

Partnering with support persons and clinicians to improve the health care experiences of patients with cirrhosis

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Abstract

Aim: To explore the care experiences of Aboriginal and Torres Strait Islander Australians diagnosed with cirrhosis with a focus on support needed.

Background: Cirrhosis disproportionately affects Indigenous Australians, and liver diseases contribute to the mortality gap between Indigenous and other Australian adults.

Design: A qualitative study.

Methods: Using yarning methods, Indigenous patients ($n = 13$) and support persons ($n = 3$) were interviewed by an Aboriginal researcher during April–July, 2020. Thematic analysis was used to identify common themes using an inductive approach.

Results: Six themes emerged. (1) *Experience of diagnosis*. This theme included stories of delays in the system, self-awareness of signs and symptoms and relief of being diagnosed. (2) *'Shame, shame, shame'*. Experiences of prejudices and discrimination from health professionals, the lack of understanding of cirrhosis among health professionals, and stories about alcohol cessation and counselling around alcohol cessation. (3) *Health literacy*. Participants' understanding of cirrhosis was variable. While the importance of knowledge was recognised, *'what works for someone might not work for others'*. Several patients partnered with their support persons and clinicians to bridge the health literacy gap. (4) *Sources of support* included family and friends, transport facilities, health professionals and peers. (5) Positive and negative aspects of *communication and patient consultation* were discussed. (6) *Psychosocial counselling to 'look after the caring side'*. The need for more mental health care services was raised.

Conclusion: Barriers related to poor health literacy, stigma and lack of practical and emotional support, and issues with communication and patient consultation, may lead to inequitable access to cirrhosis care and treatment for Indigenous Australians.

Elizabeth E. Powell and Patricia C. Valery contributed equally.

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Relevance to clinical practice: Gaining knowledge of the experiences of Indigenous Australians with cirrhosis is important for providing patient-centred and culturally appropriate care. Liver specialist nurses have an important role in bridging the health literacy gap and in supporting Indigenous patients and families.

KEYWORDS

alcohol, chronic liver disease, patient knowledge, qualitative study, stigma, supportive care

1 | INTRODUCTION

A small number of studies reported the perspectives, experiences and unmet supportive care needs of people diagnosed with cirrhosis (Hjorth et al., 2020; Valery, Clark, et al., 2017; Valery et al., 2015, 2021). In Australia, very high levels of needs among 458 patients with cirrhosis were reported, with the level of unmet need and the specific items requiring additional assistance varying according to patient age and liver disease severity and aetiology (Valery et al., 2021). In Sweden, a recent qualitative study showed that despite varying disease severity among the 20 patients with cirrhosis interviewed, most expressed anxiety or depression, and living with cirrhosis was interpreted to be unpredictable, 'like riding a roller-coaster' (Hjorth et al., 2020). In the Swedish study, to manage new demands, patients reported making an effort to understand the disease and its management on their own or with support from relatives. Bernardes et al reported that Indigenous Australians with cirrhosis ($n = 20$) had higher levels of needs for psychosocial issues and practical and physical needs, compared to non-Indigenous patients (Bernardes et al., 2021). With this being the only study examining the support needs of Indigenous Australians with cirrhosis, further research is needed to extend and complement this information, in particular exploring the experiences and support needs of Indigenous Australians through a qualitative study.

2 | BACKGROUND

Cirrhosis is the advanced stage of many chronic liver diseases (Schuppan & Afdhal, 2008) and the greatest risk factor for liver cancers (Forner et al., 2018; Parker et al., 2014). Over 80% of cases of hepatocellular carcinoma, the most common type of primary liver cancer, arise in cirrhotic patients (Forner et al., 2018; Parker et al., 2014). Importantly, cirrhosis and hepatocellular carcinoma disproportionately affect Aboriginal and Torres Strait Islander Australians (respectfully referred to as Indigenous Australians) (Powell et al., 2019), and liver diseases are the third most common contributor to the mortality gap between Indigenous and other Australian adults (Australian Institute of Health and Welfare (AIHW), 2011).

A total of 779 Indigenous patients were admitted to a Queensland hospital with cirrhosis during 2007–2016. Alcohol misuse and hepatitis C virus (HCV) were the most common specific liver disease aetiologies (Valery et al., 2020). The rate of hospital admissions for cirrhosis was 3.4-times higher for Indigenous vs. non-Indigenous

What does the paper contribute to the wider global clinical community?

- From an international perspective, the narratives of Indigenous Australians diagnosed with cirrhosis form a useful case study of how a disadvantaged group experience poor health outcomes and relatively poor access to health care.
- Many Indigenous Australians with cirrhosis confronted a range of barriers related to poor health literacy, stigma, and lack of practical and emotional support.
- Understanding the experiences of this patient group is key to achieving patient-centred and culturally appropriate care for patients with diverse backgrounds. Liver specialist nurses play a significant role in the healthcare team, in particular in bridging the health literacy gap and in supporting patients from marginalised communities and their families.

Queenslanders (Powell et al., 2019), and Indigenous patients had more emergency presentations and readmissions for cirrhosis, and lower survival (Valery et al., 2020). These findings point to the potential inequities in coordination of care of chronic liver disease for Indigenous patients.

Despite the overrepresentation of Indigenous Australians among patients with cirrhosis and liver cancer, there is no chronic disease program specifically targeting chronic liver disease in this patient group. A few community programs and resources exist specifically targeting liver health promotion and viral hepatitis among Indigenous Australians. For example, the Nunkuwarrin Yunti Primary Care services has developed a range of booklets about HCV (e.g. 'Hep C is everyone's business') (Powell et al., 2019). The Deadly Liver Mob Program is a peer-driven health promotion program on HCV conducted together with a needle and syringe program and sexual health clinics (Treloar et al., 2018). A recent Australia-wide study reported high cure rates of HCV for Indigenous Australians (94% achieved a sustained virological response), an outcome that was comparable to that of non-Indigenous Australians (95%; $p = 0.17$) (Yee et al., 2022). However, Indigenous patients appeared to have higher rates of loss to follow up (24%) compared to non-Indigenous patients (15%; $p = 0.05$).

The current mainstream clinical and support pathways may not meet the supportive care and health literacy needs of Indigenous

patients with chronic liver disease and liver cancer. With an overarching objective of investigating the efficacy and appropriateness of mainstream clinical pathways for Indigenous Australians with cirrhosis, the aim of this research was to explore the positive and/or negative care experiences of Indigenous Australians diagnosed with cirrhosis with a focus on support needed and whether the available supports were helpful or not.

3 | METHODS

3.1 | Design

A qualitative research design was chosen to explore the care experiences of Indigenous Australians with cirrhosis as it was deemed the most suitable design when there is limited research and information about a subject, and when in-depth information is required to develop a systematic understanding of the relevant issues (Creswell & Creswell, 2018). Yarning methods (Bessarab & Ng'andu, 2010) were used to conduct semi-structured interviews with Indigenous Australians who were part of the CirCare study and their nominated support person. Yarning is a culturally appropriate, informal conversational process that involves the sharing of stories and the development of a deep understanding of the research topic (Geia et al., 2013). The CirCare study included adult patients diagnosed with cirrhosis attending liver clinics or admitted to one of five hospitals in Brisbane and Logan during Jun-2017 to Dec-2018 (Valery et al., 2021). Indigenous patients were recontacted via a letter and invited to take part in an interview. At the end of the patient interview, participants were invited to nominate their primary support person. The nominated support person was then invited to participate.

3.2 | Researchers' characteristics and reflexivity

The research team included both clinicians and non-clinician researchers, namely two hepatologists (EEP and PJC), a medical epidemiologist (PCV), a registered nurse specialised in public health (CMB), two qualitative researchers (SS and MT), and the interviewer specialised in health promotion (CB). The team also comprised researchers from diverse cultural and linguistic backgrounds. Two of the authors are of Aboriginal backgrounds (CB and MT) and all the remaining authors are non-Indigenous. Most interviews were conducted with one interviewer (CB), an Indigenous woman, descendant of the Noonucal group of the Quandamooka people of Minjerribah—North Stradbroke Island. Three of the interviews were conducted by two interviewers together (CB and CMB). Both interviewers had previous experience conducting qualitative interviews. The main interviewer (CB) was unknown to all participants prior to the interview, and the second interviewer (CMB) had recruited participants into the CirCare study. The research team composition promoted reflexivity across the research process, by including Indigenous as well as non-Indigenous perspectives and clinical and non-clinical perspectives.

3.3 | Framework and data collection

An invitation letter was sent to potential participants and followed up with a telephone call where CB provided a brief explanation of the study and invited them to participate. Interviews took place between April and July, 2020 at times suitable for participants. Patients and support persons were interviewed separately. The study was conducted during the COVID-19 pandemic lock-down period when there were varying levels of restrictions depending on the place of residence. Following those restrictions, all interviews were conducted over the telephone ($n = 15$) except for one face-to-face interview. Written consent was obtained from each participant. To recompense participants for their time and effort, a \$50 gift voucher was posted to participants on completion of the interview. Interviews lasted between 44 and 100 min (average 67 min). All interviews were recorded and professionally transcribed verbatim.

The data collection followed the 'Yarning' framework described by Bessarab and Ng'andu (2010), in which the interviewer allowed time for social yarn before the formal study procedures were carried out (describing the project, obtaining written informed consent and discussing the topic) (Bessarab & Ng'andu, 2010). This moment provided space for sharing cultural protocols, building rapport and trust between the interviewer/s and participant. Topic yarn questions that are described in Box 1 were formulated to address broader study aims. Clinicians and non-clinician researchers in the research team formulated the topic yarn questions based on their practice (clinical and research experience in chronic liver disease and cancer). Open-ended questions explored participants' perspectives about how patients access care, receive care or were supported when diagnosed with cirrhosis. This interview format allowed for further investigation of relevant issues as they emerged during interviews (Harding, 2013). The interviewer started by inviting participants to talk about their journey with cirrhosis, and what factors influenced their or their family members' care and treatment. Although the direction of the interviews was largely determined by the participants, topic yarn questions assisted the interviewer to stay on track. Support persons were asked to reflect on how they believed the patient had experienced the disease process and to answer the interview questions with that in mind. Because the support person's responses were about the experience of the patient, their answers were presented in the manuscript alongside the patient's responses. Throughout data collection and analysis, memos were written by the interviewer (CB) to record reflections about the interview and notes were taken during the initial analysis. Researchers considered data saturation had been reached when no new views were arising from the interviews and verified this through the use of a cyclical process whereby preliminary analysis was undertaken during the data collection (Francis et al., 2010; Glaser & Strauss, 1967). Although it was not possible to seek validation of findings by returning the transcripts to participants for comments or corrections, clarification of key concepts was sought throughout the data collection process and, during the interview, participants were given the chance to contact the research team if

BOX 1 Semi-structured interview guide**The diagnosis**

A good place to start is to think back to the time when you first got to know there was something going on with your liver.

Where did you go to find out?

Do you know what you have got (diagnosis)?

After that, what happened? Where did you go?

How things happened to you and who supported you

Who helped you? How?

How was the decision about treatment taken?

What was your experience of treatment?

What sort of support did you seek?

Who supported you the most?

What sort of supports were helpful and what not?

What helped you get going with this journey?

Negative and positive experiences navigating the health system

As a person with cirrhosis/liver cancer or carer or family member, did you feel any aspects of health services made it harder for people diagnosed with cirrhosis/liver cancer or the experience more distressing?

Can you share some of your positive experiences (if any) with the services with us?

they had any additional questions or comments. In addition, participants were contacted 1–2 weeks after the interview to check if they received the gift voucher, giving them another opportunity for questions or comments.

3.4 | Data analysis

Thematic analysis was used in order to identify common themes using an inductive approach (Willis, 2019). Firstly, the transcripts were read by two researchers (CB and PCV) for data familiarisation. Subsequently, they reread each transcript independently to identify meaningful analytical units from each transcript, which were labelled as codes (descriptive words). The codes were refined and readjusted based on the differences and similarities between the researchers' perspectives, and meaningful categories were constructed. Disagreements were negotiated until a consensus was reached. Researchers trialled the codes and emerging categories across a number of transcripts to make sure that they captured the ideas they wanted to code (Willis, 2019). After consensus was achieved, the codes were labelled and grouped into sub-themes and themes. At this stage some amalgamation of themes occurred. This process contributed to increased reflexivity. Microsoft Excel (Microsoft Office Professional Plus 2016) was used to organise codes, sub-themes and themes. Patient characteristics were analysed using Stata/SE (Version 15; Stata Corporation).

3.5 | Ethical considerations

Approval was obtained from the Human Research Ethics Committees of the QIMR Berghofer Medical Research Institute

(P2207) and Metro South Health (HREC/16/QPAH/628). To ensure transparency, the study methods followed the Consolidated Criteria for Reporting Qualitative Research (File S1) (Tong et al., 2007).

4 | FINDINGS**4.1 | Participant characteristics**

Twenty six adults who identified as of Aboriginal or Torres Strait Islander descent were included in the CirCare study. Five were deceased when the current study was undertaken, and 21 patients were invited to participate. Thirteen participants (seven females and six males) were interviewed, six declined to take part, and two were unable to be contacted via the telephone numbers that they had provided. Of 13 patients who took part in the study, three agreed that we contact their support person to take part in the study. Three female support persons (a patient's partner, family member or caregiver) were interviewed. The characteristics of patients included in the study are described in Table 1.

Six themes and 16 subthemes were obtained through analysis of the transcripts. These are summarised in Table 2 and described as a narrative below.

4.1.1 | Theme 1. Experience of diagnosis

The 'experience of diagnosis' comprised our first theme, as this emerged from the participants' descriptions of the patient journey.

Delays in the system

For many participants, the journey before a diagnosis of cirrhosis was estimated to be several years with some participants

TABLE 1 Characteristics of patients interviewed

Characteristics	Number of participants (N = 13)
Gender	
Female	7
Male	6
Age group	
18–39 years	1
40–49 years	2
50–59 years	6
60–69 years	4
Marital status	
Married/partner/de-facto	5
Single	6
Separated/divorced	2
Education	
Junior High School or less	9
Senior High School	1
Trade/Diploma	2
Information missing	1
Currently employed	
Employed	2
Not employed	11
Socioeconomic status ^a	
Q1 Most affluent	2
Q2	1
Q4	3
Q5 Most disadvantage	7
Remoteness of residence ^b	
Major city area	10
Outside major city area	3
Child-Pugh class ^c	
A	10
B	1
C	2
Presence of complications of cirrhosis	
Compensated	10
Decompensated	3
Primary diagnosis ^d	
Alcohol	5
Chronic hepatitis C virus	4
NAFLD/NASH	3
Other	1
Non-alcoholic fatty liver disease as primary diagnosis or cofactor	5
Alcohol as primary diagnosis or cofactor	8
Diabetes	5

^aPlace of residence categorised according to the Index of Relative Socioeconomic Advantage and Disadvantage;(13).

^bPlace of residence categorised according to rurality of residence;(14).

^cSeverity of disease was classified using the Child-Pugh class.

^dPatients may have more than one presumed aetiology/cofactor.

recounting stories of delays in the system. Some participants reported seeing many different doctors before receiving a diagnosis of cirrhosis. Others recounted having difficulties organising appointments.

I was sick for years and I kept saying to my doctor it's here it's where my liver is. [And doctor responds] 'No no no it won't be your liver'. And you know when you've got pain in an organ (#4034 female, NAFLD, CP-A)

'You ring up for an appointment but you had to wait for that date because they say, 'They can't do it this month'. And they said when you get to that appointment, 'Oh sorry, we've got to re-book you. (#2123 female, alcohol, in a nursing home, CP-A)

Self-awareness

Awareness of signs and symptoms was varied among participants. Some participants with a long history of alcohol misuse were aware that alcohol was a risk factor for cirrhosis, and acknowledged that the diagnosis was not unexpected, whereas others described it as a complete surprise.

I was running out of steam more than I normally had and then, I don't know, I just sort of felt funny (#3154 male, hepatitis C/alcohol, CP-A)

I was just drinking... and the next minute I had this huge stomach. So that was really my first like wake up call of something was very alarmingly wrong, but there probably were other signs that I missed. ... So it was the shock value that sent me to the doctor (#2435 female, alcohol, CP-A)

Relieved to be diagnosed

Although the experience of receiving a diagnosis was variable, some participants found that identification of cirrhosis was a source of relief, or even reassurance and recognition of their concerns. One patient expressed gratification in receiving a diagnosis.

I was quite glad because someone found something was wrong (#3005 male, alcohol, CP-C)

A support person expressed a sense of relief that her partner was diagnosed so he could no longer ignore his symptoms.

I just didn't think it was right how his [patient] belly was swelling up all the time and I said something's going on there. And he'd get pains in the side every now and then... I just kept at him, I nagged him into it really. Yeah [patient] is the type of person generally that if he ignores it [his symptoms], it doesn't exist

TABLE 2 Supporting quotes for major categories

Sub-themes	Theme 1. Experience of diagnosis
1. Delays in the system	'Yeah I was sick for many, many years...and probably 10 years before that I actually got diagnosed and also throwing up some mornings like a vile coming out of me stomach, a yellow vile. That persisted for 10 years through five doctors and not one of them said it was me liver.... and the last 3 years before me diagnosis I was pretty, pretty, pretty sick and still no one come up with the brainwave until I turned yellow' (#3005 male, alcohol, CP-C)
2. Self-awareness	'Well I didn't really notice too much but I was getting a bit tired and I was running out of steam more than I normally had and then, I don't know, I just sort of felt funny. See when I got off the grog pretty hard gee I'd think, 'Jeez I'm getting crook, I'm getting old' or there was something not right, you know what I mean? And then I just knew something wasn't right, so they sent me off to get a heap of bloods done...and next minute we found out about the hepatitis C and cirrhosis' (#3154 male, hepatitis C/alcohol, CP-A) 'I was quite alcoholic. I knew that for a number of years before I had liver issues. I started off as a kind of a social drinker...then became a moderate drinker, then I sort of went through a life crisis... I was drunk twenty-four seven. And then I developed ascites' (#2435 female, alcohol, CP-A)
3. Relieved to be diagnosed	'... even though I was crook and I was sick, I was stuffed, it was still a relief to know why I was crook. It's like it had come to the end. It's like. 'Well I either drop dead or they fix me, either way it should be good'. I won't continue on not knowing.... you can move on with your life, you can plan it, or not plan it....but when you don't know, you just don't know. Everything's on hold' (#3005 male, alcohol, CP-C)
Theme 2. 'Shame, shame, shame'	
1. Prejudice and discrimination	'Just that everybody thinks you're an alcoholic... that's all they associate cirrhosis with' (#3122 male, hepatitis C /alcohol/fatty liver, CP-A) 'I'm an ex-addict and they [doctors] are still treating me like I'm an addict' (#4064 female, uncertain diagnosis, CP-A) 'None [stigma/discrimination] whatsoever. None whatsoever. It could have been bloody cancer or it could have been anything and I would have been treated the same. There was no discrimination against me whatsoever' (#3005 male, alcohol, CP-C) 'I didn't want to take that [stigma/discrimination] on board you know what I mean? So I didn't look for that sign.... I wanted to get better, that's all I wanted to do.... I probably could say yes to that [there was stigma/discrimination]. But at the end of the day that wasn't what I was there for. I was there to get better' (#3154 male, hepatitis C /alcohol, CP-A)
2. Health professionals' lack of understanding of cirrhosis	'When you tell people on the forms.... do you have cirrhosis; but it only has a box that ticks yes. 'Yes' or 'No'. So there's no box to tick 'fatty liver cirrhosis' or 'alcoholic cirrhosis'.... [doctors ask] 'How much do you drink?'.... I don't drink. They're assuming 'Yes'. But I love it because they say 'How much do you drink' and I say 'I don't'. A lot of people don't understand that, that I don't drink. Well 'how did you get cirrhosis of the liver?'.... I find a lot of nurses don't really understand' (#4034 female, NAFLD, CP-A)
3. Alcohol	'I haven't had a drink since the [date of cirrhosis diagnosis] and at the liver clinic, I got told about an alcohol meeting over there [that] you go to for support. You know, I said I don't need it.... If I say I'm not going to do [it] I won't do it. They said 'You've been drinking all these years and you're going to stop?' I said 'Yes'. I haven't had any alcohol since the [date of cirrhosis diagnosis], 4 years ago....the fact is, you have to want to give it up yourself. No one can force you to do it, you have to want it so badly, to stop doing it. You have to want it within. And if you don't want to, if you haven't got that within you to stop, you're not going to' (#2419 female, alcohol/fatty liver, CP-B) 'They gave me 2 years pretty much, [liver specialist] was pretty brutal, she says, 'You keep going down this path and you're dead in 2 years'.... It was like, 'Sober up or die'.... I think it was a scare tactic that worked for me' (#2435 female, alcohol, CP-A) 'A lot of people wouldn't know how to face that [quit alcohol] but I was lucky I lived out in the bush... the temptations weren't there so that helped.... [In town] you just got to walk past a pub.... First thing that comes in to your head in town is beer. So if you can avoid town you can do all right' (#3154 male, hepatitis C /alcohol, CP-A) 'That can be a little bit overwhelming in itself like saying, 'Hi I'm... and I'm an alcoholic and blah, blah, blah' in front of fifteen, twenty people is hard. And I did see a drug and alcohol counsellor for a while at [suburb name], but I don't think I was in the headspace [to] take on board anything that he was telling me that could have been helpful. You know, half the time I was half sloshed before I got to the appointment, and then I'd go straight to the pub when I finished speaking to him [counsellor].... I wasn't in that space to kind of accept that I wanted help; I didn't really want to give up drinking at that point I don't think' (#2435 female, alcohol, CP-A) 'If I knew not to drink, what the consequences were, I would not have even touched anything. No, I wouldn't have drank' (#2419 female, alcohol/fatty liver, CP-B) 'No that was a long time ago. I had to learn to stop [alcohol] myself.... They didn't really have any of that [alcohol counselling services] out in the country' (#2123 female, alcohol, CP-A)

TABLE 2 (Continued)

Theme 3. Health literacy	
1. Lack of knowledge	'I wish I'd known about a fatty liver and why wasn't there more information, and why weren't people told about it early. Now there are people out there saying yeah I've got a fatty liver, and so what. I know its fat. Oh yeah I've got a pain, so what. It's no good you've got to stop your drinking, that's number one, you've got to stop your drinking.... Now if I had known years ago what a fatty liver meant I wouldn't have raised a glass, at all' (#2419 female, alcohol/fatty liver, CP-B) 'I was aware of cirrhosis that was caused from alcohol, I was not aware of cirrhosis that was just caused by diet.... it would be really advantageous if all of us could be educated more fully about the cirrhosis.... and fatty liver disease is as harmful as cirrhosis that's caused from alcohol' (#2095 female, fatty liver, CP-A)
2. 'With knowledge comes responsibility'	'With knowledge comes responsibility, you know. You gain more responsibility for your own health that way too' (#2095 female, fatty liver, CP-A) '[Hepatic encephalopathy] It's when the toxins that your liver isn't filtering out of your blood stays in your blood. And then toxins give you a fuzzy brain... they introduced a new medication to me... I've now got to go to the bathroom and have bowel movements like four or five times a day or I get this thing [hepatic encephalopathy]. I've got to do it every day, I've got to take an antibiotic that stops this thing from happening' (#5056 male, alcohol, CP-A)
3. 'What works for someone might not work for others'—proactive learner vs. illiteracy	'It's always handy to get information to absorb later on. Because some people just can't read but they do know someone that can you know help them repack, understand' (#2095 female, fatty liver, CP-A) 'I don't read well, you know... I'm not ashamed of it. It's just the way it is and I explained to them that I can't read. And I don't know, they just think you know everybody's got somebody there to read [the brochures about liver disease] for them or whatever, or they [doctors] hope there is' (#3154 male, hepatitis C / alcohol, CP-A) 'Well the ones [leaflets about cirrhosis] I've read they're very general, they don't give you the finer points like they just tell you what the disease is, one or two hints and that's it really. The majority of the rest is like, 'Ring this mob for this support', you know that sort of crap. No real you know finer points of what might happen and what you should do' (#3122 male, hepatitis C / alcohol/fatty liver, CP-A) 'Well basically I've educated myself with Google. Oh yeah well I've used it many times. Yeah well they got me to see a specialist... I'd see him [liver specialist] once every 3 months.... Yeah I had pamphlets and that. I noticed that they [doctors] used a lot of Google themselves..... 'I've now got decompensated liver disease. It means I could drop dead any minute. Yep and I think it's about a 2-year survival before I drop dead any minute. And that was diagnosed 6 months ago.... I've got all that information off Google about the death rates and all that sort of stuff and it's come from many different clinics in the UK and the United States. I've had to research it myself because they [doctors] don't actually come out and tell me that' (#5056 male, alcohol, CP-A) 'I'm with a Facebook group with the Australian Liver Council and ... [Knowledge] It is incredible power' (#4064 female, uncertain diagnosis, CP-A)
4. Bridging the health literacy gap	'[Liver specialist] was quite good and he puts everything in to simpler terms. He can talk technical if you want to, but he puts it in to a perspective where it's easy for people to understand what's going on.... He [liver specialist] has been good and he tells me everything that I need to know' (#3152 male, hepatitis C / alcohol / fatty liver, CP-A) 'The nurse was lovely and she sat me [partner], with her [patient] and said everything that I needed to hear because I didn't know much about it [cirrhosis]' (Support person #2435) 'Everything has been good and everyone has been good and supportive.... the most positive thing is the relationship between his case nurse, himself [patient] and myself [partner]. Because without [case nurse] we would have probably been bumbling a lot around in the dark. You know like I could ring her [case nurse] and she would like go and get the answers and come back. She always rang when she said she would ring' (#3152 male, hepatitis C / alcohol / fatty liver, CP-A)
5. Suggestions around improved information flow	'...they [liver clinics] need to start getting clients to talk to each other in the waiting room..... you see the same faces regularly, you know.... something could be implemented in the actual waiting room.... if you've got that commonality, and also those foyers and waiting areas they can be used as, rather than just have random TV up they can be used as interactive education about the illnesses.... you can use the screen as an inclusive thing too. You use cartoon characters or whatever, but all different shades of the race rainbow, you know what I'm saying. Because it touches everybody, when I go there, you know wealth of nations, whatever you want to call it. It's very multicultural' (#2095 female, fatty liver, CP-A) 'I'll bring her [partner] in [to appointments with liver specialists] with me and she [partner] sort of explains, listens to them [doctors] and explains it to me' (#3154 male, hepatitis C / alcohol, CP-A)

(Continues)

TABLE 2 (Continued)

Theme 4. Sources of support	
1. Support from family and friends	'It does help being able to talk to my family.... yeah it's always very therapeutic to share, always someone to talk to' (#2095 female, fatty liver, CP-A) 'She [wife] is the heart and soul of this house and she just keeps me, she tells me what to do. You know she just keeps me going, does me appointments for me, without her I'd be nothing. She does everything for me.' (#3152 male, hepatitis C/alcohol /fatty liver, CP-A) 'I've got a friend I live with; I've lived with her for quite a while. She's like, she's really good. She helps me do stuff. She's my carer.... we go shopping together and she'll help me do that and it's just basically everything. Like family support' (#5056 male, alcohol, CP-A) 'Help from my partner was not very good.... He actually um walked... He was gone trailer and all, so I just am getting my head around that.... to me it's just a huge betrayal at this time you know' (#2095 female, fatty liver, CP-A) 'Not the true extent of it [diagnosis] no. He [patient] told me [Support person] he had cirrhosis and Hep C, but he didn't say anything about the cancer or pre-cancer or whatever it was until recently and he still hasn't explained it to me... and if he talks to me about it then he thinks he's worrying me for no reason. Let him take all the worry' (Support person #3154)
2. Transport provision	'... I can't walk far anyway and the transport to all my appointments, which is 50 Ks away really.... nearly every one of my appointments is down in Brisbane. So that [transport] is the most important bit.' (#3122 male, hepatitis C /alcohol/fatty liver, CP-A) 'They're very good [transport service]; they take me to and from appointments. They're the ones that eventually realised that something was wrong and got the police to break in.... I was sort of 5 days and no one could contact me so they all started worrying' (#3122 male, hepatitis C /alcohol/fatty liver, CP-A)
3. Public transport	'...we've got a ferry, and then we've got a bus, and then we've got a train, and then you've got to walk from [train station] to the [hospital] you know. It's like a 2-h trip there and a 2-h trip back.' (Support person of #2435 female, alcohol)
4. Support from health professionals	'I could ring her [case nurse] and like ask her with medicines, 'Is it [medicine] compatible?'.... I just got the script [from the GP] and I said, 'I'm really not sure about this, I don't think that this is one that you can have'. And so I just rang [case nurse] and I said, 'Look he's been prescribed this antibiotic'. She [case nurse] said, 'Give me a minute' and she comes back, 'No, no, no not that one', and then gave us the name of another one that he [patient] could go on.... Yeah in the doctors [GP] clinic.... Many a time I've done that and [case nurse] has just, doesn't even flinch. It's never too much trouble for her.' (Support person #3152) 'Yeah that was hammered in to me about salts and fluid building up and what to eat. They [dieticians] gave me all the brochures, they sent me stuff you could cook and eat, and different recipes and, I think there's a helpline there or something. But heaps of information about food. They give you websites you can jump on to about all that sort of stuff, and what food you should and shouldn't eat. They were really, really on to that. It's absolutely excellent' (#3005 male, alcohol, CP-C)
5. Peer support	'What we need is like a buddy system from the get go and then people identifying when to let the clients walk on their own, you know, be without someone. Well maybe volunteers, that have had or come out of the illness at a certain stage or are at a certain level and they just want to be there and talk you through, or it could be a health professional that's a paid employee or a combination of both, you know. Just being with [you] from the get go, from the first appointment, be allocated to that person.... your liver person. To support you through your journey' (#2095 female, fatty liver, CP-A) 'The Indigenous liaison officer over at [hospital] told him [patient] of the story of her brother ... that he got through it, and that he now doesn't have an active Hep C thing. And I think it was her [Indigenous liaison officer] that made him [patient] think, 'Right, I can do this. I can beat this'. (Support person #3152) 'Networking is really important to give you strength in times of finding out you've got an illness, is very similar to um being thrown into the grief because it's a loss, it's a loss of your functioning. Illness disability whatever you want to call, it's a loss of your functioning.... So networking, and that's where [liver clinic] is good, but they need to start getting clients to talk to each other in the waiting room' (#2095 female, fatty liver, CP-A) '[Liver nurse] and I [partner] used to discuss that there really should be a support group for people and partners or family members of the person going through it [cirrhosis] to have someone to talk to... Just to talk, to have someone, because to talk about other people's experiences and learn from different people how they may handle things that you could implement or I could have implemented in my life to handle situations different and be a better support person for [patient] going through it' (Support person #3152)

TABLE 2 (Continued)

Theme 5. Communication and patient consultation
'She [liver specialist] was brilliant. She explained exactly what was going on... why the cough was there... why I felt like I did... why I was throwing up that vile. She explained the whole lot and then I knew' (#3005 male... alcohol... CP-C) 'When I went in to see him [the doctor]... he goes 'have you made your will out?' I said excuse me. Anyway... he finished. I was livid... I was... my blood pressure went up that's not the first time... I've been asked about four times. All in different ways... about 'have you got someone to support you'... and 'have you got everything you need already set up'... It was like he [the doctor] read it... he read it the way it was said. Like on the template. And it wasn't nice.' (#2419 female... alcohol/fatty liver... CP-B) 'And the [specialist] at the hospital that I was with... sadly she wasn't a good fit for me. She was very glib every time... and I felt like she just was treating me like an overweight patient... which is not fair in this day and age.... and that's not taking anything away from... I respect her intelligence... I respect her ability and all the rest of it. But there's got to be a level of compassion maintained' (#2095 female... fatty liver... CP-A) 'The [liver specialist] just said... 'Listen at the end of the day if you don't stop drinking you've got maybe 12 months... 8 months to live'... she [liver specialist] was very blunt..... The nurse was lovely and she sat me [Support person] with her [cirrhosis patient] and said everything that I needed to hear because I didn't know much about it [cirrhosis]..... The doctor was very blunt.... I [Support person] just sat back and listened... and I had tears in my eyes... and I think I felt weak. [cirrhosis patient] wasn't weak in any way; she [patient] sort of just kept staring at her [liver specialist].... and we went to a nurse on the end section... and the nurse sat down and had a really good talk to her [cirrhosis patient]. I thought the nurse really pushed it more to sanity... you know what I mean?' (Support person #2435)
Theme 6. Psychosocial counselling to 'look after the caring side'
'I'm pretty anxious, so I'd already been diagnosed for anxiety and depression since childhood, so I feel those things [having cirrhosis] probably a bit harder than someone who doesn't have those mental health concerns or conditions.... I had a few incidents where I was suicidal and had to be taken by ambulance to [Hospital]' (#2435 female, alcohol, CP-A) 'At one stage I actually booked myself in to the mental clinic across the road because I had an altercation with a bloke and I was going to kill him. I was like a loose cannon. I couldn't control myself' (#3152 male, hepatitis C /alcohol /fatty liver, CP-A) 'Counselling, psychological support is essential with any chronic illness diagnosis or disability... That is the huge gap there's not enough of it.' (#2095 female, fatty liver, CP-A) 'I don't need that [counselling]. All I've got to do is tell myself and that's it. I'm pretty strong minded, very strong minded like that... you tell me I'm going to die unless I quit drinking then I'll quit drinking. I'm not ready to go yet. I don't want to see me ... me kids don't want to see me all buckled up when I had a chance to come good, that's just not cool to them either is it?' (#3154 male, hepatitis C /alcohol, CP-A)

Note: Child-Pugh class A (CP-A); Child-Pugh class B (CP-B); Child-Pugh class C (CP-C).

sort of thing. It actually ended up being his [patient] idea to finally go. He admitted that there was something going on. (Support person #3154)

health professionals. In contrast, others felt that there was no stigma or discrimination in the way they were treated or chose to ignore it. One participant articulated that:

'... you kind of earn your right of passage' by attending appointments so that medical staff come to 'recognise a person that shows up all the time' (#5056 male, alcohol, CP-A)

4.1.2 | Theme 2. 'Shame, shame, shame'

Awareness of the causative link between alcohol and cirrhosis can create health-related stigma and discrimination that can then lead to inequitable access to healthcare.

Prejudice and discrimination

A few participants recounted stories in which patients experienced prejudice and discrimination from health professionals when they received a diagnosis of cirrhosis. This was expressed particularly by participants with cirrhosis due to alcohol misuse or chronic hepatitis C.

When I had my gallbladder out the doctor that took it out was quite rude and negative about... he [doctor] goes, 'You drink' and I said, 'No'. And he goes, 'Shame, shame, shame' and he just didn't believe anything I said. He was quite rude about it actually... (#3152 male, hepatitis C /alcohol /fatty liver, CP-A)

Health professionals' lack of understanding of cirrhosis

Many participants felt that health professionals made judgements or assumed that cirrhosis was equivalent to alcohol misuse, which potentially demonstrates a lack of understanding of cirrhosis among

Alcohol

As alcohol was a cofactor or the primary aetiology of cirrhosis for eight participants, many participants recounted stories about alcohol cessation and counselling. Some accounts were given about how inner strength facilitated the process of alcohol abstinence. Others reported that 'scare tactics' worked for them (#2435 female, alcohol, CP-A). One participant articulated how he found strength to cease alcohol through his lived experience in the bush. Alcohol cessation counselling was viewed by some participants as a 'little bit overwhelming' (#2435 female, alcohol, CP-A) as they were expected to talk about alcohol misuse in front of a group of people, while others expressed interest in counselling but said it was not offered to them or was not available where they lived.

4.1.3 | Theme 3. Health literacy

Optimal management of cirrhosis can be complex. Chronic disease management is more effective if patients have the knowledge to

manage their health. Our third theme described participants' knowledge of their liver disease and the value of educational resources.

Lack of knowledge

Many participants lacked understanding of cirrhosis while others appeared to have a good understanding of cirrhosis and correctly described in simple terms the management of complications such as gastroesophageal varices and hepatic encephalopathy.

they called varices, [spelling out] V-A-R-I-C-E-S or something. It's down your chest bone you have ... like little varicose veins apparently. And that's why I take blood pressure tablets. I don't have blood pressure but they keep the tubes down so they can't burst. Cause if they burst I'll have an aneurism (#2419 female, alcohol/fatty liver, CP-B)

'With knowledge comes responsibility'

Although participants' understanding of cirrhosis was variable, many recognised the importance of knowledge and voiced their desire for more information. One patient said that 'with knowledge comes responsibility' (#2095 female, fatty liver, CP-A) to look after your own health. Some participants, though, recounted the challenges and struggles of understanding the management of cirrhosis complications. One participant articulated his initial lack of understanding about hepatic encephalopathy and the steps needed to manage it that included the use of lactulose (a laxative medication that patients need to titrate to the number of 'desired' bowel movements per day, for example dose increase if <3 stools/day, or patient is more forgetful or confused) and daily antibiotics.

I wasn't educated about it [hepatic encephalopathy]. This is one thing I should have been educated about. You tell somebody that they're going to lose their mind and they literally lose their mind.... You've got to know you've got to take the steps to get rid of it ... well the doctors were treating me for it and I didn't even know I had it. And they were doing it for months and it was only [when] they introduced a new medication to me and I said, 'What is this horrible stuff for?' And it wasn't my specialist or anything, it was another doctor explained it to me. I've gone, 'You're kidding!' ... I've now got to go to the bathroom and have bowel movements like four or five times a day or I get this thing [hepatic encephalopathy]. I've got to do it every day. I've got to take an antibiotic that stops this thing [hepatic encephalopathy] from happening (#5056 male, alcohol, CP-A)

'What works for someone might not work for others'—proactive learner versus illiteracy

Participants' perspectives of information received about cirrhosis were varied and it was noted that 'what works for someone might not

work for others' (#2435 female, alcohol, CP-A). Some participants valued having printed information to take home, whereas others noted that the content of information in pamphlets was too general and a few remarked about their difficulty in reading and understanding the content of written information.

Not everybody's going to understand the same information. Like an old person isn't going to understand the information that a 40 year old is going to understand, and it's all kind of the same approach for everyone I think. Like everybody's going to get the same service and the same treatment and the same information and the same advice and the same resources, but you know what works for someone might not work for others (#2435 female, alcohol, CP-A)

Bridging the health literacy gap

Several patients partnered with their support person and clinicians to bridge the health literacy gap. Several participants recounted how having their support person in the appointments was helpful. For many participants, liver specialists and, in particular, liver nurses played a key role bridging the health literacy gap. The 'clinician-patient-support person' triad was particularly important for some patients. One participant recounted how his support person participated in his clinical appointments with the liver specialist and liver nurse, and their questions and comments were valued and addressed, too.

I'd take me daughter and that and partner with me, and any questions just it was never a hassle. And like they [liver specialist/liver nurse] wouldn't talk to them as a secondary sort of person. They'd always turn their seat and ... talk to them directly about the question they've just asked ... they were absolutely brilliant like that, they really knew how to talk to people (#3005 male, alcohol, CP-C)

Suggestions around improved information flow

Some participants made suggestions around improved information flow and strategies that could be used to provide more patient education such as provision of information in waiting rooms. One participant recounted that she was diagnosed with cirrhosis while living in the US and how helpful it was that health professionals used models of the liver to visualise the function of the human liver.

... utilise the waiting room for information and education on the illness (#2095 female, fatty liver, CP-A)

They [liver specialists and nurses] have models of the liver and stuff and you can pull it apart and they explain to you what part of the liver does this, that and all kinds of things. The meetings [group sessions run weekly with patients, liver specialists and liver nurses] were wonderful ... (#4064 female, uncertain diagnosis, CP-A)

4.1.4 | Theme 4: Sources of support

The fourth theme describes the support mechanisms used by Indigenous Australians to lighten the burden of cirrhosis.

Support from family and friends

Support persons were reported by patients to play an important role across a wide range of practical support (e.g. assistance with daily tasks), as well as a key role in encouraging patients to seek medical care. While some participants described emotional support from their support person, others said they did not share much about their health as they did not want to worry family and friends or did not perceive family or partners as supportive.

I'm lucky that I've got [Support person] with me. She's me mate, she helps me with anything like that [reading brochures about liver disease] but she sort of just briefs it and then explains it to me like a five year old so I get it, you know what I mean?... she knows everything about me (#3154 male, hepatitis C/alcohol, CP-A)

My sister who can sometimes be more of a hindrance than a help.... she's just like this overwhelming sometimes (#2435 female, alcohol, CP-A)

Transport provision

Patient transport services designed to assist patients with chronic illnesses to access health care on a regular basis are an important aspect of health service delivery. The ability for many Indigenous Australians with cirrhosis to access cirrhosis care relied on access to suitable transport service and/or a support person to assist with transport.

Oh [Support person] does most of the driving (#3154 male, hepatitis C /alcohol, CP-A)

The clinic [liver specialist clinic] offers transport (#2095 female, fatty liver, CP-A)

One participant recounted that she no longer has a support person to assist with transport, and consequently she had to stop attending her appointments at the liver specialist clinic.

I've got to find me own way there [liver specialist clinics]..... If I had transport, yeah and someone with me (#2123 female, alcohol, CP-A)

Public transport

Public transportation may compensate for the lack of patient transport services for patients living in major city areas. For some participants, private transport provision was not an option due to fuel and parking costs, associated hassle for organising such transport, and therefore, public transport was their only means to get to

appointments. One participant articulated his preference for public transport over driving to the hospital clinic.

It's just too expensive to park in there. I do enjoy catching the bus actually. With COVID I've had a couple of appointments at the hospital that I've had to go to and I've just driven in but it's \$23.00 to park. And then it's \$2.90 return on the bus if I can get there and back on the bus within three hours. That's a big difference. (#4034 female, NAFLD, CP-A)

However, in several rural/remote/regional locations, the privilege of accessibility to public transportation is not available.

...the way for getting to an appointment was, well there was only one choice and that was public transport. Now we're on [island near Brisbane], you don't have much of a choice really unless you take a car on the barge, which is \$140 and then you've got to pay for parking, which is an expensive little exercise (#2435 female, alcohol, CP-A)

Support from health professionals

Many participants recounted stories of personalised care and dedication of the health professionals to ensure that their needs and concerns were addressed. For many, the support received from health professionals, and in particular liver specialist nurses, was instrumental in their engagement with cirrhosis self-management and care.

... the liver nurses they're all brilliant they're so helpful (#4034 female, NAFLD, CP-A)

They [Liver nurses] know all about what's going on with me. If I need to know something [support person] can ring her to find out what's going on and they're quite happy to talk to her because [support person] usually goes in there with me, and we talk to them (#3152 male, hepatitis C /alcohol /fatty liver, CP-A)

Peer support

Participants described a number of strategies that could significantly enhance the support for Indigenous Australians with cirrhosis. Some participants recognised the role that peers play in the management of cirrhosis. There was a desire to connect with peers who can share their experiences, offer advice and help each other. As one support person articulated, participants of peer support groups can 'talk about other people's experiences and learn from different people how they may handle things' (Support person #3152). Importantly, patients' success stories can encourage others to comply with treatment plans and lifestyle changes. A patient spoke about his positive attitude about hepatitis C treatment and ongoing surveillance for liver cancer, and that he would be happy to share his experience with others:

I can do this, I'm going to try to do this... I got rid of that liver disease [hepatitis C] and I get to get regular checks every six months on my blood.... if you feel that I could talk and help somebody I would be more than happy to do that [share his experience with others] (#3154 male, hepatitis C /alcohol, CP-A)

4.1.5 | Theme 5. Communication and patient consultation

The fifth theme describes the positive and negative aspects of communication and patient consultation at the liver specialist clinics. For many participants, the empathy of health professionals left a positive impression on their healthcare experiences, and thus emphasised the importance of good communication between patient and health professionals.

Well, [liver nurse] is just fantastic. She's worth her weight in gold. She was very good you know like you could ring her at any time and she'll get back to you with questions. Like I'll ring her, 'Can [patient] have this medicine? Will it affect the liver?' And whatnot. (#3152 male, hepatitis C /alcohol /fatty liver, CP-A)

Other participants experienced a lack of compassion and commented that doctors should be more sensitive when bringing up issues such as advanced care directives or the risk of death. Other negative experiences with the health care system included the lack of continuity of care, the overwhelming number of clinic appointments and the lack of flexibility with regards to changing appointments.

... every time I'd go they'd change [different doctors]... you could see a different person [doctor] each week you go (#3122 male, hepatitis C /alcohol/fatty liver, CP-A)

4.1.6 | Theme 6. Psychosocial counselling to 'look after the caring side'

The last theme describes the mental health concerns of participants. Many patients experienced psychosocial and mental health issues including depression, anxiety, post-traumatic stress symptoms, drug use and suicidal thoughts. While this sentiment was not shared by all participants, several participants raised the need for more mental health care services:

Emotional wellbeing and physical health just go hand in hand (#2095 female, fatty liver, CP-A)

Some days I just feel like I'm number three thousand and one... and I'm like a cow going along to get milked.

Go have this test, and this test, and now we're going to move you in to this room, and you're going to do that, and then we'll do these results, and then we'll give you this information, and then we'll send you away until next time... There should be people that just look after the caring side... A lot of people put on a brave face too. Like we're really crippled inside but we're just saying, 'Yes Doctor, mm hmm, okay I understand' and we're not understanding, and you're not okay but you're saying the words that you think they [doctors] want to hear. (#2435 female, alcohol, CP-A)

Others, though, appeared to be interested in counselling but said they were not offered this service.

No not yet [laughing] ... I would probably say yes [to counselling] (#2095 female, fatty liver, CP-A)

5 | DISCUSSION

5.1 | Discussion of findings

This study was informed by the stories and experiences of Indigenous Australians with cirrhosis and the support persons. From these accounts, it was clear that many Indigenous Australians with cirrhosis confronted a range of barriers that can contribute to poor health outcomes. These barriers are related to poor health literacy, stigma and lack of practical and emotional support and may lead to inequitable access to cirrhosis care and treatment. Health professionals, in particular liver specialist nurses appeared to have played an instrumental role in patient engagement with services, self-management and care.

In this study, experiences of prejudice from health professionals were reported by patients with cirrhosis due to alcohol misuse or HCV. A sense of stigma around a diagnosis of viral hepatitis-related liver disease has been reported by Indigenous and non-Indigenous patients and key informants in other settings (Davies et al., 2014; Hjorth et al., 2020; Rashidi et al., 2020). In the setting of alcohol misuse in general, other studies reported patients' descriptions of feeling ignored and shamed when accessing health care, and of indirect signs of disapproval or condemnation (Fraser et al., 2020). Past experiences of stigma can generate a high degree of sensitivity to negative judgements, and patients may be reluctant to seek health care when in need. In a mixed-methods study including Indigenous Australians who were injecting drug users and diagnosed with HCV, patients' perception of stigma was significantly associated with reluctance to undergo HCV treatment as participants believed that enduring treatment with this stigma would expose them to emotional distress (Rashidi et al., 2020). Improving health professionals' knowledge about cirrhosis along with cultural competency training could help avoid stigmatisation.

Such changes will encourage better engagement of Indigenous patients in liver disease treatment.

Health literacy refers to the degree to which individuals have the capacity to obtain, process and understand basic health-related information needed to make appropriate health decisions (Ratzan & Parker, 2000). Low health literacy among non-Indigenous patients with cirrhosis has been reported (Goldsworthy et al., 2017; Hayward et al., 2017; Volk et al., 2013), and delivery of cirrhosis education has been shown to improve patients' knowledge (Goldsworthy et al., 2017; Hayward et al., 2017; Zhang et al., 2019) and patient outcomes (e.g. reduction of unplanned hospital admissions) (Hayward et al., 2019, 2020). In this study, the challenges to understanding the management of cirrhosis and its complications emerged as a theme. Many participants highlighted the importance of knowledge and the need for use of tailored resources to overcome issues with health literacy. The use of visual resources (e.g. pictures, models of the liver that can be pulled apart) was seen to be beneficial in the provision of cirrhosis information and care. In other settings, the use of culturally appropriate language and visual aids were identified as key to improving communication and patients' health literacy among Indigenous patients with viral hepatitis, cancer and dementia (Bryant et al., 2021; Davies et al., 2014; Olver et al., 2021).

The importance of support for Indigenous Australians with cirrhosis emerged as a strong theme. As in other chronic disease settings (Garvey et al., 2012; Majoni et al., 2021; Shahid et al., 2011), access to a suitable transport service was an important factor for Indigenous Australians' engagement with cirrhosis care. The positive effect of social support was seen in the narratives of some participants included in this study, with support persons having an important role in encouraging patients to seek medical care as well as providing practical and emotional support. These results reflect those of Rashidi et al who also showed that Indigenous Australians diagnosed with HCV who had social support ($p = 0.02$) and interacted with own community ($p = 0.03$) were significantly more likely to seek HCV treatment (Rashidi et al., 2020).

The role of health professionals, mostly liver specialist nurses, emerged as a strong theme. Many participants acknowledged the importance of the established relationship of trust with their liver nurse, and recounted that liver nurses showed their commitment in this relationship by taking sufficient time with patients and support persons, and being attentive to their health literacy needs. Liver specialist nurses can play a crucial role in educating cirrhotic patients to identify and respond appropriately to their symptoms, thus promoting early intervention when complications of cirrhosis arise. This was seen in a randomised trial of a coordinated care model for non-Indigenous patients with decompensated cirrhosis where liver nurses delivered an intervention that included education and weekly monitoring checks, leading to fewer liver-related emergency readmissions and better survival than patients managed with standard care (Ramachandran et al., 2018).

Communication between Indigenous patients and health professionals has been identified as a potential impediment to good

health outcomes in other chronic disease settings such as cancer (Olver et al., 2021; Shahid et al., 2013). While many participants included in this study recounted positive interactions with the health system, others described negative experiences where attention was needed to improve health professionals' language, communication style, and use of medical terminology. Potential solutions to effective Indigenous patient-health professional communication have been suggested. These include recruiting more Indigenous staff, providing appropriate cultural training for health professionals, including a patient support person who can assist with communication during the clinical appointment, creating a safe environment and allowing time in which to build rapport (Olver et al., 2021; Shahid et al., 2013).

A previous report from the CirCare study examining the supportive care needs of patients with cirrhosis found that 10 out of 20 Indigenous patients reported anxiety, depression or worry and the rate of unmet needs for psychosocial issues was greater for Indigenous versus non-Indigenous patients (Bernardes et al., 2021). In other chronic disease settings (e.g. Indigenous Australians with cancer), psychological need was common during diagnosis, treatment and post-treatment (Valery, Bernardes, et al., 2017). Anxiety and depression may affect many aspects of cirrhosis care, from adherence to medications and self-care tasks to engagement with health services and with social risk behaviours such as alcohol misuse (Buganza-Torio et al., 2019; Rabiee et al., 2021). Embedding mental health care and social workers (Ufere et al., 2022) in the multidisciplinary care of Indigenous patients with cirrhosis may help to address the mental health concerns raised by many study participants.

5.2 | Limitations

Participants were recruited from hospitals located in a major city area and not all Indigenous patients receiving cirrhosis treatment at the participating hospitals were invited to participate. Therefore, findings may not be generalised to all Indigenous Australians with cirrhosis. In particular, missing scheduled liver clinic appointments was one of the reasons for not being approached for participation in the CirCare study (Valery et al., 2021). A potential bias may have arisen, whereby the Indigenous patients who volunteered for the study may have had a different journey with cirrhosis than those who were not approached or who declined participation in this study. Our findings, therefore, may not fully represent the perspectives of Indigenous Australians who have difficulties engaging with the health system. The small number of support persons included in the study is also a limitation. While it was clear that recurring themes could be elicited from the participants' stories, thematic saturation cannot be guaranteed with the small sample size. Despite these potential biases that may impact on the generalisability of our findings, our data provide an important perspective of Indigenous people's experiences with cirrhosis.

6 | CONCLUSIONS

Our findings highlight the need to actively raise community awareness around chronic liver disease, address issues of stigma and develop a chronic liver disease management program that includes supportive care for Indigenous patients and their support persons. Such a program needs to integrate patient needs, health literacy (information readiness), emotional and mental health support, primary care and liver specialist services to address the complex health care needs and ensure optimal coordination of cirrhosis care. Given their essential role in delivering care to Indigenous Australians, it is crucial that Aboriginal and Torres Strait Islander Community Controlled Health Services are part of the solutions (Sinka et al., 2021). At the tertiary setting, liver specialist nurses can have a positive and profound effect on patients' healthcare experiences and patient learning, thereby enabling them to make informed choices and exercise control in their lives. Importantly, it is essential that the structures and organisations that support Indigenous patients with cirrhosis are responsive to local community needs and provide culturally safe access to a chronic disease management program that has a patient-centred approach to health care delivery with multidisciplinary, proactive, longitudinal quality care between visits, rather than traditional episodic, symptom-driven care (Sinka et al., 2021).

7 | RELEVANCE TO CLINICAL PRACTICE

Gaining knowledge of the experiences of Indigenous Australians diagnosed with cirrhosis is important for providing patient-centred and culturally appropriate care. This study confirms the important role of liver specialist nurses in bridging the health literacy gap and in supporting Indigenous patients and their families.

Partnering with support persons and clinicians, specifically nurses, was perceived as essential for some patients as the partnership helped them bridge the health literacy gap. Being perceived as trustworthy and approachable offers nurses a significant opportunity and privilege to engage patients in self-management and care interventions as well as delivering better educational resources to patients and support persons. A recent review (Ufere et al., 2022) highlighted a promising role for social workers as part of an integrated hepatology care team to address the psychosocial needs, practical support and informational support for patients with cirrhosis.

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CONFLICT OF INTEREST

There are no financial disclosures. The funders had no role in study design, data collection, data analysis, interpretation or writing of the manuscript.

AUTHOR CONTRIBUTIONS

PCV, SS CMB and EEP designed the study. CB conducted all interviews (three interviews were conducted by CB and CMB). CB and PCV did the initial inductive data analysis. The final data analysis was discussed and consented by all authors. All authors contributed to the interpretation of data, revising the draft critically for important intellectual content, and approved the final version.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study contain potentially sensitive and/or identifying information that could compromise the privacy of the participants. Therefore, the data are not publicly available. Data may, however, be available from the authors upon reasonable request with approval from relevant ethics committees.

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SUPPORTING INFORMATION

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