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Two Mental Models of Integrated Care for Advanced Liver Disease: Qualitative Study of Multidisciplinary Health Professionals

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3 **Two Mental Models of Integrated Care for Advanced Liver Disease:**
4 **Qualitative Study of Multidisciplinary Health Professionals**
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ABSTRACT

Objectives: The purpose of this paper is to present two divergent mental models of integrated advanced liver disease (AdvLD) care among 26 providers who treat AdvLD patients

Setting: 3 geographically dispersed United States Veterans Health Administration health systems

Participants: 26 professionals (20 women and 6 men) participated, including 9 (35%) gastroenterology, hepatology, and transplant physicians, 2 (7.7%) physician assistants, 7 (27%) nurses and nurse practitioners, 3 (12%) social workers and psychologists, 4 (15%) palliative care providers and 1 pharmacist

Main Outcome Measures: We conducted qualitative in-depth interviews of providers caring for AdvLD patients. We used qualitative thematic analysis to identify two divergent mental models of integrated AdvLD care. These models vary in timing of initiating various constituents of care, philosophy of integration, and supports and resources needed to achieve each model.

Results: Clinicians described integrated care as an approach that incorporates elements of curative care, symptom and supportive care, advance care planning, and end-of-life services from a multidisciplinary team. Analysis revealed two mental models that varied in how and when these constituents are delivered. One mental model involves sequential transitions between constituents of care, and the second mental model involves synchronous application of the various constituents. Participants described elements of teamwork and coordination supports necessary to achieve integrated AdvLD care. Many discussed the importance of having a multidisciplinary team integrating supportive care, symptom management and palliative care with liver disease care.

Conclusions: Health professionals agree on the constituents of integrated AdvLD care but describe two competing mental models of how these constituents are integrated. Health systems can promote integrated care by assembling multidisciplinary teams, and providing teamwork and coordination supports, and training that facilitates patient-centered AdvLD care.

INTRODUCTION

Advanced liver disease (AdvLD) is a serious illness with high rates of morbidity and mortality. Liver transplantation offers an opportunity to cure AdvLD, however, few patients receive it.¹ Most patients, including those on the transplant waiting list, live with and die of their liver disease.² Their clinical course is marked by declining health, increasing symptom burden and frequent hospitalizations.³ The symptom burden of AdvLD is comparable to advanced cancers; symptoms include pain, dyspnea, difficulty sleeping, anorexia and fatigue, bleeding, confusion, depression and anxiety.⁴ Furthermore, patients and caregivers report marked uncertainty about prognosis and AdvLD course, complex care needs, and poor coordination and communication with and among clinicians.^{5 6} A recent systematic review identified significant gaps in understanding and information about AdvLD etiology, course, symptoms, and prognosis and the related psychosocial distress among patients and caregivers as well as a lack of confidence about when and how to have AdvLD prognosis and advance care planning discussions among primary care clinicians.⁷

To address these gaps, we proposed an integrated model of patient-centered AdvLD care that blends curative care (transplant referral and disease modifying treatments), supportive care (symptom management and psychosocial care), and advance care planning and end-of-life care based on identifying patient's priorities and then aligning care options to achieve the identified priorities.^{8 9} Health professionals report difficulty coordinating care, especially knowing when or how to offer supportive care, prognosis discussions and advanced care planning.⁷ To facilitate better integration of AdvLD care, the American Gastroenterological Association recently provided a clinical practice update that recommends incorporation of palliative care principles for any patient with cirrhosis, irrespective of transplant candidacy.¹⁰ In this context, palliative care is inclusive of supportive care as defined above coupled with advance care planning and goals of care conversations in the context of assessing and cultivating prognosis awareness and is delivered concurrently with life prolonging treatments, tailored to stage of disease. However, in practice, hesitancy and barriers to use of palliative care are common among AdvLD clinicians. Specialists who provide care for AdvLD often believe that palliative care instills fear and anxiety among patients because of a belief that involvement of palliative care would mean that nothing more could be done for the underlying AdvLD.¹¹ These specialists acknowledge the importance of having palliative care services available for AdvLD and trust palliative care clinicians to care for their patients but cite cultural factors and patients' unrealistic expectations about prognosis as barriers to

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3 referral.¹² Clinicians also disagree on the appropriate timing and setting of advance care planning
4 discussions.^{7 12}
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7 Implementation of integrated care models in AdvLD, like cancer¹³ and advanced heart failure,¹⁴ is
8 hindered by professional norms, insufficient training, and lack of consensus on professional roles and
9 responsibilities.¹⁵ Clinician attitudes can also affect the adoption of integrated care in serious illness.^{13 16}
10 Understanding perceptions and practices of AdvLD care integration among specialist, primary care
11 physicians, and health care professionals (i.e., mental models of AdvLD care) is a starting point. Mental
12 models are psychological representations of an individual's (or group's) dynamic beliefs about the truth
13 and nature of a phenomenon; are broad simplifications of that phenomenon; consist of knowledge,
14 behaviors and attitudes for making judgements, solving problems and ultimately acting on decisions;
15 and are formed (and reformed) from interactions with the environment and other people.¹⁷ Mental
16 models are useful for understanding key factors pertaining to diffusion of healthcare innovations:
17 perception of the change, characteristics of adopters and laggards, and perceptions of contextual factors
18 (communication, incentives, leadership, etc) related to the change.^{18 19} The current study identifies two
19 competing mental models of integrated AdvLD care and describes professional roles and contextual
20 factors that can affect adoption.
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METHODS

Study design and setting

Reporting of our research methods aligns with the consolidated criteria for reporting qualitative research (COREQ) guidelines.²⁰ We conducted in-depth qualitative interviews with clinicians who care for patients with AdvLD at three geographically dispersed sites within the VA healthcare system: Southeast Texas, Northern California, and New England. See **Table 1** for site characteristics. All 3 sites include liver tumor boards. One site (Southeast Texas) offers transplant services and two sites (Northern California and New England) refer to nearby VA regional transplant centers that provide transportation and lodging for the Veteran and caregiver.

Table 1. Study Sites and Clinical Services Characteristics (Created by the Authors)

	Site A		Site B		Site C	
	Liver Tumor Board – Yes		Liver Tumor Board – Yes		Liver Tumor Board – Yes	
Specialty	Providers (Number)	Co-located in GI clinic?	Providers (Number)	Co-located in GI clinic?	Providers (Number)	Co-located in GI clinic?
Hepatology Physicians	5		3		2 FT, 3 PT	
Hepatology PA	2		0		0	
Hepatology NP	1		3		1	
Hepatology Nurse	0		0		1 FT, 1PT	
Care Coordinator	0		0		2	
Palliative Care (Inpatient)	1 (consult)		1 (consult)		3 PT	
Palliative Care (Outpatient)	1 (consult)	No	2 (consult)	No	1 PT	Yes
Nutrition	3 PT (consult)	No	0	No	0	No
Rehabilitation	5 (consult)	No	0	No	0	No
Social Work	1	Yes	1 (consult)	No	1 PT	Yes

Clinical Pharmacist	1 (consult)	No	1 (consult)	No	1 PT	Yes
Addiction Medicine	1 (consult)	No	1 (consult)	No	1 PT	Yes
Health Psychology	0	No	0	No	1 PT	Yes

GI= Gastroenterology or Hepatology PA= Physician Assistant NP=Nurse Practitioner FT= Full Time Equivalent PT= Part time Equivalent HCV= Hepatitis C Virus

Clinicians were referred by local chiefs of hepatology and gastroenterology. Clinical leads at each site provided names of clinicians who work with AdvLD patients. We stratified the names by profession/role and recruited participants from each strata. This strategy allowed us to capture a variety of perspectives on AdvLD care. Thirty-three clinicians were invited to participate in the study; 26 completed interviews. Three non-participants declined to participate due to time constraints; remaining non-participants did not provide an explanation. Participants were thanked but did not receive incentives for their participation.

Ethics Approval

This study was evaluated and approved by Institutional Review Boards at each of the 3 VA healthcare system sites: Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals (Federal Wide Assurance No. 00000286, Protocol H33191), Stanford University (FWA00000929 (VA), eProtocol 42849), VA Connecticut Healthcare System, Human Research Protections Program, Human Studies Subcommittee (FWA00001286, MIRB 02183)

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Data Collection

Our multi-disciplinary research team developed a semi-structured interview guide designed to explore clinicians' perspectives and experiences with providing integrated care for liver disease. The interview guide was based on dimensions of the integrated model of AdvLD.⁸ The interview guide was revised throughout the interviewing process to reflect emergent findings and clarify developing areas of interest (**Appendix 1**). Two medical sociologists (JA and CG) trained in qualitative methods conducted semi-

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3 structured, one-on-one interviews between October 2018 through November 2019. Both interviewers
4 are non-Hispanic, White females with Ph.D.'s in Sociology. Both have extensive experience conducting
5 qualitative interviews with clinicians, analyzing data, and presenting qualitative findings. All interviews
6 were conducted via telephone. Interviews ranged from 31-78 minutes in duration (average 58 minutes).
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8 All participants provided verbal informed consent twice—prior to recording and then again after
9 recording started for documentation. With participants' permission, interviews were audio recorded,
10 transcribed verbatim, and pseudonymized for analysis.
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16 **Data Analysis**

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18 Data were analyzed as they were collected and emerging findings informed areas of focus for
19 subsequent interviews. Several members of the analytic team reviewed early transcripts, created
20 memos, and using a constant comparative method²¹ created a preliminary codebook. Codes were
21 anchored in interview guide questions as well as emergent findings.²² Codebooks were piloted and
22 revised with additional codes added as necessary. Two team members (JA and CG) independently coded
23 all transcripts, and a third coder performed secondary coding to ensure accuracy of code assignments.²³
24 Coding discrepancies were resolved in weekly team meetings. Coding was performed using Atlas.ti
25 (version 8.2). After initial coding, all codes were collapsed into broader categories, which team members
26 then summarized, highlighting themes that spanned across interviews.²⁴ The full study team participated
27 in the integration of codes into themes describing perspectives of integrated care and elements of an
28 ideal model of integrated care for AdvLD. At a sample size of 26, data redundancy indicated thematic
29 saturation—the point at which no new themes emerged.²⁵
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RESULTS

Participant Characteristics

Participants' characteristics are presented in **Table 2**. The sample of clinicians represented multiple professions, including gastroenterology, hepatology, and transplant physicians (34.6%), gastroenterology physician assistants (7.7%), gastroenterology/hepatology nurses and nurse practitioners (27%), social workers and psychologists (11.5%), palliative care providers (15.4%) and pharmacists (3.8%).

Table 2. Demographic Characteristics of the Study Population (Created by the Authors)

Healthcare Providers (n=26)	number (percentage)
Professional Role	
Gastroenterology, Hepatology, or Transplant Physicians	9 (34.6)
Gastroenterology Physician Assistants	2 (7.7)
Gastroenterology/Hepatology nurses and nurse practitioners	7 (27)
Social Workers or Psychologists	3 (11.5)
Palliative Care Providers	4 (15.4)
Pharmacists	1 (3.8)
Gender	
Female	20 (77)
Male	6 (23)
Years in Liver Care	
0-10	13 (50)
11-20	4 (15)
21-30	2 (8)
No Response	7 (27)

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3 Analysis revealed that clinicians value integrated AdvLD care and they identified common components
4 of an integrated care approach. However, their descriptions of integrated care diverged into two distinct
5 mental models of integrated AdvLD care: the sequential transitions model and the synchronous care
6 model. These models vary in how clinicians envision initiation of various constituents of care, their
7 philosophy of integration, and staffing and resources needed to achieve integrated care.
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11 12 **Shared views across mental models**

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15 Clinicians ubiquitously indicated that the integrated model is ideal in liver disease care, given that liver
16 disease can progress quickly and have unexpected turns. Across both mental models, clinicians
17 described integrated care as an approach that incorporates elements of curative care, symptom
18 management and supportive care, advance care planning, and end-of-life services from a
19 multidisciplinary team (see **Table 3, A**). One shared view across the two mental models is the definition
20 of curative care as remedies that bring about recovery from disease.
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25 *“When you talk about cure, you’re talking about things that actually modify or cure the*
26 *underlying liver disease or liver transplantation.” (Clinician #17, Gastroenterology Physician, >15*
27 *years in liver care)*
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31 While consensus exists on the value of integrated care and the intent of curative care, the two mental
32 models are characterized by differing views of additional constituents of care as well as how those
33 constituents are arranged and delivered. From these different views, two mental models to integration
34 appeared: sequential transitions and synchronous care (see **table 3, B**).
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Table 3. Participants' Mental Model of Integrated Advanced Liver Disease Care (Created by the Authors)

A. Constituents of Integrated Advanced Liver Disease Care (AdvLD)

Shared Mental Model of Integrated AdvLD constitutes:

- **Curative Care:** Care that cures (permanently removes) or significantly modifies the underlying liver disease or care resulting in liver transplantation.
- **Symptom Management and Supportive Care:** Pharmacologic and non-pharmacologic interventions that address symptoms from complications of cirrhosis; improve functioning, nutrition, and rehabilitation; and offer information, care planning and emotional support for patients and caregivers.
- **Advanced Care Planning and End-of-Life Care:** Discussions of prognosis and advance care preferences; comfort care and code status determinations; and care at the end-of-life focused on management of symptoms, psychosocial care, and quality of life.

Disagreements about Palliative Care: Some participants limited the definition to comfort-focused care that involves counseling, code status discussions, and end of life symptoms led by palliative care specialists. Other participants viewed supportive care, advanced care planning, and aspects of symptom management as additional components of palliative care delivered by various members of the multidisciplinary team, including but not exclusive to palliative care specialists.

B. Timing of AdvLD Care Services shape two competing mental models of integrated AdvLD care

- **Sequential Transitions:** Integration of two distinct goals of care – life prolongation versus comfort and quality of life with a clear distinction when the transition is made. Primary care and liver specialists focus on transplant referral and prevention/management of complications to prolong life. Palliative care guides comfort care, symptom management and quality of life. Clear distinctions in roles and responsibilities exist but coordination barriers remain, especially across the transition. Participants describing this model provide few details about professionals and interventions that improve function and quality of life outside of managing complications.
- **Synchronous Care:** A multidisciplinary team with distinct roles coordinates each of the AdvLD care constituents synchronously. This approach allows for earlier advance care planning and symptom management provided by various clinicians. Shared responsibilities among primary, liver specialty, and palliative care professionals exist to honor established relationships. Participants describe additional resources and personnel that further expand this model of integrated care, but barriers to dissemination exist.

C. Teamwork and Coordination Supports for Synchronous Integrated AdvLD care model

- **Co-location of care of multidisciplinary team at same site:**
 - "We started having our palliative people join us during the clinic hours on Mondays. And...if the patient needs to be seen by the palliative folks then right after the liver clinic they go straight to palliative. And it's basically one appointment." (Clinician #10, Case Manager for Liver Transplant Care Coordination, 2-5 years in liver care)
 - "When the clinic is running well and we are in good communication with the attendings, we'll be in the room when they deliver that prognosis to do like a warm handoff to our team. So you know [the] patient's family will get the news and then ... we have our palliative care team available [and ask them], 'Would you like to meet with them for a little bit?'" (Clinician #15, Palliative Care Social Worker, 2-5 years in liver care)
 - "The more people involved the more complicated it is [to coordinate schedules, and] you probably would need a lot more space. So, it is a very good concept but it is very difficult to

execute. (Clinician #5, Hepatology Physician, >20 years in liver care)

- **Encourages informal conversations that benefit patient care:**
 - “A lot of times I just ... walk in and I say hi to everybody and people just start talking to me about a particular Veteran and then I’ll let them know what I can do to help them, then we’ll put in like return to clinic orders for them to see me or some other sort of process for them to see me still. A lot of it is like that, it’s sort of informal you know chats between the different people of the liver team.” (Clinician #11, Clinical Health Psychologist, 2-5 years in liver care)
- **Weekly multidisciplinary case conference** at one site facilitates collective care plan discussion:
 - “We have a multidisciplinary conference here every week...all of us are there one morning for an hour, hour and 15 minutes and we review [patients’] images. There is a surgeon there. There are a couple hepatologists...diagnostic radiologists. There are interventional radiologists. And there are several nursing and supportive staff and mid-level providers and residents and students...And we formulate a plan for each patient... consultations are placed, and they are actually undertaken, and patients are treated.” (Clinician #18, Gastroenterology and Hepatology Physician, 2-5 years in liver care)

Sequential Transitions Model of Integrated AdvLD Care

Constituents of Care and Timing of Initiation

The sequential transitions model of care suggests that patients transition from curative focused care (led by the liver specialists) to palliative care (guided by palliative care clinicians) as health status declines. In this model, curative care and palliative care are distinct stops along the trajectory of liver disease. Clinicians who described the sequential transitions model were often unfamiliar with the term supportive care. Those who were familiar with supportive care indicated that symptom management and supportive care occur earlier in the illness trajectory and may co-occur with curative care.

“Supportive is if someone has cirrhosis and we give them diuretics to reduce the fluid...supportive is kind of symptom control. And then palliative is more, kind of more of a focus on comfort...the focus shifts from the length of life, like away from necessarily preventive testing or lab tests more to just doing symptom relief.” (Clinician #23, Gastroenterology Physician, 2-5 years in liver care)

In the sequential transitions model, some clinicians defined palliative care as comfort-focused care that involves counseling, code status discussions, and end of life decisions and specified that this occurs later in the illness trajectory.

“Palliative care happens at the very end... if it ever happens.” (Clinician #17, Gastroenterology Physician, >15 years in liver care)

Philosophy of Integration

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3 In this model, the degree of integration hinges on the ease of referrals, particularly to designated
4 palliative care providers. Integration, in this view, describes how easily patients can be referred for
5 comfort focused care when they are no longer being treated with curative intent. This view is evident in
6 the following quotation:
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11 *“If we have a patient ... and we’ve been curative and now they’re no longer a candidate and they*
12 *need to do palliative care, I think it’s integrated...I can think of a few patients of ours that we had*
13 *to...move towards palliative care and the transition went very smoothly. So I would say yeah,*
14 *they’re integrated.” (Clinician #22, RN Liver Transplant Coordinator, >20 years in liver care)*
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18 Several clinicians illustrated the sequential transitions model of care in discussing liver transplant
19 patients, who, in this view, are being treated with curative intent, and therefore, are not appropriate for
20 palliative care. Within the sequential transitions model, transplant candidates are not seen by palliative
21 care providers, but as some patients are excluded from transplant candidacy, they are no longer treated
22 with curative intent and are transitioned to palliative care.
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28 *“If those patients that are not liver transplant candidates, due to age, lack of support,*
29 *comorbidities, those patients need, automatically...consultation with palliative care...Change*
30 *in...the clinical status, those patients need to mention whether they are liver transplant*
31 *candidates or not. And if they are not, then the next step is to have goals of care discussion,*
32 *palliative care consultation, or even hospice.” (Clinician #21, Gastroenterology and Transplant*
33 *Hepatology Physician, 2-5 years in liver care)*
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38 Thus, in the sequential care approach, curative and palliative care are separate and distinct
39 points along the AdvLD trajectory.
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42 Staffing and Resources

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45 Participants who described the sequential transitions mental model were from study sites where they
46 identified more barriers and fewer facilitators to accessing supportive and palliative services. Clinicians
47 noted that many services needed by AdvLD patients are physically disbursed and thus, not well
48 integrated, and less accessible for patients. Clinicians across all three sites viewed physically disbursed
49 services as less integrated and less accessible for patients. Clinicians noted that patients can be referred
50 to services like palliative care, social work, mental health, and physical therapy, but if team members are
51 physically disbursed, patients are scheduled to receive the service at a different time. Clinicians also
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3 acknowledged that their site experienced other barriers to referrals including inadequately staffed
4 palliative care service. A participant at one such site succinctly stated:

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7 *“Palliative care is a luxury item.” (Clinician #25, Palliative Care Provider, 10-15 years in Palliative*
8 *Care)*
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10 11 **Synchronous Care Model of Integrated AdvLD Care**

12 Constituents of Care and Timing of Initiation

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16 In contrast to the sequential transitions mental model, an alternative synchronous care model emerged.
17 The synchronous care model was described as a multidisciplinary team of providers working
18 simultaneously to address patients’ needs through curative care, symptom management and supportive
19 care, advance care planning, and end-of-life services. The synchronous care approach includes
20 supportive care for patients treated with curative intent, earlier introduction of advanced care planning
21 and symptom management, and a continued relationship with the hepatologist even after the patient
22 moves toward more supportive and comfort focused care.
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29 Clinicians who described the synchronous care model defined supportive care as a host of
30 pharmacologic and non-pharmacologic interventions aimed to improve patients’ quality of life and
31 functioning. These clinicians viewed palliative care as an inseparable part of supportive care that should
32 occur throughout the illness trajectory.
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37 A palliative care social worker expressed the importance of early initiation of palliative care in the
38 synchronous care approach:
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41 *“I think it’s what we need to be doing because...they can be receiving curative intent but we also*
42 *know that these diseases are really serious and that things can change....When we can at least*
43 *start having the conversation when someone’s getting curative intent, we can be there for when*
44 *the goals start to change.” (Clinician #15, Palliative Care Social Worker, 2-5 years in liver care)*
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48 Philosophy of Integration

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51 In contrast to the view of integration as hinging on ease of referrals, in the synchronous care approach,
52 the degree of integration involves close teamwork and co-management of patients. One hepatologist
53 described her philosophy surrounding the synchronous care approach to integrated care:
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3 *"If I'm taking care of a patient for years, why should I absolve myself of the nitty gritty of the end*
4 *of their life because there's a palliative care service to do that?... I want to introduce them to the*
5 *palliative care service so that they have the comfort of knowing that I've referred them and that*
6 *we're all here together.... As opposed to, I'm done with you--go talk to the palliative care people.*
7 *I don't think that's well integrated."* (Clinician #16, Hepatology Physician, >15 years in liver care)
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12 Staffing and Resources

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15 The synchronous care model requires a high degree of teamwork and coordination among
16 multidisciplinary professionals. Participants described examples of active supports for teamwork and
17 coordination to facilitate synchronous care (see **Table 3, C**). Clinicians discussed the importance of
18 having a multidisciplinary liver team co-located in the same clinic. The co-located clinic featured at one
19 site encouraged formal collaboration often through informal conversations that benefited patient care.
20 At this site, the synchronous approach was evident in the allocation of staffing and space resources and
21 a local culture that included palliative care providers routinely consulting with patients receiving
22 curative care. Co-located services are better integrated and can ensure that patients are able to access
23 needed services. As one liver transplant hepatologist described, returning to the hospital for an
24 additional appointment can be challenging:
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32 *"Sometimes people who really need a lot of palliative care and supportive care, there are issues*
33 *related to coming back, transportation, things of that nature. So, whatever we can provide in*
34 *one session, that's always better."* (Clinician #18, Gastroenterology and Transplant Hepatology
35 *Physician, 2-5 years of liver care)*
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40 An alternative approach to co-location used at one site is multidisciplinary case conference
41 presentations.
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44 Clinicians who described the synchronous care model discussed the importance of having a
45 multidisciplinary team integrating supportive care, symptom management and palliative care with liver
46 disease care. They suggest that a multidisciplinary team for integrated AdvLD care includes:
47 hepatologists, interventional radiologist for patients with liver cancer, palliative care physicians,
48 psychologist or behavioral medicine, social worker, dietician, physical therapist, pharmacist, case
49 manager or care coordinator, administrative support staff, including a dedicated scheduler, peer
50 support, and a chaplain. **Table 4** describes specific supportive and palliative care professionals and how
51 their responsibilities support a synchronous integrated care model.
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Table 4. Multidisciplinary Team members and roles for Integrated Advanced Liver Disease Care (Created by the Authors)

Key Personnel	Role	Supporting Quotations
Palliative Care professionals	<ul style="list-style-type: none"> • Palliative care providers embedded in specialty clinics in complementary roles 	<p>“So we get to meet people really in an ideal situation versus in the emergency room or ICU, but we also meet people there too...We get a lot of consults...I think they count on us to help out with very complex symptom management issues, and goals of care conversations.” (Clinician #12, APRN for Palliative Care, 2-5 years in liver care)</p>
Behavioral and Mental Health professionals	<ul style="list-style-type: none"> • Includes therapists, behavioral health experts, psychiatrists, and psychologists • Address psychological and psychosocial issues; enhance access to addiction and substance abuse care • Chaplains can provide supplemental support 	<p>“I think the mental health and health psychology aspects are big when we’re dealing with patients that have alcohol use disorders and have substance use disorders and have advanced liver disease and don’t really see a purpose in you know stopping or cutting back on their use.” (Clinician #8, Clinical Pharmacy Specialist, 5-10 years in liver care)</p> <p>“Sometimes things like reconciling with family members, saying goodbye, saying I’m sorry.” (Clinician #25, Palliative Care Provider, 10-15 years in Palliative Care)</p>
Social Work	<ul style="list-style-type: none"> • Help patients and family members navigate complex system • Facilitate reconnections between patients and family members 	<p>“The social workers are usually the ones who work with patients to fill out their advanced directives and power of attorney forms and just kind of all of that.” (Clinician #4, Clinical Psychologist)</p> <p>“Trying to find a family member sometimes. Sometimes they have names but they don’t really know where they are, so we work with a social worker when patients have the goal of finding family members.” (Clinician #25, Palliative Provider, 10-15 years in Palliative Care)</p>
Dietitian	<ul style="list-style-type: none"> • Provide nutritional support 	<p>“I do make some referrals to nutrition and for more in-depth counseling on low sodium diet or patients who have other dietary, special diets that they need to follow because of their illness.” (Clinician #4, Clinical Psychologist)</p>
Physical Therapist	<ul style="list-style-type: none"> • Assist with physical concerns, fatigue, mobility, frailty 	<p>“We have a dedicated physical therapist because frailty is also a very big issue in terms of advanced liver disease.” (Clinician #18, Gastroenterology and Transplant Hepatology, 3-5 years in liver care)</p>
Pharmacist or Pharmacy Technician	<ul style="list-style-type: none"> • Help avoid drug interactions and adverse events, patient education, improve medication adherence 	<p>“I feel that pharmacists do definitely help out quite a bit even with patient education [and] direct management of medications. You know I...help out with drug interaction questions and even just a matter of like, this patient’s running out of his immunosuppressants and he’s a liver transplant patient can you please get these out ASAP. And I’m involved with some fatty liver treatment in the sense of using some of the weight management medications and reviewing those for appropriateness in the patients.” (Clinician #14, Clinical Pharmacy Specialist, 5-10 years in liver care)</p>

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Case manager or Care coordinator	<ul style="list-style-type: none">• Point of contact for patients and facilitates access to services• May include nurse coordinator, nurse case manager.	“Somebody who sort of fills in the blank and answers questions and available for the patient when they need the person.” (Clinician #17, Hepatology Physician, 15-20 years in liver care)
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DISCUSSION

This study examined two mental models of integrated care for advanced liver disease. Participants described the importance of an integrated approach to AdvLD care and a shared views of its core constituents: curative care, symptom management and supportive care, and advanced care planning and end-of-life care. Participants agreed on the potential role of palliative care but disagreed on the scope of palliative care and responsibilities of palliative care clinicians. This ultimately resulted in two distinct mental models of integrated AdvLD care: sequential transitions versus synchronous care. Both models envision a multidisciplinary team with specific roles and examples of teamwork and coordination facilitators. However, the timing of when to initiate AdvLD constituents and their relative importance differed between the two models. These models also vary in their philosophy of integration, and staffing and resources needed to achieve integrated care. Providers at sites that lack staffing and resources often describe the sequential transitions model, whereas providers at sites with adequate staffing and resources tend to share a mental model of care that can be described as the synchronous care model.

The sequential transitions model resembles an increasingly anachronistic dichotomy of a largely curative and symptom management focus followed by a transition to an end-of-life oriented palliative care without curative intent. The synchronous care model is consistent with our previously described conceptual model of integrated AdvLD care.⁸ In the synchronous care model, participants described early integration of a broader understanding of palliative and supportive care and emphasized the importance of education, prognostic awareness and advance care conversations that occurred in parallel with curative care. In the synchronous care model, a patient with AdvLD could be evaluated for transplant, have palliative care consultations, and receive psychosocial and nutrition counseling concurrently.⁸

Implementation of a synchronous care model of integrated AdvLD care requires a multidisciplinary team with clear roles and active facilitators in place to promote teamwork and coordination. Participants in the current study identified several facilitators including co-location of the multidisciplinary team or regular multidisciplinary case conferences, both of which can promote formal and informal conversations that benefit patient care. These facilitators can promote team convergence regarding individual and shared roles, responsibilities, and collaboration.²⁶ When team convergence is achieved, a teamwork shared mental model emerges that can improve the synchronous efforts of the multidisciplinary, integrated AdvLD team.^{27,28} In contrast, the sequential transitions model promotes individual mental models of how AdvLD is integrated and a shared mental model of how different

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3 professionals function within their roles, but leaves a barren model of teamwork across the sequential
4 transitions. When describing the sequential transitions model, participants do endorse a
5 multidisciplinary approach. However, those envisioning a synchronous care model often provide a richer
6 array of disciplinary roles and functions (see Table 4) for supportive and palliative care tasks.
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10 Prior research details why the sequential transitions model persists. Clinicians, especially those affiliated
11 with transplant services, may hold overly optimistic attitudes that hinder recommendations for
12 nonaggressive (supportive and palliative) treatment options.²⁹ Discussions of death are often used to
13 motivate behavior change for aggressive therapy rather than encourage advance care planning and
14 proactive symptom management.^{11 29} As a consequence, advanced care planning that occurs earlier in
15 the disease course in outpatient (non-crisis) settings is recommended.^{12 29} Coupling supportive care
16 (symptom management, psychosocial and caregiver support) with earlier prognosis and advanced care
17 discussions has also been recommended^{8 30} and is consistent with the synchronous model of integrated
18 AdvLD care. Adoption of the multidisciplinary team and teamwork mindset and facilitators described by
19 study participants is key to implementation of the synchronous model.
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28 This study has limitations. We recruited clinicians from three VA health systems which limits the
29 external validity of findings beyond similar VA sites. The VA patient population is mostly male and all
30 patients have served in the United States Armed Forces. We sampled clinicians who typically provide
31 liver disease care and may have skewed perspectives towards specialty care context. While potential
32 biases exist in all research, our approach to data collection, analysis, and reporting was rigorous. Non-
33 clinician interviewers conducted interviews and analyzed data. Data were coded by four individuals who
34 met frequently to discuss codes and enhance reliability. Finally, coding and emerging themes were
35 discussed among members of a multidisciplinary research team.
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43 In conclusion, clinicians who treat patients with AdvLD endorsed an approach that integrates curative
44 and supportive care and advance care planning using multidisciplinary teams. However, clinicians'
45 mental models of integrated AdvLD care differed based on the timing and conceptualization of
46 supportive and palliative care. A synchronous approach that integrates earlier supportive and advance
47 care planning with curative care is favored but tenuous without adoption of key facilitators of
48 multidisciplinary teamwork, communication, and coordination. An additional promotor of a
49 synchronous model is training on the communication skills, scripts, and tools for identifying patients'
50 priorities. Patient's health priorities (specific, realistic outcome goals and care preferences) are the
51 foundation for multidisciplinary treatment planning and referrals within an integrated, patient-centered
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3 model of care.⁸ Future research should focus on developing clinically-pragmatic approaches to identify
4 priorities and align AdvLD treatment recommendations to achieve patient priorities.⁹
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CONTRIBUTORSHIP

Jennifer Arney contributed to study design, data collection and analysis, and manuscript writing. Caroline Gray contributed to study design, data collection and analysis, and manuscript writing. Jack Clark contributed to study design, data analysis, and manuscript writing. Donna Smith contributed to funding, study design, and manuscript writing. Jennifer Melcher contributed to manuscript writing. Steven Asch contributed to funding, data analysis and manuscript writing. Fasiha Kanwal contributed to funding, study design, data analysis, and manuscript writing. Aanand Naik contributed to funding, study design, data analysis, and manuscript writing.

