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Reluctance to Accept Alcohol Treatment by Alcoholic Liver Disease Transplant Patients: A Qualitative Study

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Background. Liver transplantation (LT) is the optimum treatment for patients with end-stage alcoholic liver disease (ALD). However, despite a recognized risk of relapse to harmful drinking, ALD transplant patients are reluctant to use speciality alcohol treatment to support their abstinence, even when offered within the LT context. This study aimed to understand and identify factors contributing to alcohol treatment reluctance by ALD patients undergoing transplantation. **Methods.** We conducted an in-depth qualitative study of ALD transplant patients. Minimally structured face-to-face interviews explored participants' alcohol-related experiences and their reasons for not using alcohol treatment during the course of their transplantation. Thematic analysis was used to analyze and interpret interview data to understand treatment reluctance based on participants' experiences. **Results.** Five major themes were identified among 3 subgroups of patients (pretransplant and posttransplant abstainers and posttransplant relapsers): (i) the “contract” of mandatory abstinence, (ii) the “gap in the program” involving the lack of candour between patient and staff about alcohol-related matters and the lack of addiction services, (iii) a preference by participants to self-manage their alcohol use disorder, (iv) social support as a facilitator of abstinence and the risk of relapse when social support is diminished, and (v) the fear of stigmatization. Each of these factors were dynamically inter-related and differed slightly for each subgroup. **Conclusions.** The LT services may benefit from the inclusion of integrated specialist addiction services in their model of care. Such an approach may enhance the acceptability of alcohol treatment and reduce the risk of relapse among ALD transplant participants, especially for those whose social supports have diminished.

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Alcoholic liver disease (ALD) has become the second-leading indication for liver transplantation (LT) with survival rates and indicators of quality of life comparing favorably with non-ALD.¹⁻⁴ Although the majority of ALD patients maintain abstinence, over time the frequency of reported alcohol use after LT increases. The literature varies, but within the first 5 years posttransplant, up to 50% of recipients return to some form of drinking and, of these, an estimated 10% to 30% return to harmful drinking.⁵⁻⁸ The prevalence of any alcohol use pretransplant is less documented, ranging from 15% to 50%.⁷⁻¹⁰ Relapse to heavy drinking is linked to psychological stress and interpersonal difficulties,¹¹ recurrent ALD,^{12,13} declines in quality of life,⁶ and lower survival rates.^{12,13}

Liver transplantation for those with end-stage ALD has involved a number of unresolved controversies, with relapse being at the center.¹⁴ The general public and many physicians hold attitudes that “alcoholics” are personally responsible for the behavior that caused their disease and therefore have less LT priority than those with nonalcohol-related liver disease.^{15,16} One of the key methods of managing alcohol relapse used by LT units worldwide is a requirement of a 6-month minimum period of abstinence before being listed and a verbal, or sometimes written, contract of lifetime abstinence.^{17,18} Despite participants being medically advised and referred to alcohol rehabilitation, usually involving Alcoholic Anonymous,

both pretransplant and posttransplant ALD participants are reluctant to attend specialty alcohol treatment.¹⁷

The first published attempt at providing alcohol treatment in the LT setting was conducted by Weinrieb and colleagues¹⁹ who randomized posttransplant patients to naltrexone, placebo, or motivational enhancement therapy. However, no patients completed treatment due to significant recruitment difficulties. Weinrieb and colleagues²⁰ later randomized pretransplant patients to either motivational enhancement therapy or treatment as usual which resulted in modest outcomes and only 50% of participants completed the required 7 sessions. Explanations for poor treatment motivation derived from these studies and others have included: denial, patient preoccupation with the demands of a complex medical regimen, time scarcity, medication concerns, transportation problems, and lack of interest.²¹ The use of motivational enhancement therapy may have also affected patient engagement because it is designed to elicit behavioral change based on client-driven goals and is unsuitable for those who have successfully achieved change.

