p. 3)</p> <p>'What they are saying is, "Right, your potassium level's at such and such, your sodium level's at such and such" (...) and they do not actually tell me what it means. It is good? Is it bad? Is it happy medium? I do not know' (Kimbell et al., 2015, p. 5)</p>

et al., 2018; Gray-Renfrew et al., 2020; Patel et al., 2022). Poor physical health meant that many patients lost their independence and became reliant on other caregivers to help with basic tasks (Ellis et al., 2013; Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Patel et al., 2022). Strained social relationships were noted frequently (Fan & Eiser, 2012; Gill et al., 2018; Gray-Renfrew et al., 2020; Patel et al., 2022), and this was attributed to patients no longer being able to fulfill normal responsibilities and meet family needs (Fan & Eiser, 2012; Patel et al., 2022), as well as decreased sexual function (Patel et al., 2022). Patients felt like a burden to others, which contributed to social withdrawal (Ellis et al., 2013; Fan & Eiser, 2012). Loss of social connection was also linked to patients ceasing work (Ellis et al., 2013; Fan & Eiser, 2012) and being unable to attend social activities due to poor health (Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Patel et al., 2022).

Furthermore, the stigmatising nature of HCC and CLD caused considerable distress (Gray-Renfrew et al., 2020; Hansen et al., 2015), further decreasing QoL in the social domain. Some patients described HCC as an isolating disease without the same social supports as other cancers (Hansen et al., 2015), while others directly referred to the shameful association between liver diseases and alcoholism, drug use and sexually transmitted infections (Gray-Renfrew et al., 2020; Hansen et al., 2015). Some patients stopped going out into public to avoid embarrassment, becoming socially isolated as a result (Gray-Renfrew et al., 2020).

These findings are in contrast with previous research, which suggested that patients with HCC and CLD have better social/family-related HRQoL than the general population, as assessed by the FACT-Hep tool (Steel, Chopra, et al., 2007). This discrepancy could be due to the fact that tools such as the FACT-Hep assess social QoL using a limited number of items and may not capture subtleties of the patient experience in this domain. In addition, no QoL measurement tool currently used in the literature on HCC assesses the presence or effects of stigma. Given our findings suggest stigma was commonly perceived and contributed to social isolation, this aspect of the patient experience should be given more attention in future research and clinical efforts. For example, improving public understanding of HCC could help to reduce prejudice and minimise isolation.

3.1.4 | Spiritual wellbeing; sense of self and meaning of illness

Spiritual wellbeing encompasses concepts such as the meaning of life and illness, religiosity and identity (Ferrell et al., 1995; Firkins et al., 2021). It is important to consider spiritual wellbeing when exploring QoL in HCC, given the high mortality of this disease. Furthermore, spiritual wellbeing has been shown to protect against psychological distress in palliative care patients (Bernard et al., 2017). However, both generic and liver disease-specific QoL instruments only assess facets of physical, psychological and social QoL. As such,

there is a crucial gap in the quantitative literature regarding the spiritual domain (Firkins et al., 2021). Interestingly, analysis of the qualitative literature found that patients saw HCC as a severe disease that took over all aspects of their life and created significant shifts in their sense of spiritual wellbeing (Ellis et al., 2013; Fan & Eiser, 2012; Hansen et al., 2015).

First, the illness experience led to a change in how patients saw themselves (Ellis et al., 2013; Fan & Eiser, 2012; Hansen et al., 2015; Valery et al., 2017). This was partially a physical shift; patient's perception of their bodies changed as they got sicker (Ellis et al., 2013), and they relied increasingly on changes in physical condition to monitor disease progression (Fan & Eiser, 2012; Hansen et al., 2015). Having cancer also shifted their sense of identity, due to losses of independence, responsibilities and physical health (Fan & Eiser, 2012). Ellis et al. (2013) referred to the 'pre-illness' and 'post-illness' self and found that those who were able to accept the latter had better QoL, while those who tried to return to their 'pre-illness' self, struggled. Fan and Eiser (2012) also noted that some patients found it helpful to seek acceptance, while not letting HCC define them entirely.

Another source of spiritual distress was the impact of disease on the patient's sense of control (Ellis et al., 2013; Fan & Eiser, 2012; Hansen et al., 2015; Valery et al., 2017). Hansen et al. (2015) found that a central concern was a desire to control the impact of HCC on QoL. Making changes such as commencing treatment helped regain a feeling of control (Hansen et al., 2015); however, many factors contributed to patients feeling powerless and unable to escape from their ultimately progressive illness (Ellis et al., 2013; Fan & Eiser, 2012; Gray-Renfrew et al., 2020). Most patients understood HCC to be a terminal diagnosis (Fan & Eiser, 2012; Hansen et al., 2015), and it brought to the fore their own mortality (Ellis et al., 2013; Fan & Eiser, 2012; Hansen et al., 2015; Valery et al., 2017). While accepting this led to relief for some (Ellis et al., 2013; Hansen et al., 2015), others felt 'cheated' (Ellis et al., 2013). In addition, a small number of patients would not accept their diagnosis as terminal, as doing so would mean giving up hope and control (Hansen et al., 2015).

Patients also experienced positive changes in the spiritual domain, although this was less common. Some sought religion and greater meaning (Fan & Eiser, 2012), and others noted personal growth such as increased level of confidence (Ellis et al., 2013). Several patients found that the experience of having cancer meant they became better able to recognise, prioritise and appreciate important things in life (Ellis et al., 2013; Fan & Eiser, 2012). Overall, it was clear that spiritual concerns were central to the patient experience of HCC, adding an important dimension to our understanding of this domain.

3.1.5 | Pervasive uncertainty

Uncertainty was frequently a feature of the patient experience (Ellis et al., 2013; Fan & Eiser, 2012; Gill et al., 2018; Hansen

et al., 2015; Ibrahim et al., 2019; Kimbell et al., 2015; Valery et al., 2017). While it is difficult to change the uncertainty people with HCC face, insight into the sources of uncertainty is useful, as it helps identify areas where patients require support and reassurance. The qualitative literature raised two main sources of uncertainty: the course of disease and unmet information needs.

Uncertainty around the course of disease caused distress for patients (Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Hansen et al., 2015; Valery et al., 2017) and was difficult to manage (Ellis et al., 2013; Kimbell et al., 2015). In one instance, pervasive uncertainty led to a patient wanting to give up entirely (Gray-Renfrew et al., 2020). Patients directly linked uncertainty to insidious early symptoms (Kimbell et al., 2015), unclear prognosis (Ellis et al., 2013; Fan & Eiser, 2012; Hansen et al., 2015; Kimbell et al., 2015; Valery et al., 2017), unpredictable episodes of deterioration (Ellis et al., 2013; Kimbell et al., 2015), expectations regarding side effects of treatment (Hansen et al., 2015), the question of liver transplantation (Fan & Eiser, 2012; Gray-Renfrew et al., 2020; Hansen et al., 2015) and difficulty distinguishing effects of treatment from symptoms of disease (Hansen et al., 2015; Kimbell et al., 2015).

Uncertainty was further exacerbated by inadequate information provision and poor communication by healthcare professionals (Ellis et al., 2013; Gill et al., 2018; Hansen et al., 2015; Kimbell et al., 2015). Patients did not feel they were given enough information at diagnosis (Gill et al., 2018) nor around treatment options (Gill et al., 2018; Hansen et al., 2015; Kimbell et al., 2015), treatment complications (Ibrahim et al., 2019) or available supports (Kimbell et al., 2015; Valery et al., 2017). Provision of contradictory information from different healthcare providers was particularly stressful and generated uncertainty (Ellis et al., 2013; Kimbell et al., 2015). Furthermore, excessive information given in one sitting was confusing and overwhelming (Ibrahim et al., 2019). When information was not communicated appropriately, patients were left feeling unprepared (Ellis et al., 2013; Ibrahim et al., 2019; Kimbell et al., 2015). In contrast, when doctors took time to provide customised information and engaged patients in active dialogue, uncertainty was reduced, and patients felt more secure (Ibrahim et al., 2019).

