

Supplementary Tables

Table 1: Interview Guide

(Section 1: Establishing a Context for disease diagnosis)

First, I would like to learn a little bit about your life prior to your diagnosis of liver cancer

1. Tell me what your life was like on a day-to-day basis before being diagnosed with liver cancer
 - a. Prompt: if you had a job, what did you do? Did you go to school? What were your responsibilities at home, such as caring for family members, cleaning, cooking, and other tasks?
2. Tell me about your medical care before being diagnosed with liver cancer
 - a. Prompt: what medical appointments did you go to and what kind of providers or specialists did you see?
 - b. (if not already described by interviewee) How often would you see a medical care provider such as physician, nurse, or physician associate prior to the diagnosis of liver cancer?
3. Prior to your diagnosis of liver cancer [chronic liver disease], what did you know about causes of liver cancer?
 - a. (if not already described by interviewee) What did you know about the liver and liver health prior to your diagnosis?
4. ***If you're comfortable sharing, I'd like to hear about your experience being diagnosed with liver cancer. What were your initial thoughts and feelings?

(Section 2: Treatment and Management)

I would now like to discuss how your liver cancer was treated.

1. Can you tell me about how your healthcare provider communicated information about your diagnosis?
 - a. Prompt: Do you think the information provided was adequate or sufficient? What additional information would have been helpful?
2. What treatment options were discussed with you?
3. How did you decide what treatment option(s) to choose? What could your team have done differently to assist you with the decision-making process?
4. ***What were the most challenging aspects of understanding and treating your disease?
5. What support, services, or resources were helpful for you during treatment?

(Section 3: Barriers to Care)

Let's now discuss some barriers to care for liver cancer

1. After being diagnosed with liver cancer, what factors made it difficult to seek treatment or to see a specialist?
 - a. Prompt: can you tell me about any difficulty you had arranging transportation? With cost and finances? Health insurance coverage?
2. (if not already described by interviewee) How has the cost of care affected your personal and family finances?
3. What concerns did you have about the time required for medical appointments or treatments?
 - a. Prompt: tell me how the time required for appointments or treatments affected your work, school or home responsibilities
4. Can you tell me about language or communication difficulties that impacted your ability to receive care for liver cancer?
 - a. Prompt: tell me about problems you had navigating the healthcare system or understanding medical information related to your condition

(Section 4: Future Concerns and Needs)

In our final section today, I would like to understand any future concerns or needs you may have related to your liver cancer.

1. What are your concerns about managing your liver disease in the future?

2. How do you foresee factors such as finances, transportation, insurance status or any other barriers potentially impacting your ability to access liver care in the coming years?
3. What support or resources do you feel would be most helpful for individuals with liver disease?

Closing:

Thank you for your time. Are there any other topics that you would like to discuss with us today?

(Discuss any other topics that the interviewee would like to discuss. If nothing further, then read below)

Once again, thank you for your time today and for participating in this study. Your responses are confidential. If you have any questions or concerns, you can contact us using the information on the sheet that we provided earlier. Take care.

Code	Definition
Activities with family	can encompass various activities that the patient engages in with their family such as going for walks, travelling, family gatherings, playing with grandchildren, etc.
Barriers to care	Broad code for any barriers to accessing or receiving healthcare mentioned by the patient.
<i>Commuting to appointments</i>	Patients may have difficulty commuting to medical appointments because they are far away, because the patient does not drive, or because the patient does not have reliable transportation (e.g., car service does not show up or cancels at the last minute).
Blunt delivery of diagnosis	Patients may feel that their providers delivered their HCC diagnosis very bluntly and without compassion.
Care not delivered in a timely fashion	Patients may experience delays in care, e.g., delays in scheduling appointments due to provider availability or delays in communication of lab/imaging results or tumor board discussions.
Coping with diagnosis	How a patient copes with their diagnosis of HCC; for example, they could turn to family or religion for support, or remind themselves that they have lived a good life.
Diagnostic process	Applied when the patient discusses the process by which they were diagnosed with HCC (labs, imaging, specialists, etc.).
<i>Diagnostic process moved quickly</i>	Patients may feel that once they were diagnosed with HCC, things moved very quickly in terms of getting set up with specialists, having procedures scheduled, and completing lab and imaging studies.
Discussion of treatment options	Discussion of HCC treatment options between patient and provider.
<i>Limited treatment options discussed</i>	Patient may feel that they had few options for treatment or that their provider did not discuss all of the available treatment options with them.
Disease-related knowledge after diagnosis	Patient may describe the ways in which their HCC/liver disease-related knowledge increased after being diagnosed with HCC, either because of information relayed by their providers or through their own research (e.g., online resources).
Engagement with healthcare prior to diagnosis	Applied when the patient describes the type of healthcare they received prior to being diagnosed with HCC.
<i>PCP visits</i>	Engagement with primary care doctor.
<i>Specialist care</i>	Engagement with additional doctors such as cardiologists, pulmonologists, endocrinologists, etc.
Experience of illness	Patient's personal perception, feelings, and responses to their health condition, including concerns, emotional impact, and social implications.
Facilitation of communication by provider	Applied when the patient feels that communication is good between their providers, between patient and provider, or between family members and provider.
Family support	Broad code applied any time the patient describes ways in which their family provides support (emotional, financial, or otherwise).
<i>Care coordination</i>	Family members may engage in care coordination tasks such as scheduling medical appointments or arranging transportation.