Despite the availability of effective specialist alcohol services, reluctance to use alcohol treatment is also very common among individuals with an alcohol use disorder (AUD) in the general population.^{22,23} One of the most cited reasons for reluctance to seek alcohol treatment is a preference to self-manage the problem.^{22,24,25} The fear of stigma is also a formidable factor linked to treatment avoidance, decreased compliance, early termination of treatment, and missed appointments.²⁶ Moreover, the need for AUD treatment increases in the presence of problem recognition, accumulation of life stressors and psychosocial and addiction impairment.^{21,27,28} Treatment engagement depends on patient, clinician, and service characteristics.^{29–31}

To ensure positive LT outcomes, there is an urgent need for an effective alcohol intervention to reduce relapse rates for ALD transplant recipients.^{32,33} Qualitative data obtained directly from interviews with ALD transplant patients is a useful tool with which to explore the reasons underlying AUD treatment reluctance. The primary objectives of this study were to: (i) gain an in-depth understanding of AUD treatment reluctance as provided by ALD transplant candidates and recipients; and (ii) to provide AUD treatment recommendations for ALD transplant candidates and recipients to inform future intervention studies.

MATERIALS AND METHODS

We report on the qualitative arm of a mixed-methods study. The quantitative component, a case-control study assessing AUD treatment reluctance among ALD transplant patients, has been described elsewhere.³⁴ The participants were drawn from ALD transplant patients at the Australian National Liver Transplant Unit, Sydney, Australia, between September 2009 and July 2011, where the primary cause for their liver disease was alcohol-related (including ALD/hepatitis C virus infection). Participants were either on the transplant waiting list or in the posttransplant phase. An ALD diagnosis was determined by the transplant unit using a history of excessive and persistent alcohol consumption, together with clinical, laboratory, and liver biopsy findings. Anyone with a current substance use

disorder (other than alcohol), acute psychiatric illness, or encephalopathy was excluded. Commencement or participation in alcohol treatment during the course of LT was also an exclusion criterion, but was not reported by any screened patients.

Convenience sampling was initially used and then extended to purposive and maximum variation sampling to extend and test the emerging theory in relation to pre-ALD and post-ALD transplant patients to ensure inclusion of those who had relapsed³⁵ (see below). Relapse was defined as drinking above 140 g of ethanol per week or more than 1 episode of binge drinking (>60 g alcohol on a single occasion).³¹

The sample size in qualitative research, especially involving thematic analysis, varies depending on the research question and method of analysis. All 40 participants (comprising pretransplant and posttransplant patients) enrolled in the quantitative arm were included. This provided a sample size well above the recommended 30 interviews needed to generate sufficient data to identify patterns, concepts, and dimensions of a phenomena.^{36,37} Throughout the data analysis process, a group of patients were identified as having relapsed, thus comprising a third group, “relapsers.” Consistent with recommendations for a minimum of a 10 to 12 participants in each subgroups³⁸ a further 2 participants were recruited via purposive sampling.

Eligible patients were invited to participate by transplant staff with whom they had a clinical relationship and were assured that participation would not influence any aspects of treatment including their place on the transplant waiting list. All participants provided written informed consent and were assured confidentiality before commencing the study. Participants were offered a US \$20 gift voucher for participation, although this was refused by the majority who wished to demonstrate their appreciation of LT.

Interviews could be conducted at the LT unit or Drug Health Services, but all participants choose to be interviewed at the LT unit. Two participants who had relapsed and were infrequent with their outpatient liver clinic appointments were interviewed off-site at their request. All interviews took place during regularly scheduled clinic visits in a private room separate to the clinical operations of the LT unit. The interviews were 25 to 90 minutes in duration, audiotaped, and transcribed verbatim. Only 4 participants declined to participate, and this was due to ill health, medical commitments, and scheduling difficulties (~50% live outside the metropolitan area). Of the 10 (23%) participants who reported relapse, 6 relapsed posttransplant, 1 pretransplant, and 3 in both the pretransplant and posttransplant periods.

The interview consisted of open-ended questions designed to encourage communication and minimize any discomfort bearing in mind the reluctance among ALD patients to discuss alcohol-related subjects. The interview explored initiation and maintenance of abstinence, abstinence support during LT, relapse, and reasons for not seeking AUD treatment (Box 1). The interviewer (C.H.) used listening and mirroring statements to encourage participants to reflect and elicit additional detail or clarification of issues.^{39–41} Potentially sensitive questions were phrased in the third person or in relation to hypothetical situations to minimize discomfort. Saturation was considered to have

been achieved when the data were rich in quality and quantity, answered the research question, and no new themes emerged.³⁸

- What has it been like going through a liver transplant and giving up drinking?
- What prompted or motivated you to abstain?
- How did you manage to achieve abstinence?
- Did you have any difficulties abstaining?
- What support was behind remaining abstinent?
- How have transplant staff helped you with alcohol-related issues?
- Have staff discussed alcohol-related matters, provided information or referred you to services?
- How would they react if you told them you were having difficulties abstaining?
- Under what conditions do you think relapse is possible?
- If you relapsed what would you do?
- What was your experience of how transplant staff deal with relapse?
- Would you consider treatment? If yes, when would you consider treatment?
- What is your preferred choice of treatment?
- What support do you think transplant staff could provide?
- Why do you think ALD transplant patients may refuse to attend or participate in alcohol treatment programs when provided by liver transplant units?