Baseline understanding of disease also contributed to patients' level of uncertainty and ability to comprehend their disease (Fan & Eiser, 2012; Hansen et al., 2015; Kimbell et al., 2015). Studies undertaken in a Western population noted that patients had poor knowledge of HCC and CLD, and this led to more uncertainty at the time of diagnosis (Hansen et al., 2015; Kimbell et al., 2015). In contrast, Fan et al. (2012) found that given the high prevalence of HBV, HCV and HCC in Taiwan, the patients in their study had a high baseline understanding of their disease and its prognosis; this helped to provide a sense of control and enabled acceptance. Evidently, both adequate information provision and clear communication are critical to help mitigate some of the uncertainty around HCC.

3.2 | Limitations

Some limitations should be considered with respect to the methodology of this review. First, some relevant studies may have been missed if they were available on different databases or were grey literature. Second, critical appraisal of the studies was not performed, so judgements about the quality of original data cannot be made. However, the themes identified from all studies were consistent, and no major discrepancies were identified, supporting validity of the conclusions.

Another possible limitation lies in the decision to include studies with a broader patient population, with one study sample comprising patients with gastrointestinal cancers and two comprising patients with CLD. The justification for this was twofold: (1) The paucity of qualitative research meant there were very few studies focusing solely on the HCC population, and (2) most patients with HCC have advanced CLD (Laube et al., 2021), so it was determined that the CLD studies would yield valuable data. Nevertheless, these broad inclusion criteria may limit the applicability of the findings to the experience of patients with HCC.

Considering the literature itself, one of the main limitations was lack of diversity. While HCC is endemic in many countries in Asia and Africa (Bray et al., 2018), non-English studies were excluded in the search strategy. In addition, several of the included studies note a lack of cultural, racial and gender diversity within their patient samples (Ellis et al., 2013; Hansen et al., 2015; Kimbell et al., 2015; Patel et al., 2022). This restricts generalisability, as QoL concerns for people from diverse backgrounds may not have been captured.

4 | CONCLUSION

This review has provided a rich and nuanced understanding of QoL for patients with HCC, revealing that symptoms, treatment side effects, psychological stresses, social impacts and widespread uncertainty are all important facets of their experience. Importantly, this review also fills the evidence gap in the spiritual domain, demonstrating that spiritual concerns markedly influence QoL for people with HCC. While HCC has a largely negative impact on QoL, supportive factors that enhance QoL were also identified, including adaptive coping strategies, improved sense of connection and meaning, and effective communication by healthcare providers. By building a more complete picture of the patient experience, this review enables future research to focus on identifying where patients' needs can be better supported to improve QoL. The fact there is only a small body of qualitative literature in this space also highlights the need for more exploratory research with diverse patient samples.

ACKNOWLEDGEMENTS

We would like to thank Anna Lovang from the St Vincent's Hospital Library Service, for her expert advice and support in developing the search strategy for this review. We would also like to thank Associate Professor Suze Leitão for her input. Open access publishing facilitated

by The University of Melbourne, as part of the Wiley - The University of Melbourne agreement via the Council of Australian University Librarians.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed for this review.

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REFERENCES

- Aly, A., Ronnebaum, S., Patel, D., Doleh, Y., & Benavente, F. (2020). Epidemiologic, humanistic, and economic burden of hepatocellular carcinoma in the USA: A systematic literature review. *Hepatic Oncology*, 7(3), 1–18. <https://doi.org/10.2217/hep-2020-0024>
- Bernard, M., Strasser, F., Gamondi, C., Braunschweig, G., Forster, M., Kaspers-Elekes, K., Walther Veri, S., Borasio, G. D., Pralong, G., Pralong, J., Marthy, S., Soloni, C., Bisi, C., & Magaya, N. K. (2017). Relationship between spirituality, meaning in life, psychological distress, wish for hastened death, and their influence on quality of life in palliative care patients. *Journal of Pain and Symptom Management*, 54, 514–522. <https://doi.org/10.1016/j.jpainsymman.2017.07.019>
- Bonnetain, F., Paoletti, X., Collette, S., Doffoel, M., Bouché, O., Raoul, J. L., Rougier, P., Masskouri, F., Barbare, J. C., & Bedenne, L. (2008). Quality of life as a prognostic factor of overall survival in patients with advanced hepatocellular carcinoma: Results from two French clinical trials. *Quality of Life Research*, 17, 831–843. <https://doi.org/10.1007/s11136-008-9365-y>
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, 68, 394–424. <https://doi.org/10.3322/caac.21492>
- Ellis, J., Brearley, S. G., Craven, O., & Molassiotis, A. (2013). Understanding the symptom experience of patients with gastrointestinal cancers in the first year following diagnosis: Findings from a qualitative longitudinal study. *Journal of Gastrointestinal Cancer*, 44, 60–67. <https://doi.org/10.1007/s12029-012-9443-9>
- Fan, S. Y., & Eiser, C. (2012). Illness experience in patients with hepatocellular carcinoma: An interpretative phenomenological analysis study. *European Journal of Gastroenterology and Hepatology*, 24, 203–208. <https://doi.org/10.1097/MEG.0b013e32834ec184>
- Fan, S. Y., Eiser, C., & Ho, M. C. (2010). Health-related quality of life in patients with hepatocellular carcinoma: A systematic review. *Clinical Gastroenterology and Hepatology*, 8, 559–564. <https://doi.org/10.1016/j.cgh.2010.03.008>
- Ferrell, B. R., Hassey Dow, K., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research*, 4, 523–531. <https://doi.org/10.1007/BF00634747>
- Firkins, J. L., Tarter, R., Driessnack, M., & Hansen, L. (2021). A closer look at quality of life in the hepatocellular carcinoma literature. *Quality of Life Research*, 30, 1525–1535. <https://doi.org/10.1007/s11136-021-02789-2>
- Fush, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20, 1408–1416. <https://doi.org/10.46743/2160-3715/2015.2281>
- Gill, J., Baiceanu, A., Clark, P. J., Langford, A., Latiff, J., Yang, P. M., Yoshida, E. M., & Kanavos, P. (2018). Insights into the hepatocellular carcinoma patient journey: Results of the first global quality of life survey. *Future Oncology*, 14, 1701–1710. <https://doi.org/10.2217/fon-2017-0715>
- Gray-Renfrew, A., Kimbell, B., & Finucane, A. (2020). Emotional experience of people with advanced liver disease: Secondary data analysis. *Chronic Illness*, 16, 284–295. <https://doi.org/10.1177/1742395318803668>
- Hansen, L., Rosenkranz, S. J., Vaccaro, G. M., & Chang, M. F. (2015). Patients with hepatocellular carcinoma near the end of life: A longitudinal qualitative study of their illness experiences. *Cancer Nursing*, 38, E19–E27. <https://doi.org/10.1097/NCC.0000000000000188>
- Ibrahim, F., Sandstrom, P., Bjornsson, B., Larsson, A. L., & Drott, J. (2019). 'I want to know why and need to be involved in my own care ...': A qualitative interview study with liver, bile duct or pancreatic cancer patients about their experiences with involvement in care. *Supportive Care in Cancer*, 27, 2561–2567. <https://doi.org/10.1007/s00520-018-4548-8>
- Jones, F., Rodger, S., Ziviani, J., & Boyd, R. (2012). Application of a hermeneutic phenomenologically orientated approach to a qualitative study. *International Journal of Therapy and Rehabilitation*, 19(7), 370–378.
- Kaiser, K., Mallick, R., Butt, Z., Mulcahy, M. F., Benson, A. B., & Cella, D. (2014). Important and relevant symptoms including pain concerns in hepatocellular carcinoma (HCC): A patient interview study. *Supportive Care in Cancer*, 22, 919–926. <https://doi.org/10.1007/s00520-013-2039-5>
- Kang, D., Shim, S., Cho, J., & Lim, H. K. (2020). Systematic review of studies assessing the health-related quality of life of hepatocellular carcinoma patients from 2009 to 2018. *Korean Journal of Radiology*, 21, 633–646. <https://doi.org/10.3348/kjr.2019.0808>
- Kimbell, B., Boyd, K., Kendall, M., Iredale, J., & Murray, S. A. (2015). Managing uncertainty in advanced liver disease: A qualitative, multiperspective, serial interview study. *BMJ Open*, 5(11), 1–8. <https://doi.org/10.1136/bmjopen-2015-009241>
- Laube, R., Sabih, A. H., Strasser, S. I., Lim, L., Cigolini, M., & Liu, K. (2021). Palliative care in hepatocellular carcinoma. *Journal of Gastroenterology and Hepatology*, 36, 618–628. <https://doi.org/10.1111/jgh.15169>
- Lin, M. L., Tsang, Y. M., & Hwang, S. L. (1998). Efficacy of a stress management program for patients with hepatocellular carcinoma receiving transcatheter arterial embolization. *Journal of the Formosan Medical Association*, 97, 113–117.
- McGlynn, K. A., Petrick, J. L., & El-Serag, H. B. (2021). Epidemiology of hepatocellular carcinoma. *Hepatology*, 73(Suppl 1), 4–13. <https://doi.org/10.1002/hep.31288>
- Patel, N., Maher, J., Lie, X., Gwaltney, C., Barzi, A., Karwal, M., Macarulla, T., Sun, H. C., Trojan, J., Meyers, O., Workman, C., Morgan, S., Negro, A., & Cohen, G. (2022). Understanding the patient experience in hepatocellular carcinoma: A qualitative patient interview study. *Quality of Life Research*, 31, 473–485. <https://doi.org/10.1007/s11136-021-02903-4>
- Singal, A. G., Lampertico, P., & Nahon, P. (2020). Epidemiology and surveillance for hepatocellular carcinoma: New trends. *Journal of Hepatology*, 72, 250–261. <https://doi.org/10.1016/j.jhep.2019.08.025>
- Speck, R. M., Lenderking, W. R., & Shaw, J. W. (2018). Integrating the patient voice with clinician reports to identify a hepatocellular carcinoma-specific subset of treatment-related symptomatic adverse events. *Journal of Patient-Reported Outcomes*, 2(35), 1–10. <https://doi.org/10.1186/s41687-018-0063-4>
- Steel, J. L., Chopra, K., Olek, M. C., & Carr, B. I. (2007). Health-related quality of life: Hepatocellular carcinoma, chronic liver disease, and the general population. *Quality of Life Research*, 16, 203–215. <https://doi.org/10.1007/s11136-006-9111-2>

- Steel, J. L., Nadeau, K., Olek, M., & Carr, B. I. (2007). Preliminary results of an individually tailored psychosocial intervention for patients with advanced hepatobiliary carcinoma. *Journal of Psychosocial Oncology*, 25, 19–42. https://doi.org/10.1300/J077v25n03_02
- Valery, P. C., Clark, P. J., McPhail, S. M., Rahman, T., Hayward, K., Martin, J., Horsfall, L., Volk, M. L., Skoien, R., & Powell, E. (2017). Exploratory study into the unmet supportive needs of people diagnosed with cirrhosis in Queensland, Australia. *Internal Medicine Journal*, 47, 429–435. <https://doi.org/10.1111/imj.13380>

How to cite this article: Norman, E. M. L., Weil, J., & Philip, J. (2022). Hepatocellular carcinoma and its impact on quality of life: A review of the qualitative literature. *European Journal of Cancer Care*, 31(6), e13672. <https://doi.org/10.1111/ecc.13672>