COMPETING INTERESTS

The authors have no competing interests to declare.

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DATA SHARING

No data are available

BIBLIOGRAPHY

1. Bryce CL, Angus DC, Arnold RM, et al. Sociodemographic differences in early access to liver transplantation services. *American Journal of Transplantation* 2009;9(9):2092-101.
2. Kanwal F, Hernaez R, Liu Y, et al. Factors Associated With Access to and Receipt of Liver Transplantation in Veterans With End-Stage Liver Disease. *JAMA Internal Medicine* 2021
3. D'Amico G, Garcia-Tsao G, Pagliaro L. Natural history and prognostic indicators of survival in cirrhosis: a systematic review of 118 studies. *J Hepatol* 2006;44(1):217-31.
4. Woodland H, Hudson B, Forbes K, et al. Palliative care in liver disease: what does good look like? *Frontline Gastroenterology* 2020;11(3):218-27.
5. Kimbell B, Boyd K, Kendall M, et al. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open* 2015;5(11) doi: 10.1136/bmjopen-2015-009241
6. Low J, Davis S, Vickerstaff V, et al. Advanced chronic liver disease in the last year of life: a mixed methods study to understand how care in a specialist liver unit could be improved. *BMJ open* 2017;7(8):e016887.
7. Low JT, Rohde G, Pittordou K, et al. Supportive and palliative care in people with cirrhosis: international systematic review of the perspective of patients, family members and health professionals. *Journal of hepatology* 2018;69(6):1260-73.
8. Naik A, Arney J, Clark J, et al. Integrated Model for Patient-Centered Advanced Liver Disease Care. *Clin Gastroenterol Hepatol* 2020;18(5):1015-24.
9. Naik AD, Dindo LN, Liew JR, et al. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. *Journal of the American Geriatrics Society* 2018;66(10):1872-79. doi:10.1111/jgs.15437
10. Tandon P, Walling A, Patton H, et al. AGA Clinical Practice Update on Palliative Care Management in Cirrhosis: Expert Review. *Clinical Gastroenterology and Hepatology* 2020
11. Ufere NN, Donlan J, Waldman L, et al. Physicians' perspectives on palliative care for patients with end-stage liver disease: a national survey study. *Liver Transplantation* 2019;25(6):859-69.
12. Ufere NN, Donlan J, Waldman L, et al. Barriers to use of palliative care and advance care planning discussions for patients with end-stage liver disease. *Clinical Gastroenterology and Hepatology* 2019;17(12):2592-99.

- 1
2
3 13. Back AL, Park ER, Greer JA, et al. Clinician roles in early integrated palliative care for patients with
4 advanced cancer: a qualitative study. *Journal of palliative medicine* 2014;17(11):1244-48.
- 5
6 14. LeMond L, Allen LA. Palliative care and hospice in advanced heart failure. *Progress in cardiovascular*
7 *diseases* 2011;54(2):168-78.
- 8
9 15. Barber T, Toon L, Tandon P, et al. Eliciting and Understanding Primary Care and Specialist Mental
10 Models of Cirrhosis Care: A Cognitive Task Analysis Study. *Canadian Journal of Gastroenterology*
11 *and Hepatology* 2021;2021
- 12
13 16. den Herder-van der Eerden M, van Wijngaarden J, Payne S, et al. Integrated palliative care is about
14 professional networking rather than standardisation of care: a qualitative study with healthcare
15 professionals in 19 integrated palliative care initiatives in five European countries. *Palliative*
16 *medicine* 2018;32(6):1091-102.
- 17
18 17. Hysong SJ, Best RG, Pugh JA, et al. Not of one mind: mental models of clinical practice guidelines in
19 the Veterans Health Administration. *Health services research* 2005;40(3):829-48.
- 20
21 18. Berwick DM. Disseminating innovations in health care. *Jama* 2003;289(15):1969-75.
- 22
23 19. Wagner KK, Austin J, Toon L, et al. Differences in team mental models associated with medical home
24 transformation success. *The Annals of Family Medicine* 2019;17(Suppl 1):S50-S56.
- 25
26 20. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-
27 item checklist for interviews and focus groups. *International journal for quality in health care*
28 2007;19(6):349-57.
- 29
30 21. Glaser BG. The Constant Comparative Method of Qualitative Analysis*. *Social Problems*
31 2014;12(4):436-45. doi: 10.2307/798843
- 32
33 22. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of
34 inductive and deductive coding and theme development. *International journal of qualitative*
35 *methods* 2006;5(1):80-92.
- 36
37 23. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*
38 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
- 39
40 24. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *Bmj*
41 2000;320(7227):114-6. doi: 10.1136/bmj.320.7227.114 [published Online First: 2000/01/22]
- 42
43 25. Morse JM. The Significance of Saturation. *Qualitative Health Research* 1995;5(2):147-49. doi:
44 10.1177/104973239500500201
- 45
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2
3 26. Manges K, Groves PS, Farag A, et al. A mixed methods study examining teamwork shared mental
4 models of interprofessional teams during hospital discharge. *BMJ quality & safety*
5 2020;29(6):499-508.
6
7
8 27. McComb S, Simpson V. The concept of shared mental models in healthcare collaboration. *Journal of*
9 *advanced nursing* 2014;70(7):1479-88.
10
11 28. Salas E, Wilson KA, Murphy CE, et al. Communicating, coordinating, and cooperating when lives
12 depend on it: tips for teamwork. *The Joint Commission Journal on Quality and Patient Safety*
13 2008;34(6):333-41.
14
15 29. Patel AA, Ryan GW, Tisnado D, et al. Deficits in Advance Care Planning for Patients With
16 Decompensated Cirrhosis at Liver Transplant Centers. *JAMA Internal Medicine* 2021;181(5):652-
17 60.
18
19
20
21 30. Hudson BE, Ameneshoa K, Gopfert A, et al. Integration of palliative and supportive care in the
22 management of advanced liver disease: development and evaluation of a prognostic screening
23 tool and supportive care intervention. *Frontline gastroenterology* 2017;8(1):45-52.
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Healthcare Provider Interview Guide

“For this interview, I will be asking you some questions about your experiences caring for patients with liver disease. You can skip any questions that you do not want to answer.”

“If you agree, your answers will be recorded using a digital voice recorder. Do you agree to be recorded?”

If yes: “Thank you. Once I start the recording, I will ask you to confirm that you have given your permission to be recorded so that I will have documentation of your agreement.”

If no: “Ok, that’s fine. I will take notes and will not record the interview.”

If the participant agrees to be recorded, start the recording and say:

“Could you please confirm that you agreed to be recorded as part of a research study entitled *Patient centered care for individuals with advanced liver disease*? And that you agreed to answer questions about your usual practices managing patients with advanced liver disease?”

Begin Interview

1. Tell me about your experiences caring for patients with liver disease.

What effect does the severity or stage of liver disease have on your experiences caring for these patients? (probe for examples of care at different stages)

2. What do you think patients and caregivers need to know about liver disease? (probe: disease cause, progression/severity, prognosis and treatment related information)

How is this information currently shared with them?

In your setting, who has the responsibility of sharing that information with patients? (probe for specific persons, staff, disciplines)

3. Based on your experiences, what some common health outcome goals for patients with liver disease? (probe for specific examples).

How do these health outcome goals change as the disease advances?

How do you discuss these health outcome goals with patients and their caregivers?

4. What strategies do you use to elicit patients’ health outcome goals?

What strategies do you use to align a patient’s health outcome goals with their treatment plan? (probe for examples)

What do you do in cases where the patient’s goals do not align with the treatment plan? (probe for examples)

Information Sharing

5. Describe how you share or discuss information with patients and their caregivers about the prognosis for their illness.

6. Describe ways to improve how prognosis and risk information is shared with patients and caregivers. What tools, procedures, or staff could help you share this information?

7. Please look over the example health information we provided.

How is this information valuable or helpful to you?

In what ways is it confusing or unclear?

What could make this information more useful to you?

What other types of similar information would you want?

Do you feel patients and caregivers could understand this information?

Experiences of Care

8. In your opinion, what therapeutic options are considered curative care for liver disease?

What about supportive care?

And palliative care?

What are some examples of patient outcomes that fall into each of these categories of patient care?

9. When in the patient's illness course do you discuss treatment options that are considered curative?

What about supportive?

Palliative?

When do you discuss end of life planning?

-If participant does not have these conversations ask: Who in the healthcare team typically has these conversations? How are they typically done?

10. How well integrated are these different approaches in your current practice? In your view, how would a truly integrated approach to cirrhosis care look?

11. How would you be able to adapt your current practice to allow for a more integrated approach into the normal workflow and routines?

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3 Describe the resources, staff, and leadership you have in your setting and how they can be
4 facilitators for a more integrated approach to cirrhosis care.
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6 Describe the barriers to integrated cirrhosis care. What additional resources are needed?
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9 12. Describe your process for developing the patient's treatment plan for liver disease.

10 What role do the patient and their caregiver have in this process? (probe for examples)
11

12 What tools, resources, or staff are necessary to better engage patients and caregivers in this
13 process?
14
15

16 13. Please take a look at the journey map.
17

18 Where in the patient's illness trajectory do you think a more collaborative approach can and
19 should occur?
20

21 Where in the patient's illness trajectory would you discuss different types of prognosis data?
22 (probe: what are the different types of prognosis information that is best suited for various
23 times along the illness trajectory?)
24
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26 **Barriers & Facilitators of Advanced Liver Disease Care**

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29 14. In your opinion, what would a more collaborative approach to liver disease treatment planning look
30 like?
31

32 What skills and resources do you think you would need to facilitate developing a more
33 collaborative treatment plan with the patient and their caregiver?
34

35 15. What additional staff or health care professional are needed for a more collaborative model of
36 treatment planning?
37

38 How would their roles and responsibilities differ from yours?
39
40

41 16. What would facilitate a more collaborative approach to liver disease treatment planning? (probe:
42 context, procedures, etc)
43

44 17. How useful do you think it would be to have decision support tools to assist in conversations with
45 liver disease patients?
46

47 What kinds of tools would be most useful?
48

49 What is the best way to implement decision support tools into the routine process of liver
50 disease care?
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Two Mental Models of Integrated Care for Advanced Liver Disease: Qualitative Study of Multidisciplinary Health Professionals

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3 **Two Mental Models of Integrated Care for Advanced Liver Disease:**
4 **Qualitative Study of Multidisciplinary Health Professionals**
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ABSTRACT

Objectives: The purpose of this paper is to present two divergent mental models of integrated advanced liver disease (AdvLD) care among 26 providers who treat AdvLD patients

Setting: 3 geographically dispersed United States Veterans Health Administration health systems

Participants: 26 professionals (20 women and 6 men) participated, including 9 (35%) gastroenterology, hepatology, and transplant physicians, 2 (7.7%) physician assistants, 7 (27%) nurses and nurse practitioners, 3 (12%) social workers and psychologists, 4 (15%) palliative care providers and 1 pharmacist

Main Outcome Measures: We conducted qualitative in-depth interviews of providers caring for AdvLD patients. We used framework analysis to identify two divergent mental models of integrated AdvLD care. These models vary in timing of initiating various constituents of care, philosophy of integration, and supports and resources needed to achieve each model.

Results: Clinicians described integrated care as an approach that incorporates elements of curative care, symptom and supportive care, advance care planning, and end-of-life services from a multidisciplinary team. Analysis revealed two mental models that varied in how and when these constituents are delivered. One mental model involves sequential transitions between constituents of care, and the second mental model involves synchronous application of the various constituents. Participants described elements of teamwork and coordination supports necessary to achieve integrated AdvLD care. Many discussed the importance of having a multidisciplinary team integrating supportive care, symptom management and palliative care with liver disease care.

Conclusions: Health professionals agree on the constituents of integrated AdvLD care but describe two competing mental models of how these constituents are integrated. Health systems can promote integrated care by assembling multidisciplinary teams, and providing teamwork and coordination supports, and training that facilitates patient-centered AdvLD care.

Strengths and Limitations of this Study

- The multidisciplinary research team used a rigorous approach to data collection, analysis, and reporting
- Non-clinician interviewers conducted interviews and analyzed data, thereby reducing bias
- Findings may be limited to United States Veterans Health Administration health system
- Participants' perspectives may be skewed toward specialty care context

INTRODUCTION

Advanced liver disease (AdvLD) is a serious illness with high rates of morbidity and mortality. Liver transplantation offers an opportunity to cure AdvLD, however, few patients receive it.¹ Most patients, including those on the transplant waiting list, live with and die of their liver disease.² Their clinical course is marked by declining health, increasing symptom burden and frequent hospitalizations.³ The symptom burden of AdvLD is comparable to advanced cancers; symptoms include pain, dyspnea, difficulty sleeping, anorexia and fatigue, bleeding, confusion, depression and anxiety.⁴ Furthermore, patients and caregivers report marked uncertainty about prognosis and AdvLD course, complex care needs, and poor coordination and communication with and among clinicians.^{5 6} A recent systematic review identified significant gaps in understanding and information about AdvLD etiology, course, symptoms, and prognosis and the related psychosocial distress among patients and caregivers as well as a lack of confidence about when and how to have AdvLD prognosis and advance care planning discussions among primary care clinicians.⁷

To address these gaps, we proposed an integrated model of patient-centered AdvLD care that blends curative care (transplant referral and disease modifying treatments), supportive care (symptom management and psychosocial care), and advance care planning and end-of-life care based on identifying patient's priorities and then aligning care options to achieve the identified priorities.^{8 9} Health professionals report difficulty coordinating care, especially knowing when or how to offer supportive care, prognosis discussions and advanced care planning.⁷ To facilitate better integration of AdvLD care, the American Gastroenterological Association recently provided a clinical practice update that recommends incorporation of palliative care principles for any patient with cirrhosis, irrespective of transplant candidacy.¹⁰ In this context, palliative care is inclusive of supportive care as defined above coupled with advance care planning and goals of care conversations in the context of assessing and cultivating prognosis awareness and is delivered concurrently with life prolonging treatments, tailored to stage of disease. However, in practice, hesitancy and barriers to use of palliative care are common among AdvLD clinicians. Specialists who provide care for AdvLD often believe that palliative care instills fear and anxiety among patients because of a belief that involvement of palliative care would mean that nothing more could be done for the underlying AdvLD.¹¹ These specialists acknowledge the importance of having palliative care services available for AdvLD and trust palliative care clinicians to care for their patients but cite cultural factors and patients' unrealistic expectations about prognosis as barriers to

1
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3 referral.¹² Clinicians also disagree on the appropriate timing and setting of advance care planning
4 discussions.^{7 12}
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7 Implementation of integrated care models in AdvLD, like cancer¹³ and advanced heart failure,¹⁴ is
8 hindered by professional norms, insufficient training, and lack of consensus on professional roles and
9 responsibilities.¹⁵ Clinician attitudes can also affect the adoption of integrated care in serious illness.^{13 16}
10 Understanding perceptions and practices of AdvLD care integration among specialist, primary care
11 physicians, and health care professionals (i.e., mental models of AdvLD care) is a starting point. Mental
12 models are psychological representations of an individual's (or group's) dynamic beliefs about the truth
13 and nature of a phenomenon; are broad simplifications of that phenomenon; consist of knowledge,
14 behaviors and attitudes for making judgements, solving problems and ultimately acting on decisions;
15 and are formed (and reformed) from interactions with the environment and other people.¹⁷ Mental
16 models are useful for understanding key factors pertaining to diffusion of healthcare innovations:
17 perception of the change, characteristics of adopters and laggards, and perceptions of contextual factors
18 (communication, incentives, leadership, etc) related to the change.^{18 19} The current study identifies two
19 competing mental models of integrated AdvLD care and describes professional roles and contextual
20 factors that can affect adoption.
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METHODS

Study design and setting

Reporting of our research methods aligns with the consolidated criteria for reporting qualitative research (COREQ) guidelines.²⁰ We conducted in-depth qualitative interviews with clinicians who care for patients with AdvLD at three geographically dispersed sites within the VA healthcare system: Southeast Texas, Northern California, and New England. See **Table 1** for site characteristics. All 3 sites include liver tumor boards. One site (Southeast Texas) offers transplant services and two sites (Northern California and New England) refer to nearby VA regional transplant centers that provide transportation and lodging for the Veteran and caregiver.

Table 1. Study Sites and Clinical Services Characteristics (Created by the Authors)

	Site A		Site B		Site C	
	Liver Tumor Board – Yes		Liver Tumor Board – Yes		Liver Tumor Board – Yes	
Specialty	Providers (Number)	Co-located in GI clinic?	Providers (Number)	Co-located in GI clinic?	Providers (Number)	Co-located in GI clinic?
Hepatology Physicians	5		3		2 FT, 3 PT	
Hepatology PA	2		0		0	
Hepatology NP	1		3		1	
Hepatology Nurse	0		0		1 FT, 1PT	
Care Coordinator	0		0		2	
Palliative Care (Inpatient)	1 (consult)		1 (consult)		3 PT	
Palliative Care (Outpatient)	1 (consult)	No	2 (consult)	No	1 PT	Yes
Nutrition	3 PT (consult)	No	0	No	0	No
Rehabilitation	5 (consult)	No	0	No	0	No
Social Work	1	Yes	1 (consult)	No	1 PT	Yes

Clinical Pharmacist	1 (consult)	No	1 (consult)	No	1 PT	Yes
Addiction Medicine	1 (consult)	No	1 (consult)	No	1 PT	Yes
Health Psychology	0	No	0	No	1 PT	Yes

GI= Gastroenterology or Hepatology PA= Physician Assistant NP=Nurse Practitioner FT= Full Time Equivalent PT= Part time Equivalent HCV= Hepatitis C Virus

Clinicians were referred by local chiefs of hepatology and gastroenterology. Clinical leads at each site provided names of clinicians who work with AdvLD patients. We stratified the names by profession/role and recruited participants from each strata. This strategy allowed us to capture a variety of perspectives on AdvLD care. Thirty-three clinicians were contacted via email and invited to participate in the study; 26 completed interviews. Three non-participants declined to participate due to time constraints; remaining non-participants did not provide an explanation. Participants were thanked but did not receive incentives for their participation.

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Data Collection

Our multi-disciplinary research team developed a semi-structured interview guide based on dimensions of the integrated model of AdvLD.⁸ The interview guide was designed to elicit clinicians' perspectives and experiences providing integrated care for liver disease, including definitions of curative, supportive, and palliative care; at what point in a patient's illness trajectory the various approaches to care are emphasized; degree to which these approaches to care are integrated; and barriers and facilitators to integrated AdvLD care. The interview guide was revised throughout the interviewing process to reflect emergent findings and clarify developing areas of interest (**Appendix 1**). Two medical sociologists (JA and CG) trained in qualitative methods conducted semi-structured, one-on-one, one-time, telephone interviews between October 2018 through November 2019. Both interviewers are non-Hispanic, White females with Ph.D.'s in Sociology. Both have extensive experience conducting qualitative interviews with clinicians, analyzing data, and presenting qualitative findings. Researchers did not have a relationship to participants prior to the study. Prior to participating, clinicians were informed of the interviewers'

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3 credentials and goal of exploring clinicians' experiences treating patients with AdvLD. Interviews ranged
4 from 31-78 minutes in duration (average 58 minutes). All participants provided verbal informed consent
5 twice—prior to recording and then again after recording started for documentation. With participants'
6 permission, interviews were audio recorded, transcribed verbatim, and pseudonymized for analysis.
7
8 Interviewers also produced pseudonymized, hand-written field notes during the interviews. While
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10 participants did not review completed transcripts, interviewers were trained to check for accuracy of
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12 understanding during interviews. Interviewers confirmed accuracy of transcription upon receipt of each
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14 transcript.
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16 17 **Data Analysis** 18

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20 Data were analyzed as they were collected, and emerging findings informed areas of focus for
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22 subsequent interviews. Analysis was guided by principles of framework analysis,²¹ a form of thematic
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24 analysis, which allowed for a deductive approach to derive themes from the integrated model of
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26 advanced liver disease,⁸ as well as an inductive approach to identify themes from participants'
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28 narratives. Several members of the analytic team reviewed early transcripts, created memos, and
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30 created a preliminary codebook. Codes were anchored in domains of the integrated model of advanced
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32 liver disease as well as emergent findings.²² Codebooks were piloted and revised with additional codes
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34 added as necessary. Two team members (JA and CG) independently coded all transcripts, and a third
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36 coder performed secondary coding to ensure accuracy of code assignments.²³ Coding discrepancies
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38 were resolved in weekly team meetings. Coding was performed using Atlas.ti (version 8.2). After initial
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40 coding, coders summarized themes and identified meaningful associations and patterns in the data.²⁴

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42 The full study team participated in the integration of codes into themes describing perspectives of
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44 integrated care and elements of an ideal model of integrated care for AdvLD. At a sample size of 26,
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46 data redundancy indicated thematic saturation—the point at which no new themes emerged.²⁵
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RESULTS

Participant Characteristics

Participants' characteristics are presented in **Table 2**. The sample of clinicians represented multiple professions, including gastroenterology, hepatology, and transplant physicians (34.6%), gastroenterology physician assistants (7.7%), gastroenterology/hepatology nurses and nurse practitioners (27%), social workers and psychologists (11.5%), palliative care providers (15.4%) and pharmacists (3.8%).

Table 2. Demographic Characteristics of the Study Population (Created by the Authors)

Healthcare Providers (n=26)	number (percentage)
Professional Role	
Gastroenterology, Hepatology, or Transplant Physicians	9 (34.6)
Gastroenterology Physician Assistants	2 (7.7)
Gastroenterology/Hepatology nurses and nurse practitioners	7 (27)
Social Workers or Psychologists	3 (11.5)
Palliative Care Providers	4 (15.4)
Pharmacists	1 (3.8)
Gender	
Female	20 (77)
Male	6 (23)
Years in Liver Care	
0-10	13 (50)
11-20	4 (15)
21-30	2 (8)
No Response	7 (27)

Shared views across mental models

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3 Analysis revealed that clinicians value integrated AdvLD care and they identified common components
4 of an integrated care approach. Clinicians ubiquitously indicated that the integrated model is ideal in
5 liver disease care, given that liver disease can progress quickly and have unexpected turns. Clinicians
6 described integrated care as an approach that incorporates elements of curative care, symptom
7 management and supportive care, advance care planning, and end-of-life services from a
8 multidisciplinary team (see **Table 3, A**). One shared view is the definition of curative care as remedies
9 that bring about recovery from disease.
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16 *“When you talk about cure, you’re talking about things that actually modify or cure the*
17 *underlying liver disease or liver transplantation.” (Clinician #17, Gastroenterology Physician, >15*
18 *years in liver care)*
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21 While consensus exists on the value of integrated care and the intent of curative care, descriptions of
22 integrated care diverged into two distinct mental models: the sequential transitions model and the
23 synchronous care model. These models vary in how clinicians envision initiation of various constituents
24 of care, their philosophy of integration, and staffing and resources needed to achieve integrated
25 care.(see **table 3, B**).
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Table 3. Participants' Mental Model of Integrated Advanced Liver Disease Care (Created by the Authors)

A. Constituents of Integrated Advanced Liver Disease Care (AdvLD)

Shared Mental Model of Integrated AdvLD constitutes:

- **Curative Care:** Care that cures (permanently removes) or significantly modifies the underlying liver disease or care resulting in liver transplantation.
- **Symptom Management and Supportive Care:** Pharmacologic and non-pharmacologic interventions that address symptoms from complications of cirrhosis; improve functioning, nutrition, and rehabilitation; and offer information, care planning and emotional support for patients and caregivers.
- **Advanced Care Planning and End-of-Life Care:** Discussions of prognosis and advance care preferences; comfort care and code status determinations; and care at the end-of-life focused on management of symptoms, psychosocial care, and quality of life.

Disagreements about Palliative Care: Some participants limited the definition to comfort-focused care that involves counseling, code status discussions, and end of life symptoms led by palliative care specialists. Other participants viewed supportive care, advanced care planning, and aspects of symptom management as additional components of palliative care delivered by various members of the multidisciplinary team, including but not exclusive to palliative care specialists.

B. Timing of AdvLD Care Services shape two competing mental models of integrated AdvLD care

- **Sequential Transitions:** Integration of two distinct goals of care – life prolongation versus comfort and quality of life with a clear distinction when the transition is made. Primary care and liver specialists focus on transplant referral and prevention/management of complications to prolong life. Palliative care guides comfort care, symptom management and quality of life. Clear distinctions in roles and responsibilities exist but coordination barriers remain, especially across the transition. Participants describing this model provide few details about professionals and interventions that improve function and quality of life outside of managing complications.
- **Synchronous Care:** A multidisciplinary team with distinct roles coordinates each of the AdvLD care constituents synchronously. This approach allows for earlier advance care planning and symptom management provided by various clinicians. Shared responsibilities among primary, liver specialty, and palliative care professionals exist to honor established relationships. Participants describe additional resources and personnel that further expand this model of integrated care, but barriers to dissemination exist.

C. Teamwork and Coordination Supports for Synchronous Integrated AdvLD care model

- **Co-location of care of multidisciplinary team at same site:**
 - "We started having our palliative people join us during the clinic hours on Mondays. And...if the patient needs to be seen by the palliative folks then right after the liver clinic they go straight to palliative. And it's basically one appointment." (Clinician #10, Case Manager for Liver Transplant Care Coordination, 2-5 years in liver care)
 - "When the clinic is running well and we are in good communication with the attendings, we'll be in the room when they deliver that prognosis to do like a warm handoff to our team. So you know [the] patient's family will get the news and then ... we have our palliative care team available [and ask them], 'Would you like to meet with them for a little bit?'" (Clinician #15, Palliative Care Social Worker, 2-5 years in liver care)
 - "The more people involved the more complicated it is [to coordinate schedules, and] you probably would need a lot more space. So, it is a very good concept but it is very difficult to

execute. (Clinician #5, Hepatology Physician, >20 years in liver care)

- **Encourages informal conversations that benefit patient care:**
 - “A lot of times I just ... walk in and I say hi to everybody and people just start talking to me about a particular Veteran and then I’ll let them know what I can do to help them, then we’ll put in like return to clinic orders for them to see me or some other sort of process for them to see me still. A lot of it is like that, it’s sort of informal you know chats between the different people of the liver team.” (Clinician #11, Clinical Health Psychologist, 2-5 years in liver care)
- **Weekly multidisciplinary case conference** at one site facilitates collective care plan discussion:
 - “We have a multidisciplinary conference here every week...all of us are there one morning for an hour, hour and 15 minutes and we review [patients’] images. There is a surgeon there. There are a couple hepatologists...diagnostic radiologists. There are interventional radiologists. And there are several nursing and supportive staff and mid-level providers and residents and students...And we formulate a plan for each patient... consultations are placed, and they are actually undertaken, and patients are treated.” (Clinician #18, Gastroenterology and Hepatology Physician, 2-5 years in liver care)

Sequential Transitions Model of Integrated AdvLD Care

Constituents of Care and Timing of Initiation

The sequential transitions model of care suggests that patients transition from curative focused care (led by the liver specialists) to palliative care (guided by palliative care clinicians) as health status declines. In this model, curative care and palliative care are distinct stops along the trajectory of liver disease. Clinicians who described the sequential transitions model were often unfamiliar with the term supportive care. Those who were familiar with supportive care indicated that symptom management and supportive care occur earlier in the illness trajectory and may co-occur with curative care.

“Supportive is if someone has cirrhosis and we give them diuretics to reduce the fluid...supportive is kind of symptom control. And then palliative is more, kind of more of a focus on comfort...the focus shifts from the length of life, like away from necessarily preventive testing or lab tests more to just doing symptom relief.” (Clinician #23, Gastroenterology Physician, 2-5 years in liver care)

In the sequential transitions model, some clinicians defined palliative care as comfort-focused care that involves counseling, code status discussions, and end of life decisions and specified that this occurs later in the illness trajectory.

“Palliative care happens at the very end... if it ever happens.” (Clinician #17, Gastroenterology Physician, >15 years in liver care)

Philosophy of Integration

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3 In this model, the degree of integration hinges on the ease of referrals, particularly to designated
4 palliative care providers. Integration, in this view, describes how easily patients can be referred for
5 comfort focused care when they are no longer being treated with curative intent. This view is evident in
6 the following quotation:
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10 *"If we have a patient ... and we've been curative and now they're no longer a candidate and they*
11 *need to do palliative care, I think it's integrated...I can think of a few patients of ours that we had*
12 *to...move towards palliative care and the transition went very smoothly. So I would say yeah,*
13 *they're integrated."* (Clinician #22, RN Liver Transplant Coordinator, >20 years in liver care)
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18 Several clinicians illustrated the sequential transitions model of care in discussing liver transplant
19 patients, who, in this view, are being treated with curative intent, and therefore, are not appropriate for
20 palliative care. Within the sequential transitions model, transplant candidates are not seen by palliative
21 care providers, but as some patients are excluded from transplant candidacy, they are no longer treated
22 with curative intent and are transitioned to palliative care.
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27 *"If those patients that are not liver transplant candidates, due to age, lack of support,*
28 *comorbidities, those patients need, automatically...consultation with palliative care...Change*
29 *in...the clinical status, those patients need to mention whether they are liver transplant*
30 *candidates or not. And if they are not, then the next step is to have goals of care discussion,*
31 *palliative care consultation, or even hospice."* (Clinician #21, Gastroenterology and Transplant
32 *Hepatology Physician, 2-5 years in liver care)*
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38 Thus, in the sequential care approach, curative and palliative care are separate and distinct
39 points along the AdvLD trajectory.
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42 Staffing and Resources

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45 Participants who described the sequential transitions mental model were from study sites where they
46 identified more barriers and fewer facilitators to accessing supportive and palliative services. Clinicians
47 noted that many services needed by AdvLD patients are physically disbursed and thus, not well
48 integrated, and less accessible for patients. Clinicians across all three sites viewed physically disbursed
49 services as less integrated and less accessible for patients. Clinicians noted that patients can be referred
50 to services like palliative care, social work, mental health, and physical therapy, but if team members are
51 physically disbursed, patients are scheduled to receive the service at a different time. Clinicians also
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3 acknowledged that their site experienced other barriers to referrals including inadequately staffed
4 palliative care service. A participant at one such site succinctly stated:

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7 *“Palliative care is a luxury item.” (Clinician #25, Palliative Care Provider, 10-15 years in Palliative*
8 *Care)*
9

10 11 **Synchronous Care Model of Integrated AdvLD Care**

12 Constituents of Care and Timing of Initiation

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16 In contrast to the sequential transitions mental model, an alternative synchronous care model emerged.
17 The synchronous care model was described as a multidisciplinary team of providers working
18 simultaneously to address patients’ needs through curative care, symptom management and supportive
19 care, advance care planning, and end-of-life services. The synchronous care approach includes
20 supportive care for patients treated with curative intent, earlier introduction of advanced care planning
21 and symptom management, and a continued relationship with the hepatologist even after the patient
22 moves toward more supportive and comfort focused care.
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29 Clinicians who described the synchronous care model defined supportive care as a host of
30 pharmacologic and non-pharmacologic interventions aimed to improve patients’ quality of life and
31 functioning. These clinicians viewed palliative care as an inseparable part of supportive care that should
32 occur throughout the illness trajectory.
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37 A palliative care social worker expressed the importance of early initiation of palliative care in the
38 synchronous care approach:
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41 *“I think it’s what we need to be doing because...they can be receiving curative intent but we also*
42 *know that these diseases are really serious and that things can change....When we can at least*
43 *start having the conversation when someone’s getting curative intent, we can be there for when*
44 *the goals start to change.” (Clinician #15, Palliative Care Social Worker, 2-5 years in liver care)*
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48 Philosophy of Integration

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51 In contrast to the view of integration as hinging on ease of referrals, in the synchronous care approach,
52 the degree of integration involves close teamwork and co-management of patients. One hepatologist
53 described her philosophy surrounding the synchronous care approach to integrated care:
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3 *"If I'm taking care of a patient for years, why should I absolve myself of the nitty gritty of the end*
4 *of their life because there's a palliative care service to do that?... I want to introduce them to the*
5 *palliative care service so that they have the comfort of knowing that I've referred them and that*
6 *we're all here together.... As opposed to, I'm done with you--go talk to the palliative care people.*
7 *I don't think that's well integrated."* (Clinician #16, Hepatology Physician, >15 years in liver care)

11 12 Staffing and Resources

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15 The synchronous care model requires a high degree of teamwork and coordination among
16 multidisciplinary professionals. Participants described examples of active supports for teamwork and
17 coordination to facilitate synchronous care (see **Table 3, C**). Clinicians discussed the importance of
18 having a multidisciplinary liver team co-located in the same clinic. The co-located clinic featured at one
19 site encouraged formal collaboration often through informal conversations that benefited patient care.
20 At this site, the synchronous approach was evident in the allocation of staffing and space resources and
21 a local culture that included palliative care providers routinely consulting with patients receiving
22 curative care. Co-located services are better integrated and can ensure that patients are able to access
23 needed services. As one liver transplant hepatologist described, returning to the hospital for an
24 additional appointment can be challenging:

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32 *"Sometimes people who really need a lot of palliative care and supportive care, there are issues*
33 *related to coming back, transportation, things of that nature. So, whatever we can provide in*
34 *one session, that's always better."* (Clinician #18, Gastroenterology and Transplant Hepatology
35 *Physician, 2-5 years of liver care)*

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40 An alternative approach to co-location used at one site is multidisciplinary case conference
41 presentations.

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44 Clinicians who described the synchronous care model discussed the importance of having a
45 multidisciplinary team integrating supportive care, symptom management and palliative care with liver
46 disease care. They suggest that a multidisciplinary team for integrated AdvLD care includes:
47 hepatologists, interventional radiologist for patients with liver cancer, palliative care physicians,
48 psychologist or behavioral medicine, social worker, dietician, physical therapist, pharmacist, case
49 manager or care coordinator, administrative support staff, including a dedicated scheduler, peer
50 support, and a chaplain. **Table 4** describes specific supportive and palliative care professionals and how
51 their responsibilities support a synchronous integrated care model.
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Table 4. Multidisciplinary Team members and roles for Integrated Advanced Liver Disease Care (Created by the Authors)

Key Personnel	Role	Supporting Quotations
Palliative Care professionals	<ul style="list-style-type: none"> • Palliative care providers embedded in specialty clinics in complementary roles 	<p>“So we get to meet people really in an ideal situation versus in the emergency room or ICU, but we also meet people there too...We get a lot of consults...I think they count on us to help out with very complex symptom management issues, and goals of care conversations.” (Clinician #12, APRN for Palliative Care, 2-5 years in liver care)</p>
Behavioral and Mental Health professionals	<ul style="list-style-type: none"> • Includes therapists, behavioral health experts, psychiatrists, and psychologists • Address psychological and psychosocial issues; enhance access to addiction and substance abuse care • Chaplains can provide supplemental support 	<p>“I think the mental health and health psychology aspects are big when we’re dealing with patients that have alcohol use disorders and have substance use disorders and have advanced liver disease and don’t really see a purpose in you know stopping or cutting back on their use.” (Clinician #8, Clinical Pharmacy Specialist, 5-10 years in liver care)</p> <p>“Sometimes things like reconciling with family members, saying goodbye, saying I’m sorry.” (Clinician #25, Palliative Care Provider, 10-15 years in Palliative Care)</p>
Social Work	<ul style="list-style-type: none"> • Help patients and family members navigate complex system • Facilitate reconnections between patients and family members 	<p>“The social workers are usually the ones who work with patients to fill out their advanced directives and power of attorney forms and just kind of all of that.” (Clinician #4, Clinical Psychologist)</p> <p>“Trying to find a family member sometimes. Sometimes they have names but they don’t really know where they are, so we work with a social worker when patients have the goal of finding family members.” (Clinician #25, Palliative Provider, 10-15 years in Palliative Care)</p>
Dietitian	<ul style="list-style-type: none"> • Provide nutritional support 	<p>“I do make some referrals to nutrition and for more in-depth counseling on low sodium diet or patients who have other dietary, special diets that they need to follow because of their illness.” (Clinician #4, Clinical Psychologist)</p>
Physical Therapist	<ul style="list-style-type: none"> • Assist with physical concerns, fatigue, mobility, frailty 	<p>“We have a dedicated physical therapist because frailty is also a very big issue in terms of advanced liver disease.” (Clinician #18, Gastroenterology and Transplant Hepatology, 3-5 years in liver care)</p>
Pharmacist or Pharmacy Technician	<ul style="list-style-type: none"> • Help avoid drug interactions and adverse events, patient education, improve medication adherence 	<p>“I feel that pharmacists do definitely help out quite a bit even with patient education [and] direct management of medications. You know I...help out with drug interaction questions and even just a matter of like, this patient’s running out of his immunosuppressants and he’s a liver transplant patient can you please get these out ASAP. And I’m involved with some fatty liver treatment in the sense of using some of the weight management medications and reviewing those for appropriateness in the patients.” (Clinician #14, Clinical Pharmacy Specialist, 5-10 years in liver care)</p>

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4 Case manager
5 or Care
6 coordinator
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- Point of contact for patients and facilitates access to services
- May include nurse coordinator, nurse case manager.

“Somebody who sort of fills in the blank and answers questions and available for the patient when they need the person.” (Clinician #17, Hepatology Physician, 15-20 years in liver care)

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For peer review only

DISCUSSION

This study examined two mental models of integrated care for advanced liver disease. Participants described the importance of an integrated approach to AdvLD care and they shared views of its core constituents: curative care, symptom management and supportive care, and advanced care planning and end-of-life care. Participants agreed on the potential role of palliative care but disagreed on the scope of palliative care and responsibilities of palliative care clinicians. This ultimately resulted in two distinct mental models of integrated AdvLD care: sequential transitions versus synchronous care. Both models envision a multidisciplinary team with specific roles and examples of teamwork and coordination facilitators. However, the timing of when to initiate AdvLD constituents and their relative importance differed between the two models. These models also vary in their philosophy of integration, and staffing and resources needed to achieve integrated care. Providers at sites that lack staffing and resources often describe the sequential transitions model, whereas providers at sites with adequate staffing and resources tend to share a mental model of care that can be described as the synchronous care model.

The sequential transitions model resembles an increasingly anachronistic dichotomy of a largely curative and symptom management focus followed by a transition to an end-of-life oriented palliative care without curative intent. Previous scholarship has referred to this as the transition model of care in which a patient receives aggressive medical care until health decline necessitates transition to hospice and then death.²⁶ The synchronous care model is consistent with our previously described conceptual model of integrated AdvLD care.⁸ Our synchronous care model resembles the trajectory model of care that was identified in previous scholarship.²⁶ In the synchronous care model, participants described early integration of a broader understanding of palliative and supportive care and emphasized the importance of education, prognostic awareness and advance care conversations that occurred in parallel with curative care. In the synchronous care model, a patient with AdvLD could be evaluated for transplant, have palliative care consultations, and receive psychosocial and nutrition counseling concurrently.⁸

Implementation of a synchronous care model of integrated AdvLD care requires a multidisciplinary team with clear roles and active facilitators in place to promote teamwork and coordination. Participants in the current study identified several facilitators including co-location of the multidisciplinary team or regular multidisciplinary case conferences, both of which can promote formal and informal conversations that benefit patient care. These facilitators can promote team convergence regarding individual and shared roles, responsibilities, and collaboration.²⁷ When team convergence is achieved, a teamwork shared mental model emerges that can improve the synchronous efforts of the

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3 multidisciplinary, integrated AdvLD team.^{28 29} In contrast, the sequential transitions model promotes
4 individual mental models of how AdvLD is integrated and a shared mental model of how different
5 professionals function within their roles, but leaves a barren model of teamwork across the sequential
6 transitions. When describing the sequential transitions model, participants do endorse a
7 multidisciplinary approach. However, those envisioning a synchronous care model often provide a richer
8 array of disciplinary roles and functions (see Table 4) for supportive and palliative care tasks.
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14 Prior research details why the sequential transitions model persists. Clinicians, especially those affiliated
15 with transplant services, may hold overly optimistic attitudes that hinder recommendations for
16 nonaggressive (supportive and palliative) treatment options.³⁰ Discussions of death are often used to
17 motivate behavior change for aggressive therapy rather than encourage advance care planning and
18 proactive symptom management.^{11 30} As a consequence, advanced care planning that occurs earlier in
19 the disease course in outpatient (non-crisis) settings is recommended.^{12 30} Coupling supportive care
20 (symptom management, psychosocial and caregiver support) with earlier prognosis and advanced care
21 discussions has also been recommended^{8 31} and is consistent with the synchronous model of integrated
22 AdvLD care. Adoption of the multidisciplinary team and teamwork mindset and facilitators described by
23 study participants is key to implementation of the synchronous model.
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32 This study has limitations. We recruited clinicians from three VA health systems which limits the
33 external validity of findings beyond similar VA sites. The VA patient population is mostly male and all
34 patients have served in the United States Armed Forces. We sampled clinicians who typically provide
35 liver disease care and may have skewed perspectives towards specialty care context. While potential
36 biases exist in all research, our approach to data collection, analysis, and reporting was rigorous. Non-
37 clinician interviewers conducted interviews and analyzed data, thereby reducing bias in the research.
38 Data were coded by four individuals who met frequently to discuss codes and enhance reliability. Finally,
39 coding and emerging themes were discussed among members of a multidisciplinary research team.
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47 In conclusion, clinicians who treat patients with AdvLD endorsed an approach that integrates curative
48 and supportive care and advance care planning using multidisciplinary teams. However, clinicians'
49 mental models of integrated AdvLD care differed based on the timing and conceptualization of
50 supportive and palliative care. A synchronous approach that integrates earlier supportive and advance
51 care planning with curative care is favored but tenuous without adoption of key facilitators of
52 multidisciplinary teamwork, communication, and coordination. An additional promotor of a
53 synchronous model is training on the communication skills, scripts, and tools for identifying patients'
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3 priorities. Patient's health priorities (specific, realistic outcome goals and care preferences) are the
4 foundation for multidisciplinary treatment planning and referrals within an integrated, patient-centered
5 model of care.⁸ Future research should focus on developing clinically-pragmatic approaches to identify
6 priorities and align AdvLD treatment recommendations to achieve patient priorities.⁹ Additional future
7 research may involve developing and testing an integrated care approach informed by the synchronous
8 care model.
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CONTRIBUTORSHIP

Arney: acquisition, analysis, and interpretation of data; drafting of the manuscript; data analysis

Gray: acquisition, analysis, and interpretation of data; critical revision of the manuscript for intellectual content; data analysis

Walling: concept and design; interpretation of data; drafting of the manuscript; data analysis

Clark: interpretation of data; critical revision of the manuscript for intellectual content; data analysis

Smith: critical revision of the manuscript for intellectual content; administrative, technical, or material support

Melcher: critical revision of the manuscript for intellectual content; administrative, technical, or material support

Asch: concept and design; critical revision of the manuscript for intellectual content; supervision and material support

Kanwal: concept and design; critical revision of the manuscript for intellectual content; obtaining funding; supervision; data analysis

Naik: concept and design; acquisition, analysis, and interpretation of data; drafting of the manuscript; obtaining funding; supervision; data analysis

COMPETING INTERESTS

The authors have no competing interests to declare.

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DATA SHARING

Data are available upon reasonable request.

Ethics Approval

This study was evaluated and approved by Institutional Review Boards at each of the 3 VA healthcare system sites: Institutional Review Board for Baylor College of Medicine and Affiliated Hospitals (Federal Wide Assurance No. 00000286, Protocol H33191), Stanford University (FWA00000929 (VA), eProtocol 42849), VA Connecticut Healthcare System, Human Research Protections Program, Human Studies Subcommittee (FWA00001286, MIRB 02183)

BIBLIOGRAPHY

1. Bryce CL, Angus DC, Arnold RM, et al. Sociodemographic differences in early access to liver transplantation services. *American Journal of Transplantation* 2009;9(9):2092-101.
2. Kanwal F, Hernaez R, Liu Y, et al. Factors Associated With Access to and Receipt of Liver Transplantation in Veterans With End-Stage Liver Disease. *JAMA Internal Medicine* 2021
3. D'Amico G, Garcia-Tsao G, Pagliaro L. Natural history and prognostic indicators of survival in cirrhosis: a systematic review of 118 studies. *Journal of hepatology* 2006;44(1):217-31.
4. Woodland H, Hudson B, Forbes K, et al. Palliative care in liver disease: what does good look like? *Frontline Gastroenterology* 2020;11(3):218-27.
5. Kimbell B, Boyd K, Kendall M, et al. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open* 2015;5(11) doi: 10.1136/bmjopen-2015-009241
6. Low J, Davis S, Vickerstaff V, et al. Advanced chronic liver disease in the last year of life: a mixed methods study to understand how care in a specialist liver unit could be improved. *BMJ open* 2017;7(8):e016887.
7. Low JT, Rohde G, Pittordou K, et al. Supportive and palliative care in people with cirrhosis: international systematic review of the perspective of patients, family members and health professionals. *Journal of hepatology* 2018;69(6):1260-73.
8. Naik A, Arney J, Clark J, et al. Integrated Model for Patient-Centered Advanced Liver Disease Care. *Clinical Gastroenterology & Hepatology* 2020;18(5):1015-24.
9. Naik AD, Dindo LN, Liew JR, et al. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. *Journal of the American Geriatrics Society* 2018;66(10):1872-79. doi:10.1111/jgs.15437
10. Tandon P, Walling A, Patton H, et al. AGA Clinical Practice Update on Palliative Care Management in Cirrhosis: Expert Review. *Clinical Gastroenterology and Hepatology* 2020
11. Ufere NN, Donlan J, Waldman L, et al. Physicians' perspectives on palliative care for patients with end-stage liver disease: a national survey study. *Liver Transplantation* 2019;25(6):859-69.
12. Ufere NN, Donlan J, Waldman L, et al. Barriers to use of palliative care and advance care planning discussions for patients with end-stage liver disease. *Clinical Gastroenterology and Hepatology* 2019;17(12):2592-99.

13. Back AL, Park ER, Greer JA, et al. Clinician roles in early integrated palliative care for patients with advanced cancer: a qualitative study. *Journal of palliative medicine* 2014;17(11):1244-48.
14. LeMond L, Allen LA. Palliative care and hospice in advanced heart failure. *Progress in cardiovascular diseases* 2011;54(2):168-78.
15. Barber T, Toon L, Tandon P, et al. Eliciting and Understanding Primary Care and Specialist Mental Models of Cirrhosis Care: A Cognitive Task Analysis Study. *Canadian Journal of Gastroenterology and Hepatology* 2021;2021
16. den Herder-van der Eerden M, van Wijngaarden J, Payne S, et al. Integrated palliative care is about professional networking rather than standardisation of care: a qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. *Palliative medicine* 2018;32(6):1091-102.
17. Hysong SJ, Best RG, Pugh JA, et al. Not of one mind: mental models of clinical practice guidelines in the Veterans Health Administration. *Health services research* 2005;40(3):829-48.
18. Berwick DM. Disseminating innovations in health care. *Jama* 2003;289(15):1969-75.
19. Wagner KK, Austin J, Toon L, et al. Differences in team mental models associated with medical home transformation success. *The Annals of Family Medicine* 2019;17(Suppl 1):S50-S56.
20. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 2007;19(6):349-57.
21. Ritchie J, Lewis J, Nicholls CM, et al. Qualitative research practice: A guide for social science students and researchers: sage 2013.
22. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods* 2006;5(1):80-92.
23. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
24. Pope C, Ziebland S, Mays N. Analysing qualitative data. *Bmj* 2000;320(7227):114-16.
25. Morse JM. The Significance of Saturation. *Qualitative Health Research* 1995;5(2):147-49. doi: 10.1177/104973239500500201
26. Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age: Rand Corp Santa Monica CA, 2003.

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2
3 27. Manges K, Groves PS, Farag A, et al. A mixed methods study examining teamwork shared mental
4 models of interprofessional teams during hospital discharge. *BMJ quality & safety*
5 2020;29(6):499-508.
6
7
8 28. McComb S, Simpson V. The concept of shared mental models in healthcare collaboration. *Journal of*
9 *advanced nursing* 2014;70(7):1479-88.
10
11 29. Salas E, Wilson KA, Murphy CE, et al. Communicating, coordinating, and cooperating when lives
12 depend on it: tips for teamwork. *The Joint Commission Journal on Quality and Patient Safety*
13 2008;34(6):333-41.
14
15 30. Patel AA, Ryan GW, Tisnado D, et al. Deficits in Advance Care Planning for Patients With
16 Decompensated Cirrhosis at Liver Transplant Centers. *JAMA Internal Medicine* 2021;181(5):652-
17 60.
18
19
20
21 31. Hudson BE, Ameneshoa K, Gopfert A, et al. Integration of palliative and supportive care in the
22 management of advanced liver disease: development and evaluation of a prognostic screening
23 tool and supportive care intervention. *Frontline gastroenterology* 2017;8(1):45-52.
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Healthcare Provider Interview Guide

“For this interview, I will be asking you some questions about your experiences caring for patients with liver disease. You can skip any questions that you do not want to answer.”

“If you agree, your answers will be recorded using a digital voice recorder. Do you agree to be recorded?”

If yes: “Thank you. Once I start the recording, I will ask you to confirm that you have given your permission to be recorded so that I will have documentation of your agreement.”

If no: “Ok, that’s fine. I will take notes and will not record the interview.”

If the participant agrees to be recorded, start the recording and say:

“Could you please confirm that you agreed to be recorded as part of a research study entitled *Patient centered care for individuals with advanced liver disease*? And that you agreed to answer questions about your usual practices managing patients with advanced liver disease?”

Begin Interview

1. Tell me about your experiences caring for patients with liver disease.

What effect does the severity or stage of liver disease have on your experiences caring for these patients? (probe for examples of care at different stages)

2. What do you think patients and caregivers need to know about liver disease? (probe: disease cause, progression/severity, prognosis and treatment related information)

How is this information currently shared with them?

In your setting, who has the responsibility of sharing that information with patients? (probe for specific persons, staff, disciplines)

3. Based on your experiences, what some common health outcome goals for patients with liver disease? (probe for specific examples).

How do these health outcome goals change as the disease advances?

How do you discuss these health outcome goals with patients and their caregivers?

4. What strategies do you use to elicit patients’ health outcome goals?

What strategies do you use to align a patient’s health outcome goals with their treatment plan? (probe for examples)

What do you do in cases where the patient’s goals do not align with the treatment plan? (probe for examples)

Information Sharing

5. Describe how you share or discuss information with patients and their caregivers about the prognosis for their illness.

6. Describe ways to improve how prognosis and risk information is shared with patients and caregivers. What tools, procedures, or staff could help you share this information?

7. Please look over the example health information we provided.

How is this information valuable or helpful to you?

In what ways is it confusing or unclear?

What could make this information more useful to you?

What other types of similar information would you want?

Do you feel patients and caregivers could understand this information?

Experiences of Care

8. In your opinion, what therapeutic options are considered curative care for liver disease?

What about supportive care?

And palliative care?

What are some examples of patient outcomes that fall into each of these categories of patient care?

9. When in the patient's illness course do you discuss treatment options that are considered curative?

What about supportive?

Palliative?

When do you discuss end of life planning?

-If participant does not have these conversations ask: Who in the healthcare team typically has these conversations? How are they typically done?

10. How well integrated are these different approaches in your current practice? In your view, how would a truly integrated approach to cirrhosis care look?

11. How would you be able to adapt your current practice to allow for a more integrated approach into the normal workflow and routines?

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3 Describe the resources, staff, and leadership you have in your setting and how they can be
4 facilitators for a more integrated approach to cirrhosis care.
5

6 Describe the barriers to integrated cirrhosis care. What additional resources are needed?
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9 12. Describe your process for developing the patient's treatment plan for liver disease.

10 What role do the patient and their caregiver have in this process? (probe for examples)

11
12 What tools, resources, or staff are necessary to better engage patients and caregivers in this
13 process?
14
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16 13. Please take a look at the journey map.

17
18 Where in the patient's illness trajectory do you think a more collaborative approach can and
19 should occur?
20

21
22 Where in the patient's illness trajectory would you discuss different types of prognosis data?
23 (probe: what are the different types of prognosis information that is best suited for various
24 times along the illness trajectory?)
25

26 **Barriers & Facilitators of Advanced Liver Disease Care**

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29 14. In your opinion, what would a more collaborative approach to liver disease treatment planning look
30 like?
31

32 What skills and resources do you think you would need to facilitate developing a more
33 collaborative treatment plan with the patient and their caregiver?
34

35 15. What additional staff or health care professional are needed for a more collaborative model of
36 treatment planning?
37

38 How would their roles and responsibilities differ from yours?
39
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41 16. What would facilitate a more collaborative approach to liver disease treatment planning? (probe:
42 context, procedures, etc)
43

44 17. How useful do you think it would be to have decision support tools to assist in conversations with
45 liver disease patients?
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47 What kinds of tools would be most useful?
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50 What is the best way to implement decision support tools into the routine process of liver
51 disease care?
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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.