<i>Communication with providers</i>	Patient's family members may communicate directly with providers or accompany patients to medical appointments, serving as an advocate and/or facilitating conversation with the provider.
<i>Family member in healthcare</i>	Patient may describe that having a family member in healthcare is helpful for navigating the system and understanding their diagnosis and treatment.
<i>For relocation</i>	Patient may relocate to be close to family when receiving care for HCC. Family may help with that relocation process.
<i>Post-treatment support</i>	Patients may need extra support after medical or surgical treatment for HCC. Family may provide support by visiting the patient in the hospital or helping with activities of daily living during recovery.
Friends support	Support provided by friends during the patient's HCC diagnosis and treatment.
Frustration with waiting	Patients may describe frustration with waiting for imaging results, waiting for providers to communicate next steps or treatment options, or waiting to schedule appointments or procedures.
Good doctors	Applied when a patient refers to a positive experience with or perception of their doctor (for HCC care or otherwise).
Impact of HCC diagnosis on lifestyle	Applied when the patient describes how their HCC diagnosis has changed their day-to-day lifestyle.
Impact of HCC on family	Applied when a patient discusses the impact of their diagnosis on family members or concerns about family members as it relates to their diagnosis and/or mortality.
Inadequate explanation of MyChart results	Labs and imaging results are available to patients immediately through MyChart. Patients may feel confused by the results and that their provider is not adequately explaining what they mean and what the next steps are.
Information overload	Refers to the large amounts of information communicated to patients about their diagnosis and treatment, sometimes too much for the patient to process.
Lack of barriers to care	Applied if the patient, when asked, denies experiencing barriers to care.
<i>Patient able to afford care</i>	Patient is able to afford care either due to comprehensive insurance coverage or ability to pay out of pocket.
Lack of bedside manner	Patients may have providers whose attitudes or demeanors are off-putting.
Lack of communication	Applied when the patient mentions broadly a lack of communication between individuals involved in their medical care.
<i>Between patient and provider</i>	The patient may feel they are in the dark about aspects of their medical care, such as a lack of follow-up on imaging or lab results, a lack of explanation of treatment options, or the feeling that the provider is withholding information.
<i>Between providers</i>	Applied when a patient discusses that their various medical providers do not seem to be communicating with one another, e.g., providing conflicting information or appearing unaware of the other's recommendations.
Lack of control	Applied when a patient expresses that they feel a lack of control over their cancer or over the treatment process.
Lack of support from healthcare providers	Patients may mention that they do not feel that their provider supported them during the diagnosis and treatment of their HCC.
Lack of symptoms	Patient expresses that they did not experience symptoms attributable to their HCC. A patient's lack of symptoms may be at odds with their new identity as a cancer patient.
Life prior to diagnosis	Applied when patient discusses various aspects of their life prior to being diagnosed with HCC.
<i>Daily routine</i>	Day-to-day activities as described by the patient.
<i>Social life and leisure activities</i>	Examples include spending time with friends/family, recreational sports such as golf, going for walks, etc.
Medical decision-making	Describes the process of decision-making surrounding treatment for HCC.
<i>Patient-directed</i>	Patient takes a more active role in the decision-making process.
<i>Patient-provider disagreement</i>	Patient and provider may not agree on how the patient's HCC should be managed.