The research team is composed of an addiction specialist and psychiatrist who worked alongside the LT program and an academic staff member with no contact with the LT unit. The interviews were conducted by the first author, an experienced drug and alcohol clinician without LT unit

involvement. Patient characteristics were derived from data collected in the quantitative arm via face-to-face interviewer administered questions. Current alcohol use was based on self-report with collateral evidence from medical evaluation records and clinician reports.³⁴

Ethics approval was granted by the Human Ethics Review Committee of the then Central Sydney Area Health Service (Royal Prince Alfred Hospital Zone).

Data Analysis

Qualitative methodology was the most appropriate scientific approach to illuminating and explaining the complex phenomenon of treatment reluctance within the LT context. We used thematic analysis, a qualitative method of scientific investigation which methodically analyses interview data. It does not reflect any particular theoretical or epistemological perspective, but the epistemological leaning was toward 3 bodies of literature: (i) ALD transplant literature, (ii) alcohol treatment seeking research, (iii) symbolic interpretivism (individuals construct meaning from their interaction with the social world).⁴²

Interview transcripts analysis was informed by Strauss and Corbin.³⁵ The analysis was conducted by 2 authors (C.H., T.S.) who independently coded the transcript data, followed by a process of constant comparison (Table 1). The second phase of the analysis aimed to identify themes that represented some level of patterned response or meaning within the dataset which helped explain treatment reluctance using the conceptual framework.⁴³ Axial coding revealed that these experiences, perceptions, and responses were mutually reinforcing rather than individualized processes. Because the themes and concepts emerged from the data, they were discussed with the research team with further reading of the existing literature which formed a background for deeper examination of how these themes address the research question.⁴⁴ In qualitative

TABLE 1.

Themes and codes derived from the first phase of data analysis

The contract	Conformity to the contract—degree of conformity, degree of difficulty, degree of disclosure, breach of contract, participant response to breach, penalty, awareness of contract. Participant attitude to contract—medical, moral and social ethics, personal responsibility and critique of contract, 'gift of life'. Staff attitude and influence regarding the contract
Abstinence	Maintenance of abstinence—degree of difficulty, family support, staff monitoring, relapse prevention skills, self-transcendence, mobilizing social resources Resistance to alcohol treatment Denial of relapse
Relapse	Personal responsibility Triggers to relapse Guilt/shame Family and social support Public opinion and staff reaction
Fear of stigma	Label of "alcoholic" Personal shame, failure and responsibility Fear of disappointing staff
No available and suitable alcohol support program	Gap in the program Lack of open communication about alcohol matters Living with chronic illness Holistic perspective Wanting to talk/communicate with staff Participant treatment preferences

TABLE 2.
Basic clinical characteristics of ALD transplant participant sample

Variable	Pretransplant, n = 16	Posttransplant, n = 16	Relapsers, ^a n = 10	Total, n = 42
Age (mean), y	55	59	59	57
Sex				
Females	3 (19%)	3 (12%)	3 (30%)	6 (14%)
Males	13 (81%)	23 (88%)	7 (70%)	36 (86%)
Diagnosis of ALD	11 (69%)	18 (69%)	7 (70%)	29 (69%)
Diagnosis ALD/HCV	6 (38%)	7 (27%)	3 (30%)	13 (31%)
Median time in pre or posttransplant phase, y	1.7	5	-	-
Number reporting abstinence	16 (100%)	16 (61%)	0	32 (76%)
Mean months abstinent while on the pretransplant waitlist	8	38	9	18
Number reporting relapse to harmful drinking (>140g ethanol/week)	0	10 (39%)	10	10 (24%)
Previous substance use treatment before LT	3 (19%)	4 (15%)	4 (40%)	7 (17%)
Housing stability (>2 y in current address)	15 (94%)	23 (88%)	9 (90%)	40 (95%)
Committed cohabiting spouse or partner	11 (69%)	14 (54%)	3 (30%)	25 (60%)
General and abstinence social support	16 (100%)	15 (58%)	1 (10%)	31 (74%)

^a Ten relapsed in the posttransplant phase, 4 relapsed in both the pre and posttransplant phase.

HCV, hepatitis C virus.

research credibility is dependent on systematic and essentially taxonomic processes of data collection, sorting and classifying data, through which participant voices emerge in all their complexity and can be interpreted in relation to the developing theory.^{4,5-49}

RESULTS

Interviews with 42 participants were conducted. The study sample consisted of 16 (38%) pretransplant patients, 16 (38%) posttransplant patients, none of whom reported relapse; and a further 10 (24%) posttransplant patients who reported relapse (“relapsers”; Table 2).

During the recruitment period, 54 ALD pretransplant patients were on the transplant waiting list in New South Wales, of which our sample comprised 30%. Ninety-eight ALD transplant patients were in the posttransplant phase, of which our sample comprised 25%. Overall, our sample comprised 26% of the entire target population. Thematic analysis revealed 5 key themes: (i) determination to self-manage, (ii) social support, (iii) the contract of mandatory abstinence, (iv) a “gap in the program,” and (v) fear of stigmatization (Table 3).

Determination to Self-Manage

Most participants including those who relapsed reported an urge to handle their AUD on their own without using specialty services. Participants who had achieved a period of abstinence were convinced that alcohol services were unnecessary or unwarranted. Posttransplant participants who were abstinent valorized their use of will power, abstinence self-efficacy, and determination. Interestingly, both pretransplant and most posttransplant participants described relapse prevention skills despite most having had no previous history of alcohol treatment. Strategies included avoidance of high risk situations, challenging cravings using consequential thinking and substitute activities.

The urge to self-manage by the majority of participants was concerning because no participant could provide a relapse prevention plan in the event of a lapse and the

majority believed that they would never relapse. Furthermore, 12 (29%) posttransplant participants reported preferring to deal with a relapse themselves before informing staff. Similarly, those who did relapse preferred to handle the problem themselves, despite a clinical presentation indicating the need for specialist treatment.

Presence of Social Support

Support from family, friends, and especially partners helped abate participants' need for AUD treatment. For the 32 pretransplant and posttransplant participants who had achieved abstinence, most talked at great length about their resolve to abstain. When prompted, however, 21 (66%) participants identified the role played by their partner and family in helping them maintain abstinence. Transplant staff were also identified as providing critical support to pretransplant participants, particularly in terms of their expertise, guidance, and assistance with managing anxieties leading up to surgery.

The major trigger for relapse identified by 21 (66%) abstainers was the loss of family support. Similarly, those who relapsed spoke about the loss of general and/or abstinence support (including that of a partner), but also the loss of drinking peers as major factors contributing to their relapse.

The Contract of Mandatory Abstinence

The “contract” of long-term abstinence as a requirement for LT candidacy was the most dominant theme to emerge from 40 (95%) participants. For pretransplant participants, treatment seeking was minimized by the contract requiring mandatory abstinence as a condition of transplant (ie, lifesaving surgery) alongside serious concerns regarding medical problems. The alcohol management program which supported the “contract” (ie, “monitoring,” “routine questions,” “blood tests” “education,” “advice”) provided “positive pressure” supporting abstinence. Abstinence was felt to be “easy” at this stage for the majority of participants. The majority of pretransplant participants stated they were willing to disclose alcohol use to staff because doctors “need the facts” for optimal medical care.

TABLE 3.**Examples of ALD transplant participant responses illustrating factors behind treatment reluctance according to themes emerging from the thematic analysis****(1) The “contract”**

Pretransplant	
Medical compliance	<p>“I do what they tell me to do because I know if I don't help myself here I don't have long to live. I just have to keep doing the right thing.”</p> <p>“In pretransplant you are busy with medical issues, you have the liver problem and you are focused on the transplant.”</p>
Fear of penalty	<p>“I don't know how they would react if I told them I was drinking.”</p> <p>“The concern would be that I would be shuffled down the transplant list.”</p>
Posttransplant	
Social moral obligation	<p>“Having an organ is a very precious commodity and should only be given to people are most likely to have a successful outcome. If you don't look after it you shouldn't have one.”</p> <p>“Someone has given an organ up for me If you fail you feel that you have let so many people down not just yourself.”</p>
Relapse prevention tool	<p>There are times when you think about going back to drinking. The obligation stops you from drinking. It is a gift with conditions.”</p> <p>“Apart from occasionally you smell a beer and you would love one, but, as I say someone lost their life for me?”</p>
Relapsers	
Self-medication	<p>“Before the transplant I was crook from the liver disease and I was given a death threat.</p> <p>The drinking helped with the pain and the depression.</p> <p>I tried to give up but I couldn't. You were in so much pain and the only thing that relieves that pain was alcohol.”</p>
Criticism of the contract	<p>“The idea that the person who needs a liver transplant due to drug use will have some sort of epiphany or is told by their doctor that you will not get a transplant unless you remain abstinent.”</p>
Secrecy	<p>“So in my mind, because I'd been told abstinence was mandatory, I was not going to tell them about my past relapse.</p> <p>I was told I would not be given a transplant. I felt that this was unfair on the balance of my behavior over a period of time.”</p>
(2) The gap in the program	
Pretransplant	<p>“It seems strange that they would have to farm it (alcohol treatment) out to someone else and that there is no service here.”</p>
Posttransplant	<p>“There is no one here to talk to about it (difficulties with abstinence) I wouldn't mind if there was someone with the liver clinic that I could talk to.</p> <p>I would gladly be happy to talk to someone here. They should have a drug and alcohol (service) here.”</p> <p>“Staff don't talk about it. They don't approach the subject...they could be more initiating and elicit some discussion.</p> <p>Perhaps having a drug and alcohol person on staff would help.”</p> <p>“I think it important for staff to understand what causes you to drink and the pressures you have to deal with.</p> <p>Encourage people to talk about it and if you have people trained in that manner, those with people handling skills I think that is important.</p> <p>Current staff are not able to do this; you need staff specialised in that area.”</p>
Relapsers	<p>“There is a gap between the clinical side of the transplant and the emotional difficulties of going through a transplant.</p> <p>You need something less clinical, a presence to help you get through it, something friendlier, a drug and alcohol support worker.”</p> <p>“Staff did not tell you who to see when you have problems with alcohol or having stressful changes in your life.”</p> <p>“You have to be strong physically and mentally to get through the transplant. I lost my wife, drinking lifestyle, female companionship, my career, employment and had financial problems. I didn't see how you could get through it.”</p> <p>“After the transplant my new wife of four years left me. The drinking slowly increased over time.</p> <p>Call it arrogance, lack of will power whatever. I had no support.”</p>
(3) Self-management	
Pretransplant	<p>“If people have solved the problem themselves, then obviously they don't need help.</p> <p>You have to identify the people who need help if they don't need help that is not a case of refusing help it is a case of them not needing it.</p> <p>If you don't have a broken leg why put a splint on it?”</p> <p>“I don't need treatment. I have made a decision not to drink and I am very confident that I will never drink and that I am in control of myself.</p> <p>“I approached stopping drinking the same way I stopped smoking...I said I will never have another drink.”</p>
Posttransplant	<p>“If I thought alcohol was causing a problem I would have no problem going. If I thought I was losing control, I would be very happy to go.</p> <p>Those that are not drinking...what would they be treated for?”</p> <p>“Because you don't drink anymore, your mind is clear. Having a transplant changes your attitude you see things different in life, even nature you see different.</p> <p>Like a baby is born again you see life in totally different eyes I appreciate my life more now than I ever did.”</p> <p>“You have to be strong physically and mentally to get through the transplant. I lost my wife, drinking lifestyle, female companionship, my career, employment and had financial problems. I didn't see how you could get through it.”</p>
(4) The presence of social support	
Pretransplant	<p>“Family support has helped big time. My wife is 101% beside my side. I don't know why as I have been a nightmare at time.</p> <p>She does not drill me but support me, fantastic.”</p> <p>“Family support has been terrific. They would shoot me if I started drinking or had a drink.”</p>
Posttransplant	<p>“There has been nothing but pure excellence from all staff.”</p> <p>“The staff here are brilliant. They are part of your family as well. I trust this place.</p> <p>They see the worst of you and then they see the best of you.”</p> <p>“Everyone in my family has been supportive and understanding. They know I can't drink.”</p>

Continued next page

TABLE 3. (Continued)**(1) The “contract”**

Relapsers	“There was support in the beginning from family and friends but then it dropped after the transplant.”
Lack of social support	“Before you could talk to your mates: with drinking came a sense of camaraderie.”
(5) The fear of stigma	
Pretransplant	“People can feel shame, stigma, exposed and uncomfortable when someone gets that close to the drinking issue.” “I coped with it when I was first diagnosed with it (ALD) and I knew I drank but as soon as you say cirrhosis, that is one of the biggest stigmas. Everyone thinks you are an alcoholic and then you start thinking, was I?”
Posttransplant	“You can approach staff if you have problems but staff will be disappointed and unhappy if you told them that you are having problems with drinking.” “I could not look my doctor in the face or the organ donor’s family if I was to damage this liver all because of careless personal behavior.” “I probably wouldn’t want to tell staff. If I did relapse I would feel a bit of a loser. I wouldn’t have the strength to come back and ask for help.” “I don’t like being labelled as being an alcoholic. It means that you haven’t got your shit together. They are belittling you. They are basically saying you are weak (<i>if referred to treatment</i>).”
Relapsers	“I feel guilty about letting people down. ‘I do think with the drinking you hit it harder than before perhaps it is because you feel guilty or depressed and there is an aspect of medicating yourself.’ “There was a lot of guilt for going back to the grog. It is right high up there with the highest guilt you can have. I was adamant prior to the transplant that I would never drink again but you should never say ‘never’.” “I will always be indebted. I always appreciate what I have been given however it gives you a great deal of guilt (relapse).”

Conversely, uncertainty, and a fear of penalty were associated with disclosure of drinking with participants expressing concern about being delisted or given less priority for LT. Additionally, many participants were concerned about disappointing staff if they were perceived as requiring alcohol treatment.

For the majority of posttransplant participants ($n = 14$, 88%), the contract was infused with a social and moral obligation to partners, family, transplant staff, the donor, and the donor’s family. A typical response was: “If you give in [relapse], it is a breakdown of your whole moral fibre.” Some participants spoke about abstinence as a repayment for the “gift of life” and a “duty of care to the organ donor family.” For 6 (38%) posttransplant participants, abstinence was a struggle, and they used the contract in the form of the “gift of life” as a relapse prevention tool to challenge cravings. The struggle for posttransplant participants to maintain abstinence and not disappoint staff was a strong deterrent to alcohol treatment and closely linked to a fear of stigma.

No pretransplant participant disclosed any alcohol use, and although the 10 participants that reported relapse (the relapsers) were all posttransplant, they reported that relapse occurred during the pretransplant and/or posttransplant period. For the relapsers, the contract had to be secretly breached as drinking had a self-medicating and pain killing function. In the pretransplant phase, it helped with the distress of diagnosis, waiting for lifesaving surgery and physical pain. Although in the posttransplant period, it helped participants cope with biographical disturbances and life stressors created by illness and transplantation. Breaching the contract, however, was associated with ongoing guilt: “survival is higher up in the hierarchy of things than honesty and dishonesty” and “you keep drinking to yourself.” Indeed 3 participants challenged the tenets of the contract on the grounds that AUDs are an ongoing relapsing condition or wanting the right to make choices regarding their alcohol use.

Gap in the Program

This theme consisted of the absence of addiction specialists during the course of transplantation and the lack of open communication about alcohol-related matters with transplant

staff. Together, these 2 factors contributed to reluctance by ALD transplant participants to approach staff about treatment especially when such treatment is not an accessible and realized service. This theme was strongly endorsed by relapsers and posttransplant participants at risk of relapse, 6 (38%) of whom reported cravings, life stressors, and high risk situations. Although abstainers noted an absence of alcohol treatment, it was not experienced as a strong need.

Fear of Stigmatization

Twenty-six (62%) participants stated without prompting that “stigma” was the strongest deterrent to them using specialty alcohol treatment. Alcohol treatment was associated with being “labeled” an alcoholic and exposing oneself to judgement and alienation by others. For most participants, such labeling was recognized as an inevitable feature of attending specialty alcohol programmes and a public marker of character weakness, failure and poor self-management. Indeed, 4 participants expressed their dislike of being referred to Alcoholics Anonymous for the above reasons. For some, even the diagnosis of ALD was stigmatizing. Twenty-seven (64%) participants mentioned being “embarrassed talking to staff” or the fear of “disappointing staff” if they were to seek support. Guilt and the adverse effects of stigma manifested as heavy alcohol consumption, avoidance of both AUD and other health care services, experiences of discrimination, and a poorer quality of life, all of which were evident throughout the transcripts of those who had relapsed.

DISCUSSION

This qualitative study identified 5 interdependent themes which help to explain ALD transplant participants’ reluctance to pursue alcohol treatment. These themes can be broadly divided into person-related and program-related factors. Consistent with other research,²¹ the majority of ALD patients perceived no need for alcohol treatment and therefore were reluctant to use alcohol treatment services because they had already achieved a substantial period of abstinence motivated by life-threatening end-stage ALD. Both pretransplant and

posttransplant ALD abstainers demonstrated a strong desire to self-manage their drinking problem^{22,24} and valorized their willpower and self-efficacy.

When the urge to self-manage is combined with robust social support, the need for professional support is reduced.⁵⁰ The pivotal role of social support in maintaining abstinence is constant in both the addiction and transplant research fields and its absence is an acknowledged antecedent to relapse.^{7,12,51} These findings are also consistent with a large body of evidence highlighting the benefits to health and well-being from social relationships.^{52,53}

The policy of mandatory abstinence was a key influence in the lived experiences of ALD patients undergoing transplantation and it influenced treatment seeking in divergent ways. It has been proposed that this policy and its associated alcohol management program exerts a positive therapeutic effect by incorporating Valliant's prognostic factors predictive of stable abstinence these include: finding a substitute dependence, experiencing negative consequences of drinking, close relationships and social support, and a source of inspiration and hope.⁵⁴⁻⁵⁶ For pretransplant participants, the policy and the alcohol management program provided sufficient support to minimize treatment seeking. There was a reminder of the negative consequences of drinking, the presence of rehabilitative relationships with transplant staff,^{32,55,57} and the medical regimen and management of ALD operated as a substitute activity to drinking.⁵⁶ Finally, the hope derived from being released from the edge of death, given new life and an expensive operation also played a role.

The reliance, however, on the policy of mandatory abstinence as a condition of transplantation, without the integration and access to onsite specialist addiction services, generated a set of understandings, expectations and a social context which contributed to alcohol treatment reluctance for all ALD transplant patients. For pretransplant patients, the policy was also a powerful deterrent to both alcohol use disclosure and treatment seeking. This is consistent with the literature that has identified that patients are at risk (or perceive to be) of jeopardizing their LT candidacy if they are candid about their alcohol use. This places patients in a position of having to conceal their alcohol use for fear of penalties at a time when reestablishing abstinence is most needed.⁵⁸ Addiction medicine, in contrast, considers alcohol dependence as a relapsing condition and admissions of relapse are used therapeutically.⁵⁹ When patients are encouraged to discuss their alcohol use without fear of judgement or penalty they are more likely to disclose honestly.^{7,58,60} This is considered a more effective way of identifying alcohol use^{57,58,60} and engaging patients in treatment.

From a sociological perspective, the policy of lifetime abstinence establishes an in-group prototype⁶¹ of an ideal ALD transplant patient who is able to self-manage and who shows an invincibility to relapse to match the "heroic" medicine provided by transplant staff. Therefore, in the absence of alcohol services to facilitate long-term abstinence, the policy gives a message that treatment is unnecessary, further reinforcing self-management. Disclosing alcohol use or requiring alcohol treatment could then be stigmatizing as it polarizes and disaffiliates treatment-seeking participants from an in-group membership of the ideal ALD transplant patient. Moreover, most ALD transplant patients in this study believed that treatment seeking could be interpreted as a sign of poor

commitment to sobriety and feared it could be met with staff disappointment.^{14,58}

Stigma refers to an "attribute" or "label" which is a deeply discrediting experience in the course of social interaction reducing the worth and social self-esteem of the individual.^{62,63} For ALD transplant patients, reluctance to seek alcohol treatment appeared to be a way to mitigate stigma or, as described by Link and Phelan (p16),⁶⁴ a means to "artfully dodge or constructively challenge stigmatising processes."⁶⁴ The utilization of alcohol treatment was perceived to be highly stigmatizing because of its strong association with the label "alcoholic" and thus tantamount to an admission of character weakness and personal failure.^{25,26,65} Men with alcohol problems, who comprise the large majority of ALD transplant patients, are particularly vulnerable to stigma and are reluctant to seek help because it can challenge the masculine hegemonic ideal of strength and may be linked to stereotypical femininity.⁶⁶

Stigma as a deterrent to participation in alcohol treatment is not unique to the ALD transplant population, but an exclusive set of unique circumstances with potentially self-stigmatizing processes do exist for ALD patients undergoing transplantation. Alcoholism continues to be the most highly stigmatized psychiatric disorder, with persistent public perceptions of the alcohol-dependent person as irresponsible, blameworthy, immoral, and more at fault for their illness.⁶⁷⁻⁶⁹ Such a perspective is intensified in relation to controversy surrounding the offer of scarce donor organs for those considered to have a self-inflicted condition. A stigmatizing diagnosis or label, such as "alcoholic" liver disease, if accepted by the individual, can activate powerful stereotypes containing stigmatizing images and negative attributes, which, if internalized, can have a number of adverse effects including treatment avoidance.⁶⁴ Although little reference has been made in the transplant literature regarding stigma and ALD, studies have found that patients with cirrhosis and nonalcohol-related liver disease felt stigmatized due to their liver disease being associated with "alcoholism."^{70,71} The "contract" and the "gift of life" was a discursive frame for posttransplant participants who embraced the role of being a responsible organ carrier and valuable contributors in a shared project by committing to abstinence. Returning the gift, through abstinence, reduces the sense of inferiority associated with gift receiving, maintains moral integrity, and creates ties in social relations.⁷² Reliance on this as a relapse prevention strategy, however, is limited and is not an evidence-based alcohol intervention.

In this study, those who relapsed tended to experience the loss of a social support network, especially that of a partner, and became less able to manage their lives. Social relationships and peer support have a positive influence on identity, self-esteem, and recovery from relapse and act as an antidote to stigma,⁷³ but were absent among our relapse participants.

Access to health care is critical to promoting treatment engagement with this responsibility lying as much with dynamics of social organisation as it does with individual factors. Although the ability to self-recover from an AUD without using treatment has been well documented, relapse can still occur.^{74,75} The findings from this study have significant implications for service delivery and implementation. We recommend the following to promote the use of alcohol services and reduce barriers to treatment:

- Addiction services need to be embedded in the transplant program consisting of drug and alcohol assessment, individual and group-tailored interventions, assistance for mandated clients,⁵⁹ and telephone interventions;
- Education in the pretransplant phase about alcohol dependence and the risk of relapse;²³
- Individuals with a high self-reliance may be aided to work collaboratively with experienced alcohol treatment providers without feeling that their need for self-sufficiency is threatened;
- Involvement of patients' supports, especially partners,⁷⁶ so that they can better understand AUDs and how to foster abstinence.

Limitations

This study was part of a mixed method study relying mainly on convenience sampling thus some bias, incomplete conclusions or inadequate saturation may have occurred. However, thematic analysis provides a flexible method with no clear agreement on how it should be implemented or clear guidelines on when saturation is achieved.⁴³ Despite the small sample size of each subgroup, the richness of data and repetition of themes indicated that saturation had been achieved sufficiently to address the research question. The inclusion of a subgroup of participants who were engaged in alcohol treatment would have provided further insights; however, we did not encounter any during the life of this study. Moreover, recruitment of such a subgroup would have been difficult given the prevalence of treatment reluctance in the LT setting. Social desirability and fear of jeopardizing candidacy may have limited alcohol use disclosure and limited open expression despite efforts to ensure confidentiality. Areas for further research not explored in this study include the antecedents of stigma and experiences of enacted stigma, participant interaction styles with transplant staff and the role of chronic illness.

CONCLUSIONS

This study has identified a significant gap in the understanding of treatment reluctance by ALD transplant participants highlighting the conceptual and empirical neglect of stigma, self-management, social support, health delivery, and policy as explanatory tools. The LT services may need to reflect critically on the ways in which they have positioned ALD participants and their respective relapse prevention as they attempt to engage patients with alcohol treatment. Such an approach would be more consistent with the reality of the challenges that participants face in maintaining abstinence while undergoing the long course of transplantation.

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