Medical information difficult to understand	Applied when a patient describes difficulty understanding medical information communicated by their providers.
Mental well-being	Broad code that encompasses patient discussion of mental health.
<i>Mental strength</i>	The idea that a patient is mentally strong or resilient in the face of their diagnosis.
MyChart beneficial for results communication	Applied when a patient describes MyChart as a useful tool for accessing and understanding their test results.
Need for support group	Desire for peer support or group-based resources to share experiences, gain information, and reduce feelings of isolation.
Negative experience with HCC care	Broad code for negative experiences with providers, medications, procedures, etc.
Negative impact of HCC on life	Diagnosis and/or treatment of HCC having a negative impact on any aspect of a patient's life.
<i>Social activities</i>	HCC or its treatment negatively impacts the patient's ability to participate in social activities.
<i>Work</i>	HCC or its treatment negatively impacts the patient's ability to work.
Negative impact of treatment/disease on physical well-being	Applied when the patient describes physical symptoms or side effects attributable to HCC or its treatment.
<i>Fatigue</i>	Fatigue due to HCC or its treatments.
<i>Hospital conditions not conducive for recovery/rest</i>	Could include a noisy environment, disruptive roommates, or frequent awakenings for labs or vital sign checks.
<i>Lack of strength</i>	Lack of physical strength due to HCC or its treatments.
<i>Pain</i>	Broad code for pain associated with HCC itself or its treatments.
No impact of HCC on overall life	Patient describes a lack of HCC affecting their day-to-day life in any substantive way.
Overcoming barriers to care	Applied when a patient discusses a potential barrier to care that was overcome by something they themselves, their family, or their healthcare team did.
Patient concerns about HCC care	Applied when a patient expresses concerns about their HCC care more broadly.
<i>Affording care</i>	Patients may express concerns about being able to afford healthcare related to their HCC.
Patient concerns about HCC diagnosis	Patient's specific concerns about being diagnosed with HCC, e.g., impact on family, symptoms they will have, prognosis.
Patient expectations vs. reality	Applied any time the patient discusses what they thought life would look like after HCC diagnosis compared to what life is actually like.
Patient involvement in care	Broadly refers to a patient's engagement with their medical care (HCC-related and otherwise).
<i>Patient monitoring of health</i>	Patient may keep tabs on MyChart test results, vitals, symptoms, medication dosages, etc.
<i>Self-management of medical issues</i>	Patient may mention taking matters into their own hands when it comes to their health (e.g., deciding which medications to take or which lab tests they need).
Patient lack of participation in decision-making process	The patient may not have participated in the decision-making process regarding treatment for their HCC, either of their own volition (feeling that the doctor knows best) or because they were only presented with one viable option.
Patient reaction to diagnosis	Patient's internal and external reaction to being diagnosed with HCC (initial thoughts, feelings, or actions taken).
Patient suggestions for improvement	During the interview, patients may make suggestions for improvement of HCC care, such as clearer communication regarding next steps after lab and imaging results, more thorough discussion of treatment options, or upfront mention of side effects of various treatments.
Patient's preferred provider style	Patients may describe their preferred style of provider during the interview, e.g., someone who communicates directly and does not minimize difficult information.
Physically active lifestyle	Applied when patient discusses being physically active as a part of their day-to-day life and/or identity.

Positive provider interaction	Respectful, supportive, and attentive behaviors by healthcare providers that contribute to a positive patient experience.
Prior disease-related knowledge	Patient's knowledge about HCC, cirrhosis, or liver disease prior to being diagnosed with HCC.
<i>Lack of knowledge</i>	Many patients have a lack of knowledge about HCC, cirrhosis, or liver disease prior to their diagnosis.
Proactive patient support	Regular follow-up calls and reminders that support and engage the patient.
Providers changing treatment decisions	The concept that providers change their mind about treatments to offer or recommend to patients.
Setbacks in care	A change to treatment that delays care or a treatment that is found to be ineffective.
Symptoms from HCC	Applied when a patient describes symptoms attributable to their HCC.
Treatment process	Steps and methods used in a participant's care or treatment journey.
Trust in provider	Applied when a patient describes having trust in their healthcare provider.
Uncertainty in prognosis	Relaying that there is uncertainty in what will happen next; HCC can grow, metastasize, recur, regress, make a patient feel sick, or be fatal.
<i>Always think of the worst</i>	The notion that a patient always plays out the worst possible outcome in their mind (e.g., spread of cancer or death).
Uprooting life due to diagnosis	Patient has to make drastic changes to life due to being diagnosed with HCC, e.g., moving to be closer to family or medical care, modifying work schedule, or retiring.
Use of health technology	Participant's engagement with digital tools, apps, or platforms related to their care.

Supplementary Table 2: Codebook.

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	4
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	4
3. Occupation	What was their occupation at the time of the study?	4
4. Gender	Was the researcher male or female?	4
5. Experience and training	What experience or training did the researcher have?	4
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	4
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	4
12. Sample size	How many participants were in the study?	5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	5

<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	4
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	4
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	5
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4, Supplemental Table 1
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	4
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	4
20. Field notes	Were field notes made during and/or after the inter view or focus group?	4
21. Duration	What was the duration of the inter views or focus group?	4
22. Data saturation	Was data saturation discussed?	5
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	4
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	4
25. Description of the coding tree	Did authors provide a description of the coding tree?	Supplemental Table 2
26. Derivation of themes	Were themes identified in advance or derived from the data?	5
27. Software	What software, if applicable, was used to manage the data?	5
28. Participant checking	Did participants provide feedback on the findings?	4
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 2
30. Data and findings consistent	Was there consistency between the data presented and the findings?	5-8, Table 2
31. Clarity of major themes	Were major themes clearly presented in the findings?	5-8, Table 2
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	5-8, Table 2

Supplementary Table 3: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist