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Barriers and Resistance to Speciality Alcohol Treatment amongst Alcoholic Liver Disease Transplant Candidates Preceding and Following Liver Transplantation

Cathy Heyes
B.App.Sc (OT) MA (Drug and Alcohol Studies)

A thesis submitted in accordance with the requirements for admission to the degree of

DOCTOR OF PHILOSOPHY

The University of Sydney
2013
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CANDIDATE’S STATEMENT

I hereby declare that this submission is my own work and to the best of my knowledge and belief, is original except where due acknowledgement is made in the thesis. The thesis was undertaken by the author in the School of Community and Behavioural Health Sciences Faculty of Health Sciences, Sydney University and The Royal Prince Alfred Hospital, Sydney Australia. The author was responsible for the initiation and conduct of the work which was performed under the joint supervision of Professor Paul Haber, Associate Professor Toni Schofield and Associate Professor Andrew Baillie.

Any contribution made to the research by others, with whom I have worked work with at the University of Sydney, Royal Prince Alfred Sydney Australia Hospital or elsewhere is explicitly acknowledged in this thesis.

I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project’s design and conception or in style, presentation and linguistic expression is acknowledged.

Cathy Heyes

Date

10/10/2013
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10th October 2013

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Cathy Heyes

Date
ABSTRACT

End stage alcoholic liver disease (ESALD) is a leading yet controversial indication for orthotopic liver transplantation (OLT). Around one third of these patients will return to harmful alcohol use after transplantation, against medical advice. Relapse to harmful drinking contributes to mortality, morbidity and poor quality of life for the individual and impacts on the reputation of the program. Despite the availability of established alcohol treatment, ESALD transplant patients avoid such services. The current research investigated the barriers to and reasons for treatment resistance amongst ESALD transplant patients. A mixed method approach was utilized, consisting of a quantitative prospective case control study and a qualitative in-depth interview study.

The case control study compared 40 ESALD transplant patients (cases) matched for age and sex with 40 alcohol treatment seekers without liver disease (controls). The aim of the study was to identify barriers and reasons for treatment resistance by ESALD transplant patients in comparison with alcohol treatment seekers. The qualitative in-depth interview study involved semi-structured interviews amongst 42 ESALD transplant candidates. The aim was to illuminate the cognitive processes, experiences and understandings of ESALD transplant participants regarding abstinence, alcohol relapse, and alcohol treatment seeking in the context of liver transplantation.

The results of the case control study showed that ESALD transplant patients perceive no need for treatment due to their lengthy abstinence and high motivation for change. Standard alcohol interventions are not tailored to the ESALD transplant population as they differ from ATS on alcohol severity, health beliefs, psychiatric co-morbidity and quality of life. No differences were found between the two groups with regard to HCV, co-morbid substance abuse and education levels. Barriers to help seeking amongst ESALD transplant subjects consisted of possible fear of stigma and limited access to alcohol services.

The in-depth interview study found 62% of ESALD transplant participants reporting stigma to be a major deterrent to utilizing specialty alcohol treatment because of its association with the label ‘alcoholic’ and its inconsistency with the criteria for membership of a group prototype of ideal transplant candidates. Self-management by ESALD transplant participants to achieve substantial abstinence removed the necessity for professional support services. Abstainers were strongly supported by intimate partners, social networks
and a moral obligation inherent in ‘the contract’ with the liver team, none of which they acknowledged as significant in their capacity to remain abstinent. A major barrier to alcohol treatment seeking was the lack of an appropriate and suitable alcohol treatment service which was medically justified, integrated with the transplant program and actively incorporating the social and interpersonal dimensions of transplantation.

The findings of the research provide significant therapeutic implications to tailoring a more suitable and efficacious approach to the management of alcohol relapse within the liver transplant context.
ACKNOWLEDGEMENTS

The research for this thesis was undertaken from March 2007 to March 2013 as part of the requirements of the Doctor of Philosophy program through the University of Sydney in which the author has been enrolled in. The project, from which this thesis is derived, was made possible only through the interest, support and co-operation of many people. First, I wish to express my gratitude to all my supervisors Professor Paul Haber, Associate Professor Toni Schofield, Associate Professor Andrew Baillie for their constant enthusiasm, support and guidance of this research project and thesis. Observing the scientific intellectual rigour, creativity and personal qualities you have developed as researchers and educators has been a very rewarding experience. I also would also like to acknowledge the ongoing support from a number of professionals who provided me with support during this research: Dr Robert Gribble, Dr Claudia Sannibale, Dr Devanshi Seth, Anne Sophie Veillad, Professor Cherry Russell, Dr Chris Lennings, Dr George Ridgway, Ron Perry, Dr Rob Heard, Tracey Jarvis, Margaret Glesson and a very special thanks to Eric Stevenson for his endless encouragement and practical support.

I wish to express my gratitude to all the participants who gave generously with their time and were willing to participate in my research. Your life experiences and altruism is incredible and without your support this research would not have been completed. I hope that this research may in some way help others who continue to struggle with alcohol use.

I would like to thank my family, Jason, Lauren and Ivan (junior), for their constant love and patience over the years and for never losing faith that I would finally finish my studies. My deepest thanks to my partner, Ivan Milostic, who can only be described as my ‘rock’ providing me with food, patience, encouragement and belief in my ability to successfully complete this project.

It is with sadness that I acknowledge my late husband Geoffrey Heyes, whose life was tragically cut short in November 2000 whilst receiving treatment at RPAH. You are dearly missed in my life. This thesis helped fill the void created by your absence and it is through this project that I remained symbolically connected to you through the ‘adventure of ideas’.
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<table>
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<th>Description</th>
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<tbody>
<tr>
<td>AA</td>
<td>Alcoholics Anonymous</td>
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<tr>
<td>ALD</td>
<td>Alcoholic Liver Disease</td>
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<td>AD</td>
<td>Alcohol Dependence</td>
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<td>ANLTU</td>
<td>Australian National Liver Transplant Unit</td>
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<td>ATS</td>
<td>Alcohol Treatment Seekers</td>
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<td>ANOVA</td>
<td>Analysis of Variance</td>
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<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<td>DASS</td>
<td>Depression Anxiety Stress Scales</td>
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<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>ESALD</td>
<td>End Stage Alcoholic Liver Disease</td>
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<tr>
<td>HCV</td>
<td>Hepatitis C Virus</td>
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<tr>
<td>HRAR</td>
<td>High Risk Alcoholism Relapse Scale</td>
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<tr>
<td>LDH</td>
<td>Lifetime Drinking History</td>
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<tr>
<td>LT</td>
<td>Liver Transplantation</td>
</tr>
<tr>
<td>MELD</td>
<td>Model for End Stage Liver Disease</td>
</tr>
<tr>
<td>MET</td>
<td>Motivational Enhancement Therapy</td>
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<tr>
<td>NIH</td>
<td>National Institute of Health</td>
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<tr>
<td>OLT</td>
<td>Orthotopic Liver Transplantation</td>
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<tr>
<td>QOL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>QLI</td>
<td>Quality of Life Index</td>
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<tr>
<td>SIP 2-R</td>
<td>Short Inventory of Problems – Recent</td>
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<tr>
<td>SADD</td>
<td>Short Alcohol Dependence Data</td>
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<tr>
<td>SOCRATES</td>
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<td>IVDU</td>
<td>Intravenous Drug use</td>
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CHAPTER 1

Introduction

Carlo DiClemente (2007), a leading author and researcher in the field of the psychology of change and addictive behaviours wrote:

Natural or self-directed change is the fundamental process where we should be looking for mechanisms of change. It is the change process that interacts with any efforts to assist individuals to change drinking behavior. Treatment is not a powerful force meeting an immovable object. From this perspective it is the change processes or mechanisms located in the person and person-environmental interactions that are the critical mechanisms for creating change. Treatments then are viewed as an extension of the person’s process of self-change and not as a unique and critical mechanism for change. [1] (p.19S)

People needing to change after facing personal problems or life setbacks may prefer to solve their own problems rather than pursue professional help. Such people will seriously consider professional treatment only when all efforts at self-help have been exhausted. The preference for self-directed change in place of seeking professional help, can also apply to individuals who have developed a problem of excessive alcohol use [2]. While a large number of people in society drink safely, a substantial number can experience alcohol use problems resulting in issues such as alcoholic liver disease and yet do not seek professional treatment [3-4].

Alcoholic liver disease (ALD) due to excessive alcohol consumption is a major health problem in the western world [5]. ALD involves a spectrum of disease severity ranging from fatty liver to a more severe form of the condition termed alcoholic
cirrhosis, which is one of the leading causes of morbidity and mortality [6]. The progression of the disease involves scar tissue increasingly replacing normal liver tissue, thus preventing healthy liver function. For patients with end-stage alcoholic liver disease (ESALD) abstaining from alcohol use is imperative to preserve life [7]. However liver damage may still progress despite months or years of abstinence and the only effective treatment option to staying alive is a liver transplant.

Liver transplantation is a surgical procedure in which the diseased liver is removed and replaced by a healthy liver in the original anatomic location. This treatment was pioneered by Thomas Starzl in 1963 in Denver, Colorado with the first successful one year human survival transplant occurring in 1967 [8]. Improvements in survival rates after transplantation continued thereafter. Over the following two decades a number of medical and surgical advancements has resulted in a dramatic increase in the number of transplants performed worldwide [9-10]. The goal of liver transplantation is the treatment of irreversible life-threatening liver disease which has not responded to alternative medical and surgical interventions. The success of liver transplantation has resulted in an ever increasing demand for donor organs but there is an inadequate rate of organ donation causing a deficit between the number of donor organs and the number of patients requiring a transplant [11]. After almost a half century of liver transplant experience, one of the key issues facing transplant programs is less related to scientific medical advances and more concerned with access and equity around the provision of a life saving treatment [12].

One of the leading indications for transplantation is ESALD, second only to liver disease as a result of chronic HCV infection [13]. The provision of liver transplantation for those with ESALD is problematic. Michael Lucey, Professor of Medicine Chief, Section of Gastroenterology and Hepatology, recently stated that ‘..the apparent success of LT for ALD masks a more complex reality. There are still unresolved controversies about LT for patient with ALD’ [14] (p.751).

Central to the controversy, is the issue of alcohol relapse during the pre- and post-transplant period [13, 15]. Firstly, relapse to harmful drinking has been found to
contribute to mortality and morbidity, mental health problems and poor quality of life. Secondly, transplant programs are concerned that relapse to any alcohol use by ESALD transplant recipients may affect the readiness of the public to donate affecting access to transplantation for all diseases [16]. Relapse occurs despite transplant programs carefully selecting and evaluating potential candidates and a mandatory period of sustained abstinence before being listed.

Transplant research literature to date continues to highlight the need for an effective alcohol treatment approach in order to reduce the risk of relapse but identifying the most acceptable and effective intervention for ESALD transplant patients continues to remain a problem. There are conflicting views within the transplant field about the model behind the provision of alcohol treatment. Transplant physicians and hepatologists consider relapse a failure of transplantation because their goal is lifelong abstinence even after the patient has positively recovered from transplant surgery. This approach contrasts with that of addiction specialists where alcohol use disorders are understood as a separate medical condition to ALD characterised by remission and relapses and where open disclosure of alcohol use during the course of treatment is encouraged. It has been argued that the policy requiring strict abstinence inhibits the lack of candour by patients for fear of being penalised. This becomes counter-therapeutic as it inhibit treatment seeking and re-establishing sobriety [17] [14].

Controlled studies have attempted to attend to the risk of relapse by providing established alcohol interventions within the liver transplant setting [18-19] but ESALD transplant patients did not perceive a need for alcohol treatment and these interventions were not successful.

**Focus and aim of the study**

In order to understand the barriers, and reasons for, resistance to alcohol treatment by ESALD patients within the context of liver transplantation, this research draws on
five fundamental areas: liver transplantation and ESALD, alcohol use disorders and relapse, alcohol treatment seeking, cognitive behavioural change and the sociology of alcohol use disorders. As discussed earlier the majority of people with alcohol use disorders will not seek treatment despite its effectiveness. The resistance to treatment by ESALD transplant patients presented an interesting and challenging research project.

Alcohol treatment seeking often entails a complex and multi-factorial process dependent on the interaction of psychological, social, biological but also organisational factors [20-22]. Liver transplantation for those with ESALD involves a number of issues including: medical, political, economic, moral and ethical, adding to the complexity surrounding treatment resistance by this client population.

This study proceeded from the concern regarding alcohol relapse amongst ESALD transplant patients and their rejection of alcohol treatment considering their history of alcohol dependence or abuse and the negative outcomes associated with relapse. This study will investigate factors contributing to treatment resistance and barriers amongst ESALD transplant patients to guide design of effective treatment approaches.

**Research question**

The primary research question for this project is:

What are the barriers to, and reasons for, resistance to specialty alcohol treatment amongst ESALD transplant candidates before and after liver transplantation?

Sub-questions include:
1. Do ESALD transplant patients need alcohol treatment?
2. How are ESALD transplant patients different from those who actively pursue specialist alcohol services? The difference here will be identified by establishing the correlates of alcohol treatment seeking.
3. What is the experience of help seeking for ESALD transplant patients considering the medical and social factors surrounding liver transplantation?
4. Can ESALD transplant relapsers and abstainers inform us about what treatment approach may be more suitable and effective within a transplant setting?
5. How do we identify those amongst the ESALD transplant population who may need or benefit from treatment?
6. How do we set up treatment services that engage ESALD transplant patients towards alcohol treatment?

**Overview of the research approach**

The present study is the first systematic attempt to investigate reasons for treatment resistance and barriers to alcohol dependency treatment amongst ESALD transplant patients. As treatment seeking is a complex process and in order to identify the most salient variables, processes or themes behind treatment resistance and barriers to treatment, two research paradigms were chosen to optimally address the research question. A mixed method research design involving both quantitative and qualitative data collection techniques was adopted and is illustrated in Figure 1.

The advantages of combining the qualitative and quantitative approaches is that the different data sets can be both illuminating in terms of similarity and differences of findings yielding a unitary picture providing breadth and depth to the problem.
Study 1

Study one utilized the empirico-analytical paradigm research approach (commonly referred to as quantitative research). Its epistemological and ontological position means the researcher is able to isolate and define variables and variable categories framed in the hypothesis and allows that to be tested against the data. The use of instruments or measures which are pre-determined and specifically selected allows the researcher to effectively prove or disapprove the hypothesis. From the range of research approaches in this paradigm, the case control study was the most suitable in order to investigate factors contributing to treatment resistance. This enabled a comparison to be made between those who actively participate in professional alcohol treatment services and ESALD transplant patients who are non-treatment seekers, while controlling for liver disease as a primary motivator for treatment.
Study 2

The interpretive paradigm was chosen for Study 2 as it focuses on accessing and understanding the meanings of participants’ experiences rather than testing a theoretical assumption. This approach was utilized as it is the most direct method to extract and uncover the beliefs, meanings and experiences of ESALD transplant candidates in the social world of the transplant setting. Thematic approach to analysis of interview data was chosen as this enables the research to develop a substantive theory.

Significance of the research

This study addresses an important gap in the literature as there are no empirical findings to explain the lack of treatment seeking or resistance amongst ESALD transplant patients to find the most effective alcohol approach considering the clinical characteristics and experiences of this population.

Organisation of the thesis

Three extensive bodies of literature relevant to the topic under investigation were critically reviewed. Chapters 2 and 3 provide an introduction and background to key issues surrounding liver transplantation and ESALD transplant patients for the two research studies. Chapter 2 discusses alcoholic liver disease, selection, evaluation and stages of liver transplantation. ESALD as an indication of transplantation is discussed attending to key issues including: historical factors, the medical and ethical controversy, selection and evaluation procedures, liver transplant outcomes and alcohol relapse. Chapter 3 contains a critical review of the current management of alcohol problems by liver transplant programs. This chapter pays special attention to four studies which have attempted to treat alcohol use disorders within the context of the liver transplantation exploring findings and methodological limitations. The chapter ends by presenting the current research examining the demographics and
clinical characteristics of the ESALD transplant population to alcohol treatment seekers.

The thesis is then divided into two parts. Part 1 contains the literature review, method, results and discussion for the case control study. Part 2 presents the in-depth interview study similarly.

Part 1 commences with Chapter 4 which provides the literature review for the case control study. A number of factors are known to keep people from seeking professional help and are outlined in this chapter. A brief review of the general psychotherapy literature explaining treatment resistance is provided. This is followed by the theoretical models conceptualising the alcohol treatment seeking process along with the research findings concerning the correlates and barriers to alcohol treatment seeking.

Chapters 5, 6, 7 discuss the case control study. Chapter 5 details the methodology utilized including subjects, study procedures, measures, data management and statistical analysis. Chapter 6 presents the results. Chapter 7 discusses the research findings in relation to the hypotheses and wider research literature.

Part 2 commences with Chapter 8 which draws on sociological theories of alcohol use with attention to alcoholism and stigma to develop a conceptual framework that locates excessive alcohol use and transplant policies and practices within a medical and social context. Chapter 9 presents the qualitative research paradigm and approach, methodology; and quality management. Chapter 10 presents the characteristics of the participants, the results of the thematic analysis highlighting the key themes and key quotes. Discussions of the findings are presented in Chapter 11.

Chapter 12 consists of a conclusion drawing the findings of both the case control and qualitative study in relation to the research question. Recommendations for the
management of problematic alcohol use within the liver transplant setting are presented.
References


End Stage Alcoholic Liver Disease (ESALD) is a leading indication for Orthotopic Liver Transplantation (OLT). Before directly addressing the topic of the research investigation pertaining to the lack of voluntary participation in specialty alcohol treatment by ESALD transplant candidates it is important to present the background, practices and key issues surrounding liver transplantation, especially as it relates to those with ESALD. This chapter commences with a brief overview of alcoholic liver disease (ALD) followed by discussion about current practices, procedures and research findings concerning OLT. A key issue facing transplant programs worldwide which will be discussed is the provision of a medically intensive life saving procedure in the climate of organ shortage and growing patient demand. Furthermore ESALD is the most controversial indication for OLT and one which is subject to more intensive evaluation and monitoring than other conditions causing end stage liver disease. At the centre of this debate is relapse to alcohol use after liver transplantation and the latest research findings and understandings about alcohol relapse amongst ESALD transplant candidates are reported including: relapse rates, the medical and psychosocial consequences and predictors of relapse.

Alcoholic Liver Disease

Alcohol remains a major cause of liver disease worldwide especially in established market economies and accounts for 50% of cirrhosis deaths in the western world [1-2]. Alcoholic Liver Disease (ALD) accounts for a conservative estimate of 3% (1.8 million) of the global burden of death [3]. In the United States in 2007, liver cirrhosis was the 12th most common cause of death accounting for 29,165 deaths, of these 14,406 (49%) were alcohol-related [4]. Similarly in 1996 Australian mortality figures showed ALD as the 13th leading cause of death [5]. Between 1992 and 2001, 31,133 Australians died from alcohol related disease and
injury with alcoholic cirrhosis accounting for 6,825 deaths (22%) [6].

ALD is defined as acute or chronic liver disease in the presence of regular alcohol consumption where no other cause of liver injury can account for the disease [7]. To be more confident of the role of alcohol in an individual case, a history of sustained excessive alcohol use (normally ≥ 20g ethanol/day in women; ≥ 60g ethanol/day in men) is typically found [8]. ALD involves a disease spectrum that ranges from fatty liver or simple steatosis, alcoholic hepatitis and eventually alcoholic cirrhosis [9]. Alcoholic cirrhosis is the most serious form of ALD causes most deaths and morbidity from this disorder. In cirrhosis scar tissue replaces normal liver tissue, disrupting blood flow through the liver thus preventing healthy liver function. ALD develops over a long period and during the early years of the disease patients with cirrhosis may only present mild and non-specific symptoms [10]. ALD at the end stage of the spectrum manifests usually in the older patient who starts showing signs of liver failure which can eventuate in the end of life. Once cirrhosis has developed, the prognosis is dictated by the evolution of complications such as encephalopathy, bleeding, fluid retention, cachexia (generalised wasting) and hepatocellular carcinoma (liver cancer).

The amount of alcohol ingested is the most potent risk factor for the development of ALD. Epidemiological data shows a strong correlation between levels of alcohol consumption with numbers of cases of ALD [11-13]. In the United States cirrhosis mortality increased steadily following the end of Prohibition in 1933 until 1973 where it peaked at 18.1 deaths per 100,000 population followed by a steady decline in the last four decades (Figure 2.1).
One study estimated that for every additional litre per capita in alcohol consumption there was a corresponding 14% increase in cirrhosis in men and 8% increase in women [15]. Higher rates of cirrhosis death are seen in countries where people traditionally consume more alcohol (such as Spain, France and Italy) and lower rates in countries where alcohol consumption is lower (such as Iceland, NZ and Norway) while countries such as the United States are in the middle range along with Belgium and Canada [2, 11] (WHO, 2000). Mortality from ALD has been steadily declining in most countries worldwide including Australia, European countries and the USA since the mid or late 1970s, mainly as a result of
reduction in alcohol consumption [10, 16]. By contrast, steady upward trends have been seen more recently in the United Kingdom and central and eastern European countries, and ascribed to the continual increase in alcohol consumption [16]. A striking increase in hospital admissions and mortality in England from chronic liver disease with mortality rates doubled between 1979 and 2005 [17]. Hospital admission rates for ALD doubled between 1989/1990 and 2002/2003 and in 2005 ALD contributed to two thirds of chronic liver disease deaths. Alarmingly, increases in ALD were reported amongst those in the 25-34 age groups along with increased incidence in females between the ages of 35 to 54.

According to Thomson a number of significant factors play a role in the increase mortality and morbidity due to ALD. These include: increased availability of alcohol due to increase in the number of licensed premises and broader licensing laws; drop in the cost of alcohol; media and advertising portraying binge drinking and popular celebrity culture, public health ignorance especially around addiction; and modern life stressors. Thomson noted that many will perceive cirrhosis as a disease of people who are ‘alcoholic’ or ‘addicted’ despite the fact that many patients with chronic liver disease do not fit profile of those who are severely dependent [18]. In Australia between 1993 and 2005, Liang and colleagues reported significant decreases in the mortality rate of ALD coinciding with a gradual increase in hospital admissions for alcoholic hepatic failure and alcoholic cirrhosis especially among younger age groups. The increase in admissions and reduction in mortality was believed to be due to an increase in screening of alcohol-related and improvements in disease management in primary care settings [10].

Epidemiological data suggest that a threshold of 80g of daily alcohol in a male and 20g in a female for an average of 10-12 years is necessary for alcoholic injury to develop [19-21]. Fatty liver develops in about 90% of individuals who drink more than 60g/day of alcohol but can occur in those who drink less [13]. However there are data showing lifetime risk of death from alcohol use increases with consumption and not necessarily within the threshold [22]. In Australia 44% of Australians were drinking amounts which exceeded the 2001 National Health and Medical Research Council (NHMRC) guidelines for minimising problems from the chronic effects of alcohol (an average of no more than 2 drinks per day for women and 4 drinks per day for men ) [6].
Cirrhosis mortality rates are substantially lower among the young but increase considerably in middle age reaching a peak in the 45-54 age group, making it the fourth leading cause of death in this age group [11]. Cirrhosis mortality rates are two times higher in men than in women despite the higher risk for developing cirrhosis in women at an individual level due to physiological factors. The higher rate of cirrhosis mortality amongst men is probably due to a greater alcohol consumption and a higher rates of alcohol use disorders amongst men compared to women [11].

Not all patients who drink excessively develop life threatening alcoholic liver disease as the severity of liver damage is not consistently related to the amount and years of alcohol consumption. While 90% - 100% of heavy drinkers will develop fatty liver, only 10% to 35% develop alcohol hepatitis and 8% to 20% develop alcohol related cirrhosis [23]. A number of other risk factors have been associated with the development and progression of liver disease including: the type of alcohol consumed, pattern of drinking, sex, ethnicity, malnutrition, obesity, iron overload and chronic hepatitis virus infection [13]. Genetic factors involving polymorphisms of hepatic alcohol-metabolizing enzymes play a central role in the tissue tropism of alcohol injury [24]. Also a large proportion of patients with ALD have coexisting chronic Hepatitis C Virus (HCV) infection suggesting that the virus may accelerate the development of cirrhosis and the progression to end stage liver failure [9].

A diagnosis of end-stage ALD is determined medically based on a history of significant alcohol consumption, physical examination, laboratory and pathologic evaluations. Other causes for liver disease are excluded by appropriate medical evaluation. Abstinence is the cornerstone of therapy in the management of the condition along with nutrition, diet and certain medications [9]. However despite months or years of abstinence some patients with end stage ALD will require liver transplantation due to signs of far advanced hepatic damage or complications such as bleeding varices or the hepatorenal syndrome [9, 25]. Without liver transplantation the 5 year patient survival rate for those with ESALD has been reported to be as low as 23% [1] whereas with OLT the survival rate is increased to 88% [26].

In conclusion ALD is a leading cause of death especially in industrialised western countries with high levels of alcohol consumption. While ALD can be attributed to heavy alcohol
consumption there are a number of other aetiological factors leading to the development of the disease. ALD can be perceived as a diagnosis associated with the stereotype of alcoholism or found only amongst those with severe alcohol dependence syndrome. This review reveals that ALD can affect individuals in the wider community with a range of alcohol consumption patterns and co-existing aetiologies.

**Orthotopic Liver Transplantation**

**Background to OLT**

Orthotopic Liver Transplantation (OLT) is the most effective treatment for patients with irreversible liver disease, who have not responded to alternative medical and surgical interventions and who are approaching the terminal phase of their illness [27-28]. This surgical technique has extended the survival and improved the quality of life of patients with end-stage liver disease who previously would have died within a few months to a few years [29-30].

OLT is the most commonly used technique for liver transplantation which involves removal of the recipient native liver and replacement with the transplanted donor liver in the same anatomic location as the original liver. The majority of liver transplants use the whole liver from a heart beating brain-dead donor. Further developments in OLT include: split liver transplantation, in which a single donor liver is used to provide transplants for two recipients, living donor liver transplantation, in which a portion of a healthy person’s liver is removed and used as the allograft; and auxiliary liver transplantation in which a portion of the diseased liver is removed and the reduced-size graft is implanted alongside the native organ [28].

In 1983 a consensus conference held in the United States under the auspices of the National Institutes of Health (NIH p.110S) formally announced that liver transplantation had become a ‘therapeutic modality for end stage liver disease that deserved broader application’ as
opposed to it being considered an experimental procedure[32]. By 1988 over 1,700 transplants were conducted in the United States alone with an overall 5 year survival rate of 70% [33]. Continuing advances over the next two decades in surgical and anaesthetic techniques, availability of new immunosuppressive agents for rejection, more reliable technology for organ preservation, advances in microbiology and critical care medicine resulted in a dramatic increase in the number of transplants performed [7, 29, 34].

Liver transplantation is now available worldwide and is offered in the United States, Europe, Great Britain, Australia, Asia, Africa and South America. Transplant registry figures show that in Europe between 1968 to 2009, 93,634 liver transplants were performed [35], in the United States between 1999 and 2008, 54,446 patients received OLT [36], and in Australia between 1985-2008, 3305 transplants were conducted [37]. In addition survival rates after OLT have continued to improve compared to the survival rates of the 1980s. Current survival data for the United States, Europe and Australia are provided in Table 2.1. Overall OLT has contributed substantially to a significant decrease in cirrhosis mortality worldwide [38].
The number of medical conditions considered as suitable indications for OLT has also expanded. These include: cholestatic liver disorders, metabolic disorders causing cirrhosis, metabolic disorders causing severe extrahepatic morbidity, primary malignancies of the liver, fulminant hepatic failure, retransplantation and chronic noncholestatic liver disorders comprising of chronic hepatitis C, chronic hepatitis B, autoimmune hepatitis and alcoholic liver disease [30].

### Selection criteria

The principles and practice behind the selection and allocation of donor organs varies between continents, countries and even states with different models for selection and listing being introduced in America, Europe and Australia [41]. According to Neuberger [34] in 1991 the World Health Organisation stated that donated organs should be allocated based on medical need and not financial or other considerations [42]. This was followed by the United Network for Organ Sharing (UNOS) stating that donated organs should balance medical usefulness and justice (equity in distribution of the benefits and burdens among all transplant patients). Thus in 1997 the American Medical Association Committee on Ethical Issues developed acceptable selection criteria for OLT which included: the likelihood of benefit for the patient, importance of the treatment in improving the patient’s quality of life, duration of

<table>
<thead>
<tr>
<th>Country</th>
<th>Time period</th>
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<tr>
<td>Europe [40]</td>
<td>1988-2009</td>
<td>82-70%</td>
<td>71-58%</td>
<td>61-45%</td>
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<tr>
<td>Australia [37]</td>
<td>1986-2007</td>
<td>85%</td>
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benefit, urgency of treatment and the amount of resources likely to be required. Unacceptable criteria for OLT included: ability to pay, the patient’s contribution to society, perceived obstacles to treatment (e.g. antisocial behaviour), past use of medical resources and the patient’s contribution to the medical disorder (e.g. drug or alcohol abuse). However these may not be actually followed in practice [34].

In 2002, UNOS for the United States, introduced standardized minimal criteria or system for allocating organs based on a disease severity score called the model for end-stage liver disease (MELD). MELD is an objective method of predicting liver disease mortality without transplantation by calculating a score based on three blood test parameters: serum creatinine, serum total bilirubin and international normalized ratio (INR) [43]. Other countries such as France, Israel and Eurotransplant countries and Brazil have followed this system of selection establishing nationally agreed selection criteria with the graft being offered to identified patients, selected according to MELD scores, body size and blood group [41].

In Australia the Transplantation Society of Australia and New Zealand (TSANZ) [44] developed nationally uniform allocation protocols outlining the eligibility criteria for patients to be listed for OLT. The eligibility criteria and allocation protocols are followed by all Australian and New Zealand transplant units. Decisions regarding eligibility and allocation include: relative urgency of need, medical factors which affect likelihood of success (e.g. tissue matching); relative severity of illness and disability; relative length of time on the waiting list; likelihood that the recipient will (be able to) comply with the necessary ongoing treatment after transplantation. The general recipient suitability criteria for OLT according to the Transplantation Society of Australia and New Zealand (TSANZ) are outlined in Table 2.2.
Table 2.2 General Recipient Suitability Criteria by the Transplantation Society of Australia and New Zealand [44]

1) Accepted indication for listing  
   a) Life threatening acute or chronic liver disease not amenable to alternative therapy  
   b) Extrahepatic manifestations of inborn error of metabolism (FAP, GSD, hyperlipidaemia).

2) Transplant to improve quality of life but not life expectancy (i.e. palliative transplant) is accepted indication.

3) Accepted onto the waiting list by a recognised liver transplant unit.

4) Absence of contra-indications e.g.:  
   a) Life threatening non-hepatic illness considered to preclude successful liver transplantation  
   b) Persisting alcohol or substance abuse  
   c) Inability to co-operative with lifelong medical supervision  
   d) The presence of significant malignancy (except for hepatocellular cancer)  
   e) Severe neurologic or development impairment.

The stages of liver transplantation

Liver transplantation can be viewed as a continuum involving five stages: referral and review of clinical history by the transplant unit, the liver transplant evaluation process, the waiting list period, the peri-operative period and finally post-operative recovery period [45]. Stage 2, the liver transplant evaluation process, is especially important in order to yield successful transplant outcomes and for the patient to be placed on the waiting list for OLT.

According to Murray [30] there are three steps in the evaluation process. The first step entails determining a need for liver transplantation which involves a medical assessment which carefully examines the natural history of the patient’s disease with the expected survival after the operation. A number of clinical tools involving disease-specific models are utilized to score the relative risk of mortality amongst patients with chronic liver diseases, such as the Child-Turcotte-Pugh (CTP) and the prognostic model for end-stage liver disease.
(MELD). The second step is to ensure that every alternative form of medical or surgical treatments for chronic liver disease have been attempted before committing a patient to OLT. The final step is determining the potential for successful liver transplantation involving a comprehensive medical and psychosocial evaluation.

The objective of the evaluation is to identify indications and exclude contraindications as listed in Table 1.2 to discern whether the patient is able to survive the operation and post-operative period, their medical compliance and the impact of co-morbid conditions such as psychiatric disorders or drug and alcohol dependence. Positive OLT outcomes are dependent not only the high degree of medical and nursing expertise but also patient compliance with the treatment regimen throughout the pre and post-transplantation process. The treatment regimen involves taking immunosuppressive and other medication, regular outpatient follow-up appointments and lifestyle changes involving diet, nutritional supplementation, exercise, smoking and drug and alcohol use.

The evaluation by the transplant unit usually takes a few days to a few weeks. It may extend for months or more in some cases particularly those where substance use issues are uncertain. Patients may be refused OLT due to medical contraindications and/or active alcohol or substance abuse or other factors. In Australia the decision to select a patient for OLT is usually made by a transplant committee consisting of transplant physicians, transplant surgeons, hepatologists, psychiatrists, nurses and allied health professionals [27]. Once the decision is made to place the patient on the liver transplant waiting list patients may wait a year or more for a suitable liver to be available. For all transplant candidates this can be a stressful period where they may experience complications of their disease and/or return to alcohol or drug use. Patients with alcohol-induced liver disease have the longest waiting time and highest risk of death on the waiting list followed by viral hepatitis [46].

**An era of donor organ shortage**

The success and effectiveness of OLT resulted in the revision of medical management guidelines recommending that patients with end-stage liver disease be considered or referred
for liver transplant evaluation. This contributed to an ever growing number of potential transplant recipients on waiting lists which became increasingly disproportionate to the supply of cadaveric donor organs [29, 41]. In the United States in 2007 there were 12,213 patients on the waiting list of whom 6489 (53%) received a transplant. 11,081 new patients for candidacy were registered that year [47]. In Australia from 1985 to 2007, a total of 1946 patients were assessed and 892 (46%) proceeded to transplantation [48] with a growing waiting list (Figure 2.2). Studies report that between 10-20% of patients die while waiting [46, 49-50]. This shortfall between supply and demand continues despite more recent approaches to increase the pool of available organs and reduce the wastage of organs including: rehabilitating marginal grafts, splitting livers, improving selection criteria and efforts to generate greater public interest in organ donation [29, 34].

**Figure 2.2** Australia and New Zealand Liver Transplant statistics based on the 20th Report 2008 [37].
According to Starzl [31], the original pioneer of liver transplantation, the major issue facing OLT today does not involve medical scientific problems associated with patient survival and quality of life. Rather they are issues to do with ethics, equity and other humanitarian issues concerning the allocation of scarce donor organs. Transplant services over the last two decades have been involved in a continuous process of developing and implementing more precise selection guidelines to optimize the allocation of a limited supply of donor grafts. According to Neuberger [41] transplant services have to balance the competing demands involving the individual autonomy of the recipient, the utility of the donor organ against a background of justice, access and equity.

Liver transplantation programs are dependent on the generosity of the general public who are the suppliers of donor organs. Transplant units are expected by the general public to maximise the utility of the organ, to be publicly and professionally accountable and to operate from sound medical and ethical principles [7, 34].

In conclusion liver transplantation is a successful treatment for irreversible liver disease but the shortfall in the supply of donor organs means that transplant units have to rely on comprehensive medical and psychosocial evaluation in order to assess who will be prioritized for OLT. Furthermore the public expect transplant programs to maximise the utility of each organ donated making patient selection very important. This is particularly the case for ESALD as an indication for OLT.

**End-stage Alcoholic Liver Disease and OLT**

**Key Developments in end-stage Alcoholic Liver Disease and OLT**

In the first decade of OLT there was widespread concern that those with alcohol related liver disease would have a high peri-operative mortality, higher complication rate, poor compliance and post- transplant outcomes; and if they were to survive, they were at risk of redeveloping ALD [33, 51]. In a 1983 conference the National Institutes of Health (NIH)
formally pronounced that OLT was a viable treatment for patients with ALD who were able to abstain from alcohol and who showed no clinical indicators of mortality [32]. The NIH (p.108) concluded that “only a small proportion of alcoholic patients with liver disease would be expected to meet these rigorous criteria”. In fact, at that time only 25 of 540 patients (4.6%) had received transplants for ESALD [52]. This statement marks the beginnings of careful selection processes for those with ESALD and suggests an intention to restrict the use of OLT for those with ESALD [53-54]. Nevertheless the NIH conference marked the acceptance of transplantation for ESALD.

The chief criterion for consideration (and exclusion) for OLT for ESALD transplant candidates involved a substantial period of abstinence from alcohol prior to pre-transplant evaluation. In 1986 in a court case in Michigan, an alcoholic patient sued the state Medicaid Board for declining to pay for a liver transplant operation on the grounds that the patient had not been alcohol free for a sufficient period of time [55]. The court established the legal precedent that alcoholism alone did not contraindicate liver transplantation on the grounds that the Board had set a pre-operative abstinence period of two years which was longer than the likely natural course of the end-stage liver disease itself. The court also highlighted the lack of any reasonable set of criteria challenging both the transplant and the alcohol research communities to establish a reasonable set of criteria for use in selecting alcoholic patients for liver transplantation [56].

Between 1980 and 1987, Starzl transplanted 42 patients with ESALD reporting a 73% survival rate in the first year, equal to that of patients with ESLD attributable to other causes. Three decades later a large body of evidence reported equal if not better patient and graft survival rates for ALD transplant recipients compared to patients transplanted for non-alcoholic liver diseases [25, 57-61]. One of the largest studies ever conducted examined adult survival rates of over 3,700 adults transplanted between 1987 and 1995 for ALD, showing survival rates for 1, 3 and 7 years post--transplantation to be 81%, 73% and 59% respectively [62]. A step further was taken by Burra [63] who compared the 1, 3, 5 and 10 year survival rates of 9880 ALD patients with 10943 viral cirrhosis (VC) patients and 2410 cryptogenic cirrhosis (CRYP) patients and found higher survival rates amongst ALD patients of 84%, 78%, 73%, and 58% respectively. Transplant outcomes in Australia are equal and even slightly higher. Transplant registry reports show that between 1985 and 2008 survival
outcomes for ALD patients at 5, 10 and 15 years were 85%, 74% and 61% respectively [37].

ALD patients have been reported to have lower rates of liver rejection, graft failure and the need for re-transplantation compared with patients transplanted for other conditions [64]. Medical compliance involving immunosuppressive medication, adherence to follow-up clinic appointments and sobriety has been found to be generally good [61, 65] but poor compliance has been reported amongst those to relapse to heavy alcohol use [60].

The majority of studies have found the quality of life (QOL) for ESALD patients (medical, social and employment status) to improve following transplantation and to be similar to non-alcoholic transplant recipients [66-70]. Numerous studies have shown that QOL improves within 1 year after OLT. A long term study by Ruppert [71] involved collected clinical information, survival data and data on five quality of life domains for 381 liver transplant patients over a 12 year period rather than the usual 1 year study period. Mixed model analysis was used to determine whether initial gains in QOL were sustained long term. A gradual and consistent decrease in physical and social role function for all transplant recipient was observed. Within- group comparisons showed that ALD and HCV reported worse QOL in all domains at year 1 and had the greatest rate of decline physical functioning and physical symptoms over time. According to Ruppert the first post-operative year represents a critical time for QOL recovery, and may be an optimal time for intervention. Studies investigating the quality of life specifically amongst ALD patients have reported lower employment opportunities [72], poorer social re-integration [73], less life satisfaction [66], higher stress levels and worse health outcomes after transplantation [74], especially amongst those who had relapsed.

**ESALD a leading but controversial indication for OLT**

The distribution of liver grafts to individuals with ESALD has grown beyond the original framework created by the National Institutes of Health in 1983. ESALD is now one of the leading indication for liver transplantation, second only to liver disease as a result of chronic HCV infection [62, 75]. In the United States between 1988 and 1995, 3,785 (23.4%) had
ALD while 24.8% of transplant recipients were patients with hepatitis C viral liver disease [62]. In Europe between 1988 and 2008, 33% of OLT were conducted for patients with alcoholic cirrhosis while 38% were for those with virus–related cirrhosis [40]. In the United Kingdom the percentage of ESALD patients receiving OLT increased two fold from 7.5% during 1987 and 1996, to 16% between 1996 and 1999 [57]. In Australia between 1985 and 2008, 2516 liver transplants (OLT) were performed, 307 (12%) were ALD patients and 20% had chronic viral hepatitis the remainder consisted of small percentages of other liver diseases [37]. A randomised controlled trial found no survival benefit and an increased risk for extrahepatic cancer when less sick ALD transplant patients with Child Pugh Stage B alcoholic cirrhosis were immediately listed for OLT versus patients assigned to standard treatment until they progressed to stage C disease [76].

According to the UNOS database, the number of OLT procedures performed annually for ESALD has been relatively constant between 1992 and 2001 with an increase in the number of liver transplants for those with combined ESALD and HCV infection (Figure 2.3) [77].

**Figure 2.3** Liver transplantation for alcoholic liver disease (ALD) and hepatitis C (HCV), 1992–2001 in the U.S.A. [77].
Public and professional attitudes to transplantation for ESALD transplant candidates

Despite OLT being an effective treatment for ESALD the provision of donor organs to those with ESALD continues to attract considerable debate and controversy amongst the transplant community, non-transplant medical practitioners in the community and the general public [78]. Public attitudes to transplanting ALD patients have been shown to be unfavourable as assessed by the use of standardized surveys or questionnaires [79-80]. In the United States, when the public were asked to assign organ priorities for 714 disorders or treatments, OLT for non-ALD patients was ranked by respondents as 364 out of 714 whilst OLT for ALD patients was rated 695 out of 714 [81]. This lack of enthusiasm for offering liver transplants to those with ESALD is believed by many authors to be based on the assertion that alcoholics are considered to be personally responsible for engaging in behaviour that caused their disease [56, 82-83]. The stereotypical view of the recalcitrant alcoholic is deeply entrenched in the public psyche. The public are not well informed about the genetic predisposition to ESALD, the role of environmental factors and that those individuals chosen for OLT sometimes drink no more than their peers, friends or family [83-84]. Neither is the public aware that OLT is also an indication for other behaviourally associated cases of end stage liver disease such as chronic hepatitis C viral infection which is a consequence of intravenous drug use and for non-alcoholic fatty liver disease associated with obesity [85-86].

Non-transplant physicians were more than twice as likely as the general public to consider a patient with any alcohol use that harmed his liver as being unsuitable for transplantation. In the United Kingdom, non-transplant family physicians who are the main referrers to OLT have been found to believe that alcoholic patients should take lower priority than other candidates given the scarcity of donor organs [87]. Similarly a recent study found that 55.2% of French physicians, when asked to allocate transplants, would have allocated less than 50 out of a 100 transplants to ALD patients. Also only 14.1% of French physicians endorsed the opinion that alcoholics were not responsible for their condition or that alcoholism was not morally reprehensible [88]. Studies have reported referral rates by physicians for transplantation to be around 5% to 10% of all patients diagnosed with ESALD [83, 89]. Professional reluctance, continuing alcohol use by ALD patients (therefore not meeting
selection criteria) and the patient’s personal choice not to undertake OLT, have been considered influential factors in the low referral rate.

In contrast, transplant physicians and psychiatrists from 13 out of 14 transplant centres held it acceptable to consider ESALD patients for OLT despite their past alcohol drinking history [90]. However leading transplant physicians, Moss and Seigler [91], in 1991 published an article titled, ‘Should alcoholics compete equally for liver transplantation?’, arguing that patients who have end-stage liver disease which was not self-induced deserve a higher priority than those with ESALD. The latter were seen as having a self-induced condition, failing to seek treatment for their alcoholism prior to the stage of requiring OLT. They were therefore less deserving of priority. They proposed more rigorous standards in the selection of OLT for ESALD on the grounds that ESALD is a principal cause of liver failure and such patients can therefore become high utilisers of donor livers.

The controversy is especially heightened whenever the public receives news of a celebrity liver transplant recipient relapsing to alcohol use. This can have a negative impact on the transplant team, can be demoralising for the transplant coordinators, social workers and nurses, and can affect donor rates [86]. Subsequently transplant centres have been reported to be reluctant or ambivalent about providing OLT to ESALD transplant candidates due the perennial risk of alcohol relapse after transplantation [86, 92-93].

According to Lucey [94], the key issue at the core of the debate and controversy is that of alcoholism and the significant risk of relapse rather than liver disease itself. The debate becomes complicated by the shortage of available donor organs to meet the demands of increasing number of candidates, the medical and hospitalization costs of OLT, and issues concerning equity and access [89].

**Evaluation and selection of ESALD candidates: overview**

The majority of patients with advanced ALD never come to transplantation. A recent review
estimated that around 70-100,000 patients with ESALD per year would warrant a referral for OLT each year but fewer than 10% of these are actually referred [89]. ESALD patients referred to a liver transplant unit and selected for OLT represent a highly selected group, comprising fewer than 50% of all ESALD patients referred for OLT evaluation and considered to be the best candidates amongst a cohort of better prognosis patients [95-96]. While the principles of evaluation for liver transplantation apply equally to patients with ESALD, the process of evaluation is more rigorous and stringent than other forms of end-stage liver disease due to concerns about relapse to alcohol use following transplantation [78, 97].

The evaluation of ESALD transplant candidates considers both medical and psychiatric issues. The medical assessment examines coexisting alcohol related medical problems or contraindications which may complicate transplantation such as neurological injury, pancreatitis, heart disease, myopathy, peripheral neuropathy and other conditions [98]. A psychiatric evaluation is essential in order to assess the presence of other psychiatric conditions, the patient’s compliance with the medical regimen and to identify those patients who are most likely to maintain long term abstinence from alcohol and other drugs [99]. It has become more common for transplant units to utilize the services of psychiatrists and specialists in substance misuse in order to carry out the evaluation. The psychiatric and substance abuse evaluation is considered to be crucial as OLT is a demanding procedure due to the stress and uncertainty of waiting for OLT, as well as the physical and psychological demands of the procedure in the pre and post-transplant period [43, 78]. The most commonly assessed psychosocial factors utilized by transplant units to determine the likelihood of maintaining long term abstinence include: pre-transplant abstinence, other substance abuse, stable social support, family history of alcoholism, psychiatric disorders, insight, compliance and previous treatment responses [100].

Most liver transplant centres worldwide require patients with ESALD to demonstrate a commitment to alcohol abstinence prior to being accepted for listing, usually for at least 6 months of abstinence [101-102]. Extending OLT to selected patients with severe alcoholic hepatitis is still being debated and is compounded by the lack of data on the outcome of OLT amongst those with the condition. In the United Kingdom alcoholic hepatitis is considered a contraindication to OLT. In the United States, the 6 month period of mandatory abstinence,
is considered an essential requirement for OLT which can preclude all patients with severe alcoholic hepatitis, as they are unlikely to survive [86].

In conclusion the provision of OLT to ESALD patients reveals a careful and comprehensive process of selection in order to achieve medical outcomes and to ration scarce donor organs. Despite the positive medical outcomes concerning the transplantation of those with ESALD the issue of relapse and stereotypes associated with alcoholism contribute to the controversy surrounding the provision of OLT to those with ESALD. Therefore it is important to examine the nature and extent of relapse especially as relapse is a rationalization for prescribing alcohol treatment.

**Alcohol Relapse**

**Defining relapse**

There is no standard definition for alcohol use relapse in the transplant literature. The term ‘recidivism’ is utilized heavily in the literature and is associated with individual blame, just as it is in the criminal justice system [103]. The literature reveals a semantic distinction in how the term, relapse, is utilized between liver transplant physicians and surgeons and amongst those in the addiction medicine field [98, 104]. Studies of alcohol use after OLT generally define relapse as the use of any alcohol. For example, a transplant patient drinking a glass of champagne at his daughter’s wedding a few years after OLT might be classified as a relapse, along with the patient who returns to dependent daily alcohol use immediately after transplantation [78]. The clinical significance of labelling episodes such as these as relapse can be questioned. Such a definition of relapse is in contrast to how the term is utilized in the addiction field where a relapse refers to prolonged and harmful drinking behaviour. Consumption of lesser amounts of alcohol is described as a lapse. The term, slip, is sometimes used to describe a sporadic drinking event followed by re-establishment of abstinence.
In an article by Fuller [103] titled ‘Definition and diagnosis of relapse to drinking’ the author highlights the problems associated with the lack of a standard definition of relapse in the treatment research and the definition of relapse as a deviation from abstinence used in the transplant context. According to Fuller, outcomes such as frequency of drinking, quantity, proportion of days drinking versus abstinence or measuring the physical and social consequences of drinking are not elucidated when researchers rely on a strict definition of relapse as no alcohol use. Also there have been few data defining ‘relapse’ after transplantation for ALD in terms of the level of alcohol consumption that would contribute to hepatotoxicity or how long or short the duration of drinking must be before the risk of cirrhosis is increased. Likewise the threshold of consumption associated with psychosocial harms has not been defined. These are all important variables to consider when evaluating treatment outcomes.

**Pre-transplant alcohol use**

Pre-transplant abstinence is required for two reasons. Firstly, to provide adequate time for natural improvements in liver function and potentially obviate the need for OLT [105]. Secondly, a period of abstinence has been argued as a reliable indicator of long term post-transplant abstinence. There are only four published studies on alcohol use in patients with ESALD while listed for liver transplantation. The pre-transplant rates of alcohol use established in these studies were 15% [106], 17% [107], 50% [108] and 25% [109]. None of these studies correlated pre-transplant drinking with post-transplant drinking so there are no research data investigating the relationship between pre-transplant drinking and the likelihood of relapse after transplantation. Pre-transplant drinking can result in temporary removal or permanent delisting from the waiting list, making it difficult to obtain truthful and accurate information about alcohol use in circumstances in which the consequence of admitting drinking would be risking the opportunity to receive a transplant [93]. The United Kingdom has introduced nationally agreed and clear criteria for both selection and listing. ESALD must comply with abstinence requirements and recommends permanent delisting in cases of non-compliance with an appeals system [41].
Alcohol use after transplantation

The rate of return to alcohol use, after liver transplantation has been reported to be between 10% to 50% in over 30 studies with follow up periods of up to 5 years [25-26, 57, 60, 65, 110-115]. One of the primary reasons for the wide variation in relapse rates is due to different definitions of relapse across studies [77, 101]. As already mentioned, the above definition of relapse in these studies has not been consistent and has ranged from any use of alcohol involving drinking one standard drink at any time over the course of the study period, to over 20 drinks per week. According to Lim [101], studies which have used the definition of relapse as “any alcohol use” tend to report a very high relapse rate during the post-transplant period. This is consistent with the fact that most, if not all, transplant centres view any alcohol use to be unacceptable and define relapse as any use of alcohol [116-117]. The variation in reported relapse rates are also due to different lengths of follow up periods and diverse sample populations in terms of sample size and selection criteria.

A number of methods of detecting and eliciting alcohol consumption have been utilized across studies. These include: the use of medical records, biochemical testing, retrospective analysis of interviews with patients and/or family during routine follow up, the use of screening tests and questionnaires. These methods may underestimate consumption due to reporting errors arising from retrospective accounts and the pressure on patients to deny drinking when patients know that it may not be in their best interests to be candid [86, 93, 118]. Biochemical markers such as blood alcohol, urine toxicology screens, carbohydrate deficient transferrin and other methods are attractive due to their objectivity but have been hindered by their low sensitivity or lack of specificity making it difficult to interpret the histological and biochemical changes in the post-transplant liver patient [114, 119].

More recent research studies examining relapse rates in this population have started to apply more consistent and systematic use of collaborative evidence involving interviews with patient and family, supplemented by random urine and liver function tests, including the observation by medical staff with all monitoring and recording occurring post-operatively at outpatient clinic visits. Additionally they have distinguished a slip from a return to harmful drinking [118].
The study which provides the best data about post-transplant drinking practices by ESALD candidates was conducted by Di Martini and colleagues [120]. This study overcame many of the methodological shortcomings found in previous relapse research studies, by relying on objective methods of detecting relapse and by distinguishing slips from relapses. Di Martini’s study was a large prospective study sample of 167 ALD liver transplant recipients who were observed over a 5-year period. Four ascertainment measures of alcohol use were utilized every 3 months for the first year followed by every 6 months and included: clinical interview, prospective patient report utilizing a daily profile of alcohol use, caregiver reports and biochemical markers. Three alcohol use outcomes were used by the authors to define a drinking event which included: time to first drink (onset of use), time to six drinks in a day for men and four drinks in a day for women (termed binge use) and time to four drinking days in a week (frequent use).

By the end of the first year 22% of ALD transplant recipients had used any alcohol with 10% having had their first drink within 3.5 months post-discharge. Figure 2.4 does show that most of those who returned to drinking did so by two years post-transplant. By five years post-transplantation 42% of alcoholic recipients had consumed at least one drink; 20% drank in a frequent pattern and 26% drank in a heavier binge pattern (six drinks a day for men, four drinks a day for women).
Figure 2.4 Time to alcohol use outcomes following discharge (N=167). Reprinted from [120].

An Australian study, based at the Australian National Liver Transplant Unit in Sydney, reported by Kelly et al [121], also stratified alcohol use and examined time to harmful drinking. Harmful drinking was defined as recorded medical or social harm or drinking above 140 g ethanol/week. ‘Harm’ included evidence of ongoing abnormal liver tests consistent with alcohol and not accounted for by other investigations as well as any other documented complication related to alcohol use. Based on the medical notes of 90 patients, 18 (20%) relapsed to harmful drinking, 10 (11%) drank below harmful levels and 62 (69%) remained abstinent after a mean of 5.6 years follow-up. Forty percent of patients had returned to harmful consumption by 10 years post-transplant. A number of other studies also report a return to heavy or frequent alcohol use of 10%-20% post-transplant patients [26, 92,
This relapse picture is different to the 60% to 80% rate of relapse found amongst alcohol treatment seekers without liver disease who complete a structured alcohol rehabilitation program [127] or higher rates of 90% for those who complete less intensive treatments. The lower rate of relapse amongst ESALD transplant candidates is believed to be associated with selection and management of ESALD transplant candidates and life threatening liver disease and OLT as a potent motivating force [24, 78, 99, 127]. Program elements, including the close and supportive contact with the OLT clinical team, have been credited with exerting a therapeutic effect on alcohol addiction, serendipitously providing effective relapse prevention [127].

Di Martini’s study provided important data about the time to relapse. The time to relapse was early amongst those who drank heavily in their first drinking episode with 40% bingeing within 6 months and most advancing to heavy use within the first or second year. There was a steady decline in the number of abstinent subjects over the 5 year post-transplant period suggesting that adherence to lifelong abstinence may be difficult in this population. This pattern of relapse, marked by early instigation of heavy drinking within the first two years of transplantation and a steady increase in relapse involving any alcohol use, has been suggested by other studies [61, 110-111, 114, 121, 128]. In Kelly’s [121] study, time to relapse post- transplant varied from 2 months to over 10 years, but 50% of relapses occurred in the critical 1 to 2 years post- transplant (Figure 2.5).

Another illustration of time to relapse patterns was provided by Dew showing relapse (any alcohol use) beginning early post-transplantation with a cumulative decline in abstinence for around 5 years post-transplant (Figure 2.6).
Figure 2.5. Cumulative survival to time to first record of harmful drinking following transplant (days) (N=90). Reprinted from [121].

![Cumulative survival to time to first record of harmful drinking following transplant](image)

Figure 2.6. Time to alcohol relapse (any use) after OLT in 11 studies reporting time to relapse after adjusting for differences in patients’ follow up duration, the range of time to relapse is plotted (earliest point, midpoint, latest point) as well as length of total follow in the sample. Reprinted from [129].

![Time to alcohol relapse after OLT](image)
A major gap in relapse research has been the absence of data investigating the duration of relapse and whether there is a return to abstinence by ESALD transplant candidates who have relapsed. Recently Di Martini and colleagues [130] examined trajectories of alcohol consumption following liver transplantation, collecting detailed prospective data to elaborate on the ongoing patterns of use. Four distinct alcohol use trajectories were identified: those able to abstain or drink minimally and three distinct patterns of moderate-to-heavy consumption (Table 2.3). These trajectories showed that a return to alcohol use varies for different patients with different timing of onset, quantity and duration. One group will maintain complete abstinence, two had early onset with either rapid moderate or heavy use while another group will return to a gradual increase to moderate use over a few years. It does show that after transplantation some recipients can quickly lose control over their alcohol use while others can begin years after OLT. However the amount of alcohol in standard drinks shown in this study is surprisingly less compared with pre-transplant drinking.
Table 2.3 Specific characteristics of alcohol use trajectories. Reprinted from [130]

<table>
<thead>
<tr>
<th>Group</th>
<th>Onset of use after LTX discharge</th>
<th>Pattern of use</th>
<th>Average consumption at peak amount*</th>
<th>Timing of Heaviest Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>None</td>
<td>Complete Abstinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2.8 months</td>
<td>Fluctuating low level of use</td>
<td>0.5 standard drink/week</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>3.5 months</td>
<td>Early onset rapidly accelerating moderate use</td>
<td>3.5 standard drinks/week</td>
<td>Peaked 1.7 years</td>
</tr>
<tr>
<td>4</td>
<td>2.8 months</td>
<td>Steady increase to moderate use after 3 years post--LTX</td>
<td>2 standard drinks per day</td>
<td>Peaked at year 6</td>
</tr>
<tr>
<td>5</td>
<td>42 days</td>
<td>Early onset continuously increasing heavy use</td>
<td>3.7 standard drinks a day</td>
<td>Peaked at year 3</td>
</tr>
</tbody>
</table>

* USA standard drink units (14 grams alcohol i.e. one 12-ounce beer, 5–6 ounces of wine or a one-ounce ‘shot’ of hard liquor).

Medical consequences of alcohol relapse after transplantation

Recent studies examining post-transplant outcomes reveal significantly lower long term survival rates amongst ESALD transplant recipients who relapse to heavy or frequent
alcohol use compared to ESALD transplant recipients who maintain abstinence. Pfitzmann [26] conducted a 7.5 year retrospective analysis of 300 alcohol liver disease patients after transplantation investigating survival rates and alcohol consumption. Researchers graded ALD patients into 3 groups: those who had minor lapses or slips, abusive drinking and those who resumed drinking with unknown severity. Patients who resumed abusive drinking had substantially lower survival rates at 5 and 10 years post-transplant of 69.5% and 20.1% respectively while abstinent patients experienced a 90.3% and 81.5% survival rate. Cuadrado [123] evaluated the rate of alcohol relapse after OLT amongst 54 subjects and the impact of relapse on allograft and patient survival including the development of co-morbidities and de-novo cancers. The major finding was a significantly lower survival rate after 10 years close to 50% in those who relapse, and attributed to a higher frequency of death primarily from cancer and cardiovascular events (Figure 2.7). Other studies have also found an association between heavy drinking and both mortality and morbidity [122-123, 128] (Table 2.4).

**Figure 2.7** Kaplan-Meier survival curves from patients with alcoholic liver disease, with or without alcohol relapse. Reprinted from [123].
Table 2.4 Survival rates for 1, 5 and 10 years with alcohol liver disease patients with or without relapse

<table>
<thead>
<tr>
<th></th>
<th>1 year</th>
<th>5 year</th>
<th>10 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstainers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cuadrado [123]</td>
<td>100%</td>
<td>92.4%</td>
<td>85.5%</td>
</tr>
<tr>
<td>Pfitzmann [26]</td>
<td>90.3%</td>
<td></td>
<td>81.5%</td>
</tr>
<tr>
<td>Pageaux [128]</td>
<td>97%</td>
<td>80%</td>
<td>69%</td>
</tr>
<tr>
<td>Relapsers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cuadrado</td>
<td>100%</td>
<td>92.9%</td>
<td>45.1%</td>
</tr>
<tr>
<td>Pfitzmann</td>
<td>69%</td>
<td></td>
<td>20.1%</td>
</tr>
<tr>
<td>Pageaux</td>
<td>100%</td>
<td>95%</td>
<td>64%</td>
</tr>
</tbody>
</table>

Several studies have shown that liver damage may develop rapidly after alcohol relapse including steatosis, alcoholic steatohepatitis and alcohol induced fibrosis [65, 114, 131]. Steatosis and pericellular fibrosis have been observed in the liver biopsy specimens of patients who reported heavy drinking compared with abstinent patients [124].

There are mixed findings regarding whether relapse to heavy drinking affects compliance with clinic visits and immunosuppressive therapy. Some studies have found an association [60, 124] with one study directly relating relapse and non-compliance with graft injury and organ rejection [124]. Another study reported no impact of relapse on compliance but this may be due to close follow up interventions in that program [61]. Little is known about the impact of slips or moderate drinking on the health outcomes of ESALD transplant candidates. Further research is required involving long term prospective follow-up, careful monitoring of alcohol consumption, regular planned liver biopsies and stratification based
on alcohol use.

**Psychosocial consequences of alcohol relapse post-OLT**

There is little research examining the psychosocial consequences of alcohol relapse post-OLT. Poor post-transplant health has been reported by those who relapse to harmful alcohol use involving more bodily pain, less energy, more perceived stress and benzodiazepine use [68,146]. Coffman [67] reported high correlations between a return to drinking and poor relationships with immediate family members, psychological distress, and poor sexual relations with spouse. [68]. Anecdotal reports in the literature regarding the consequences of relapse to harmful drinking include common alcohol related problems such as drink driving offences, hospitalizations and marital breakdown [121]. Post--transplant quality of life scores have been shown to be poorer in patients who relapse to harmful drinking [67, 72]. Reduced quality of life and increased physical morbidity have been linked to poor psychological adjustment in organ transplantation studies [134].

To summarise, there is sufficient evidence showing an increasing risk of relapse over time after transplantation. Also there are sufficient data reporting a link between harmful alcohol use and a number of negative medical and psychosocial consequences for the 10% to 30% of patients who relapse to harmful alcohol use. However at this stage there is minimal evidence showing any negative health outcomes as a result of low to moderate drinking after OLT. Therefore there is little ground for requiring that the large majority of ESALD transplant patients who remain abstinent or engage in light to moderate drinking participate in treatment programs for managing alcohol use.
Table 2.5 Predictors of relapse and literature investigating both an association and no association

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Associated</th>
<th>Not Associated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gish et al (2001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pfitzmann et al (2007)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Karman et al (2001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gish et al (2001)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coffman et al (1997)</td>
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</tr>
<tr>
<td></td>
<td>Tripp et al (1996)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Karman et al (2001)</td>
<td></td>
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<tr>
<td></td>
<td>Karim et al (2010)</td>
<td></td>
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<tr>
<td></td>
<td>De Gottardi (2007)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hillebrand et al (1997)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Di Martini et al (2010)</td>
<td></td>
</tr>
</tbody>
</table>
Relapse research outside the transplant field has identified the lack of personal and social resources and interpersonal difficulties to be strongly associated with alcohol relapse [137-138]. Similarly, there is ample evidence pointing to the lack of social support as predictive of a higher risk for relapse amongst ESALD transplant candidates (Table 2.5). The presence of a partner or spouse has been associated with greatly reducing the risk of relapse [67, 119, 121, 139-140] and a high divorce rate has been found amongst those who relapsed [92, 113]. Family and psychosocial support networks have been observed to play an important role with respect to survival and morbidity across organ transplantation in general [134, 141-143]. Again, the presence of a spouse has been found to be significant [144]. A large epidemiologic study found marriage to be positively associated with recovery from alcohol dependence [145]. Recently Di Martini [146] found poor health-related quality of life to be linked to relapse with subjects reporting more medical and life stress, worse health, pain and less energy after transplantation. As discussed earlier quality of life has been found to be poorer amongst some ESALD transplant patients especially those who relapse.

The 6 month rule as a predictor of abstinence

The 6 month period of pre-transplant abstinence has been used as a condition of eligibility for OLT and several studies have examined whether it is a predictor of relapse. Research findings have been divided regarding the 6 month mandatory period of abstinence as a reliable predictor of relapse with some studies supporting the 6 month abstinence period [25, 113, 119, 147-149] while other studies have not found a significant association between the 6 month rule and relapse [8, 57, 60, 110-112, 121, 150-152].

These studies have faced a number of methodological shortcomings. The majority have been retrospective, involving short periods of follow up and have not been stratified based on alcohol use. Many of these studies have included patients with varying degrees of sobriety, some less than or greater than 6 months. Accordingly, the exact threshold for determining a predictive interval of sobriety is yet to be investigated [93, 153]. The positive association of the 6 month rule with long term abstinence may be a result of having selected those with a number of favourable criteria for listing apart from the 6 month period of abstinence [154]. Thus the 6 month rule may be filtering out high risk patients from those with less than 6 months of abstinence [155]. Finally, no study has randomly assigned patients to a waiting list on the basis of duration of pre-transplant abstinence. These studies are thus limited by a number of confounders.
In sum, there is insufficient evidence to conclude whether the 6 month rule of pre-transplantation abstinence is a reliable predictor of long term stable abstinence especially in the context of end-stage liver disease. Research findings from the general addiction field suggest that the marker of true predictive abstinence for alcohol dependent patients involves years, not months. Relapses occur commonly for up to five years after initial sobriety [127]. Thus it could be argued that more than 6 months are required to identify patients at low risk of relapse. Many seriously ill patients, notably those with hepatocellular carcinoma, could not wait longer, making six months a pragmatic rule.

Insight

Insight or awareness that alcohol is the cause of liver disease is considered a good prognosis for stable abstinence and used extensively as part of the psychiatric evaluation for suitability for liver transplantation [154]. However the findings are mixed as to whether the lack of insight is a predictor for alcohol relapse. Most studies have reported no association between lack of insight and stable abstinence [61, 96, 110, 113, 156] and this may due to the fact that patients who deny the etiology of liver disease and alcohol dependence are less likely to be considered for transplantation. Recent studies however appear to be finding a relationship between lack of insight and relapse [121, 157-158]. The large majority of studies rely on the evaluation by either transplant hepatologists or psychiatrist and do not use any empirically based psychometric measure.

Limitations of relapse research

One of the major gaps in the research investigating predictors of relapse is the paucity of supporting prospective and longitudinal data. Most studies rely on the antecedents of relapse collected retrospectively or are based on pre-transplant variables. However variables collected in the pre-transplant period such as social support, marital status, mental health and substance abuse can alter and fluctuate over the long course of transplantation.

Alcohol use is known to be highly influenced by personal risk factors such as genetic predisposition, as well as environmental and psychological factors. Miller [159] examined a number of variables to account for relapse including: pre-treatment characteristics and potential antecedents of relapse. The latter included: negative life events, cognitive appraisal variables, coping resources, craving and mood states. More recent or proximal antecedents (from the prior 2-month interval) and an
individual’s coping resources proved to be most predictive variables in relapse. This finding underscores the importance of addressing current events in the client’s life and the value of teaching coping skills. Among pre-treatment characteristics, alcohol dependence symptoms were the only variable positively associated with relapse.

There are few data available in the literature reporting the social and psychiatric outcomes and life events for ESALD post-transplant candidates and their association with relapse. For example, the stress associated living with a chronic life threatening illness and waiting for organ transplantation can contribute to psychiatric difficulties, including adjustment disorder, depression and anxiety in a small proportion of patients. A cohort of 75 patients discovered that 23% of patients developed a psychiatric disorder following OLT. Of these 50% developed major depression, 5.3% post-traumatic stress disorder (PTSD) and 17.3% partial PTSD [160]. In a recent study DiMartini [74] collected data on psychological and medical stressors within 3 months post-liver transplantation, assessing symptoms of depression (Beck Depression Inventory-BDI), anxiety (Zung Anxiety Scale-ZAS), perceived stress (Cohen’s Perceived Stress Scale-PSS), health-related quality of life (SF36) and several items reflecting transplant-specific concern. Those more likely to drink in the early post-transplant period and in a problematic pattern (groups 3 and 5) were more stressed, reported worse health, and reported more pain and less energy. It was proposed that alcohol use may have been a way of handling stress by ESALD transplant patients gravitating to drinking in response to the difficulties of the early post-transplant phase. Di Martini recommended early identification and treatment of stress especially as it relates to early post-transplant recovery, attention to complaints of pain and fatigue, and resumption of addiction counselling in aiding the stabilization of these patients.

Another limitation of the research into relapse predictors amongst ESALD transplant candidates is that it has tended to evaluate the independent effect of each risk factor. Dew [129] and others have proposed that future research into relapse will need to consider investigating relapse as involving a constellation and concomitant risk factors, each having predictive power, with the number of risk factors possibly contributing to a critical threshold of risk burden [129, 161]. Therefore predictors such as lack of social support and psychiatric illness may work in tandem to increase the risk of relapse. This is suggested by studies which have found lower rates of depression amongst ESALD transplant candidates with good social support, suggesting a link between poor mental health, limited social support and relapse [61]. Studies have found that social support is known to be an important contributor to protecting individuals from depression [162].

More recent models conceptualise relapse as involving multidimensional and dynamic variables and
processes incorporating key predictors rather than one single factor. Witkiewitz & Marlatt [163] developed a model of relapse which views the individual as a self-organising system. Relapse is considered to occur as a result of changes involving the interplay of both proximal and distal risk factors (e.g. years of dependence, family history, co-morbid psychopathology, and limited social support), cognitive processes and coping skills, physical withdrawal, substance use behaviour. Such a model may help explain triggers to relapse amongst ESALD transplant candidates in the context of post-transplant recovery.

**Conclusion**

ESALD is a widely accepted indication for OLT and is associated with good outcomes in health, survival rates and quality of life in appropriately selected patients. Whilst the majority of ESALD patients selected for transplantation are able to comply with the transplant program requirement of long term stable abstinence, relapse to heavy or frequent drinking has been reported amongst a proportion of recipients. Relapse to heavy drinking has been found to be detrimental, contributing to morbidity, mortality, poorer psychological functioning and reduced quality of life. Transplant programs are also concerned about unfavourable public reactions to reported relapse amongst transplant candidates, potentially influencing the reputation of the program and/or supply of donor organs. In order to reduce the likelihood of relapse, transplant programs have devised and validated evaluation and selection criteria and a predetermined length of sobriety. However alcohol use disorders often involve a continuing relapsing and remitting course, and despite abundant research into the predictors of relapse clinically it is difficult for transplant programs to reliably predict who will relapse. Considering the role of a number of psychosocial factors, which can change over the long course transplantation, OLT programs may need to monitor and treat changes in psychological and social status in order to minimise the relapse rate. Psychiatric distress, limited social support and poor quality of life, may be amenable to intervention while others such as familial alcoholism are more immutable and not responsive to treatment.

The next chapter will discuss the current approaches utilized by transplant units to clinically manage ESALD transplant candidates, and the preliminary research efforts into providing onsite and appropriate alcohol treatment for this highly selected group of patients in order to address the problem of relapse.
References


CHAPTER 3

Management and clinical characteristics of ESALD transplant candidates

This chapter will discuss the current alcohol management program utilized by the majority of liver transplant programs. This is followed by a review of the alcohol treatment research studies which have attempted to provide on-site treatment for ESALD transplant patients in order to address the problem of relapse. The chapter ends by presenting the current research examining the demographics and clinical characteristics of the ESALD transplant population compared to alcohol treatment seekers. This chapter will close with a discussion on alcohol use disorders and subgroups, and will present research findings which assist towards building a clinical profile of ESALD transplant patients compared with ALD patients and alcohol treatment seekers.

Clinical management of ESALD transplant patients

The majority of transplant programs utilize a standard approach to the clinical management of alcohol use disorders amongst ESALD transplant candidates. The approach relies heavily on the selection and evaluation of patients likely to maintain abstinence and on the 6 month period of mandatory abstinence as a prerequisite for transplantation [1, 2]. A verbal and at times written ‘contract’ is initiated in the pre-transplant phase whereby transplant recipients understand the requirement of lifelong abstinence and compliance. Referrals to alcohol rehabilitation usually involving Alcoholic Anonymous (AA) or off site alcohol treatment services [3] are typically offered, with variable compliance. This approach heavily relies upon ongoing monitoring of alcohol use during the pre- and post-transplant period by random blood or breath alcohol testing, routine questioning about alcohol use and reminders not to drink at outpatient clinic appointments [4]. It may be considered as a form of brief intervention. Most transplant units do employ the services of psychiatrists, and addiction specialists for the purposes of pre-transplant assessment and evaluation of candidates with ALD [5], but these workers play a secondary role in ongoing treatment.
There are few data evaluating the effectiveness of this management approach by liver transplant programs, especially in terms of reducing the rate of alcohol relapse. Everhart [6] and colleagues was the first and only group to investigate the management of ESALD transplant candidates by transplant program and to verify the approach taken. A total of 69 centres in the United States were surveyed, capturing information about the number of transplants conducted, pre-transplant evaluation, post-transplant monitoring and relapse prevention efforts. Survey forms were completed by transplant surgeons (57%), hepatologists (20%), co-ordinators (15%) and other persons familiar with the evaluation of alcoholism (8%). The adherence to a contract of abstinence was evident with 81% of programs considering any alcohol use by pre-transplant patients on the wait list a contraindication to transplantation. Relapse to alcohol use during this period generally results in a removal of a relapsed patient from the list permanently or for at least 6 months. If drinking relapse occurred, 15% of centres would permanently remove the patient from the transplant list. Most centres would remove and re-evaluate the patient: 5 centres (7%) in 3 months (7%), 32 centres (47%) in 6 months and 14 (21%) as clinically indicated. Only two (3%) of the centres would recommended counselling but not remove the patient from the list. The 6 month rule of abstinence before listing was utilized by 85% of centres, 39% always asked patients to sign a contract, 39% usually and 23% never. Most programs told patients not to drink after transplantation and all programs were found to monitor drinking by asking the patient and the patient’s family.

**Critical appraisal of current alcohol management programs**

It has been argued that the management approach taken by transplant programs to ESALD transplant candidates exerts a therapeutic effect contributing to the substantially lowering relapse rates amongst ESALD patients compared to relapse rates found in standard alcohol treatment settings [7-9]. The four key prognostic factors predictive of stable abstinence identified by Valliant [10] are believed to be naturally incorporated throughout the processes of the transplant procedure, follow up-care and the transplantation experience itself [7, 8, 11-13].

These factors include: (i) the presence of a rehabilitation relationship found in the therapeutic and caring bond established with transplant staff, and the support of spouse, family and friends who understand the necessity for abstinence [3, 9, 14]; (ii) substitute dependencies or activities that structure time otherwise spent in drinking with the structured medical regimen of transplantation [13, 15]; (iii) a source of hope derived from being released from the edge of death, given new life and an expensive operation. Also, involvement in a health care team unscarred by past misuse of alcohol all helping to generate a ‘born again’ quasi-religious experience [9, 13, 14] (iv) negative consequences of drinking whereby any
exposure to an episode of drinking is an unpleasant and humiliating experience [14]. However these therapeutic aspects of transplantation tend to diminish as the original relationship and intense contact with the transplant team lessens over time following successful transplantation [16].

The importance of lifelong abstinence for patients undergoing OLT is never disputed in the literature but authors have strongly proposed incorporating a relapse prevention approach whereby transplant programs recognize lapses in abstinence as slips that indicate a need for treatment [5, 17-21]. According to Lucey [4], “although few would claim ab initio that the efficacy of liver transplantation should be measured by its ability to treat alcoholism, liver transplantation is sometimes considered a failure when it is accompanied by a relapse into drinking” (p.228). Thus relapse may be considered by transplant staff as a failure (even shameful behaviour by candidates themselves). Further research is required to determine the impact of the strict abstinence model on ESALD transplant candidates.

The strict requirement for abstinence, especially the 6 month rule of abstinence and de-listing for any recognised alcohol use in the absence of a relapse prevention approach, is seen as a powerful inhibitor on the patient for disclosing any alcohol use. According to Weinrieb [2], admission of drinking with the strict implementation of the 6 month rule can have potentially harsh clinical consequences resulting in delisting or requests by transplant centres for a further 6 months of sobriety where a patient risks serious illness and death. Fifty six percent of patients with severe alcoholic cirrhosis referred for OLT will otherwise die within 6 months [22]. Patients thus have a vested interest in maintaining secrecy about drinking and importantly may also be reluctant to be seen as requiring help or treatment for the same reason [2, 19, 23-25]. Offending ESALD transplant candidates are placed in a difficult position of having to choose between hiding their drinking in order to remain eligible for transplantation or forfeiting a life-saving liver transplant by disclosing slips or for asking for alcohol treatment. Research studies investigating relapse rates have confirmed that some ESALD transplant candidates do conceal alcohol use [26]. Anecdotal reports have been made in the literature about incidents where transplant staffs were unaware that patients had relapsed only to discover this after patients had been admitted to an emergency department with life threatening illnesses related to alcohol use [15].

More open discussion between patient and transplant staff about alcohol use is considered an important area for improvement. Weinrieb [2] has advocated that transplant programs strive for an atmosphere of candour in which patients can feel safe about reporting alcohol use and about asking for addiction treatment if they return to drinking while awaiting transplantation. Wagner recommends a more open and less defensive patient-clinician relationship starting from the selection period, to allow for more accuracy of prediction of future relapses and a decrease in relapse rates. Wagner [19] writes
Therapists may not be perceived as collaborative consultants with expertise in helping individuals resolve substance related issues through a collaborative relationship......Instead they may be perceived as powerful individuals with preconceived and rigid notions of patients’ problems, whose goals include catching patients in the act of using, proving that patients are addicts, and punishing them for delaying or preventing organ transplantation. Patients may deny problems with substances in order to present themselves in a more positive light and prevent themselves from being disqualified from consideration for transplant (p.392).

To conclude, liver transplant programs follow a strict abstinence policy, consider relapse as a failure of transplantation and do not provide relapse prevention support considering the physical and psychosocial demands of transplantation. The literature is replete with recommendations for an effective alcohol intervention to support abstinence amongst ESALD transplant candidates, especially for those who are at increased risk of drinking or who have resumed drinking [3, 8, 12, 23, 27-33].

**Alcohol treatment research amongst ESALD transplant patients**

Early studies reported a lack of treatment motivation or treatment seeking by ESALD transplant candidates. Tang [25], in a case-controlled study involving a sample of 56 ALD patients, reported that 33 (59%) could not recollect receiving advice on post-transplant alcohol consumption during the period, 18% recalled receiving advice to abstain completely, and 23% claimed they were advised to drink in moderation. In a comparison group of matched non-alcoholic liver transplant patients, 40% accurately recalled medical advice regarding alcohol use. The majority of ALD transplant recipients have been reported to have stopped drinking on their own and to have not attended any formal treatment or AA meeting [32].

Only four studies have attempted to treat alcohol use disorders within the context of the liver transplantation and these will be discussed individually.
Study 1

The first attempt to provide alcohol treatment within the liver transplant setting was conducted by Weinrieb and colleagues [33] at the University of Pennsylvania Liver Transplant Centre. The study involved 55 alcohol dependent liver transplant recipients with a diagnosis of alcohol dependence, who last used alcohol no more than 12 months before being placed on the waiting list. Patients were randomised after transplantation to one of three groups: naltrexone (50mg), placebo (once/day) and motivational enhancement therapy MET (4 sessions). Motivational enhancement therapy (MET) was chosen being an established alcohol treatment regimen based on Project MATCH (Matching Alcoholism Treatment to Client Heterogeneity, Miller 1994). MET involves personalized feedback of assessment results and counselling, aimed at producing internally motivated change, by mobilizing the individual’s own change resources. Weinreib and colleagues postulated that MET would mobilize a patient’s motivation towards maintaining abstinence and enhance insight and acknowledgment of alcoholism. The utilization of a pharmacotherapy agent, naltrexone, was selected to assist in reducing cravings to prevent relapse.

The authors encountered significant recruitment difficulties and treatment resistance. Of the 55 subjects identified, 9 died and 15 were not approached as they rarely came to clinic appointments and were difficult to contact. Of 31 potential subjects, 20 were ineligible (7 abstinent beyond 12 months, 5 did not meet DSM IV criteria for alcohol dependence, 2 lived too far away, 1 with opiate and alcohol dependence and five too ill to participate in the study). Out of the remaining 11 potential subjects, 6 refused or declined to enter the study. Only 5 subjects were randomized with no patient completing more than 4 months of the 6 month treatment period. One of the main reasons for the lack of treatment motivation was ‘denial’ as patients did not perceive a current problem or past problem with alcohol. Other reasons identified by the researchers included the demands of a complex medical regimen and fear of naltrexone induced hepatotoxicity. Weinreib and colleagues concluded that it was important to initiate therapy in the pre-transplant phase in order to avoid conflict with post-transplant management, to increase motivation for treatment and strengthen the need for long term abstinence.

Study 2

More recently Weinreib and colleagues [34], conducted another controlled clinical trial of MET and case management (MET/CM), offered in the pre-transplant period and designed to be
incorporated into the patients’ medical care. It did not target abstinence alone but included other self-identified health behaviour problems. The study randomised 91 subjects to either motivational enhancement therapy (MET) (n=46) or treatment as usual (TAU) (n=45). MET consisted of 7 sessions over a period of 3 to 6 months and addressed relevant health-related behaviours and included case management. TAU involved a referral to community AA and a standard out-patient therapy. Alcohol use was measured at each study visit using self reporting via the time line follow back measure, collateral interviews and use of a breathalyser. Candid responses about alcohol use were encouraged by providing confidentiality without jeopardizing their position on the transplant waiting list, except cases involving life threatening emergencies. Baseline and follow up measures after randomization included: mood and anxiety symptoms (Beck Depression Inventory, Beck Anxiety Inventory, treatment motivation (Stages of Change Readiness and Treatment Eagerness Scale), quality of life (Medical Outcomes Study Short Form-12). Follow up of subjects occurred every three months until transplantation and then again at one month post-transplant, six months and one year post-transplant. The aim of the study was to evaluate whether patients randomized to MET/CM had lower rates of drinking compared to those receiving TAU.

In this study, the prevalence of drinking was the same in both groups with 26% (12) for MET and 24% (11) for TAU. The 24 subjects who drank reported a total of 64 episodes over 2 years of pre-transplant observation. The median number of drinks per drinking day was 3.75 for MET and 4.3 for TAU (p=0.025) including an outlier. When the outlier was excluded, MET drinkers had significantly fewer total number of drinks than the TAU group 7 for MET and 59 for TAU (p=.003). Also MET had lower total number of drinking days, 2 for MET and 7 for TAU (p=0.004). Quality of life was similar in both groups. The scores measured by the Stages of Change Readiness and Treatment Eagerness Scale were similar for both groups; however the MET group showed a small decrease in ambivalence and a significant decrease in problem recognition scores over time. Treatment adherence was similar except that MET did result in greater attendance for at least one session (83%) over TAU (40%). Only 50% of MET subjects attended the required 4-7 sessions. The failure to attend more than four MET sessions was attributed to illness, transplantation and transportation problems. The limited efficacy of an established alcohol intervention with this population was considered to be due to insufficient number of subjects experiencing enough MET sessions. Also the change in transplant classification system and a lack of detailed information regarding treatment attendance in the TAU group limited comparisons. The impact of MET on post-transplant alcohol consumption was not investigated in this study.
To summarise, MET resulted in a reduction in number of drinks per drinking day, decrease in ambivalence for change, and engaged more patients in treatment completion. No significant effect on alcohol consumption was found in terms of the total number of drinks and total number of drinking days when an outlier was included. Treatment adherence was unsatisfactory as nearly half of the MET group attended fewer than 4 of the 7 sessions, despite some having relapsed. MET was found to have no effect on mood, general health or psychosocial outcomes despite high Beck Depression Inventory scores being found amongst those involved in high risk drinking.

The limited effectiveness of MET to reduce the quantity and frequency of drinking, may be explained by the fact that it does not directly assess and target the complex and multiple psychological and environmental factors contributing to relapse, especially in context of transplantation. MET is primarily a cognitive behavioural approach which aims to build a commitment to change based on an individual’s awareness of the disadvantages of an undesired behaviour. Dropout or lack of treatment persistence may be due to patients not seeing the value or purpose in this treatment approach contributing to a lack of internal motivation for change [35].

**Study 3**

Georgious and colleagues [36] conducted a feasibility study offering a brief psychosocial intervention in the pre-transplant phase, titled Social Behaviour and Network Therapy (SBNT). This was offered to 32 patients with alcoholic liver disease undergoing transplantation at the Birmingham Liver Transplant unit in the United Kingdom. SBNT is a treatment currently being evaluated by a United Kingdom national alcohol treatment trial. The intervention offered in this study consisted of three one hour sessions every 2 to 4 weeks including education about alcohol related liver disease and abstinence, relapse prevention, developing positive social support and pleasurable activities. Members of the patient’s social network participated. A contract showing a commitment to abstinence from alcohol post-transplant was agreed by all parties and signed by the patient. The alcohol liaison nurse and social worker then followed up the patient and family member regularly pre-transplant, and subsequent follow up at 6 months post-transplantation. Relapse was generally defined as persistent use of alcohol determined by interview and random blood alcohol testing.

Of the 32 patients offered the intervention at time of assessment for transplantation, 20 accepted the offer, 5 patients declined the brief intervention and 7 failed to be assessed based on study time
schedule. It is unknown why 5 of the 32 possible subjects declined to participate in the study. No clear conclusions can be derived from this study regarding treatment outcomes as it did not involve a control group and was not a randomised trial. Alcohol rates seem to be equivalent to rates found generally in studies into relapse not involving an intervention. Eight (42%) of 19 reported drinking some alcohol after transplantation; of these 4 (21%) drank weekly, and 1 (5%) drank more than 21 units per week. This study nevertheless illustrates that it is possible to deliver an acceptable time-limited psychological intervention which can be readily integrated into the OLT process. ESALD transplant candidates and close family members reported feeling less stigmatized and judged, and appreciated being able to communicate their experiences in an open and neutral situation.

It is important to note the presence of treatment resistance. A proportion of patients initially approached the sessions with scepticism, annoyance and sometimes hostility feeling that alcohol was no longer a problem in their lives but nevertheless completed the sessions. The authors recommended further research to clarify the treatment outcomes of SBNT and emphasized the importance of carefully matching the intervention to the individual patient’s history and other clinical factors.

These findings concur with anecdotal reports about ESALD transplant candidates showing significant treatment responsiveness. In research studies where patients have been encouraged to openly discuss their alcohol use without fear of judgement or penalties, patients have been willing to listen to advice and recommendations on addiction treatment and to actively request assistance with alcohol rehabilitation [3, 37]. Also, no patient denied the potentially detrimental effects of alcohol on their health. Some patients who had resumed drinking were relieved to learn that the liver transplant team would not abandon them because of their alcohol use [3].

Study 4

An uncontrolled, single-centre Scandinavian study by Bjornsson et al [38] examined the impact of structured management on the risk of relapse following transplantation for ESALD. Structured management (SM) involved the introduction and involvement of a dedicated addiction team lead by a psychiatrist with addiction specialisation and involving a transplant coordinator, social worker, general practitioners and patient coordinator. At the work-up before transplantation, there was an obligatory interview and evaluation by the specialist and the team. This included an
Interview with close family members examining patients’ current and previous abuse problems, referral to a motivation program to assure total abstinence, a formal contract on abstinence, agreement to follow up and alcohol treatment involving 12 step therapy for those with no prior treatment history. After surgery the transplant unit’s social worker and transplant coordinator kept in contact with the patient and local physician and clinic visits after 3 months. At 1, 3 and 5 years, transplantation interviews were conducted by the addiction team.

Alcohol relapse was defined as any alcohol use. This was detected either through patient and family reports at interview and during clinic follow up appointments, from medical records and clinical judgment of transplant team. Heavy drinking was loosely defined as periods involving repetitive and excessive drinking where the patient reported intoxication versus those who had used alcohol on special occasions.

The impact of SM was investigated by comparing ALD patients transplanted from 1998 to 2003 (63 patients) who received SM, with a control group of ALD patients before the introduction of SM during the period 1988-1997 (40 patients). SM was found to halve the relapse rate. The original program before the introduction of SM reported a 48% (40) relapse rate compared to a 22% (13) relapse rate with SM. Treatment completion was higher amongst those transplanted from 1998 onwards 58% compared to only 30% before SM. The lower relapse rates could have been attributed to improved selection of candidates during that period of transplantation due to the introduction of formal psychiatric evaluation. Alcohol use was retrospective based on medical records and the clinical judgement of medical staff, self or family reports. No figures were given about the percentage of heavy drinkers in either group to assess the impact of SM on heavy drinking. Despite these limitations, SM generated positive outcomes by providing a medically endorsed program, integrated with the liver transplant program that combined monitoring and professional support by a dedicated group of addiction specialists.

This study suggests that the addition of an alcohol support service, offered by multidisciplinary staff experienced in the field of addiction medicine, and integrated with the standard liver transplant program, can enhance treatment outcomes. Similarly another study reported lower relapse rates from 31% to 13% with the introduction of specialist psychology services involved in pre-transplant evaluation and patient selection, long term psychological follow up and CDT monitoring coinciding with transplant program clinic appointments with transplant surgeon [39]. Consistent and close monitoring of ESALD transplant candidates, especially in the post-

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transplant period is important to preventing relapse rates, particularly in light of absences in outpatient appointments and/or breakdown in the family and other support systems [15, 40, 41].

Summary

Alcohol treatment studies have reported reluctance by ESALD transplant patients in participating in alcohol treatment with initial scepticism, anger, low retention or recall of referral for treatment, treatment dropout, poor attendance and lack of therapeutic outcomes. Explanations for treatment resistance amongst ESALD transplant candidates have been suggested which have included: denial, patient preoccupation with the demands of a complex medical regimen, time scarcity, transportation problems and lack of interest due to current abstinence.

Clinical characteristics of the ESALD transplant patient

Although there is mixed evidence regarding whether matching clients to treatment type results in better treatment outcomes [42] in clinical practice patients characteristics are considered to determine the most suitable treatment [43]. Also while project MATCH failed to demonstrate a significant matching effect but results may not be applicable to the full spectrum of disorder beyond that included in that study. This section will begin with a discussion on alcohol use disorders followed by the clinical characteristics of ESALD transplant patients, ALD patients and ATS as reported in the literature.

Alcohol use disorder subtypes

The diagnosis of an alcohol use disorder as defined by DSM V is a psychiatric diagnosis that includes the diagnoses of alcohol dependence (AD) or alcohol abuse (AA) according to DSM IV. A wide range of subtypes have been identified amongst those with an alcohol use disorder, based on a number of covariates including: age of onset of alcohol dependence, childhood risk factors, physiological factors, severity of dependence, familial alcoholism, antisocial behaviour, alcoholic course and co-morbid psychiatric disorder. Alcohol dependence however manifests with diverse
In 1960, Jellinek [44] was one of the first researchers to develop an alcohol use typology and described five different types of alcoholism defined in terms of their abnormal physiological processes. Beta alcoholism was marked by polyneuropathy or cirrhosis of the liver, with or without physical or psychological dependence and influenced by social customs. The more severe AD, gamma alcoholism showed tissue tolerance, physical dependence and loss of control typified by the more severe alcoholic attending AA meetings. Since Jellinek’s, research a number of other researchers have classified individuals with AD into a number of subtypes based on the influence of family history of alcoholism and co-morbidity [45, 46], the complexity of genetics and environmental factors on biopsychosocial etiology of AD [45]; while others have taken a life course perspective revealing long-term prognostic outcomes [47, 48]. Sannibale [49] concluded that existing typology for alcohol dependence could not be empirically confirmed and this remains a controversial question.

One of the few studies to examine the typology of alcohol treatment utilization was by was a national epidemiological survey conducted by Moss in the United States [50]. This study revealed subgroups of alcohol dependence along a severity spectrum and identified treatment seeking behaviour (Table 3.1). Five clusters were found with specific characteristics: Cluster 1 (Young Adult Subtype), Cluster 2 (Functional Subtype), Cluster 3 (Intermediate Familial Subtype), Cluster 4 (Young Antisocial), and Cluster 5 (Chronic Severe Subtype). Clusters 4 and 5 were the most likely to seek alcohol treatment and had the most severe AD profile including: co-morbid psychiatric and other drug use disorder, and lower levels of psychosocial functioning. These findings are consistent with studies which reveal that those with alcohol dependence and a co-morbid affective disorder are more likely to seek treatment [51]. Moss’s findings are also consistent with studies which have found that only 15% of the general population with alcohol dependence will attend specialty treatment [51-53], and those over 55 years of age and male with alcohol dependence are less likely to attend treatment [51].
<table>
<thead>
<tr>
<th>Variables</th>
<th>Cluster 1 Young Adult subtype</th>
<th>Cluster 2 Functional Subgroup</th>
<th>Cluster 3 Intermediate Familial</th>
<th>Cluster 4 Young Antisocial</th>
<th>Cluster 5 Chronic Severe Subtype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>Younger (24.5 years)</td>
<td>Older (average 41 years)</td>
<td>Older age (average 38 years)</td>
<td>Younger age (26.4)</td>
<td>Average age (37.8 years)</td>
</tr>
<tr>
<td>Onset of AD</td>
<td>Early (19.6 years)</td>
<td>Later onset (mean 37 years)</td>
<td>Onset of AD at age 32 years</td>
<td>Earliest onset (18.4 years)</td>
<td>Later onset (29 years)</td>
</tr>
<tr>
<td>Rate of ASPD</td>
<td>Low probability (1%)</td>
<td>Low probability (&lt;1%)</td>
<td>Modestly elevated (12.5%)</td>
<td>High probability (54%)</td>
<td>47% diagnosis of ASPD</td>
</tr>
<tr>
<td>Familial alcoholism</td>
<td>Moderate probability (22%)</td>
<td>Moderate probability (31%)</td>
<td>Elevated levels (47%)</td>
<td>High levels (52.5%)</td>
<td>Highest levels (77%)</td>
</tr>
<tr>
<td>Co-morbidity probabilities</td>
<td>Low probability relative to other clusters</td>
<td>Major depression (24%) Low rates of anxiety disorders Low probabilities of SUDs</td>
<td>Major Depression (47%) Bipolar disorder (22%) Anxiety disorder (15%) Elevated levels of SUDS</td>
<td>Major depression (37%), Bipolar disorder (33%) Social phobia (14%) Highest probability of SUD</td>
<td>Major depression (55%), Dysthymia (25%) Bipolar disorder (34%) Generalized anxiety (24%) Social phobia (26%) Highest for elevated SUDs</td>
</tr>
<tr>
<td>Pattern of alcohol use</td>
<td>High probability of hazardous use</td>
<td>Lowest probability for using alcohol despite problems (14%)cluster Endorsement of all alcohol abuse criteria, show tolerance</td>
<td>Highest endorsement for most AD criteria</td>
<td>Highest endorsement for most AD criteria</td>
<td></td>
</tr>
<tr>
<td>Demographics</td>
<td>75% never married</td>
<td>Males (60%) to females (40%)</td>
<td>64% males 36% female 38% are married, 21% divorced</td>
<td>76% males and 24% females</td>
<td>65% males 35% females</td>
</tr>
<tr>
<td></td>
<td>54% work full-time</td>
<td>50% married</td>
<td>15.3% married</td>
<td>28.7% married</td>
<td></td>
</tr>
<tr>
<td></td>
<td>36.55% at school f/t or p/t</td>
<td>62% work full-time</td>
<td>Lowest proportion college degree (7.6%) 47% employed.</td>
<td>Highest divorce rate (25.1%)</td>
<td>9% college educated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>26% with college degree</td>
<td></td>
<td></td>
<td>Lowest employment 4% full time 7.6% disabled</td>
</tr>
<tr>
<td>Amount of alcohol use</td>
<td></td>
<td></td>
<td>Average 201 drinking days in last year of which 54% of this 5+ drinks Maximum 9.8 std when they drink 17.1 drinks on drinking day</td>
<td></td>
<td></td>
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<td>----------------------</td>
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<td>-----------------</td>
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</tr>
<tr>
<td>Less frequent use</td>
<td>143 days in last year</td>
<td>73% of this is 5+ std drinks</td>
<td>Maximum 13.8 std on drinking days</td>
<td>181 in days in last year 54% of this 5+ std drinks on drinking days</td>
<td>172 days in the last year of which 54% of this 5+ drinks Maximum 10 std on drinking days</td>
</tr>
<tr>
<td>Treatment seeking</td>
<td>8.7% have ever sought help and will choose AA rather than professional or specialty treatment</td>
<td>17% have ever sought help and tend to participate in 12 step groups or treated for AD by private health care professional</td>
<td>27% have ever sought help, they tend to go self-help groups, specialty treatment programs, detoxification programs and individual private health care providers</td>
<td>35% tend to go to self-help groups, specialty treatment programs, detoxification and individual private health care providers</td>
<td>Highest treatment attendance 66%, self-help groups, specialty rehabilitation programs specialty alcohol treatment with high rates inpatient programs, emergency room visits, psychiatrists, social workers and psychologists</td>
</tr>
</tbody>
</table>
Alcohol use disorder and the ESALD transplant candidates

The diagnosis of ALD is a complex pathophysiological process involving sufficient exposure to alcohol to cause significant liver injury. As stated earlier the diagnosis of an alcohol use disorder is a psychiatric (behavioural) diagnosis involving alcohol dependence (AD) or alcohol abuse (AA). This is to be distinguished from the diagnosis of ALD [54]. The majority of cases of ALD have both the physical and psychiatric diagnosis but proportions have a physical diagnosis of ALD without the psychiatric diagnosis of alcohol dependence (Figure 3.1).

Figure 3.1 Overlap of psychiatric versus physical diagnoses in patients with ALD and alcohol dependence (SE, sufficient ethanol exposure; ESALD, end-stage ALD; TX liver transplant; AD, alcohol dependence). Reprinted from [54].

Only two studies in the transplant literature have examined alcohol use disorder subtypes amongst ESALD transplant patients. DiMartini [55] found that 75-80% of the ESALD transplant population have alcohol dependence, 20-25% alcohol abuse and 4-5% did not meet diagnostic criteria for any alcohol use disorder. In the following year, DiMartini [56] conducted a study to determine whether there were distinct clusters of liver transplant
recipients who showed specific combination of alcohol-related symptoms. 120 ALD liver transplant recipients received the Structured Clinical Interview for DSM-IV (SCID) for alcohol abuse/dependence and a cluster analysis was performed. Four clusters where identified as illustrated in the following figure.

**Figure 3.2** Proportion (%) in four Cluster Groups who endorsed each DSM-IV Alcohol Criterion Symptom and their rates of DSM-IV Alcohol Abuse and Alcohol Dependence Diagnoses. Reprinted from [56]

Cluster 1, (25.6%) of the sample presented with a full range of the DSM symptoms. These were less educated, had higher daily alcohol consumption pre-transplant, were more likely to have attended alcohol rehabilitation, and had an additional diagnosis of non-alcohol substance use disorder. Cluster 2 (18.6%) met all the criteria for alcohol dependence but showed a greater likelihood of symptoms of tolerance. Cluster 3 (17.7%) reported no
withdrawal symptoms but alcohol consumption had interfered with social roles. Cluster 4 (29.2%) tended to meet a criteria of abuse and were least likely to endorse DSM symptoms. Cluster 4 reported that alcohol use did not interfere with their daily activities and life roles, nor did it contribute to legal problems. Cluster assignment did not predict those likely to relapse but those assigned to Cluster 4 were significantly less likely to drink any alcohol or binge drink than those with alcohol dependence. Again further research is required to confirm these subtypes.

To conclude this section it is important to note that recent research has disputed the existence of a typology of alcohol use disorders in the general population. Investigations into the taxonomy of alcohol use disorders have prompted experts in the field to move from categorical classification systems to a dimensional system encompassing symptom clusters. This is due to the numerous possible theoretical subtypes [57] and because taxonomic systems fail to take into account factors such as family history, personality or gender differences [49]. Efforts to classify ESALD transplant patients should also be treated cautiously until there is sufficient and consistent empirical evidence. The examination of sub-groups of alcohol use disorders has been used for the purpose of determining what variables may be associated with alcohol treatment seeking.

ESALD transplant candidates and alcohol treatment seekers

In this section a review of the small body of research which has compared ESALD transplant patients, ALD patients with alcohol treatment seekers is provided to help characterise and distinguish these groups. Table 3.2 presents a summary of research findings investigating the baseline characteristics of ESALD transplant candidates, ALD patients attending liver or gastrointestinal clinics and alcohol treatment seekers.

A little more addiction data is available about ALD patients with severe liver disease who attend gastroenterology outpatient clinics than ESALD transplant patients. However ESALD transplant patients are likely to be selected from an ALD population. Lower alcohol dependence has been reported among ALD patients. A UK study by Wodak [58] found only 18% of patients with ALD attending a liver unit showed severe alcohol dependence compared with 56% in an alcohol treatment group. Similarly Smith [59] found
58% of those with severe alcohol-induced liver disease scored none/mild dependence, 32% moderate and 9% severe in contrast with patients attending detoxification with 76% graded as severe and 34% as moderate. Figlie [60] compared the clinical characteristics of 151 outpatients from a gastroenterology clinic and 175 patients from the specialist alcohol treatment service also found less dependence on alcohol. As a clinical population ALD patients tend to have lower alcohol consumption indices [58, 61], less severe psychological problems [60, 61], fewer consequences from alcohol [60] and more likely to be married or employed [61]. According to Smith [61] the majority of patients presenting with ALD appear to be heavy controlled or social drinkers, leading relatively controlled lives, perhaps not feeling that their drinking is necessarily a major health issue until they present with end-stage liver disease, at which point the liver has been silently damaged to the extent that only 30% will be long term survivors (p.279).

In contrast those with an alcohol use disorder who attend specialty treatment tend to have high levels of co-morbidity, high severity of alcohol dependence, co-morbid substance abuse, more likely to be divorced and socially under resourced (Table 3.2).

The only study to compare ESALD transplant patients with ATS was conducted by Weinreib and colleagues [28] where 30 ESALD patients with prolonged abstinence on a pre-transplant waiting list were matched to a group of alcohol patients seeking alcohol treatment without clinical evidence of end-stage liver disease and recruited to a research trial of naltrexone. Addiction severity, alcohol and drug use, alcohol craving, treatment motivation, psychiatric symptoms and interpersonal adjustment were examined. The ESALD transplant group had a lengthy period of abstinence, higher lifetime alcohol consumption, more standard drinks per drinking day and more drinks per drinking month but no differences in duration of alcohol drinking career, periods of abstinence or age of onset. Few group differences existed in terms of psychiatric symptoms and interpersonal adjustment using the addiction severity Index.

These findings contrast with studies which have compared ALD patients attending liver clinics and what is known about treatment seeking populations. Apart from differences in methodology, one explanation for the differences between Weinrieib’s findings and these studies is that the former study recruited subjects from advertisements and for medication
trials, perhaps attracting a different AD population to the alcohol dependent treatment seeking population.

In relation to motivation or readiness to change both ALD and ESALD patients have been good making behavioural change but have been reported to be pre-contemplative or contemplative or having low problem recognition [28, 62, 63]. It has been proposed that medical treatment may be a reason for the temporary alcohol abstinence behaviour among ESALD and ALD population. Wagner [19] posited that ESALD transplant patients have a cognitive-behavioural split across stages of change being cognitively stuck in pre-contemplation and behaviourally in maintenance. The lack of problem recognition among ESALD transplant patients has been suggested as a reason for the lack of treatment motivation among ESALD transplant patients.
Table 3.2. Comparison of baseline clinical characteristics of ESALD transplant candidates, ALD patients and Alcohol Treatment Seekers

<table>
<thead>
<tr>
<th>Patient group</th>
<th>Alcohol Diagnosis</th>
<th>Severity of Dependence</th>
<th>Alcohol Consumption</th>
<th>Psychiatric Diagnosis</th>
<th>Motivation</th>
<th>Other Substance Abuse</th>
<th>Social Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>20-25% alcohol abuse [55]</td>
<td>No cravings[28]</td>
<td>Tend to be abstinent [28, 55]</td>
<td>12% anxiety disorder [64]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4-5% no criteria [55]</td>
<td>Less alcohol related consequences [58]</td>
<td>Lower daily intake [58]</td>
<td>20% depression or anxiety [68]</td>
<td>Pre-contemplative low problem recognition but high action [71]</td>
<td></td>
<td>68% married [59] and tend to be in stable relationships [59]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SADD [71]</td>
<td>Less alcohol per month when drinking [59]</td>
<td></td>
<td></td>
<td>More likely to be employed [59]</td>
<td></td>
</tr>
<tr>
<td>ALD</td>
<td>50% dependence [68]</td>
<td>Lower scores for alcohol dependence [58, 59, 70]</td>
<td>Lower daily intake [58]</td>
<td>20% depression or anxiety [68]</td>
<td>Pre-contemplative low problem recognition but high action [71]</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>33% no dependence</td>
<td>Less alcohol related consequences SADD [71]</td>
<td>Less alcohol per month when drinking [59]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>77% some dependence (consisting of 19% severe, 21% moderate, 28% mild) [69]</td>
<td>SADD [71]</td>
<td>Lower daily intake [58]</td>
<td>20% depression or anxiety [68]</td>
<td>Pre-contemplative low problem recognition but high action [71]</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>SADD [71]</td>
<td>Less alcohol per month when drinking [59]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol Treatment Seekers</td>
<td>Over 80%-100% are dependent [68, 72]</td>
<td>Higher scores for alcohol dependence [58, 59, 71, 73-75]</td>
<td>Higher rate of alcohol consumption or heavy daily intake [58, 77]</td>
<td>25%-44% Depressive Disorder [75, 78-80]</td>
<td>Higher motivation for change and treatment SOCRATES [28, 71]</td>
<td>26-60% [81-83] greater odds of drug dependence [55]</td>
<td>42-48% married [81-84] less likely to be in stable relationship more likely to be divorced [59, 75, 81, 82, 85] Less social network [84, 86] Less likely to be employed [59, 77] Less education [77, 84, 87]</td>
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<tr>
<td></td>
<td></td>
<td>More alcohol related consequences [71, 74, 76]</td>
<td>High prevalence of Personality disorder [79]</td>
<td>26-37% Anxiety [79]</td>
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Conclusion

Alcohol management programs utilized by liver transplant programs around the world rely heavily on the careful selection and evaluation of potential ESALD transplant patients, and ongoing monitoring of alcohol use in order to ensure abstinence. It has been argued that this alcohol management approach exerts a therapeutic effect contributing to the substantially lowering relapse rates amongst ESALD patients compared to relapse rates found in standard alcohol treatment settings. Personal and motivational factors, as well as program factors, including: rehabilitative relationships with staff, the medical regimen and consistent reminders regarding the negative effects of alcohol, are believed to help patients maintain abstinence. Transplant programs, however, remain concerned about alcohol relapse rates firstly because of the negative health effects on the individual and secondly, public reactions that can potentially influence the reputation of the program and the supply of donor organs.

ESALD transplant patients and those with ALD, tend to be on the low end of the severity continuum marked by less psychiatric co-morbidity, less alcohol dependence, few cravings, greater social resources and longer periods of abstinence. In contrast, alcohol treatment seekers, tend to require more intensive and specialised treatment due to problems with mental health, drug use, severity of dependence and limited social support. There is some evidence to suggest that there are subgroups within the ESALD transplant population with one subgroup sharing similarities with alcohol treatment seekers and thus are at risk of reinstatement of alcohol dependence especially in the context of mental health problems, life stressors and limited social support.

Attempts at providing alcohol interventions within the transplant program have faced significant treatment resistance. Only two of the four studies involved randomised controlled trials using evidence based alcohol interventions, limiting the confidence in these findings. Key unresolved issues include the factors that precipitate treatment resistance and treatment seeking by ESALD transplant patients, and the barriers and reasons for not seeking treatment.

The next chapter will provide a special literature review for the case control study, discussing treatment resistance and treatment seeking.
References


PART 1 STUDY ONE CASE CONTROL STUDY
CHAPTER 4
Treatment resistance and treatment seeking

The development of an alcohol problem is not straightforward and there is no reason to expect the process of recovery, nor help-seeking as part of that process to be so

Vaillant [1] (p.455)

This chapter reviews literatures that informs the design and conduct of the case control study, and will identify factors contributing to resistance to alcohol treatment by ESALD transplant patients. Psychosocial and pharmacotherapy treatment for alcohol use disorders are effective and available to the community [2]. However few people with an alcohol use disorder seek professional help despite the harmful effects of excessive alcohol consumption. As a result of the treatment resistance by ESALD transplant patients, it is important to understand what factors contribute to treatment resistance. This chapter will begin by discussing the existing literature explaining the phenomenon of treatment resistance from a number of psychotherapeutic perspectives. Secondly it will present the theory and research pertaining to the treatment-seeking process and the correlates of treatment seeking amongst clinical and community populations. It will also explore the clinical characteristics of ESALD transplant patients, patients with ALD and those with alcohol use disorder without liver disease. The chapter will close with a discussion on the aims, hypotheses for Study 1- the case control study.

Theories of treatment resistance

Since the emergence of Freud’s endeavours in the area of psychoanalysis, resistance has intrigued and perplexed clinicians whose efforts have been directed towards assisting the client achieve their goals and overcome their psychological problems. 'Treatment resistant' is a term used by clinicians to refer to an individual who is not improving or having difficulty improving in spite of treatment provided and/or who is resistant to following treatment recommendations. It can manifest in a variety of ways including: slow or reluctant compliance, compliance with resentment, passive
withdrawal, anger, emotional exacerbation, cognitive dissonance, helpless withdrawal, premature termination from treatment and poor treatment outcomes [3]. In substance abuse treatment, resistance may manifest as: no change in drug consumption, scepticism regarding the value of treatment, dropout from treatment including not taking prescribed medication, reluctance to self-disclose, resentment of limitation of one’s freedom to act or denial of one’s problem [4, 5].

Psychotherapy research and practice provides a number of different theories for explaining treatment resistance. According to classical psychoanalytic theory, resistance is attributed to the individual’s unconscious conflicts and serves as a psychological defence against conscious awareness of unacceptable drives, feelings, fantasies and behaviour patterns [6]. From this perspective, resistance acts to maintain the sense of self and is an adaptive response to traumatic memory which can cause considerable distress whilst in psychotherapy [3]. Research have identified that individuals resist seeking professional help due to a desire to avoid discussing distressing personal subjects and experiencing painful feelings [7].

In contrast, behaviour therapy generally ignores resistance or attributes it to inadequate or incorrect techniques used by therapists in relation to behavioural tasks [8]. The cognitive and behavioural approach to treatment resistance proposes that it is a natural, healthy and adaptive mechanism which protects core cognitive structures from rapid reconstructive change. According to the theory, individuals actively organise and construct their perception of the world or reality into meaning systems known as cognitive schemata which consist of core and peripheral belief systems. The core cognitive structures involve beliefs by which an individual actively organises and constructs their perception of the world, serving to preserve meaning structures from too rapid change and potential loss of self identity. Core cognitive structures are more resistant to change as they provide meaning structures. Resistance, therefore, is not an expression of neurotic needs, perverse unwillingness, and inappropriate therapeutic technique. Rather, it is a psychological mechanism to protect the individual from data arising from the occurrence of specific schema-disconfirming events which do not conform to or confirm the individual’s core cognitive structures or beliefs [9].

With the advent of social-psychology theory, the concept of resistance achieved extensive recognition and was referred to as reactance. The theory of psychological reactance was first developed by Brehm [10, 11] who proposed that psychological reactance is a state of mind aroused by a threat to an individual’s perceived legitimate freedom and which motivates them to restore the thwarted freedom. The assumptions of this theory are that freedom of choice and action is valued by all human beings and that human beings will react negatively to perceived or actual threats to
their freedoms. Reactance arousal reflects an individual’s striving or motivational force for control as they attempt to restore the endangered freedom [12]. Unlike psychodynamic theories which see resistance as originating purely from the client’s intrapsychic processes, reactance theory takes a more relational approach. Resistance is seen as a phenomenon that emerges between the client and therapist as their differently organised subjective experiential worlds interact in a mutually influential manner [13]. A therapist’s intrapsychic view in itself can be sufficient to arouse an adversarial reaction from a client while a more collaborative alliance has been found to contribute to treatment success [3]. Kirmayer argues that resistance, is as much a reaction of the therapist’s perceptual rigidity as it is a feature of the client’s interpersonal style [14].

Reactance theory, when combined with cognitive theory, suggests that reactance involves a challenge to very powerful core cognitive assumptions that individuals should be in control of self and situations [15]. Treatment resistance or reactance is significantly higher amongst those who perceive that they are forced into treatment versus those who perceive themselves as having volunteered [16] with more compulsory treatment practices reported in the area of substance misuse treatment [17-19]. Coercion has been defined as a form of institutionalised pressure resulting in an individual feeling pressured to enter treatment [20]. Coercion has been presumed to be a dichotomous variable applying only to those in the criminal justice system and other extreme cases of coercion, thus limiting its investigation, relevance and scope. However coercion can involve referral to treatment, workplace referrals, early and family intervention programmes. Whilst some research findings have found treatment coercion to be positively related to treatment attendance, it is negatively related to therapeutic involvement and behavioural change [21, 22].

**Denial**

ESALD transplant patients who resist alcohol treatment have been described as in ‘denial’ – a psychological state reported as a major reason for treatment resistance. Denial is a concept which emerged over 100 years ago and has bewildered theorists, clinicians and researchers. Sigmund Freud (1925) first introduced the concept of denial describing it as a defence consisting of an individual’s refusal to acknowledge both the internal and external experience resulting from trauma. It is essentially a disavowal of reality [23]. From the psychoanalytical perspective, denial is a mechanism which functions to reduce or shield an individual from unpleasant realities and reduce psychic distress. It is distinguishable from insight which generally involves the experience of increasing knowledge, awareness and acceptance of a condition.
In the early 1900’s, an organic perspective was favoured with denial being associated with neurological illness or deficit signified by the term, ‘anosognosia’. By 1970’s cognitive behavioural theorists no longer used the term denial. The focus of research turned to coping theory and conceptual frameworks for understanding how individual with medical illness/injury responds to the stressors and demands of their conditions. Contemporary psychodynamic theorists however reintroduced the concept. Horowitz (1986), for example argued that denial is a normal temporary response to trauma, overwhelming stress or disruptive situations and has a self-protective function [24]. Denial operates as a means to restore homeostasis as an individual experiences gradual innoculation of painful affective states characterised by alternating states of intrusion and denial.

Denial remains a complex psychological construct which has no standard definition, measurement or comprehensive theoretical conceptualisation [25, 26]. The consensus in the literature is that denial is no longer considered an ‘all or nothing’, rigid, maladaptive mechanism preventing healthy adjustment but a dynamic process which may be used in adaptive and maladaptive ways [27]. Researchers have focused on describing the indicators and markers of denial in terms of affect, cognitions and behaviour; and adaptive and maladaptive presentation. Adaptive denial is essential to maintaining health giving the individual time to mobilize coping strategies and resources and has been found to improve patient outcomes in social and psychological functioning and improvement in quality of life [26]. Research amongst patients with heart disease and cancer has revealed that when denial is used excessively and over a long period of time, it can become maladaptive. This manifests in non-compliance, rejection of a diagnosis and future implications or consequences, lack of mastery of important coping skills, relapse, interpersonal difficulties with friends, family and professional staff and importantly refusal, to participate in treatment [26].

**Substance abuse treatment seeking**

**Rates of treatment seeking for alcohol use disorders**

Only a small proportion of the population with alcohol use disorders will enter treatment for a substance abuse problem despite the related harms, and the availability and effectiveness of treatment. A US epidemiological study involving 40,093 people drawn randomly from the general population found that while 4781 (30.3%) meet the criteria for alcohol dependence, only 24.7%
had sought help at some point in their lifetime [28]. Other national surveys in the United States, Canada and the Netherlands show that 10% to 30% of individuals with alcohol use disorder seek alcohol treatment[29-33]. In Australia Proudfoot and Teesson examining patterns of alcohol dependence and treatment seeking in Australia and using the data from the Australian National Survey of Mental Health and Wellbeing (ANSMHWB), found 29.5% of those with alcohol dependence sought help from a general practitioner or other professional in the last 12 months [34]. Amongst those with a lifetime diagnosis of alcohol abuse or dependence, the most commonly utilized service was consulting a medical practitioner (29.7%), followed by attending the self-help group, Alcoholics Anonymous (12.3%). Formal addiction services were seen to be utilized by those with more severe alcohol problems [35]. Several explanations for this low uptake of treatment have been proposed including stigmatisation of alcohol use disorders and its treatment, limited access to treatment, perceived lack of effectiveness of treatment, and the perception that alcohol use is a lifestyle rather than a health disorder.

Models of treatment seeking

.... there must surely be a process which leads up to this point [of help-seeking], a sequence of events, actions and reactions, self-appraisals and appraisals by others.

Edwards [36] (p.307)

Various models have been developed to describe health care or treatment seeking behaviour. The models that will be discussed will be those which have been selected to guide this research study. Three key health services models emerged in the 1970s and 1980s examined the utilization of health services and have influenced the development of models of treatment seeking in the substance abuse field. These include Aday and Andersen, Becker’s Health Beliefs Model and Goldberg’s Model of Pathways to Care.

Aday and Andersen’s framework of access to health care

The first and the most comprehensive framework for understanding access to health care was devised by Aday and Andersen [37]. It stressed the interaction between characteristics of the health care system (health policy and health delivery system) and personal variables (Figure 4.1).
The individual determinants consisted of predisposing, enabling and need factors. Predisposing factors are variables associated with the propensity to use services consisting of socio-cultural characteristics of the individual such as social background, demographics, and health beliefs. The enabling component is the means individuals have for obtaining health care such as knowledge of how to access health services, income, health insurance coverage, available health personnel and facilities. The need factors is the most immediate cause for health care use according to Andersen, and involves an individual’s perceived need for health care due to symptoms of illness, pain and worries about their health and whether they judge their problems to be of sufficient importance and magnitude to seek professional help. Professional judgement and recommendation for medical care also heightens an individual’s need for treatment.

In revised versions of the model Andersen (1995) has highlighted the role of the health services and professionals to creating ‘potential access’ and ‘realized access’ which involves the actual use of services. This model is especially relevant to this investigation as it takes into account the interaction between individual and health care service (policy, delivery and utilization of treatment services).
Figure 4.1 Aday and Andersen’s Framework for the study of access. Reprinted from [8]

**Health Beliefs Model**

The Health Beliefs Model attempts to explain health behaviour based on an individual’s assessment and expectancies involving perceived susceptibility, severity of the illness threat, benefits seen in taking action and where costs and barriers are not seen as negative [38]. In the revised model, Becker [39] introduced the concept of motivation proposing that positive compliant responses to health risk situations are a result of personal readiness interacting with modifying and enabling factors (demographics, relationships with service staff, social or professional pressure/advice) (Appendix A, Figure 1). This model tends to focus on the individual cognitive factors that elicit treatment seeking and behavioural change, particularly in response to medical illness.
Pathways to Care Model

Goldberg & Huxley’s Pathways to Care Model (1980), developed for mental health services, focuses on system variables which affect help seeking [40]. This model is particularly interesting as it illustrates the filters and levels of care which can ultimately lead to specialist service use. This model provides a context for exploring structural barriers to care at various levels within the system. No progress to care can take place without recognition of a problem (filter 1) and no referral to specialist services can occur if the case is not recognised at the primary care level (filter 2) and so forth (Appendix A, Figure 2).

Substance abuse models of treatment seeking

A number of models exist in the addiction literature and majority of these conceptualize the treatment-seeking process as consisting of a series of steps or decisions [41-46]. The general consensus on treatment seeking in the addiction research literature is that treatment seeking involves a complex multi-step process dependent on the interplay of a number of intra- and extra-personal influences which promote or hinder treatment entry [47-49]. For the purpose of this research, three models are discussed as they will guide the research project and will be useful when interpreting and analysing the data.

Saunders and colleagues [44], in an attempt to understand barriers and deterrents to treatment experienced by those with alcohol use disorders, proposed a model where treatment seeking consists of four steps and at each step there exist possible barriers to the next step (Figure 4.2). Barriers are categorised as either ‘person-related’ or ‘treatment-related’ barriers. Person-related barriers consist of cognitive and emotional factors such as negative attitudes toward treatment or failure to realise the seriousness of the drinking problem. While treatment-related barriers include: format, cost, availability or access difficulty. To validate the model, researchers provide empirical support from research into correlates of treatment seeking and these are highlighted in italics in the text below.
The first step in the process of treatment seeking begins with problem recognition, followed by deciding that change is required. This model is relevant to the study as it refers to barriers or reasons for not seeking professional help (Step 3) which can include denial, minimization, self-recovery, self-help groups and stigma. At this point, self-stigma rather than public stigma may be activated. Self-stigma involves damage to self-esteem as one recognises a problem and that change is required. Self-stigma may be overwhelmed by a desire to reduce the problems associated with drinking.

**Stress and coping model**

The second model of relevance to this thesis is that by Finney and Moos (1995) who developed a Stress and Coping Model involving three sets of variables similar conceptually to Andersen’s predisposing, enabling and need factors in health care utilization [46] (Appendix A, Figure 3). The impetus to enter treatment is considered to be a response to the degree of hardship or distress as a
result of drinking and/or psychological distress, accumulation of stressful events or and/or social pressure to seek help. The impetus to treatment may be diminished, however, by counteractive factors which can act as barriers to treatment. These include having more social resources, a problem-focused rather than affect-focused coping response, and limited optimism regarding the effectiveness of treatment. Factors which may facilitate treatment will include prior help seeking, referral to treatment, treatment availability.

**Transtheoretical model**

The third and most extensively utilized model in the addictions field is the Transtheoretical Model (TTM) of behaviour change by Prochaska, DiClemente and Norcross [50]. TTM provides a comprehensive explanation for how people change their behaviour proposing that change involves a movement through a process of five discrete and sequenced stages with each stage being marked by a constellation of attitudes beliefs and behaviours. The stages therefore describe a person’s motivational readiness or progress. Returning back to earlier stages can occur before achieving sustained change such as long term abstinence or controlled use. The stages include: pre-contemplation, contemplation, preparation, action and maintenance. Individuals in the pre-contemplation stage are either unaware of their drinking problem or unwilling to change their drinking. In the contemplation stage, individuals think seriously about change and evaluate the pros and cons both of the problem behaviour and the change required. Those in the preparation stage intend to take action in the near future, while individuals in the action stage have started to modify or alter their behaviour in order to overcome their drinking problem. Engagement in treatment is one of the potential actions. The maintenance stage is characterized by taking steps to maintain stable behaviour change and avoid relapse. Figure 4.3 presents the spiral pattern which illustrates how people move through the stages of change.
While this model does not explain the process of treatment seeking, the stages and processes of change are similar for persons who change their drinking without utilizing treatment as for treatment seekers. It is expected that those in the maintenance stage are unlikely to seek treatment as they would have made sustained behavioural and environmental changes. While there have been several criticisms of the Transtheoretical Model, there is empirical evidence that it can predict clinical outcomes and it has been used to enhance treatment amenability by tailoring interventions to the client’s motivational level or stage of change.

**Correlates of treatment seeking**

A body of research has investigated the barriers and correlates of treatment entry amongst clinical populations of those with alcohol and drug misuse. These studies have compared treatment seekers
with non-treatment seekers in the general population, examining a variety of biological, psychological and social factors. Much of this research has been marred by methodological and conceptual problems including: a lack of standardized measures, not controlling the presence of other variables, lack of multivariate analyses illustrating how variables interact, and the lack of qualitative studies revealing the client’s perspective [48, 51]. Despite this, a number of key correlates have been consistently associated with treatment utilization. Identification of these key correlates will be useful to understanding which variables predispose, facilitate or create the need for professional help. This research is briefly presented in this section.

Problem recognition

Problem recognition has been identified as one of the primary correlates of treatment seeking in clinical populations. In a recent review by Tsogia and colleagues [48] involving 17 quantitative studies exploring reasons for or against entering treatment for alcohol and drug misuse, problem recognition was one of the most powerful predictor of treatment entry. Accordingly the lack of recognition that one’s problem is serious enough to require professional help was found to be a major barrier to treatment entry. The importance of problem recognition in influencing treatment entry was identified by an earlier review by Jordan & Oeil (1989) [49] and supported by more recent studies [47].

Cognitive appraisal is a related process that can lead to problem recognition which involves evaluating and weighing up the pros and cons of drinking or not drinking and making the decision that change is required. Studies have identified that many substance misusers engage in a cognitive appraisal process prior to seeking treatment. Cunningham and colleagues (1994) asked subjects to give 10 reasons leading to treatment seeking and to how much they were influenced by these reasons Weighing the pros and cons, along with hitting rock bottom and experiencing a major lifestyle change were predictive of professional help seeking and treatment completion. [52]. Treatment seekers generally exhibit high internal motivation and tend to be in the contemplative or action stage of change [53-56].
Accumulation of negative life problems

Problem recognition alone however does not inevitably lead to help-seeking as there is a time lapse between problem recognition and entry into treatment which can range from 1-15 years [48]. Studies suggest that problem recognition works closely with the impact of negative life events as impetus for treatment entry. The intensity or frequency of these negative life events and psychosocial impairments related to drinking has also been found to be predictive of treatment seeking [34, 46, 47, 57-62]. Life events or stressors found to be significant to treatment entry have included: drinking while driving and traffic crashes, arrests for criminal offenses, relationship problems, health and work problems. One of the few well conducted and largest qualitative studies was by Orford [47] in the United Kingdom which involved open ended interviews asking 98 clients who self referred to treatment about their reasons for seeking treatment. According to Orford (2006, p. 174) the most influential factor in help seeking was ‘the sheer weight of problems, often in several life domains, worsening to the point at which their meaning was inescapable and action unavoidable’.

Psychiatric problems

Co-morbid mental health problems, especially involving a diagnosis or symptoms of depression and anxiety, have been reported to be a major factor in treatment utilization [30, 63-68]. Recognising a problem with alcohol use and the necessity for change is more probable when emotional distress is substantial and when psychiatric problems are present [44]. Lower levels of co-morbidity and higher psychosocial functioning have been found to result in moderate levels of help-seeking compared with those with higher psychiatric problems [69].

Severity of dependence and other drug use

Severity of dependence and its association with alcohol treatment utilization has not been consistently investigated. A small number of studies however have found an association between alcohol treatment utilization and severity of dependence symptoms [70-75]. In a recent study Moss (2007), using data from a nationally representative epidemiological survey examining alcohol dependence subtypes, found that those with substantial rates of multigenerational AD, severe AD
criteria profile engaged in significant help seeking. The presence of three or four symptoms of dependence has been found to be a strong factor for treatment seeking among individuals with alcohol dependence [76-78]. Those with additional substance dependence other than alcohol are also more likely to seek treatment [74, 79, 80].

**Demographics**

Efforts to identify which individuals based on demographics are most likely to enter treatment has yielded mixed findings. Only a few studies have examined demographic variables and treatment entry, most of which have not employed a prospective research design or used comparison groups [48]. Studies of the relationship between age, ethnicity, gender and alcohol treatment utilization reveal variable findings. A number of studies report treatment seekers to be generally female [64, 81-83], unmarried [41, 80, 84-86], lower income [61, 79], having less education [74, 79] unemployed [61, 87], middle aged rather than older [57, 64] and lacking a good support network [74, 88]. These characteristics are common in treatment populations but may not necessarily be predictive of treatment uptake.

**Social Pressure**

Social pressure is considered to involve confrontation from members of one's social environment concerning the negative aspects of one's substance use and a request that the need for treatment be seriously considered by the substance misuser. Early studies focused on mandated forms of social control and its impact on treatment utilization [89]. More recent studies have found informal social pressure to significantly influence treatment entry more than even mandated social controls [90, 91]. Nevertheless adults seeking treatment solely in response to social or external pressure were less likely to make decrease their substance use, make positive behavioural change and engage in treatment compared to those who self refer for treatment [92].
Health problems

There are mixed findings as to whether health problems contribute to treatment utilization [49, 60, 93-95]. This may be due to studies not adequately assessing medical and health problems at the time of assessment. Health problems however are common reasons for individuals changing their drinking without accessing treatment [96], especially amongst those who have decided to become abstinent [97]. Health beliefs specifically involving high perceived illness severity and cues to action are endorsed by alcohol treatment seekers compared with those with an alcohol use problem and not seeking treatment [98]. These perceptions appear to pre-date entry into treatment.

Quality of life

The complications of alcohol misuse affecting nearly all life domains are well known and alcohol treatment seekers may enter treatment as way of managing physical, mental, social and economic problems. Quality of life as a predictor of treatment seeking has not been specifically researched however numerous studies have reported very low quality of life scores among those who enter specialty alcohol or substance abuse treatment [99-101] and these scores can be lower than those with chronic medical conditions [102].

Barriers at the latter steps of treatment seeking

Barriers to treatment are factors which hinder or counteract decisions that otherwise lead to treatment seeking. Once the decision is made that change is needed, research suggests that there are certain factors which hinder the decision to seek professional help and complete treatment.

Stigma

According to Vogel, stigma is the perception of being flawed because of a characteristic (personal or physical) which distinguishes an individual as socially unacceptable [7]. Stigma is the most cited reason for not seeking both general and substance abuse professional treatment. Studies
reveal that the fear of stigma represents a major barrier to the utilization of substance abuse treatment with consumer concerns about being labelled an ‘alcoholic’, loss of privacy and it being seen as an admission of personal failure [49, 82, 103-105]. A recent U.S. study by Keyes and co-workers [106] involved a nationally representative sample of adults with an alcohol use disorder. It tested whether perceived stigmatization of alcoholism was associated with a lower likelihood of receiving alcohol-related services. The study involved a face-to-face epidemiologic survey of 34,653 adults interviewed in 2004-2005. Their alcohol use was formally diagnosed and stigma measured using a perceived Devaluation-Discrimination Scale. The main outcome was that individuals with a lifetime diagnosis of an alcohol use disorder were less likely to utilize alcohol services if they perceived higher stigma toward individuals with alcohol disorders. The relationship between stigma and treatment seeking decreased in a stepwise fashion after controlling for demographic characteristics and alcohol disorder severity. Higher perceived stigma was associated with male gender, non-white compared with non-Hispanic white race/ethnicity, lower income, education and being previously married.

It has been argued that self-stigma is more important than public stigma and contributes to an individual shunning treatment in order to avoid a lower of self-esteem whereas public stigma involves the fear of others’ reaction [107]. Self-stigma involves a lowering of an individual’s self-esteem or self-worth which emerges from identification with a stigmatised group. The prospect of voluntarily utilizing substance abuse treatment according to Saunders [44] (p.268) presents ‘a self-stigmatizing challenge threatening an individual’s sense of control and self-esteem’. Seeking help from another individual can be internalized as feelings of inferiority, inadequacy, a sign of weakness or failure [7], making help-seeking a threat to an individual’s self-esteem and an avoidance of treatment a means of maintaining a positive self image. Thus a strong personal and public admission and acceptance of a stigmatizing diagnosis is needed before need for outside help to overcome it but also a failure at self-help [108].

‘Prefer to manage the problem myself’

The most frequently endorsed reason for not utilizing formal treatment services provided in both quantitative and qualitative studies involves ‘wanting to solve one’s drinking problem on one’s own’ without the need of professional help [32, 44, 104, 105, 109, 110]. Self-stigma may be a factor behind an individual’s preference for handling the problem without treatment, perhaps reflecting misplaced self-efficacy and fear of challenges to one’s self-esteem’[44].
**Program attributes**

While individual variables correlated to treatment seeking play a pivotal role in treatment seeking, service delivery plays a significant especially in the latter steps of the treatment seeking process [29, 44]. In 1964 Chafetz was one of the first to illustrate that retention in alcohol treatment could be enhanced by altering service delivery [111]. He conducted a series of experiments with patients in an alcohol clinic after referral from an emergency service in a general hospital to see whether improving service approach would alter retention. The changes he incorporated to the standard approach included: welcoming patients and treating them with respect at initial contact, reducing waiting times, increasing patient contact, and offering service that dealt with patient concerns (housing, finances). All these interventions caused a manifold increase in initial and long term attendance despite the patients’ poor prognoses. In a later study Beckman and Kocel studied aspects of the treatment delivery system as it related to women entering 53 alcohol treatment agencies and found that organisation and attitude of treatment agencies influenced the initiation and maintenance of treatment [42].

One study found that 10% of the variance in therapeutic involvement was due to program attributes [112]. Even after adjusting for patient differences, programs offering the same type of treatment orientation have been shown to have differential effectiveness and influence the initiation and maintenance of help seeking [113]. Program attributes which have been found to alter treatment seeking and retention include: providing a broader array of service [112], improving access by reducing wait time [114-116], role induction [117], staff composition and attitudes, agency attitudes [42], cost [70], structured programming and clear policies [118], offering more psychosocial treatment [118] and treatment matching[119, 120]. The literature suggests that treatment agencies have an important role in shaping community attitudes and response to alcohol problems and may indirectly influence the personal beliefs that lead to initiation and maintenance of treatment.

**Temporal sequencing of treatment seeking**

There are few data about the timing of treatment seeking in relation to the clinical course of an alcohol use disorder and the development of alcohol-related problems. Jellinek (1964) placed clinical treatment late in the developmental sequence after drinking problem onset, developmental milestone and problem recognition. Schuckit found that 74% of war veterans hospitalized for
alcohol problems reported early problems in their early 20s, a worsening of their problem in their 30s and treatment contact in their 40s [121].

**Figure 4.4** Temporal sequence of Alcohol-related events and Treatment Seeking

A recent study conducted by Simpson [122] extended past research examining temporal sequencing of contact with formal services. A community sample of 101 male and female problem drinkers who varied in their help seeking histories (no assistance, AA only, treatment plus AA) were assessed on past and present drinking practices, other drug use, help seeking episodes for alcohol related problems and the date that participants first experienced alcohol related problems. They were also questioned about the year in which they had initial contact (if ever) with alcohol focused interventions including professional treatment providers. A rank order analysis was conducted to examine the temporal sequence of alcohol related events and significant milestones in their drinking careers. Although individual differences were observed, generally pathological drinking practices emerged early in the general sequence and were often closely connected with problem recognition. Legal, relationship and financial problems tended to develop somewhat later, followed by the development of dependence symptoms such as tolerance, withdrawal, neurological consequences (e.g. memory impairment, blackouts). Emotional problems emerged after these
events with alcohol related health problems being the last adverse consequences to develop. Physical health problems due to drinking were relatively late occurrences (Figure 4.4) just prior to treatment. These results complement the findings of past studies.

Simpson proposes that the reticence of ‘problem drinkers’ to seek help is not driven by denial and believes that there is the opportunity to introduce lower threshold interventions in order to engage individuals in treatment. Nonetheless, initial help seeking occurred on average about a decade later than problem recognition [113]. Problem recognition was found to occur somewhat early in the overall sequence shortly after the onset of pathological drinking practices. Greater alcohol related problems and higher dependence levels were reported by resolved participants who were quicker to recognise their drinking problems and to seek help compared to non resolved participants. Less severe but serious drinking problems and a social network which accommodates to the drinker may make problem recognition more difficult thereby functionally ‘enabling’ the problem drinking pattern and delaying help seeking. Informal help seeking occurred 4 years before professional help seeking.

**Recovery from substance dependence without treatment**

All recovery is natural recovery

Griffith Edwards [123] (p.747)

One reason for individuals with alcohol use disorders refusing to participate in treatment and which is extremely relevant to this investigation is the issue of self-change or natural recovery. Natural recovery studies have examined abstinence or controlled drinking for at least a period of 12 months. Natural recovery has been defined by Cloud and Granfield as ‘termination or ‘cessation’ of substance dependence without the aid of formal treatment or participation in 12-step groups such as Alcoholics Anonymous, Narcotics Anonymous or other mutual-help groups, including non-12 step groups such as SMART, Moderation Management etc.’ [124]. In the addictions field, several terms have been utilized namely: spontaneous remission, auto-remission, self-change, natural resolution, maturing out, spontaneous recovery, natural recovery, untreated remission, untreated recovery [125].
Prior to the emergence of natural recovery research in the 1970’s, natural recovery was considered a taboo subject. Addiction was considered not self-curing and that without treatment, alcoholism could lead to fatal consequences such as total degradation, prison and mortality [126-128]. The recognition of natural recovery continued to be underreported in the literature due to the bulk of research taking place within the context specialized treatment for a treatment seeking population further reinforcing the assumption that treatment is essential to mobilizing behavioural change [108]. With the increase in natural recovery research studies, it has been uniformly demonstrated that a large majority of individuals with alcohol problems in the general population resolve their alcohol problem without specific help from formal treatment services or self-help groups [93, 129, 130].

Epidemiological studies using general population surveys have found that between 54% and 85% of those with alcohol use problems make change without professional help [131-133]. The variability in the range is influenced by the definition of natural recovery and methods of measuring alcohol problems. Natural recovery may be defined either by abstinence, moderate drinking or a reduction in the DSM symptomatology maintained for at least a 12 month period. More than three quarters of subjects in natural recovery studies had a less severe drinking problem. However, recovery from severe dependence has also been reported.

Little is known about how natural recovery occurs. Studies have tended to be exploratory or retrospective, frequently fail to identify many of the antecedents or events associated with the self change process, have a short follow up period, and are lacking in corroboration of respondent reports [93, 126]. A review of 40 natural recovery studies by Sobell [93] highlighted the reasons for natural recovery. The most frequent reason for natural resolution involved health concerns with 17 samples (42%) reporting these concerns. Others were financial issues (30%), negative personal issues relating to substance use (30%), cognitive changes (27.5%) and influence from significant others (22%).

Natural remitters as a group show different clinical characteristics to treatment seeking populations:

1. Demographics: they tend to be older, married, have greater education, employed and greater social stability [109, 129, 134-136].
2. Alcohol indices: they tend to experience less severe forms of alcohol dependence [133, 137-139], less lifetime alcohol consumption [135, 140, 141] and less alcohol related consequences and psychosocial problems, especially in social and interpersonal relationships compared to treatment seekers [109, 132, 142, 143].

3. Health problems can be a major reason for change [93, 97, 109, 144].

4. Greater social resources in terms of a socially stable support network of family [109, 135, 139, 145, 146] and a view of their spouse as integral to recovery [142].

Natural remitters rely on cognitive appraisal in order to facilitate change with a reliance on will power and reasoning [109, 147, 148]. They also show greater self-efficacy [149]. Maintenance of change has been largely attributed to: adequate social resources, financial stability, greater self efficacy, and use of will power, an approach rather than avoidance coping style and alternative non alcohol related activities.

Barriers to seeking professional treatment for natural remitters include:

1. not wanting to be stigmatized or labelled [59, 109, 142, 150]
2. believing that they could quit on their own [59]
3. privacy or not wanting to share one’s problems with others [59, 151]
4. perceiving their problems as not severe enough to warrant treatment [59].

An important point to note about those who abstain without treatment is that they are more likely to involve a return to low risk drinking or controlled drinking while treatment seekers have been found to achieve a longer period of abstinence [129, 152, 153]. Moos (2006) examined the rates and predictors of 3 year remission among untreated individuals and treatment individuals with alcohol use disorders with a 16 year follow up period. Those likely to relapse were less likely to see their drinking as a significant problem, had less self-efficacy, and relied on avoidance coping. By Year 16, 60% had relapsed amongst self remitters versus 43% amongst the treatment group.

**Research aim and design**

As discussed in the literature review the need for alcohol treatments is involves a number of complex factors. Comparing the clinical characteristics of ESALD transplant subjects with alcohol treatment seekers (ATS) will help to explain resistance to alcohol treatment by ESALD
transplant patients. The case control design was selected in order to test the hypotheses by comparing cases with controls. The primary aim of the case control study is to compare ESALD transplant patients who see no need for alcohol treatment (cases) with a group of alcohol treatment seekers (ATS) who are actively engaged in treatment (cases) on variables correlated with treatment seeking.

The case control design was also selected as it involves fewer and more readily accessible subjects, requires less time to complete and relatively inexpensive to administer. To help guide this investigation a model of alcohol treatment seeking was formulated (Figure 4.5) incorporating the theoretical tenets of treatment seeking models along with clinical and demographic variables linked with alcohol treatment seeking.

**The research question and hypotheses**

The primary research question of this project is:

> What are the barriers and factors associated with the lack of participation in specialist alcohol treatment seeking amongst ESALD transplant patients?

In this study treatment seeking refers to the voluntary utilization of professional, formal or specialist alcohol treatment services including both medical and psychological/counselling based interventions aimed at addressing alcohol use disorders.

**Hypothesis 1**

ESALD transplant patients differ from alcohol treatment seekers (ATS) and they do not perceive the need for specialty alcohol treatment nor are they well matched to standard alcohol interventions. These groups differ in length of abstinence, motivation, health beliefs, alcohol severity, psychiatric and substance abuse co-morbidity, quality of life and demographics.
Hypothesis 2

ESALD transplant patients are less comfortable with seeking professional help for alcohol related problems.

Conclusion

This chapter has outlined factors contributing to treatment resistance and treatment seeking. Treatment resistance is likely to occur when core cognitive structures or beliefs are challenged, if treatment is perceived as coercive, incorrect use of therapeutic approaches or if interventions activate distressing feelings and memories. The pathway to specialty treatment is a complex, multi-step process involving the interaction of a number of factors involving biological, psychological, social and organisational variables. Alcohol treatment seeking is more likely to occur in the presence of problem recognition, culmination of adverse negative life events or stressors as a result of drinking, psychiatric problems and social pressure. Treatment related barriers may hinder individual motivation for help seeking and treatment completion. Natural recovery is also a possible explanation for treatment refusal as at least half of those with an alcohol use disorder in the wider community will make changes to their alcohol consumption without participating in treatment. The majority of those with an alcohol use disorder including natural remitters will be deterred from accessing professional treatment due to the fear of stigma and believing that they can change without utilizing professional help. The aims, research questions and hypotheses for Study 1, a case control study, have been provided. Chapter 5 will discuss the method to be used in the case control study.
Figure 4.5 Alcohol treatment seeking model based on the correlates of alcohol treatment seeking

**Predisposing Factors**
- Female, Middle aged, Unmarried, Unemployed
- Higher education
- Poor support network
- Past treatment history

**Need Factors**
- Readiness to change
- Positive health beliefs
- Perceived severity, of alcohol problems: diagnosis, symptoms, consequences
- Substance abuse
- Psychiatric comorbidity

**Problematic Drinking**

**Decision that change is required**

**Self Change**

**Decision that professional help is required**

**Relapse**

**Contact with professional alcohol service**
References


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CHAPTER 5

Case Control Study - Method

This chapter outlines the methodology for Study 1 - the case control study. It includes ethics approval, participants, recruitment and assessment procedure. Details of all measures and instruments utilized are explained in detail followed by a description of the approach to statistical analysis.

The study was carried out between September 2009 and July 2011. Prior to recruitment commencement, the study protocol was approved by the Ethics Review Committee of Sydney Southwest Area Health Service (RPA Zone) (Appendix B). Ethics approval was also granted by the Ethics Committee of Concord Repatriation General Hospital Research Office to distribute a flyer or recruitment advertisement (Appendix C) to potential participants. Interview data was collected by the student investigator. Blood samples and fibroscans were conducted at Royal Prince Alfred Hospital. The study was undertaken in collaboration with University Sydney Faculty of Health Sciences and Royal Prince Alfred Hospital.

Study variables

The dependent variables in this study included a diagnosis of ESALD and being a liver transplant candidate or recipient. The independent variables included many of the correlates of treatment seeking namely: demographics (marital status, education, employment history, social support network, housing stability), alcohol use, severity of alcohol dependence, substance use history, alcohol treatment history, psychological distress, motivation, quality of life, risk of relapse, health beliefs and help seeking. It is expected that variations in any of these variables could affect treatment motivation.
Participants and recruitment

A total of 40 cases and 40 controls were recruited. Controls were matched to cases based on age and gender. This sample size was considered adequate to achieve the goals of the study and to elicit an effect of scientific and statistical significance.

Cases consisted of patients with a diagnosis of ESALD and who were either in the pre-transplant or post-transplant stage of liver transplantation. All cases were recruited from the Australian National Liver Transplant Unit (ANLTU) Royal Prince Alfred Hospital, Sydney Australia. As requested by the Ethics Committee, subjects were approached and informed about the study by transplant staff including the nursing unit manager, drug and alcohol specialist and transplant psychiatrist. According to the Ethics the researcher has no clinical relationship with the patient and therefore it would not be appropriate for the researcher to approach the patient whilst they are in hospital for care. In such circumstances, the HREC routinely requires a member of the patient’s clinical team to tell the patient that the study is taking place and seek the patient’s permission for the researcher to approach them to discuss possible participation. This was considered important to avoid any breach of patient privacy.

Potential participants were informed about the study and presented with the recruitment advertisement by transplant staff and encouraged to contact the investigator if they were interested in participating in the study. The flyer was worded and designed so that it would not be directly confronting regarding alcohol use problems (C).

On receiving a phone call from the potential participant, screening for suitability was conducted along with attending to any queries or concerns the participant may have had about the study. If eligible for the study an appointment was made for an assessment. Potential participants were given the choice of being assessed at the liver transplant unit or at the outpatient drug health service situated in another building on the same hospital campus. The large majority of potential participants preferred to be assessed at the liver transplant unit whilst attending their outpatient appointment at the transplant unit.

Controls included 40 individuals with alcohol use disorders, without significant end-stage liver
disease who had commenced alcohol treatment. Controls were recruited from outpatient counseling services, an inpatient detoxification unit and residential rehabilitation program. All of the above organizations serviced the same area as the liver transplant unit to minimize the effects of population stratification.

Controls were approached by the intake officer, treating staff member and the investigator about participation in the study. On receiving a participant’s willingness to be involved in the study an appointment was made. Controls were interviewed either at the outpatient drug health service or the residential treatment facility.

Other organizations and services were targeted for recruitment and were contacted on a regular basis however did not prove to be sources of potential participants. These included other residential rehabilitation programs (Kathleen York House, We Help Ourselves (WHOS), Foundation House and Alcoholics Anonymous (AA). Recruiting controls matched in age and gender took twice as long as recruiting cases which pointed to the lack of alcohol treatment seeking by males in that age group.

**Inclusion and exclusion criteria**

All potential participants who were interested in participating in the study were screened for eligibility.

Cases were eligible on the following criteria:

1. Age 18 years or over.
2. A clinical diagnosis of ESALD and either in the pre or post-transplant stage. Patients transplanted for ALD and Hepatitis C Virus (HCV) were also included.
3. Adequate understanding of English (essential for informed consent and comprehension in order to complete questionnaires and interviews).
Cases were excluded on the following criteria:

1. Current history of injecting drug use
2. Acute psychiatric illness (e.g., schizophrenia, psychosis, bipolar disorder)
3. Hepatic encephalopathy
4. Alcohol dependence treatment since being placed on the pre-transplant waiting list. Treatment seeking was defined as the commencement of specialist alcohol treatment such as inpatient or residential treatment programs, outpatient counseling treatment with or without specialist medical treatment. No subject was excluded based on this criterion.

During the recruitment period no patients were excluded due criteria 1, 2, 4 and only one patient for criteria 3.

Controls were considered eligible based on the following criteria:

1. Age 18 years or over
2. Diagnosis of alcohol dependence or abuse
3. Basic literacy and ability to communicate in English to ensure comprehension and ability to complete questionnaires and interviews
4. Commenced alcohol treatment

Controls were excluded on the following criteria:

1. Current evidence of substance use disorder other than alcohol or nicotine drug dependence
2. Life threatening medical conditions contributing to initiation of alcohol treatment
3. Involuntary treatment seeking including referrals by probation and parole
4. Major psychiatric illness (e.g., schizophrenia, psychosis, bipolar disorder).
5. Serum liver tests (AST, ALT, GGT) greater than 1.5 times normal within the last three months or findings on a fibroscan suggesting advanced liver disease (liver stiffness > 13kPa).
Study procedure

This research project used a structured interview as the primary research instrument. The interviews were conducted face to face on an individual basis. All participants were required to read the ‘Information for Participant Sheet’ (Appendix D) which provided detailed information about the study procedures, assured confidentiality and provided the option to withdraw from the study at any time. Written consent (Appendix D) was obtained from each participant before data collection commenced. Participants were informed that they would be given a $20 gift voucher at the end of the interview.

Interviews took on average one hour for controls and one and half hours to two hours for cases to complete. Assessment sessions were longer for cases as they had the extra component of the semi-structured interview. Measures were conducted by the investigator experienced with conducting drug and alcohol assessments and with a master’s degree in drug and alcohol studies.

All measures were selected based on sound psychometric properties and for the purpose of testing the hypotheses. We expected the majority of ESALD transplant participants to report being abstinent in order to assess certain variables, it was important to select measures which had a retrospective perspective so the participant could respond in relation to a period when he/she was drinking.

Both cases and controls were asked to complete the following measures. Copies of all assessment measures used in this study are contained in Appendix E.

Assessment measures

Demographics

Participants were asked their age, gender, marital status, presence of HCV, past IVDU, family history of alcoholism, housing stability, history of mental illness, employment, social support network, education level (Appendix E).
The Lifetime Drinking History (LDH)

The Lifetime Drinking History (LDH) [1] is a retrospective, structured interview designed to provide quantitative data on an individual’s alcohol consumption patterns in a chronological manner. It was chosen in order to compare a number of alcohol indices throughout the lifetime drinking careers amongst cases and controls. The data obtained from LDH included: duration of regular drinking (years), duration of “heavy” drinking (years), duration of abstinence (years), lifetime total (grams absolute alcohol/kilograms body weight), daily average (g/kg), average per drinking day (g/kg), volume variability (maximum per day – daily average), beverage Type: % Beer, spirits, Wine, style: Occasional, weekend, binge, frequent, life events that influenced consumption levels, context: % drinking Alone vs. With Others, time: % drinking during Morning, Afternoon, Evening.

The LDH interview takes approximately 20 to 30 minutes to complete. The investigator used probing, cross referencing of facts, provided participants with a chart showing the number of standard drinks in various beverages, and used memory aids to assist in accurate recall. The measurement of standard drinks was based on the Australian National Guidelines [2] where a standard drink is defined as 10g of alcohol (equivalent to 12.5 mL of pure alcohol. Harmful drinking whilst using the LDH was defined as reported drinking above 2 standard drinks daily for females and 6 standard drinks daily for males. Harmful drinking also included regular binge drinking of over 6 standard drinks.

LDH is one of the most widely used lifetime drinking measures and has been used in a number of research projects including amongst those with alcohol-related liver disease [3-4]. Reliability estimates [5] [6-7], correlations for a number of drinking indices [1], validity and concurrent validity has been high [8] [9] [10].

SCID I

The Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders DSM-III and DSM-IV (SCID I) [11] was used with the LDH to determine alcohol use diagnosis at the time of problematic drinking. As the majority of ESALD transplant patients were abstinent
and in remission a retrospective account was required in order to make a diagnosis. A diagnosis of alcohol dependence is based on 3 dependence items coded ‘3” having occurred within same 12 month period. The diagnosis of alcohol abuse requires 1 item coded “3”. No diagnosis is made if no items were reported. The SCID has been reported to yield highly reliable diagnoses when using appropriate semi-structured interviews [12-13] and moderate to excellent inter-rater reliability [13-15]. The SCID I was conducted by the investigator experienced with conducting drug and alcohol assessments and with a master’s degree in drug and alcohol.

**Mini-Mental State Examination (MMSE)**

The MMSE or Folstein test is a brief 30 point questionnaire used to screen cognitive impairment providing a brief, objective measure of cognitive functioning [16]. The MMSE was used in the current study only if the participant appeared to be have cognitive impairment, difficulties with comprehending questionnaires or with retrospective recall during the interview.

**SIP 2-R**

The Short Inventory of Problems – Recent (SIP-R) is a 15 item self report questionnaire with sensitivity for measuring alcohol related consequences amongst a wider sample of problem drinkers not just those with severe alcohol dependence. Version SIP2-R asks respondents to rate consequences at the time their drinking was the most problematic or heaviest allowing for recall of past drinking consequences. The SIP provides a total score and scores on each of the domains based on a clinical treatment population. A profile sheet provides a means of interpreting the decile range as either: very low, low, medium, high, very high consequence. The original SIP-R was derived from DrInC-R questionnaire by Miller [17]. Miller developed a shorter version of the DrInC-R to develop the SIP which included 15 items from the original. The latter version showed internal consistency, test-retest stability [18-19].

**Short Alcohol Dependence Data (SADD)**

The Short Alcohol Dependence Data (SADD) was developed by Raistrick [20] and based on the Alcohol Dependence Syndrome created by Edwards and Gross [21]. The SADD was chosen for
its discriminative power to measure the degree of alcohol dependence among drinkers in the mild to moderate range of dependence rather than strictly for the clinical population who tend to have severe dependence [22]. Questions are framed for participants to provide a retrospective account about when their drinking was the most problematic or heaviest again suitable for participants who are abstinent.

A total score is obtained by adding the score from each of the items. Scores between 1 and 9 indicate low dependence, those between 10 and 19 indicate medium dependence and a score of 20 or more indicates high dependence. Each item is scored as follows: never = 0; sometimes = 1; often = 3; nearly always = 4. Davidson and colleagues [23] demonstrated that the SADD measured the alcohol dependence syndrome. The instrument has also been found to show good test-retest reliability ($r = .87$), acceptable split-half reliability (a correlation between total score on odd and even numbered questions) [20, 24] and construct, concurrent and content validity[22-23].

**Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES 8A)**

The Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES) developed by Miller & Tonigan [25] is one of the most extensively cited and utilized instruments for measuring readiness for change amongst adults with alcohol problems. This study utilized SOCRATES (Version 8A) consisting of 19-items. SOCRATES was chosen over other readiness to change scales due to its good psychometric properties. The theoretical underpinnings of the SOCRATES are based on the Transtheoretical Model (TTM) and was modelled after a general stages of change measure known as the University Of Rhode Island Change Assessment (URICA) [26]. While the URICA asks about the client's "problem" and receptiveness to change in relation to problem behaviours, the SOCRATES on the other hand, was specifically intended to categorize alcoholism treatment clients according to their motivation for change. The measure identifies continuously distributed motivational processes that may underlie stages of change allowing for the degree of problem recognition, ambivalence and taking steps to be measured as three separate and validated subscales.

As the majority of ESALD transplant patients are abstinent in order to assess their stages of change and readiness for treatment, both cases and controls were asked to complete a past and present SOCRATES. The retrospective assessment using the SOCRATES involved measuring the
motivational processes when alcohol use was most problematic. The second assessment involved a current measure of readiness to change. Items on the SOCRATES were modified slightly in terms of tense but not content in order to capture retrospective data and to adjust to the probability that both cases and controls may be abstinent or drinking.

The psychometrics of the earlier SOCRATES (Version 5.0) was extensively evaluated in two studies associated with Project MATCH multisite clinical trial and conducted by Miller and Tonigan [27-28]. The three-factor structure described above was identified as stable and good internal consistency of each subscale verified by a number of other studies [29-31]. The Ambivalence scale has been found to have lower internal consistency than the other two scales [32] consistent with the Project Match findings. This may be due to a problem inherent in the measurement of ambivalence [27]. These findings generalise to SOCRATES 8A. Two studies have reported good predictive validity one involved a sample of 125 male clients who met DSM-III-R criteria for alcohol dependence and who were treatment seekers, high ‘Taking Steps’ scores were predictive of abstinence during the 1 year post-treatment period while high ‘Recognition’ scores predicted participation with Alcoholics Anonymous (AA)(Isenhard -1997). A large sample of alcohol-dependent inpatients (n = 350) the association of client motivation with alcohol use, self-efficacy and treatment outcome at 3-month follow-up was examined. Readiness to change was positively associated with pre-treatment self-efficacy and accounted for 9.4% of the variance in treatment outcome (Demmel 2004).

**History of Substance Use**

Past use of cannabis, opioids, sedatives, methadone, amphetamines, cocaine and ecstasy was assessed by asking participants whether this involved: never having used, having used a few times only, past non-problem, past problem, current non-problem and current problem.

**Previous substance abuse treatment**

Participants were asked about past treatment history and how many treatment episodes or times they had utilized the following: inpatient detoxification units, outpatient detoxification, residential treatment, day programs, outpatient counselling and Alcoholic Anonymous (AA) meetings.
Health Beliefs

The Health Beliefs model [33] proposes that positive behavioural responses to health risk situations result from an individual’s assessment of perceived susceptibility, severity of the illness threat, benefits seen in taking action and where costs and barriers are not obstructive. There are no standardized questionnaires based on the health beliefs model. Researchers developed scales based on the theoretical model while these scales showed face validity they lacked construct validity [34]. Latter scales improved the construct validity but were not tested on specific patient groups thus limiting their applicability to different groups. Cockburn and colleagues [35] developed and tested a questionnaire measuring health beliefs amongst a large sample of general practice patients with a wide range of different illnesses examining factor analysis, reliability and validity testing based on the responses. The results of the analysis provided empirical evidence for the reliability and construct validity of the questionnaire. Factor analysis and theory supported that ‘perceived severity’ and ‘perceived susceptibility’ be grouped under ‘threat of illness’.

The questionnaire for this study was developed for the study based on the Cockburn questionnaire measures 4 scales namely: perceived illness threat (items 2,4,5,10,11,12), perceived barriers to abstinence (items 6,7), medical motivation (8,14,17) and perceived control over illness (Item 9). Two items were included to examine beliefs regarding causal attribution for liver disease. Only 14 of the 22 items were included in the questionnaire as some appeared to be irrelevant to this patient population or were duplicates.

Depression Anxiety Stress Scales (DASS-21)

The Depression Anxiety Stress Scales (DASS) was originally developed by Lovibond & Lovibond [36] consisting of a 42-item self-report questionnaire designed to be a valid and reliable measure of three dimensions of negative emotional states namely: depression, anxiety and stress/tension. Participants were asked to rate the extent to which they had experienced each symptom for the previous week on a four point Likert scale ranging from 0 to 3. The original DASS 42-item has been reported to be a psychometrically sound instrument with high internal consistency [37], good convergent and discriminant validity [36], test-retest reliability [38], a replicable three-factor structure [38-39].

The DASS-21 [36] is a short-form of the DASS in which each of the three subscales contain
seven (rather than 14) items. This instrument has been widely used Australian population norms have been published allowing results to be reported against a normal range. DASS-21 was chosen for its brevity, sound psychometric properties and most importantly as it discriminates between anxiety and depression disorders amongst both clinical and non clinical populations. It has a number of advantages over the full-length version. It is less time consuming. The items retained from the full-length version are generally superior to those not present and as a result it has a cleaner factor structure. The downside is that, although the DASS-21 has high reliability, its reliability is a little lower than that of the full-length DASS [39]. There appears to be a ceiling effect limiting the capturing of symptoms indicative of severe depression limiting assessment of ‘pure’ cases of depression involving vegetative symptoms and suicidal ideation [37]. Antony [40] compared the two instruments and reported high Cronbach alphas for both scales. Cronhach’s alpha is used as an estimate of the reliability of a psychometric test.

**Quality of Life Index (QLI)**

The Quality of Life Index (QLI) was developed by Ferrans and Powers [41-42] was chosen to measure subjective quality of life in terms of satisfaction with a number of life domains. The QLI is a self-report scale where the scales (satisfaction and importance) are on a 6-point Likert scale, ranging from 1, very dissatisfied (very unimportant), to 6, very satisfied (very important). Respondents are asked first to rate their satisfaction followed by importance for in 4 major life domains: health and functioning, psychological/spiritual, social and economic, and family. Importance ratings are weighted against satisfaction responses so that the respondent’s subjective satisfaction with their life can be determined. Five scores are generated consisting of a total score and the 4 domains each giving a score from 0 to 30. General population data are available for research interpretive purposes. The QLI is a well-established instrument with sufficient evidence of reliability, validity and sensitivity and has been utilized in more than 200 published studies [43] [41].

**High-Risk Alcoholism Relapse Scale (HRAR)**

The High Risk Alcoholism Relapse (HRAR) [44] is a scale comprising of three items: duration in
years of heavy drinking, usual number of daily drinks and the number of prior alcoholism inpatient treatments. Each item can be scored between 0 and 2 for a total possible score ranging from 0 to 6. Subjects scoring between 0 and 2 are considered a low risk for relapse, 3 to 4 at medium risk and 5 to 6 at high risk for relapse.

The scale was developed from a study of relapse following in-patient alcoholism treatment in a cohort of male US veterans who were asked to rate the risk of alcohol relapse after alcohol rehabilitation [44-45]. The HRAR scale identified 107 (35.8%) alcoholics at high-risk for relapse prior to discharge. Of the HRAR group 61% were re-admitted within 6 months compared to 28% of the low-risk alcoholism relapse (LAR) group (OR = 4.0, 95% CI = 2.4-6.8). The HRAR was found to have predictive validity for early relapse in the first 6 months after treatment with a sensitivity of 69% and a specificity of 65% The items in the HRAR were derived from a Cox proportional hazards model that used alcoholism severity variables present at the index treatment [44]. Another study by Yates [46] also found a high correlation between HRAR scores and duration of sobriety. Recently De Gottardi [47] used the HRAR to test 387 patients who underwent liver transplantation for alcohol cirrhosis and found a HRAR score higher than 3 (P=.001) as one of the predictors of relapse. The HRAR is the only standardized instrument developed to assess risk for alcohol relapse in this population. One of the advantages of the questionnaires is that it did not require subject involvement being derived from the data supplied by other study measures.

Help seeking

A help seeking questionnaire was developed based on issues raised in the literature concerning barriers to and factors contributing to treatment resistance taking into account patient-program factors. There were no suitable measures for this patient population in the literature. This survey consisted of nine items where participants were asked to rate their confidence about seeking help for alcohol related matters from staff. Participants were asked to rate on a Likert scale of 1 to 7 to what degree they would endorse each item where 1 = disagree strongly and 7 = agree strongly. The 9 items included: how comfortable they felt about discussing alcohol related matters, whether staff would be disappointed or see them as a failure for drinking, whether they would be embarrassed to disclose alcohol use with staff, whether treatment would be altered by disclosure of alcohol problems, whether staff encourage candour and their perception of staff support. They were also asked about how much they wanted alcohol treatment. To interpret the results of the
survey a scoring system was constructed whereby items 2, 3, 4, 5 and 9 were reversed scored therefore providing a means of generating a total scores. The survey’s reliability as psychometric measure were investigated and a Cronbach’s alpha of 0.74 was identified suggesting good internal reliability of the survey.

Data management and statistical analysis

Data were analyzed using Statistical Package for the Social Sciences (SPSS 2006 ) for Windows (Version 15.0). Matched cases were compared with controls. ESALD transplant candidates were compared with non-ESALD treatment seekers on a number of variables. Missing data, involving 3 questionnaires for two participants, was indicated using a user-defined method whereby missing values were given numeric value which was defined as missing for SPSS.

In order to identify the factors contributing to treatment resistance by ESALD transplant patients to specialist alcohol services a comprehensive examination and comparison with alcohol treatment seekers was required. Comparisons across the samples were made using chi-square analyses, ANOVA and Paired Samples T Test. Chi-Square (χ²) tests were used for categorical independent variables. Significant mean group differences for parametric variables were analysed using one-way analysis of variance (ANOVA) statistical procedures. Analysis of variance was used for comparison of continuous normally distributed variables. Continuous variables are presented as the mean, standard deviation (SD) and categorical variables are presented as proportions. Cohen’s d standardized measure of effect size was utilized to compare the means and the strength of the relationship between two variables. Box plots provided visual presentation of the data and were also utilized to determine whether an association exists. The Paired Samples T Test was used to compare the means of two variables to see if the average difference is significantly different from zero. For all statistical analyses reported, the alpha was set at p<.05, unless otherwise indicated. All tests performed were two-tailed.
References


This study sought to identify the reasons for and barriers to the use of alcohol treatment by ESALD transplant patients. The results are presented in relation to the two hypotheses. The first hypothesis was that ESALD transplant patients do not participate in alcohol treatment as they see no need for treatment. The second hypothesis was that ESALD transplant patients tend to not seek professional help from transplant staff for alcohol related issues. The final section of the chapter provides the results of an exploratory data and analysis investigating who amongst ESALD transplant patients may need alcohol treatment.

**Participants**

The study participants consisted of 40 end-stage alcoholic liver disease (ESALD) transplant patients and 40 alcohol treatment seekers (ATS). The ESALD group comprised of 16 (40%) pre-transplant patients and 24 (60%) post-transplant patients. The ATS group consisted of 40 subjects from three alcohol treatment sites: 24 (60%) outpatient counselling service, 8 (20%) inpatient detoxification unit and 8 (20%) from two residential rehabilitation programs. The majority of ATS were interviewed within the first week or month of commencing treatment. For the ATS group the primary reasons for entering treatment include 15 (37.5%) due to mental health issues (depression), 11 (27.5%) life stress (including relationships), 7 (17.5%) legal (DUI), 4 (10%) dependence and 3 (7.5%) work issues.

**Hypothesis 1**

ESALD transplant patients differ from ATS and they do not perceive the need for specialty alcohol treatment nor are they well matched to standard interventions. These groups were expected to differ on length of abstinence, alcohol severity (lifetime drinking history, diagnosis, severity of dependence, alcohol related consequences, risk of relapse). It was also hypothesized that they were also likely to have a progressive readiness to change profile and
health beliefs supportive of behavioural change. Also ESALD were expected to have less past substance abuse, less psychiatric co-morbidity, better quality of life, different demographic profile, and less likely to have utilized specialty substance abuse treatment in the past. The results for each of these clinical variables will be present as follows.

**Current alcohol use**

The majority of ESALD group reported being abstinent and had been so for a longer period of time compared to ATS who were more likely to be drinking at harmful levels (Table 6.1).

**Table 6.1. Baseline measures of alcohol use**

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS (n=40)</th>
<th>Statistical Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number abstinent since</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>commencing treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any use*</td>
<td>28 (70%)</td>
<td>22 (55%)</td>
<td>( \chi^2 (1) = 7.0 )</td>
<td>0.008</td>
</tr>
<tr>
<td></td>
<td>33 (83%)</td>
<td></td>
<td></td>
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<tr>
<td>Abstinence since</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>commencing treatment</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Pre-Transplant</td>
<td>9.1 months (7.8 months)</td>
<td>9 weeks (20 weeks)</td>
<td>( F(1,79) = 0.18 )</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Post-Transplant</td>
<td>4.1 years (4.4 years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent harmful</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking</td>
<td>7 (18%)</td>
<td>18 (45%)</td>
<td>( \chi^2 (1) = 10.3 )</td>
<td>0.001</td>
</tr>
<tr>
<td>(( \geq 140g ) ethanol/week)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number with past</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>abstinence period prior</td>
<td>11 (27.5%)</td>
<td>22 (55%)</td>
<td>( \chi^2 (1) = 6.2 )</td>
<td>0.021</td>
</tr>
<tr>
<td>to treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Commencement of treatment for the ESALD group was defined as participating in the liver transplant program while for ATS it was the commencement of alcohol treatment. Abstinence included nil alcohol use or occasional infrequent drinking no more than 2 standard drinks on any one occasion as recommended by the transplant program. ** For continuous variables, P values were derived from one way ANOVA test for comparing mean values between groups. For categorical variables P values were derived from \( \chi^2 \) Square test.
Liver function tests

Liver function tests at baseline for pre-transplant ESALD were abnormal for total bilirubin, GGT, ALT, AST, INR along with low platelet counts (Table 6.2). LFTs were normal or near normal for ATS due to the selection criteria for this study which excluded any significant liver disease. ESALD post-transplant patients were just within the normal high range on all liver function tests except for GGT. However GGT values fell to normal range when LFT for relapers were removed showing no difference in LFT with ATS. As a group ATS had fewer subjects with positive Hepatitis C than the ESALD group however the latter was most likely due to opportunistic recruitment practice with ATS.
Table 6.2. Liver Function tests in Pre- and Post- ESALD transplant patients, ATS, ESALD post-transplant abstainers and relapers

<table>
<thead>
<tr>
<th>ESALD Transplant group</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>ATS (n=40)</td>
<td></td>
</tr>
<tr>
<td>Pre-Transplant (n=16)</td>
<td></td>
</tr>
<tr>
<td>Post-Transplant (n=24)</td>
<td></td>
</tr>
<tr>
<td>P/T Abstainers (n= 17 )</td>
<td></td>
</tr>
<tr>
<td>P/T Relapers (n= 7)</td>
<td></td>
</tr>
<tr>
<td>Pre/Post transplant</td>
<td></td>
</tr>
<tr>
<td>Abstainers/Relapers</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Serum albumin (g/L)</th>
<th>Total bilirubin (umol/L)</th>
<th>ALP (U/L)</th>
<th>GGT (U/L)</th>
<th>ALT (U/L)</th>
<th>AST (U/L)</th>
<th>Platelets (x10^9/L)</th>
<th>INR</th>
<th>HCV Seropositive</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATS</td>
<td>41.9 (9.9)</td>
<td>10.1 (8.8)</td>
<td>73.2 (27.2)</td>
<td>57.5 (55.3)</td>
<td>33.9 (34.6)</td>
<td>65 (16.4)</td>
<td>226.6(113)</td>
<td>0.94 (0.22)</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>Pre-Transplant</td>
<td>36.1 (6.5)</td>
<td>29.1 (22.2)</td>
<td>153.3 (126.9)</td>
<td>130.3 (117.4)</td>
<td>125.6 (159.6)</td>
<td>106.1 (114.9)</td>
<td>98.9 (42.6)</td>
<td>1.5 (0.4)</td>
<td>8 (50%)</td>
</tr>
<tr>
<td>Post-Transplant</td>
<td>39.5 (9.9)</td>
<td>12.4 (8.8)</td>
<td>129.6 (93.8)</td>
<td>123.5 (170.3)</td>
<td>50 (44.8)</td>
<td>48.1 (34.4)</td>
<td>180.5 (76.4)</td>
<td>1.1 (0.18)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>P/T Abstainers</td>
<td>38.9 (10.8)</td>
<td>12.3 (9.6)</td>
<td>127.8 (100.4)</td>
<td>63.9 (46.3)</td>
<td>43.1 (48)</td>
<td>38.5 (24.9)</td>
<td>204.4 (71.4)</td>
<td>1.0 (0.1)</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>P/T Relapers</td>
<td>41 (7.70)</td>
<td>12.6 (7.1)</td>
<td>134 (82.3)</td>
<td>268 (266.4)</td>
<td>66.7 (33)</td>
<td>71.4 (44.3)</td>
<td>122.4 (56.6)</td>
<td>1.2 (0.3)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Pre/Post transplant</td>
<td>0.06</td>
<td>&lt;0.001**</td>
<td>0.34</td>
<td>0.878</td>
<td>0.226</td>
<td>0.088</td>
<td>&lt;0.001**</td>
<td>0.088</td>
<td>0.02*</td>
</tr>
<tr>
<td>Abstainers/Relapers</td>
<td>0.542</td>
<td>0.524</td>
<td>0.829</td>
<td>0.002 **</td>
<td>0.813</td>
<td>0.482</td>
<td>0.173</td>
<td>0.79</td>
<td>0.020</td>
</tr>
</tbody>
</table>

*PT= Post transplant * For continuous variables, P values were derived from one way ANOVA test for comparing mean values between groups. For categorical variables P values were derived from $\chi^2$ Square test.
Past alcohol consumption

The Lifetime Drinking History questionnaire showed that ESALD transplant subjects had lower past alcohol consumption (lifetime drinking total, daily average, average per drinking day and fewer years of heavy drinking) than the ATS group (Table 6.3).

There were no clear trends or differences between the two groups in relation to the volume variability, duration of overall drinking in years, the type of alcohol consumed and style of drinking. For the ESALD group alcohol consumption was significantly influenced or associated with peer pressure and social events while ATS were more likely to drink in response to emotions and stressors (Table 6.3). There were no significant differences between the two groups regarding the drinking context or time of drinking.
Table 6.3. Past alcohol use based on Lifetime Drinking History (LDH)

<table>
<thead>
<tr>
<th>Quantity</th>
<th>ESALD (n=40) Mean (SD) or n (%)</th>
<th>ATS (n=40) Mean (SD) or n (%)</th>
<th>Statistical Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Drinking total (kg/ kg body weight)</strong></td>
<td>12.8 (7.7)</td>
<td>19.9 (16.7)</td>
<td>F(1,78)= 6.1</td>
<td>0.016</td>
</tr>
<tr>
<td><strong>Duration lifetime drinking (years)</strong></td>
<td>32.7 (6.5)</td>
<td>35.5 (80.1)</td>
<td>F(1,78)=2.9</td>
<td>0.088</td>
</tr>
<tr>
<td><strong>Duration of heavy drinking (years)</strong></td>
<td>25.1 (8.8)</td>
<td>30.6 (12.4)</td>
<td>F(1,78) =5</td>
<td>0.027</td>
</tr>
<tr>
<td><strong>Daily average (g/kg body weight)</strong></td>
<td>1.10 (0.7)</td>
<td>1.5 (1.0)</td>
<td>F(1,78)=4.2</td>
<td>0.043</td>
</tr>
<tr>
<td><strong>Average per drinking day (kg body weight)</strong></td>
<td>1.25 (0.7)</td>
<td>2.2 (1.7)</td>
<td>F(1,78)=11.3</td>
<td>0.001</td>
</tr>
<tr>
<td><strong>Volume variability</strong></td>
<td>5.2 (3.5)</td>
<td>5.3 (4.3)</td>
<td>F(1,78) =0.2</td>
<td>0.887</td>
</tr>
<tr>
<td><strong>Type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beer</td>
<td>56.3% (34.3)</td>
<td>54.6 % (37.9)</td>
<td>F(1,78)= .04</td>
<td>0.829</td>
</tr>
<tr>
<td>Spirits</td>
<td>14.8% (16.2)</td>
<td>17.3%  (20.5)</td>
<td>F(1,78)=3.6</td>
<td>0.546</td>
</tr>
<tr>
<td>Wine</td>
<td>28.9% (31.1)</td>
<td>28.3% (34.7)</td>
<td>F(1,78)=.007</td>
<td>0.933</td>
</tr>
<tr>
<td><strong>Style</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasional</td>
<td>4.8% (12.4)</td>
<td>1.8%  (7.7)</td>
<td>F(1,78)=0.69</td>
<td>0.198</td>
</tr>
<tr>
<td>Weekend</td>
<td>4.9%  (9.2)</td>
<td>3.7%  (8.7)</td>
<td>F(1,78)=0.38</td>
<td>0.538</td>
</tr>
<tr>
<td><strong>Life Events</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peers</td>
<td>45.8% (27.5)</td>
<td>28.5% (19.7)</td>
<td>F(1,78)=10.5</td>
<td>0.002</td>
</tr>
<tr>
<td>Work</td>
<td>17.9% (20.1)</td>
<td>12.6% (17.1)</td>
<td>F(1,78) = 1.6</td>
<td>0.215</td>
</tr>
<tr>
<td>Family</td>
<td>13.4% (17.3)</td>
<td>13.7% (17.2)</td>
<td>F(1,78) =0.006</td>
<td>0.938</td>
</tr>
<tr>
<td>Emotion/Stress</td>
<td>11.6% (13.4)</td>
<td>30.2% (20.7)</td>
<td>F(1,78) = 22.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Drug use</td>
<td>6.3% (13.9)</td>
<td>6.7%  (20.7)</td>
<td>F(1,78) = 0.15</td>
<td>0.903</td>
</tr>
<tr>
<td>Other</td>
<td>1.9% (5.1)</td>
<td>7.4%  (12.4)</td>
<td>F(1,78) = 6.7</td>
<td>0.012</td>
</tr>
<tr>
<td><strong>Context</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>20.8% (20.9)</td>
<td>26.6 (20.9)</td>
<td>F(1,78)= 1.5</td>
<td>0.232</td>
</tr>
<tr>
<td>Others</td>
<td>79.2% (20.9)</td>
<td>73.9(21.7)</td>
<td>F(1,78)=1.2</td>
<td>0.280</td>
</tr>
<tr>
<td><strong>Time</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morning</td>
<td>6.8% (22.1)</td>
<td>9.5 (16.1)</td>
<td>F(1,78) = 0.50</td>
<td>0.233</td>
</tr>
<tr>
<td>Afternoon</td>
<td>29.5% (24.8)</td>
<td>28.6 (21.2)</td>
<td>F(1,78) = 0.59</td>
<td>0.823</td>
</tr>
<tr>
<td>Evening</td>
<td>63.5% (8.8)</td>
<td>59.5 (12.4)</td>
<td>F(1,78) = 5.1</td>
<td>0.446</td>
</tr>
</tbody>
</table>

% refers to the percentage of time that drinking was associated with specific life events
Past alcohol severity

The ESALD group had a significantly lower alcohol problem severity compared with ATS (Table 6.4). The SCID 1 interview schedule used to measure retrospective diagnosis (at the time when drinking was considered to be a problem) found fewer of the ESALD group had a diagnosis of alcohol dependence. Also the ESALD group had fewer symptoms of dependence compared to ATS. ESALD also had less severe alcohol dependence than ATS based on SADD scores. They also had fewer negative consequences as a result of alcohol use using the SIP measure in the areas of social responsibility, impulse control, interpersonal and intrapersonal experiences. However negative consequences of alcohol use in terms of physical health were no different between the groups. No differences were found in terms of familial alcoholism.

Table 6.4. Past alcohol dependence

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS (n=40)</th>
<th>Statistical Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCID Alcohol diagnosis</td>
<td></td>
<td></td>
<td>F or χ²</td>
<td></td>
</tr>
<tr>
<td>Dependence</td>
<td>23 (58%)</td>
<td>35 (88%)</td>
<td>χ² (2) = 10.04</td>
<td>0.007</td>
</tr>
<tr>
<td>Abuse</td>
<td>13 (33%)</td>
<td>5 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No diagnosis</td>
<td>4 (10%)</td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCID Number of symptoms</td>
<td>3.7 (2.5)</td>
<td>5.5 (2.0)</td>
<td>F(1,78) = 13.2</td>
<td>0.001</td>
</tr>
<tr>
<td>SADD</td>
<td>13.9 (11.2)</td>
<td>22.8 (10.5)</td>
<td>F(1,78) = 13.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>SIP-2R</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>4.9 (2.9)</td>
<td>6.0 (2.8)</td>
<td>F(1,78) = 3.34</td>
<td>0.071</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>4.0 (3.2)</td>
<td>5.5 (2.7)</td>
<td>F(1,78) = 4.91</td>
<td>0.030</td>
</tr>
<tr>
<td>Intrapersonal</td>
<td>4.0 (3.2)</td>
<td>5.8 (2.8)</td>
<td>F(1,78) = 7.05</td>
<td>0.010</td>
</tr>
<tr>
<td>Impulse control</td>
<td>3.4 (2.8)</td>
<td>6.3 (2.5)</td>
<td>F(1,78) = 24.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Social responsibility</td>
<td>4.0 (3.1)</td>
<td>5.5 (2.9)</td>
<td>F(1,78) = 5.10</td>
<td>0.027</td>
</tr>
<tr>
<td>Total Score</td>
<td>20.2 (13.6)</td>
<td>29.0 (11.4)</td>
<td>F(1,78) = 9.77</td>
<td>0.002</td>
</tr>
</tbody>
</table>

SCID 1 - Structured Clinical Interview for DSM IV, SADD- Short Alcohol Dependence Data, SIP
Risk of relapse

The risk of relapse derived from the High Risk Alcoholism Relapse Scale (HRAR) showed the ESALD group having a significantly lower risk of relapse 3.4 (S.D =1.3) (p value = 0.034). and ATS having a mean score of 4 (S.D = 1.4). A closer evaluation of HRAR scores based on low risk = 0-2, medium risk 3-4 and high risk 5-6 [1] are illustrated in Figure 6.1 revealing that the majority of ESALD transplant subjects showed a medium risk of relapse while most ATS had a high risk of relapse.

Figure 6.1. Risk of relapse based on High-Risk Alcoholism Relapse (HRAR) score comparing ESALD and ATS groups.

<table>
<thead>
<tr>
<th>Degree of Risk</th>
<th>ATS</th>
<th>ESALD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low risk</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Medium risk</td>
<td>17</td>
<td>22</td>
</tr>
<tr>
<td>High risk</td>
<td>16</td>
<td>13</td>
</tr>
</tbody>
</table>

Readiness to change

Readiness to change is one of the most significant factors contributing to a change in alcohol consumption and is strongly associated with the need or participation in treatment. The SOCRATES measure was used retrospectively (at the time of problematic drinking) and at current (baseline) to develop a stage of change profile in order to assess readiness to change for both groups overtime (Table 6.5). In the past ESALD transplant subjects reported lower Problem Recognition than ATS but no difference in their Ambivalence or
Taking Steps. At baseline ESALD were equivalent to ATS in Problem Recognition and Taking Steps however their Ambivalence had decreased significantly.

**Table 6.5.** Past and current readiness to change SOCRATES scores

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS (n=40)</th>
<th>Statistical Test</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socrates (Past)</strong></td>
<td></td>
<td></td>
<td>F</td>
<td>p value</td>
</tr>
<tr>
<td>Problem Recognition</td>
<td>21.3 (8.3)</td>
<td>27.0 (8.1)</td>
<td>F(1,79) = 9.44</td>
<td>0.003</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>15.8 (7.2)</td>
<td>14.2 (4.8)</td>
<td>F(1,79)= 1.42</td>
<td>0.238</td>
</tr>
<tr>
<td>Taking Steps</td>
<td>18.3 (8.2)</td>
<td>21.4 (8.3)</td>
<td>F(1,79) = 2.74</td>
<td>0.102</td>
</tr>
<tr>
<td><strong>Socrates (Current)</strong></td>
<td></td>
<td></td>
<td>F</td>
<td>p value</td>
</tr>
<tr>
<td>Problem Recognition</td>
<td>27.0 (9.2)</td>
<td>28.8 (7.4)</td>
<td>F(1,79)= 0.90</td>
<td>0.346</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>10.8 (4.7)</td>
<td>15.5 (4.8)</td>
<td>F(1,78)=20.2</td>
<td>0.000</td>
</tr>
<tr>
<td>Taking Steps</td>
<td>33.8 (8.3)</td>
<td>33.8 (8.2)</td>
<td>F(1,79) =0.16</td>
<td>0.694</td>
</tr>
</tbody>
</table>

* Retrospective account referring to time when drinking was perceived as a problem

** Current account at the time of interview

A paired Sample T-test comparing past and present readiness to change using the SOCRATES was used to develop stages of change profile in order measure what changes in the subscales had occurred over time (Table 6.6, Figure 2). The ESALD group had a progressive readiness to change profile from the time of problematic drinking to their current participation in a liver transplant program. There were significant change on all SOCRATES subscales with an increase in Problem recognition, decrease in Ambivalence and increase in Taking Steps since the time of their problematic drinking. ATS on the other hand only showed a change in Taking Steps since the time of problematic drinking and current participation in treatment.
### Table 6.6. Paired Samples T-test showing Past and Current SOCRATES Scores

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Past Score Mean (SD)</td>
<td>Current Mean (SD)</td>
</tr>
<tr>
<td>Problem Recognition</td>
<td>21.3 (8.3)</td>
<td>27.0 (9.2)</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>15.8 (7.2)</td>
<td>10.8 (4.7)</td>
</tr>
<tr>
<td>Taking Steps</td>
<td>18.3 (8.2)</td>
<td>33.8 (8.3)</td>
</tr>
</tbody>
</table>

**Figure 6.2.** Past and Current SOCRATES scales for the ESALD group and ATS group
Health beliefs

The health beliefs model predicts that individuals are likely to change their behaviour if they perceive certain health behaviours to be a threat, perceive benefits of and minimal barriers with respects to behavioural change. A questionnaire by Cockburn [2] which standardized the measurement of the components of the health belief model showed that the ESALD group and ATS had equivalent and high scores on perceived illness threat, alcohol as causative in liver disease and medical motivation (Table 6.7). Therefore both groups acknowledged the risks to healthy liver functioning as a result of alcohol consumption and the benefits of adhering to or considering medical advice. The ESALD group perceived fewer barriers to abstinence and a greater sense of control over cravings and alcohol related behaviour than ATS.

Table 6.7. Health Beliefs

<table>
<thead>
<tr>
<th>Health Belief</th>
<th>ESALD (n=40) Mean (SD)</th>
<th>ATS (n=40) Mean (SD)</th>
<th>Statistical Test F</th>
<th>Significance p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness threat</td>
<td>41.9 (11.6)</td>
<td>43.5 (10.2)</td>
<td>F(1,79) = 0.43</td>
<td>0.514</td>
</tr>
<tr>
<td>Barriers to Abstinence</td>
<td>3.7 (3.1)</td>
<td>6.7 (4.1)</td>
<td>F(1,79) = 13.45</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Medical Motivation</td>
<td>16.7 (5.5)</td>
<td>17.4 (4.4)</td>
<td>F(1,79) = 0.42</td>
<td>0.517</td>
</tr>
<tr>
<td>Control</td>
<td>5.8 (2.1)</td>
<td>4.8 (2.0)</td>
<td>F(1,79) = 5.11</td>
<td>0.027</td>
</tr>
<tr>
<td>Causation</td>
<td>12.3 (3.4)</td>
<td>12.1 (2.9)</td>
<td>F(1,79) = 0.283</td>
<td>0.596</td>
</tr>
</tbody>
</table>

Past substance abuse

There were no significant difference between the groups regarding the number of subjects who had never used cannabis, heroin, methadone, benzodiazepines, amphetamines, cocaine and ecstasy or had a problem with those substances (Table 6.8). No differences were found between the groups on IVDU.
Table 6.8. Past history of no substance abuse problems

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS (n=40)</th>
<th>Statistical Test</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannabis</td>
<td>33 (83%)</td>
<td>31 (78%)</td>
<td>$\chi^2(1) = 1.0$</td>
<td>0.31</td>
</tr>
<tr>
<td>Heroin</td>
<td>30 (75%)</td>
<td>34 (85%)</td>
<td>$\chi^2(1) = 1.5$</td>
<td>0.22</td>
</tr>
<tr>
<td>Methadone</td>
<td>38 (95%)</td>
<td>38 (95%)</td>
<td>$\chi^2(1) = .033$</td>
<td>0.96</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>37 (93%)</td>
<td>38 (95%)</td>
<td>$\chi^2(1) = 0.27$</td>
<td>0.60</td>
</tr>
<tr>
<td>Amphetamines</td>
<td>36 (90%)</td>
<td>34 (85%)</td>
<td>$\chi^2(1) = 97$</td>
<td>0.70</td>
</tr>
<tr>
<td>Cocaine</td>
<td>38 (95%)</td>
<td>37 (93%)</td>
<td>$\chi^2(2) = 1.63$</td>
<td>0.34</td>
</tr>
<tr>
<td>Ecstasy</td>
<td>40 (100%)</td>
<td>37 (92.5%)</td>
<td>$\chi^2(1) = 3.12$</td>
<td>0.09</td>
</tr>
<tr>
<td>IVDU</td>
<td>10 (25%)</td>
<td>7 (17.5%)</td>
<td>$\chi^2(1) = 0.67$</td>
<td>0.41</td>
</tr>
</tbody>
</table>

Psychiatric co-morbidity and Quality of life

The ESALD group were significantly less likely to have had a past history of mental health problems or to have utilized formal mental health treatment. Also the ESALD group showed significantly lower DASS scores on the anxiety, depression and stress subscales (Table 6.9). They also showed fewer severe or extremely severe ratings on all these scales. DASS scores for the ESALD group were equivalent to normative data.
derived from a number of Australian samples [3]. Quality of life using the Quality of Life Index measure was significantly higher for the ESALD group than the ATS especially in the socio-economic, psychological/spiritual and health function domains (Table 6.9). The total quality of life score, psychological/spiritual, socio-economic domains for the ESALD group was close to that found amongst the general population.

**Table 6.9. Psychiatric history, DASS and QLI scores**

<table>
<thead>
<tr>
<th></th>
<th>ESALD(n=40) Mean (SD) or n (%)</th>
<th>ATS(n=40) Mean (SD) or n (%)</th>
<th>Statistical Test F or χ²</th>
<th>Significance p value</th>
<th>Healthy Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis of mental disorder (past or present)</td>
<td>9 (23%)</td>
<td>30 (75%)</td>
<td>χ²(1) = 22.06</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>DASS Total Score</td>
<td>17.8 (19.5)</td>
<td>46.2 (33)</td>
<td>F(1,78) = 23.1</td>
<td>&lt;0.001</td>
<td>6.34 (6.97)</td>
</tr>
<tr>
<td>Depression</td>
<td>5.6 (6.5)</td>
<td>16.7 (13.6)</td>
<td>F(1,78) = 21.8</td>
<td>&lt;0.001</td>
<td>4.7 (4.91)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>3.9 (6.5)</td>
<td>12.2 (9.3)</td>
<td>F(1,78) = 21.0</td>
<td>&lt;0.001</td>
<td>10.11 (7.91)</td>
</tr>
<tr>
<td>Stress Score</td>
<td>7.9 (8.9)</td>
<td>17.3 (11.8)</td>
<td>F(1,78) = 16.0</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Quality of Life (QLI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Function</td>
<td>21.8 (3.8)</td>
<td>18.4 (6.2)</td>
<td>F(1,78) = 8.27</td>
<td>0.005</td>
<td>23.19 (4.47)</td>
</tr>
<tr>
<td>Socio-economic</td>
<td>22.1 (4.3)</td>
<td>18.7 (5.6)</td>
<td>F(1,78) = 9.30</td>
<td>0.003</td>
<td>21.83 (4.11)</td>
</tr>
<tr>
<td>Psychological/spiritual</td>
<td>22.2 (5.0)</td>
<td>17.1 (7.2)</td>
<td>F(1,78) = 12.45</td>
<td>0.001</td>
<td>22.95 (5.21)</td>
</tr>
<tr>
<td>Family</td>
<td>23.4 (5.7)</td>
<td>21.1 (6.5)</td>
<td>F(1,78) = 2.86</td>
<td>0.095</td>
<td>25.60 (4.49)</td>
</tr>
<tr>
<td>Total Score</td>
<td>22.1 (3.5)</td>
<td>18.5 (5.5)</td>
<td>F(1,78) = 11.57</td>
<td>0.001</td>
<td>23.0 (4.49)</td>
</tr>
</tbody>
</table>

**Demographic Factors**

The following section provides the findings for gender, age, marital status, education, social support network, and prior treatment at baseline for both groups. These variables have been associated with alcohol treatment.
Demographic characteristics of both ESALD and ATS at the time of the interview are presented in Table 6.10. The ESALD group were significantly more likely to be married and perceived themselves as having good general and abstinence social support consisting of family and friends who support their abstinence. They were also more likely to have stable housing in the last 2 years, and to be unemployed at the time of the interview. There were no differences between the groups on education.

### Table 6.10. Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>ESALD(n=40)</th>
<th>ATS(n=40)</th>
<th>Statistical Test</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) or n (%)</td>
<td>Mean (SD) or n (%)</td>
<td>F or $\chi^2$</td>
<td></td>
</tr>
<tr>
<td>Age at interview</td>
<td>57 (5.9)</td>
<td>55 (6.2)</td>
<td>F(1,78)= 4.3</td>
<td>0.042</td>
</tr>
<tr>
<td>Gender (Males)</td>
<td>34 (85%)</td>
<td>34 (85%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/De facto</td>
<td>25 (64%)</td>
<td>12 (30%)</td>
<td>$\chi^2$(1) = 9.22</td>
<td>0.002</td>
</tr>
<tr>
<td>Perceived social support</td>
<td>36 (85%)</td>
<td>5(38%)</td>
<td>$\chi^2$(1)= 23.85</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Employed at interview</td>
<td>13 (33%)</td>
<td>23(58%)</td>
<td>$\chi^2$(1 )= 5.05</td>
<td>0.025</td>
</tr>
<tr>
<td>Housing stability (≥ 2 years)</td>
<td>38 (95%)</td>
<td>26 (65%)</td>
<td>$\chi^2$(1)= 11.25</td>
<td>0.001</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤SC</td>
<td>19 (48%)</td>
<td>19 (48%)</td>
<td>$\chi^2$(3)= 0.150</td>
<td>0.985</td>
</tr>
<tr>
<td>≥HSC</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤TAFE</td>
<td>6 (15%)</td>
<td>6 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤University</td>
<td>6 (15%)</td>
<td>7 (18%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9 (23%)</td>
<td>8 (20%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* For continuous variables, P values were derived from one way ANOVA test for comparing mean values between groups. For categorical variables P values were derived from $\chi^2$ Square test.
Prior treatment

The ESALD group was less likely to have had prior treatment contact. ATS were significantly more likely to utilize residential rehabilitation, outpatient counselling services or AA meetings (Table 6.11).

**Table 6.11. Prior substance use treatment**

<table>
<thead>
<tr>
<th></th>
<th>ESALD (n=40)</th>
<th>ATS(n=40)</th>
<th>Statistical Test</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
<td>χ² (1)</td>
<td></td>
</tr>
<tr>
<td>Prior treatment</td>
<td>13 (33%)</td>
<td>30 (75%)</td>
<td>14.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Inpatient detoxification</td>
<td>10 (25%)</td>
<td>18 (45%)</td>
<td>3.5</td>
<td>0.061</td>
</tr>
<tr>
<td>Outpatient detoxification</td>
<td>0 (0%)</td>
<td>7 (18%)</td>
<td>3.1</td>
<td>0.077</td>
</tr>
<tr>
<td>Residential rehabilitation</td>
<td>8 (20%)</td>
<td>18 (45%)</td>
<td>5.7</td>
<td>0.017</td>
</tr>
<tr>
<td>Day Program</td>
<td>0 (0%)</td>
<td>3 (8%)</td>
<td>3.1</td>
<td>0.077</td>
</tr>
<tr>
<td>Outpatient Counselling</td>
<td>4 (10%)</td>
<td>21 (53%)</td>
<td>16.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Alcoholics Anonymous</td>
<td>10 (25%)</td>
<td>17 (43%)</td>
<td>12.1</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

**Hypothesis 2**

The second hypothesis was that ESALD transplant patients are less comfortable with seeking professional help from transplant staff for alcohol related issues compared to those who seek alcohol treatment. Scores on a help-seeking survey revealed significantly higher scores on 6 out of 9 items for the ESALD group (Table 6.12). Each item was scored out of 7; items closer to a score of 7 indicate strong endorsement. The highest total score is 63. ESALD transplant patients were significantly more concerned about disappointing staff, reported being embarrassed about seeking help, did not feel encouraged by staff to discuss alcohol use, perceived less availability of alcohol support from staff; and were less motivated to utilize alcohol treatment if it were available within their treatment setting. These findings suggest that ESALD transplant patients may fear being stigmatized as a result of participating in speciality alcohol treatment programs.
<table>
<thead>
<tr>
<th>Item*</th>
<th>ESALD Mean (SD)</th>
<th>ATS Mean (SD)</th>
<th>T-value</th>
<th>Significance</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel comfortable letting staff know about problems I may be having with alcohol.</td>
<td>6.2 (1.6)</td>
<td>6.5 (1.4)</td>
<td>F(2.77)= 8.15</td>
<td>0.369</td>
<td></td>
</tr>
<tr>
<td>2. Staff would not be disappointed if I was to tell them about problems with drinking</td>
<td>3.2 (2.6)</td>
<td>5.7 (2.2)</td>
<td>F(2.77)=20.97</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>3. I would not be embarrassed to let staff know about any problems with abstinence</td>
<td>4.7 (2.6)</td>
<td>5.9 (2.0)</td>
<td>F(2.77)=5.15</td>
<td>0.026</td>
<td></td>
</tr>
<tr>
<td>4. If I let staff know about problems with alcohol they will not see me as a failure</td>
<td>5.4 (2.5)</td>
<td>5.5 (2.4)</td>
<td>F(2.77)= 2.1</td>
<td>0.129</td>
<td></td>
</tr>
<tr>
<td>5. If I talk about alcohol with staff it will not affect the type of treatment I get.</td>
<td>5.2 (2.7)</td>
<td>6.0 (2.0)</td>
<td>F(2.77) = 0.77</td>
<td>0.383</td>
<td></td>
</tr>
<tr>
<td>6. Staff encourage patients to talk about their alcohol use.</td>
<td>5.2 (2.1)</td>
<td>6.1 (1.6)</td>
<td>F(2.77)=5.06</td>
<td>0.027</td>
<td></td>
</tr>
<tr>
<td>7. Staff have provided help and advice with any alcohol related problems</td>
<td>4.9 (2.3)</td>
<td>6.2 (1.6)</td>
<td>F(2.77)=9.04</td>
<td>0.004</td>
<td></td>
</tr>
<tr>
<td>8. I want alcohol treatment provided by this service</td>
<td>4.4 (2.3)</td>
<td>6.3 (1.7)</td>
<td>F(2.77)=15.49</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>9. There is a staff member available who you can discuss alcohol issues with</td>
<td>5.4 (1.9)</td>
<td>6.5 (1.1)</td>
<td>F(2.77)=10.30</td>
<td>0.002</td>
<td></td>
</tr>
<tr>
<td>Total Scores</td>
<td>42.6 (13.8)</td>
<td>54.6 (11.7)</td>
<td>F(2.77) = 8.7</td>
<td>&lt;0.001</td>
<td></td>
</tr>
</tbody>
</table>

*Some items have been reversed for ease of scoring
Indicators for alcohol treatment amongst ESALD transplant patients

As discussed in the literature review, studies have estimated that between 10% and 25% of ESALD transplant patients will relapse to harmful drinking within two to five years of being transplanted. Relapse occurs despite transplant programs carefully selecting and evaluating potential candidates and a mandatory period of sustained abstinence before being listed. An exploratory analysis was undertaken comparing ESALD transplant patients who relapsed firstly with ESALD transplant abstainers and secondly with ATS. The aim of this analysis was to explore the clinical characteristics of relapsers to determine under what conditions ESALD transplant patients may need treatment and what kind of treatment may be more suitable for this population.

As reported earlier of the 24 post-transplant ESALD participants, 12 (50%) returned to any alcohol use, 5 (21%) drank alcohol in low amounts infrequently while 7 (29%) had relapsed to harmful alcohol use (defined as drinking above 140g ethanol/week for both males and females). Pre-transplant participants were not directly asked about current alcohol use at the time of the interview and no subjects reported any alcohol use at baseline. Due to the small numbers of abstainers and relapsers the following results concerning relapse are only a preliminarily exploration into possible trends regarding the possible need for treatment amongst the ESALD transplant population.

ESALD post-transplant abstainers and relapsers

ESALD post-transplant abstainers were significantly different to ESALD relapers on a number of measures. Abstainers were less likely in the past to have used other substances (heroin, amphetamine, and methadone) whilst they were drinking, more likely to be beer drinkers and to have HCV. Abstainers were more likely to be married. In terms of motivation for change, abstainers had higher scores on past Problem recognition and Ambivalence suggesting that in the past abstainers had higher perceived severity and acknowledgment of their alcohol problem and conflicted about their alcohol use (Figure 6.3). At baseline Abstainers had higher Taking Steps in the high decile range (36.41) with a paired -t test showing a p value of 0.001. In contrast relapers scored in the very low decile (22.71) with a significance of p= 0.03 in a paired t-test [4].
Abstainers perceived drinking as causative in liver disease and as threat to their health. They also perceived themselves as medically motivated and having more control over cravings and drinking behaviour than ATS. No differences existed between the two groups on perceived barriers to abstinence (Figure 6.4). Abstainers had higher quality of life total score particularly in health and family domains (Figure 6.5). There was no statistical significance between the groups on previous history of mental illness or DASS scores.

There were no differences ESALD abstainers and relapers on the total help seeking score except that relapers strongly endorsed they were not comfortable letting staff know about problems they may be having with alcohol related matters and that they did not perceive that staff were available to support them with alcohol related matters (Table 6.13). Relapers were more likely to have used outpatient detoxification or rehabilitation services in the past.
Figure 6.4. Health Beliefs scales for ATS, ESALD post-transplant abstainers and relapsers

Figure 6.5. Quality of life for ESALD post-transplant abstainers and relapsers
ATS and ESALD relapers

ESALD relapers had less past severity of dependence, fewer alcohol related negative consequences, less likely to have alcohol dependence diagnosis and fewer symptoms of alcohol dependence than ATS. They were less likely to drink in response to emotions/stressors but more likely to be influenced by their peers and less likely to drink alone. ESALD relapers were also more likely to have used heroin in the past and less likely to have had a history of mental illness. On the SOCRATES profile (Figure 6.6) ESALD relapers had a lower past Problem Recognition, Ambivalence and Taking Steps scores than ATS. At baseline relapers had lower scores on all the subscales. They had lower Problem Recognition, less Ambivalence and lower Taking Steps scores.

Figure 6.6 Past and Current SOCRATES scores for ATS and ESALD relapers

In terms of Health Beliefs (Figure 6.4) ESALD relapers were less likely to perceive drinking as a threat to their health and as causative in liver disease than ATS. They were also less medically motivated and perceived less control over cravings and their drinking behaviour. There were no differences between ESALD relapers and ATS in terms of housing, presence of partner, IVDU, Hepatitis C, prior treatment history, social support or family history of alcoholism. Quality of life was the same for ESALD relapers and ATS. ATS scored significantly higher on all help seeking items compared with relapers (Table 6.13)
Table 6.13. Help seeking beliefs comparing ESALD abstainer and relapsers and ESALD relapsers and ATS

<table>
<thead>
<tr>
<th>Item</th>
<th>ESALD Abstainers</th>
<th>ESALD Relapsers</th>
<th>ATS</th>
<th>Abstainers and Relapsers</th>
<th>ESALD relapsers and ATS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel comfortable letting staff know about problems I may be having with alcohol.</td>
<td>6.71 (0.59)</td>
<td>3.83 (2.79)</td>
<td>6.5 (1.4)</td>
<td>F(1,23) = 17.3 ** 1.99</td>
<td>F(1,46) = 14.5** 1.65</td>
</tr>
<tr>
<td>2. Staff would not be disappointed if I was to tell them about problems with drinking</td>
<td>3.00 (2.57)</td>
<td>1.71 (1.70)</td>
<td>5.7 (2.2)</td>
<td>F(1,46) = 20.6** 1.91</td>
<td></td>
</tr>
<tr>
<td>3. I would not be embarrassed to let staff know about any problems with abstinence</td>
<td>4.59(2.647)</td>
<td>3.14 (3.07)</td>
<td>5.9 (2.0)</td>
<td>F(1,46) = 9.2* 1.30</td>
<td></td>
</tr>
<tr>
<td>4. If I let staff know about problems with alcohol they will not see me as a failure</td>
<td>4.24 (2.25)</td>
<td>2.43 (2.9)</td>
<td>5.5 (2.4)</td>
<td>F(1,46) = 9.7* 1.27</td>
<td></td>
</tr>
<tr>
<td>5. If I talk about alcohol with staff it will not affect the type of treatment I get.</td>
<td>5.59 (2.32)</td>
<td>4.14 (3.58)</td>
<td>6.0 (2.0)</td>
<td>F(1,46) = 3.5** 1.63</td>
<td></td>
</tr>
<tr>
<td>6. Staff encourage patients to talk about their alcohol use</td>
<td>4.88 (2.18)</td>
<td>3.33 (2.42)</td>
<td>6.1 (1.6)</td>
<td>F(1,46) = 6.1* 1.07</td>
<td></td>
</tr>
<tr>
<td>7. Staff have provided help and advice with any alcohol related problems</td>
<td>4.76 (2.02)</td>
<td>4.33 (2.66)</td>
<td>6.2 (1.6)</td>
<td>F(1,46) = 6.3** 2.31</td>
<td></td>
</tr>
<tr>
<td>8. I want alcohol treatment provided by this service</td>
<td>4.00 (2.09)</td>
<td>2.17 (2.48)</td>
<td>6.3 (1.7)</td>
<td>F(1,46) = 6.3** 2.31</td>
<td></td>
</tr>
<tr>
<td>9. There is a staff member available who you can discuss alcohol issues with</td>
<td>5.47 (1.63)</td>
<td>3.33(2.5)</td>
<td>6.5 (1.1)</td>
<td>F(1,23) = 5.782 *0.32</td>
<td>F(1,46) = 28.3** 2.36</td>
</tr>
<tr>
<td><strong>Total Scores</strong></td>
<td>42.4 (9.83)</td>
<td>38.14(18.3)</td>
<td>54.4(11.7)</td>
<td>F(1,46) = 9.6* 1.34</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.05, **p<0.001
Table 6.14 Severity of alcohol dependence, mental health and stages of change scores amongst ESALD post-transplant abstainers and relapers, ESALD relapers and ATS

<table>
<thead>
<tr>
<th></th>
<th>ESALD Abstainers</th>
<th>ESALD Relapers</th>
<th>ATS</th>
<th>ESALD abstainers and relapers $\chi^2$ Significance or P significance and d value</th>
<th>ESALD relapers and ATS $\chi^2$ Significance or P significance and d value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alcohol Dependence</strong></td>
<td>7 (41%)</td>
<td>3 (43%)</td>
<td>35 (60%)</td>
<td>0.976</td>
<td>0.005</td>
</tr>
<tr>
<td><strong>Number of symptoms</strong></td>
<td>3.2 (2.5)</td>
<td>2.9 (2.4)</td>
<td>5.5 (2.0)</td>
<td>0.774</td>
<td>0.004</td>
</tr>
<tr>
<td><strong>SADD total</strong></td>
<td>13.7 (10.3)</td>
<td>8.4 (7.8)</td>
<td>22.8 (10.5)</td>
<td></td>
<td>** 1.44</td>
</tr>
<tr>
<td><strong>SIP Total</strong></td>
<td>18.7 (11.4)</td>
<td>15.9 (14)</td>
<td>28.98 (11.4)</td>
<td></td>
<td>* 1.14</td>
</tr>
<tr>
<td><strong>DASS Total</strong></td>
<td>17.7 (21.8)</td>
<td>23.4 (23.9)</td>
<td>46.2 (31.9)</td>
<td></td>
<td>* 0.78</td>
</tr>
<tr>
<td><strong>Socrates Retrospective</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem recognition</td>
<td>22.4 (5.0)</td>
<td>13.9 (8.2)</td>
<td>26.95 (8.1)</td>
<td>*1.47</td>
<td>** 1.65</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>15.4 (5.3)</td>
<td>8.7 (4.5)</td>
<td>14.2 (4.8)</td>
<td>*1.35</td>
<td>* 1.19</td>
</tr>
<tr>
<td>Taking steps</td>
<td>18.1 (6.6)</td>
<td>13.9 (9.9)</td>
<td>21.4 (8.3)</td>
<td></td>
<td>* 0.90</td>
</tr>
<tr>
<td><strong>Socrates Baseline</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem recognition</td>
<td>27.2 (9.4)</td>
<td>19.4 (11.8)</td>
<td>28.8 (7.4)</td>
<td></td>
<td>* 1.17</td>
</tr>
<tr>
<td>Ambivalence</td>
<td>12.5 (4.6)</td>
<td>7 (8.4)</td>
<td>15.5 (4.8)</td>
<td>** 1.16</td>
<td></td>
</tr>
<tr>
<td>Taking steps</td>
<td>36.4 (3.6)</td>
<td>22.7 (13.0)</td>
<td>33.8 (8.1)</td>
<td>**1.96</td>
<td>* 1.27</td>
</tr>
</tbody>
</table>

*p<0.05, **p<0.001
Table 6.15  Health beliefs, Quality of life, Partner, HCV, past treatment history and substance use amongst ESALD post-transplant abstainers and relapers, ESALD relapers and ATS

<table>
<thead>
<tr>
<th>Health beliefs</th>
<th>ESALD Abstainers</th>
<th>ESALD Relapers</th>
<th>ATS</th>
<th>ESALD abstainers and relapers $\chi^2$ Significance or P significance and d value</th>
<th>ESALD relapers and ATS $\chi^2$ Significance or P significance and d value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>6.7 (0.59)</td>
<td>2.9  (2.7)</td>
<td>4.6   (1.96)</td>
<td>**2.71</td>
<td>*1.65</td>
</tr>
<tr>
<td>Illness threat</td>
<td>44.8 (5.7)</td>
<td>25.4 (19.1)</td>
<td>43.5 (10.2)</td>
<td>**1.85</td>
<td>**1.57</td>
</tr>
<tr>
<td>Medical motivation</td>
<td>17.7 (3.7)</td>
<td>9.4  (7.9)</td>
<td>17.4  (4.4)</td>
<td>*1.65</td>
<td>**1.63</td>
</tr>
<tr>
<td>Alcohol Causation</td>
<td>12.9 (1.9)</td>
<td>8.3  (5.96)</td>
<td>12.1  (2.9)</td>
<td>*1.37</td>
<td>*1.12</td>
</tr>
<tr>
<td>QOL Total</td>
<td>23.2 (3.3)</td>
<td>19.1 (4.4)</td>
<td>18.5  (5.5)</td>
<td>*1.18</td>
<td></td>
</tr>
<tr>
<td>Partner (%)</td>
<td>72.7</td>
<td>16.7</td>
<td>30</td>
<td>0.008</td>
<td>0.499</td>
</tr>
<tr>
<td>Hepatitis C (%)</td>
<td>11.8</td>
<td>42.9</td>
<td>15</td>
<td>0.020</td>
<td>0.084</td>
</tr>
<tr>
<td>Inpatient detox (%)</td>
<td>5.9</td>
<td>42.9</td>
<td>45</td>
<td>0.027</td>
<td>0.916</td>
</tr>
<tr>
<td>Rehabilitation (%)</td>
<td>5.9</td>
<td>42.9</td>
<td>45</td>
<td>0.027</td>
<td>0.916</td>
</tr>
<tr>
<td>Nil Heroin use (%)</td>
<td>100</td>
<td>42.9</td>
<td>85</td>
<td>0.001</td>
<td>0.012</td>
</tr>
<tr>
<td>Nil Methadone (%)</td>
<td>91</td>
<td>71.4</td>
<td>95</td>
<td>0.021</td>
<td>0.039</td>
</tr>
<tr>
<td>Nil Amphetamines (%)</td>
<td>100</td>
<td>85.7</td>
<td>85</td>
<td>0.004</td>
<td>0.084</td>
</tr>
</tbody>
</table>

*p<0.05, **p<0.001
Conclusion

ESALD transplant patients will not identify nor perceive a need for speciality alcohol treatment due to their lengthy abstinence, a progressive readiness to change profile and constructive health beliefs. ESALD transplant patients are less likely to engage in standard alcohol treatment having a less severe alcohol problem, good social support, better quality of life, less psychological distress and less contact with mental health or substance abuse treatment services. There were no differences between the ESALD group and ATS in perceived physical harm due to alcohol use, a family history of alcoholism, IVDU and past substance use. ESALD transplant patients unlike those in an alcohol treatment setting were less comfortable with reaching out for help from transplant staff which suggests that stigma may be relevant in respects to treatment resistance. Tentative findings suggest that ESALD transplant patients may need treatment if there is deterioration in quality of life, poor social support, changes in health beliefs and motivation. Those with a history of IVDU, prior substance abuse treatment and other substance abuse at the time of drinking may perceive alcohol as not strongly contributing to their liver disease. Unlike ATS, ESALD transplant patients who relapse are less confident about seeking professional help from staff.
References


CHAPTER 7
Case Control Study - Discussion

This chapter provides an overview of the case control study and discusses the results in relation to the previously outlined objectives and hypotheses. The results of the case control study pointed to two reasons why ESALD transplant patients will resist alcohol treatment and confirmed the two hypotheses. Firstly, the majority of ESALD transplant patients do not perceive a need for treatment lacking many of the need and predisposing variables significantly correlated with alcohol treatment seeking. Secondly, ESALD transplant patients, unlike ATS are less comfortable and experience barriers to treatment seeking suggesting a fear of stigma and lack of access to alcohol services. Indications for alcohol treatment for ESALD transplant patients, strengths and limitations of the current study are also discussed.

Absence of need factors

ESALD transplant patients who have achieved a considerable period of abstinence are likely to perceive alcohol treatment as unwarranted and therefore will resist treatment. In this study 70% of ESALD transplant subjects reported abstinence (which included minor infrequent alcohol use) since being diagnosed with ESALD and accepted for liver transplant candidacy (Table 6.2). Weinreib and colleagues in a similar case control study also concluded that ESALD pre-transplant patients who have achieved abstinence will naturally reject established alcohol treatment. In that study ESALD pre-transplant patients had a mean of 36 months abstinence compared with only 20 days in the past month for alcohol treatment seekers [1].

Lengthy periods of abstinence by ESALD transplant patients have been widely reported in the literature. Recently, Di Martini (2010) reported that 54% of post-transplant patients had maintained complete abstinence for nearly four years. Maintenance of long-term abstinence by ESALD transplant patients is not surprising considering selection and evaluation procedures, mandatory abstinence,
monitoring of alcohol use by transplant programs and the patient’s personal motivation to remain abstinent due to a life threatening medical condition.

**Motivation, health beliefs and abstinence**

In order to determine whether poor motivation or readiness to change is a contributing factor to treatment resistance by ESALD transplant patients this study examined past and current SOCRATES subscales. A progressive stages of change profile was found amongst ESALD transplant patients showing an increase in problem recognition, decrease in ambivalence and increase in taking steps. This readiness to change profile suggests that since the time of problematic drinking and on being diagnosed with ESALD, transplant patients had gained awareness of the problems associated with harmful alcohol use, had made behavioural changes to achieve abstinence and experienced little struggle with maintaining change [2].

The results of this study of ESALD subjects showed a low ambivalence score of 10.8 and a high current taking steps score of 33.8 which were very similar to those of Weinreb [3] who found a mean score of 10 for Ambivalence and a Taking Steps score of 36 among pre-transplant subjects. The same profile of low ambivalence and high taking steps has been found amongst abstainers in the PROJECT MATCH study and was associated with alcohol treatment completion, high abstinence self-efficacy, less temptation to drink, greater control and more behavioural change [4]. High action scores amongst medical inpatients with unhealthy alcohol use strongly predicted readiness to change and reduced alcohol consumption [5, 6].

In this study while problem recognition for the ESALD group had increased over time and it was equivalent to the current problem recognition score of ATS, it was a low score. The problem recognition score for ESALD transplant subjects in the current study was 27 which is a low. Weinreb [3] found an even lower problem recognition score of 17. The presence of low problem recognition amongst ESALD transplant subjects despite low ambivalence and high taking step scores suggests that ESALD are behaviourally in the action stage but cognitively in the pre-contemplative or contemplative stage. As discussed in Chapter 3 there have been a few reports of ESALD and ALD patients as being in the pre-contemplative stage despite evidence of abstinence or marked reduced
drinking. This pre-contemplative status has suggested that abstinence by these patients is only due to medical illness, associated with less insight, and raises concerns that their abstinence may not be enduring.

However cognitive processes found to be important in the contemplation stage decrease as behaviour changes. Research evidence has found a reduction in problem recognition among individuals who have made behavioural change due to increasing self-efficacy and no longer requiring maximum awareness of the alcohol problem [4, 7]. Similarly, recent research has found high problem recognition scores to be associated with more severe alcohol consumption and alcohol problems while high scores on Taking action have been found to be the strongest predictor of decrease in drinking [5, 8, 9]. In this study the use of the SOCRATES measure did have limitations as it was observed that some subjects preferred not to endorse items where the word ‘alcoholic’ appeared therefore lowering their problem recognition score. Finally, to be behaviourally in action stage but cognitively in the pre-contemplative stage points to the presence of cognitive dissonance [10]. To maintain abstinence but continue to be pre-contemplative suggests that ESALD patients are able to maintain dissonance in their motivation for change over a number of years. However the increasing tension and discomfort of dissonance motivates people to alter their attitudes, beliefs or behaviours to reduce the discomfort and restore consonance; especially if there is high discrepancy and subsequently higher magnitude of dissonance [11].

The data on health beliefs does suggest that ESALD have sufficient problem recognition. The majority of ESALD subjects acknowledged heavy alcohol use as causative in liver disease, had a sense of illness threat, recognised the importance of medical motivation, and showed greater control and fewer barriers to abstinence. Similarly, a recent study found that 60% of alcohol liver disease patients at their first psychosocial evaluation for transplantation were aware of alcohol toxicity [12].

Together the findings of lengthy abstinence, a progressive SOCRATES profile and constructive health beliefs suggest that ESALD transplant patients who are abstinent have made a genuine change to drinking behaviour and therefore do not require a specialty alcohol treatment intervention. These findings do not support denial and the denial stereotype of ESALD transplant patient as a reason for treatment resistance in the majority of cases. As discussed in Chapter 4, ESALD transplant patients have been observed as being in ‘denial’, having limited insight or awareness of their alcohol problem.
Denial is widely regarded as a prognostic factor for the likelihood of relapse and may jeopardize liver transplant candidacy depending on other factors associated with stable remission from alcohol relapse. There is little in the transplant literature defining, identifying or measuring denial nor is the context where denial manifests (e.g. personal, interpersonal, medical) taken into account. In the transplant field, denial may involve any one or combination of the following mechanisms: the denial of alcohol dependence, denial of the etiology of liver disease or denial of the diagnostic label of alcoholic liver disease. It may also involve denying the need for abstinence, the possibility of relapse or the need for treatment. It may be a defensive reaction to the fear of stigma associated with alcoholism or a reaction to transplant evaluation which may involve direct or confrontational strategies by the clinician. Also as discussed in Chapter 4 patients facing threatening medical illness such as end-stage liver disease will experience a period of denial. According to Travis [15], in the field of gastroenterology, denial can be both adaptive and maladaptive and should not be stigmatized. Denial in the early phase of illness can act to minimize emotional flooding and disturbing cognitions while helping to preserve the individual’s hope of the invincibility of the body and psychological integration [16]. This complexity and issues surrounding denial have yet to be addressed in the literature [17].

A less severe alcohol problem

The need for specialty alcohol treatment is heightened not only by motivation for change but a number of other factors including the severity of the alcohol use disorder. This study found that during the period of problematic drinking ESALD transplant patients had a less severe form of alcoholism than the ATS group. ESALD subjects were less likely to have an alcohol dependence diagnosis, fewer symptoms of dependence, less severity of dependence, lower past alcohol consumption and fewer negative alcohol related consequences.

There is a small body of research investigating the severity of alcohol problems among ESALD transplant patients using standardized addiction measures. The current study’s finding of lower severity of alcohol dependence is consistent with reports amongst those with severe ALD or awaiting transplant evaluation [18-23]. In one of the few studies to use a severity of dependence scale among ESALD transplant patients Gledhill [24] found very low SADQ scores before and after transplantation. In this study the proportion of ESALD patients meeting diagnostic criteria for alcohol
dependence was 58%, a similar percentage found among ALD patients however much lower than the 75% to 80% usually reported using pre-transplant evaluation data [25-27]. Although Kelly and colleagues reported only 32% of their sample as having a diagnosis of dependence based on case notes records of diagnosis of dependence, withdrawal, alcohol seizures or treatment for withdrawal. The disparity of these findings may be due to the retrospective review of dependence at the time of problematic drinking which usually predated medical problems and therefore subjects were less likely to meet the necessary three symptoms to meet the criteria for an alcohol dependence diagnosis.

ESALD transplant subjects had a lower lifetime alcohol consumption with less daily average and average per drinking day (Table 6.3) consistent with studies comparing ALD patients with treatment seekers presented in Chapter 3 [28, 29]. However this finding contrasts with Weinreb [1] who found higher lifetime alcohol consumption and more standard drinkers per drinking day amongst ESALD transplant patients compared with alcohol dependent patients seeking treatment. This study reported an average intake of 6.7 drinks per day for the ATS group and 9.8 drinks per day for ESALD subjects. Other studies have reported around 15 standard drinks for treatment seekers [30] and 107 to 144 grams of alcohol per day for ESALD transplant patients [25, 27, 31, 32]. A possible reason for the higher alcohol consumption found in Weinrieb’s study among ESALD subjects compared with ATS was this study used subjects who were part of a research trial for pharmacotherapy and not typical of alcohol treatment seekers. If ESALD transplant patients were to have a lower level of alcohol dependence with fewer symptoms it is expected that they are likely to drink somewhat less than alcohol treatment seekers due to fewer symptoms of dependence [19].

No studies have measured alcohol related consequences among ESALD subjects but alcohol treatment seekers are known to have a high prevalence of behavioural, social and interpersonal problems concomitant to alcohol consumption which increases their need for alcohol treatment [19]. Based on the above finding the cohort of patients in this study match the profile of ALD patients (discussed in Chapter 3) who are described as engaged in heavy controlled drinking most of their lives, have minimal consequences as a result of drinking and a pattern of drinking which existed in a stable peer and social structure [19, 28, 33-36].
Psychiatric co-morbidity

Psychiatric co-morbidity is a key predictor for alcohol treatment seeking as discussed in Chapter 4. In the current study lower rates of psychiatric co-morbidity were found amongst ESALD subjects with 23% of the sample having had any formal treatment for a mental health problem compared with 75% of ATS. Furthermore ESALD transplant subjects had lower anxiety, depression and stress scores on the DASS. These levels were lower or equivalent to values found in the general community. The rate of mental health problems found in this study is consistent with studies reporting between 20% and 35% of ESALD transplant patients will have had a history of depression or other mental health problem based pre-transplant evaluations [37, 38]. A recent comprehensive study into trajectories of depressive symptoms within the first post-operative year in a cohort of 167 patients transplanted for alcoholic cirrhosis found 56% with low depression levels and only 18.6% with consistently high depression levels [37]. Again low levels of psychiatric morbidity is expected considering liver transplant selection criteria whereby those with good mental health are considered more suitable candidates due to the physical and psychological stressors associated with liver transplant surgery and recovery.

Quality of life

In this study quality of life was defined an individual’s own perception of wellbeing that stems from the discrepancy between satisfaction and importance with aspects of life that are considered personally important. The ESALD group had a higher quality of life than alcohol treatment seekers. As discussed previously a poor quality of life amongst alcohol treatment seekers in substance abuse treatment has been reported [39-41] and a quality of life which can be lower than those with chronic medical health conditions [42]. Accordingly an improvement in quality of life has been linked with reduction in alcohol consumption [43].

Quality of life scores for ESALD pre- and post-transplant subjects (excluding relapsers) in the same age group using the same measure as that used in this study (QLI) were found to be similar to cancer
survivors [44] and blood stem cell transplant patients [45]. Quality of life scores for the ESALD group in this study when compared with the general population norms were lower in the health and family but equal on the psychological and social domains.

**Social resource**

In this study the ESALD group were more likely to be married, to have stable housing, general and abstinence social support but no difference in education levels. Kelly [32] who investigated ESALD transplant patients in the ANLTU between 1987-2004 noted that the majority of patients (n=72) 79% had family/friends, 84% stable housing, 78% had a partner. Studies have reported only 16% to 26% of ESALD transplant patients to lack family support or live alone [32, 46, 47] while ATS are known to have a much poorer social network [48, 49]. As presented in Chapter 3, research shows that between 50% and 78% of ESALD transplant patients tend to be married [1, 25, 32, 50, 51] while marital rates among ATS range from 42% to 48% [48, 52-54] and they are more likely to be divorced [28, 53-56].

Based on the treatment seeking model used in this study the lower levels of current employment among the ESALD group compared with ATS could predispose them to seeking alcohol treatment if there is a return to drinking. As a result of the medical demands of transplantation and ill-health, and therefore unsatisfactory unemployment may contribute to psychosocial and economic difficulties Research has pointed to the lack of employment among ESALD transplant patients as contributing to relapse [57].

**Barriers to treatment seeking**

One of the most unique contributions of this study was its inclusion of a help seeking survey to assess the views of ESALD transplant patients regarding seeking help from transplant staff for alcohol related issues. ESALD transplant patients were less confident than alcohol treatment seekers about reaching out for professional assistance. They were significantly more concerned about disappointing staff, reported being embarrassed about seeking help, did not feel encouraged by staff to discuss
alcohol use, perceived less availability of alcohol support from staff; and were less motivated to utilize alcohol treatment even if it available. The endorsement of these kinds of statements suggests the threat of self-stigma. Self-stigma associated with professional help-seeking involves the perception of oneself as inadequate or weak, the fear of losing self-regard, self-competency, and overall self-worth [58]. As discussed in Chapters 4 and 8, self-stigma is the most cited reason for individuals’ avoidance of substance abuse treatment (particularly in the latter stages of the treatment seeking process) in order to avoid negative self-evaluation and loss of self-esteem. The in-depth interview study (Study 2) of this thesis found stigma to a major barrier to utilizing alcohol treatment by ESALD transplant participants. Lucey [59] refers to contextual factors reducing professional help-seeking by ESALD transplant patients.

This resistance to treatment may reflect the fear that a declaration of a desire for alcohol will be interpreted by the transplant team as a sign of poor candidacy or a lack of commitment to sobriety. (p.757)

As discussed in Chapter 3 the clinical management of alcohol use disorder by transplant programs and the contrasts with alcohol treatment provided by addiction medicine services. Long term abstinence after transplantation continues to be an important goal for liver transplant programs with relapse considered as a failure by hepatologists. While in addiction medicine, alcohol dependence is recognised as a relapsing condition and individuals are encouraged to discuss their alcohol use, relapse and any difficulties they may have with maintaining change. It has been argued that the strict abstinence policy by transplant programs is not conducive to patients seeking help for alcohol related issues [59]. Weinreb and colleagues [60] have written extensively about how transplant programs do not encourage candour about alcohol use and the negative consequences for patients if they were to disclose any alcohol use especially during the pre-transplant period.

The findings of this survey are consistent with these comments. Relapse to alcohol use is a time when professional treatment needs to be seriously considered. Disclosure of alcohol use in this setting not only threatens an individual’s candidacy for transplantation but also a lack of candour establishes a state of affairs which prevents the patient seeking help from transplant staff in the event of a relapse [59].
Indications that treatment is required

A comparison of clinical variables between ESALD transplant abstainers and relapsers was used to identify the type of treatment that may be more suitable for this population. Relapsers had lower scores on the SOCRATES showing less motivation for change on all the SOCRATES subscales than ATS and less taking steps than ESALD abstainers. This suggested that ESALD transplant relapers are less open to making change or seeking treatment. Cognitively relapers perceived more barriers to abstinence, were less likely to be medical compliant, and less likely to consider alcohol as a contributing factor to liver disease.

A tentative finding was that relapers tended to have HCV and co-morbid substance abuse. It is possible that among ESALD transplant patients with a co-morbid substance dependence whose liver disease involved HCV and where alcohol may have been a secondary dependence may not be fully convinced that alcohol was causative factor in their ESALD. DiMartini and colleagues found ESALD transplant patients with a history of other substance use and HCV had more depressive symptoms and had greater alcohol consumption when they relapsed [37, 61].

One of the key findings of the study was that relapers had a lower quality of life than ESALD abstainers but equivalent to ATS. These findings are consistent with studies which have referred to poor quality of life among ESALD relapers discussed in Chapter 3 in the areas of employment, social life, health, psychological wellbeing. A recent study by Di Martini [61] found relapse to moderate or heavy pattern of drinking occurred amongst those who were more stressed, reported worse health, had more pain and less energy. She proposed that alcohol was being used to handle these stressors and the difficulties of the early post-transplant phase. Interestingly, Ruppert [62] found a steady decline in most quality of life domains over a 12 year period for all transplant patients with patients with ESALD and hepatitis C having the lowest quality of life in all domains. Relapers were also less likely to be married or in a cohabitating relationship than abstainers, commensurate with studies which have found an association between a lower risk of relapse amongst ESALD transplant patients with the presence of a partner or spouse [32, 63-67] while a high divorce rate has been found amongst those who relapsed [68, 69]. Similarly the wider drug and alcohol research literature has also shown a link between relapse and the absence of social support and being unmarried [70-76].
An unexpected finding was the relative lack of psychiatric co-morbidity among ESALD relapsers considering the large body of research which has linked psychiatric co-morbidity with relapse both in general substance abuse area and the ESALD transplant area [32, 64, 77]. A recent study found a lack of association between relapse and presence of low to high depressive symptoms among ESALD transplant patients in the first year post-transplant [37] but another study by the same researcher found quality of life as predictor for relapse. Quality of life may be a good predictor of relapse. As discussed in the literature review quality of life has been found to be poorer among some ESALD transplant patients especially those who relapse and may be a good predictor of relapse.

Overall, the findings derived from this study of relapsers compared to abstainers and treatment seekers, suggests that changes in motivation, health beliefs, quality of life, marital and social support are factors that may contribute to relapse. Interventions that address these areas may enhance willingness to enter treatment and improve transplant outcomes.

**Study Strengths**

This research focused on an important gap in the research. Rather than trial another alcohol treatment program the present study took a different approach by asking why ESALD transplant patients resist alcohol treatment. A significant strength of the current study is that, to the best of the author’s knowledge, it is the first study of its kind to comprehensively profile the pre-transplant and current clinical characteristics amongst ESALD using a number of standardised alcohol measures. Furthermore ESALD transplant subjects were effectively matched to those who commonly utilize alcohol treatment services on age and gender whilst effectively controlling for the presence of liver disease by providing laboratory results.

An innovative approach used in the current study was an examination of the stages of change amongst ESALD transplant subjects from the time of problematic drinking to becoming a transplant patient. The purpose of this was to accurately explore and measure the process of behavioural change by ESALD transplant subjects allowing for the identification of continuously distributed motivational processes and behaviours that underlie stages of change. Another original aspect of the current study was the surveying of the attitudes and perceptions of ESALD transplant patients regarding the alcohol management program provided by liver transplant programs. While a number of researchers and
clinicians have pointed to the controversy and complexities surrounding the transplantation of ESALD patients there has been no research investigating client satisfaction of the alcohol management approach utilized by liver transplant programs.

**Limitations**

One of the main limitations of the study was the reliance on standardized measures as these depend on self-reporting and retrospective responses. While standardised measures selected for the current study had good psychometric properties (reliability and validity) in the general alcohol using population, they have a number of shortcomings. These include the validity of causal conclusions due to social desirability, systematic response distortions, the influence of setting or context in which self-report occurs, method variance and rely formally on the honesty and conscious awareness of the individual. These measures were not validated in the population with ESALD.

Retrospective measures are prone to memory biases, especially considering the presence of mild cognitive impairment amongst pre-transplant patients. To minimise these limitations, measures and procedures were used to enhance memory, patients were carefully screened out who had encephalopathy and a cognitive impairment test (Mini-Mental State Examination test) was used if cognitive impairment was suspected. It was observed that subjects, being older in age, enjoyed the retrospective nature of the measures.

A number of limitations need to be discussed in relation to use of the SOCRATES measure. The validity of stage assessments as discrete stages by the SOCRATES measure has been reported [77] however the subscales represent attitudes and activities related to the stage of change and are not designed to precisely measure stage status rather they reflect dimensions of the process of change [2]. It may be argued that the use of past and present SOCRATES may not be reliable for assessing shifts in subscales and that subscales change over time. However studies reporting good predictive validity with the SOCRATES and movement towards high action scores have been related to positive outcome and congruent with the tasks, attitudes and activities related to that stage [78, 79]. Higher motivation for change has been correlated with greater reductions in substance use and treatment
engagement, retention and outcomes [80].

The SOCRATES measure (including other readiness to change measures) has limitations as it is not able to sufficiently measure the maintenance stage and is not setting-sensitive [81]. Anecdotally, this study noticed subjects rejecting the stereotypical word “alcoholic” found in many items of the measure affecting the response and endorsement of these items by subjects due to the stigma associated with this term.

The method of detecting and eliciting alcohol consumption in this study relied on self-report with occasional blood analysis and staff reports. However more recent research studies examining relapse rates in this population have started to utilize collaborative evidence involving interviews with patients and family, medical records, random toxicology screen, and collateral information from primary supports. While more biochemical markers could have been utilized such as urine toxicology screens, carbohydrate deficient transferrin and other methods they can be limited by low sensitivity or lack of specificity [14, 63]. The biochemical markers do not provide a measure of the amount of alcohol confirmed or frequency of use [82]. They are less useful for this study than self-report.

Discrepancies can exist due to self-reports of alcohol use as patients may underestimate consumption due to reporting errors arising from retrospective accounts and the pressure on patients to deny drinking when patients know that it may not be in their best interests to be candid [60, 83, 84]. However retrospective self-reporting continues to be one of the most effective methods of estimating lifetime alcohol consumption in clinical populations. In general, several studies have validated self-report for alcohol research [85-87] and the use of measure LDH has been reported to have good validity and reliability (Chapter 5).

Confidence in self-report data used in this study was increased with the use of the following strategies. The use of memory aids, the preponderance of abstinent subjects, corroborative data from liver function tests, exclusion of cognitively impaired subjects, lack of acute psychiatric problems, assurances of confidentiality and independent administrator [15, 88]. Special care was taken to ensure the confidentiality of disclosures about alcohol use in order to encourage candor lest patients perceive that there would be negative consequences for open disclosures. However despite these measures it
remains possible that subjects were reluctant to accurately report their alcohol or drug use.

Another limitation was the lack of standardized measures and medical records to confirm or assess for the presence of familial alcoholism, history of mental illness and presence of a social support network. This study also did not examine the role of medical health problems, demands of the transplant regimen and geographical location and these may constrain or impact on treatment motivation or attendance. Finally and importantly the small sample size may limit the generalisability of the findings and comparisons were not made with healthy controls which could have further improved our understanding of this population. For example Glesson [20] recently pointed out that while dependence amongst ALD patients may be not as high as alcohol treatment seekers, it was not as low as heavy drinking controls or those in the general population sample of ‘heavy drinkers’ who were not seeking health care. This can distract clinicians from recognizing that some may have severe dependence.

The use of multiple hypothesis testing and repeated statistical testing is known to increase the potential for Type I error increasing the probability that a statistically significant outcome appears at least once especially in a small sample. In order to reduce the chance of type I error a Bonferroni adjustment was utilized in most statistical tests. Importantly the current study was an explorative study and a stringent criterion for statistical significance and methodological rigour would have compromised the opportunity to research a range of variables essential to developing a clinical profile on these two clinical populations.

Another possible bias may be selection bias as patients were drawn from two distinct groups as demonstrated on demographic characteristics. Patients were selected on matching variables of age and gender which may be considered potential confounders and perhaps not true in the population of interest. However the average age of liver transplants is around 50-60 years old and thus representative of the liver transplant sample. Also this age group is unlikely to be treatment seeking and therefore is not a significant confounder. As the majority of the transplant population is male and again older males are less likely to seek treatment, the use of gender was not considered a significant bias. Other potential matching variables may be been added such as dependence severity, consumption (history), relationship status. These were considered however due to difficulties recruiting older ATS males a further matching variable would have delayed completion of the study.
for another 12 months. Thus there were pragmatic reasons for restricting to age and gender. It may be argued that pre and post-transplant patients are a different population and this would have influenced results on a number of the markers of treatment seeking. We did a few comparisons between pre and post transplant subjects however there were no identifiable differences between these two groups on. Importantly due to small sample size this study had limited statistical power to evaluate this question.

**Conclusion**

ESALD transplant patients are less likely to seek or utilize specialty alcohol services as these services are not tailored to their needs. Firstly, their clinical profile of lengthy abstinence, progressive stages of change, constructive health beliefs, less severe alcohol problem, less psychiatric co-morbidity, higher quality of life and social resources make alcohol treatment unsuitable among those who can maintain abstinence.

Secondly, alcohol treatment programs are not suitable to ESALD transplant patients who generally have a very different clinical profile to those who would attend speciality alcohol services. Stigma and structural factors such as the lack of onsite suitable alcohol support services act to minimise help seeking by ESALD transplant patients.

According to Tripp [86]

> "The vast majority of our patients are maintaining sobriety without treatment, without reported psychosocial sequelae, cravings or relapse behavior, and without any feeling on their part or the part of their families that treatment is needed. They are people who say that if we insist on AA they will go, but they really feel very little need. (p252)"

The clinical profile of most ESALD transplant patients is closer to ALD patients who have changed their drinking or self-changers who have recovered from an alcohol use disorder without needing professional help. Like self-changers they have used a cognitive appraisal to generate change, have a less severe form of alcohol dependence, less alcohol consumption, fewer alcohol related
consequences, married and tend to have greater social stability. Health problems are the primary motivation for change.

Chapter 12 will present the final conclusions and recommendations for alcohol treatment for ESALD transplant patients.
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PART 2  STUDY TWO  IN-DEPTH INTERVIEW STUDY
CHAPTER 8

Harmful alcohol use, stigma and treatment: a review of the literature

Beyond the richness and complexity of their interpersonal (and inter-role) meeting, doctor and patient are surrounded by rich and complex contexts. They are surrounded by the claims and concerns of their families. They are surrounded by societal values and expectations and by those of their small religious and social circles. They are often surrounded by a hospital or clinic and other members of the health care team. They are surrounded by hospital policies, governmental regulations, the demands of third-party payor paperwork, the limitations of the law, and the possibility of malpractice suits. From this perspective neither patients nor caregivers will be regarded as naked individuals stripped of all historical, social, institutional and convictional connections [1] (p.21).

Spectacular results, especially improved physical, emotional and social function of those with ESALD, have been achieved through the process of medical management of ESALD and execution of liver transplants (Chapter 2). Similarly, advances in addiction medicine have increased the understanding of harmful alcohol use and improved the treatment of this condition. At the same time, however, there remains significant resistance to the use of alcohol treatment services by those who engage in damaging alcohol use, including those who seek liver transplant surgery. As previously explained, this resistance poses considerable challenges for managing and preventing relapse into alcohol use of those who engage in transplant surgery.

As mentioned in Chapter 4, arguably the most significant barrier to treatment is stigma. This chapter conducts a review of the literature that focuses on stigma as a deterrent or obstacle to medical treatment. Despite the availability of effective alcohol treatments by medicine, 54% to 85% of those with harmful alcohol use in the general community will not pursue treatment, with stigma being frequently identified as a major reason. Little is known about the relationship between stigma and why medical treatment for harmful alcohol use. Few studies have identified the mechanisms behind why medical treatment triggers a fear of stigma by those with harmful alcohol use [2]. This is a complex issue and most of the research has been conducted with those with mental health problems. In order to explore this issue, it is important to first refer the sociological literature pertaining to chronic illness as ESALD transplant patients deal with two chronic illnesses, firstly end-stage liver disease and secondly, harmful alcohol use therefore the sociology of chronic illness is important to
The Sociology of Chronic illness

Chronic illness has been defined as those forms of health disorders that hinder an individual’s social interaction and role performance. The sociological interest in chronic illness has partly developed due to the limitations of medical treatment for chronic illnesses. While the medical management of disease is an important resource to people in times of illness, especially useful for quantifying, measuring and treating illness, it has however been criticised for being too narrow. Sociologists have argued that chronic illness is more than the disease and it’s pathophysiology and that medical practice disregards the social aspects of illness, its meaning and experience for those living with a chronic illness [3, 4]. Research exploring illness perception has found illness behaviour significantly contributing to mental health, coping responses, health behaviours and interestingly degree of involvement with healthcare professionals [5].

A great deal of sociological work has been on the conceptualisation and consequences of chronic illness. Over the last 50 years the conceptualisation of illness behaviour by medical sociologists has been modified and broadened since Talcott’s Parson’s more static conceptualisation of the ‘sick role’ in 1951. The results of suggest the need for a multidimensional view. A number of important social and psychological processes associated with chronic condition/s and the illness experience have been reported as a result of recent interpretive sociological studies of chronic illness.

Charmaz (1991) landmark research highlighted that chronic illness was not only an assault on an individual’s physical self, but also their self-identify and self-worth [6]. Charmaz referred to the potential for ‘loss of self’ as individuals become more immersed in the illness experience and the day-to-day aspects of managing illness. Illness can contribute to a restricted life through the loss of conventional life activities, social isolation, with nothing to look forward to, and nothing to do. According to Charmaz without the development of an equally valuable and meaningful new selfhood, the individual with chronic illness may feel the loss of self-image. Similar to the ‘loss of self’
described by Charmaz, Anderson (1991) spoke about the devalued self experienced by women with type 1 diabetes and the need to reconstruct a new self [7].

Another leading figure in the sociology of chronic illness has Bury (1982) who argued that chronic illness might be conceptualized as form of ‘biographical disruption’ [8]. Chronic illness can prompt disruption in a number of areas – assumptions and behaviours, explanatory systems, self-concept and resources. It can require a re-evaluation of one’s former life and identity and new illness identity, reflection on consequences and mobilisation of social-economic resources.

A number of sociologists have also referred to the ‘moral’ dimension of illness. According to Parsons, the sick role obliges the patient to do everything possible to achieve ‘the goal of complete recovery’ [9]. More recently, Townsend and colleagues (2006) in their qualitative study describe how participants feel the need to demonstrate their moral worth as individuals, that to manage symptoms and their daily lives becomes a moral obligation [10].

Sociological taxonomies include stigma as an important component of the lived experience of chronic illness especially for those with a chronic stigmatizing condition such as alcoholic liver disease.

**What is stigma? Erving Goffman and the creation of ‘spoiled identities’**

One of the major contributors to understanding stigma in health settings is Erving Goffman, an American sociologist. His work on stigma provides a necessary and comprehensive understanding of the core processes connected with stigma. His work, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (1961), was the first sociological examination of the social experiences of patients with mental health problems in the hospital environment. He described the social processes that are set in motion on entering the hospital and how they challenge and change people’s pre-institutional social roles and identity. He observed the ‘moral career’ of patients, referring to the experience of being a ‘good patient’, to the humiliating circumstances of being a ‘bad patient’, to the changes in judgement of self and others, to restrictions of freedoms and, finally, the need for defensiveness. Goffman’s study highlights the process of medical socialization as patients experience the disorienting processes associated with entry into hospital-based social relations and the change in identity that such institutionalised arrangements necessitate.

Goffman (1963) further explored the experience of stigma associated with addictions, mental illness, deformity and disability in his *Stigma: Notes on the Management of Spoiled Identity* (1963). Here he
proposed that stigma was an ‘attribute that is deeply discrediting’ reducing the stigmatized person ‘from a whole and usual person to a tainted, discounted one’ [11] (p.3). In describing the sociological and psychological antecedents of stigma, Goffman drew attention to the ‘ground rules’ or structures involved in human social interaction. He proposed that individuals, like actors on a stage, attempt to sustain a positive and consistent self-image and to acknowledge the same in others. He referred to one’s virtual social identity, which he differentiated from actual social identity, attributes a person in fact possesses. According to Goffman, some attributes, such as a physical or mental disability, can discredit or ‘spoil’ the virtual identity of the bearer, making them undesirable, bad, dangerous or weak.

A central idea in Goffman’s work is that the self is ‘not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by himself and those around him’ [34 (p168)]. Stigma arises in the course of social interaction whereby a person’s identity is marked or rendered as unacceptable – what Goffman called ‘spoiled’. This dynamic can lead to exclusionary social processes that limit the individual’s ability to fully participate in everyday life, including social relationships. Goffman proposed a taxonomy of stigma based on three distinct types: overt or external physical deformations, ‘tribal traits’ such as those pertaining to ethnicity, and finally, ‘blemishes of individual character’ connected with weak will, passions and dishonesty. Based on Goffman’s classic formulation, stigma has been identified by sociologists as a social process involving a relationship that can operate inter-personally, between groups and institutionally. It is a dynamic process of interaction that produces adverse personal effects including profoundly damaging affect. Since Goffman, there has been an explosion of research emphasizing the situational nature of stigma, the cognitive social components and the role of the self and identity in responses to stigma.

**Health-related stigma research**

Stigma has become an important topic in health and health care research, as contributions by medical sociologists, social psychologists, public health researchers and clinical psychologists, on the relationship between stigma and the social burden of illness attest [12-17]. These researchers have been working to formulate a concept of health-related stigma to guide health social science research, policy and practice. The results of this enterprise, however, have been overly broad, lacking the detailed specification and depth of conceptualisation and analysis of the relationship between self-conception and social identity theory.
Health-related stigma theory and research continue to be guided by Goffman’s ideas and therefore focuses on stigma as a social process linked to an ‘attribute that is deeply discrediting’ as demonstrated by exclusion, rejection, blame or devaluation. According to health-related stigma researchers, a medical diagnosis or health problem elicits stereotyping, prejudice and discrimination. Weiss and colleagues offer a definition of stigma that illustrates this approach:

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgement is based on an enduring feature of identity conferred by a health problem or health-related condition and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgement may also be applied to the disease or designated health problem itself with repercussions in social and health policy [18] (p280).

American socio-medical scientists, Link and colleagues (1989), influenced by Goffman’s construct of discrediting attributions which reduce the self-worth of individuals, developed what they called a modified theory of stigmatization. The modified labelling theory emphasizes that individuals, as part of daily socialization, internalize the negative stereotypes and conceptions of what it means to be labelled with a mental illness. These stereotypes are fully in place before an individual enters treatment and, according to Link and colleagues (1989), are activated and internalized by individuals once they enter treatment and are officially labelled through diagnosis. This triggers an array of cognitive and behavioural responses in which people involved in the labelling process (the labelled and labellers) infer that the labelled person possesses undesirable characteristics [19]. This is acute if labelling is conducted within specialist medical settings as specialist treatment is perceived by individuals as a more powerful labelling event. [20].

The official public label brings personal relevance to a labelled person’s views about the attitude of the community towards those with a stigmatized condition. If the person accepts the label, he/she internalises the attributes associated with the stereotype and devaluation becomes a part of a person’s view of him/herself. It also shapes the nature of their social relations and connectedness. According to Link and associates [19] ‘labelling triggers powerful expectations of rejection that in turn erode confidence, disrupt social interaction and impair social and occupational functioning’ (p.179). They argue that stigma might be expected to occur in situations where sufficient power exists to confer a label which resonates in public culture.

In health care, such a label has the potential to control access to services and core institutions. Therefore, stigma may be embedded in health systems through the application of certain diagnoses, the attitudes and behaviours of health care providers towards the condition, the organisation of health
services and the design of health interventions and health policies [18]. In terms of treatment seeking, those who perceive high levels of stigma may avoid contact with treatment services as it may confirm their membership of a stigmatized group. Individuals may opt to avoid the stigma all together by denying their group status and not seeking to participate.

Link and colleagues conducted research which tested modified labelling theory showing that despite diagnosis and contact with treatment services, stigma continued to have a relatively strong and pervasive effect on mental health, functioning and behaviour linked to labelling-activated expectations of rejection [19, 21, 22]. Psychiatric labels, including diagnosis of substance abuse, were found to be associated with stereotypes by the public, leading to social withdrawal, avoidance and rejection and maladaptive interaction strategies, including secrecy coping, in order to deal with their stigmatized status [21, 23].

Recently, Link and Phelan [13] expanded their definition of stigma to include ‘elements of stereotyping, separation, status loss and discrimination occurring in a power situation that allows these processes to unfold’[13] (p.367). They explain how stigma operates through a combination of five interrelated components: i) differentiation and labelling human differences, ii) linkage of labelled persons with negative stereotypes associated with dominant cultural beliefs, iii) categorization of labelled persons in order to accomplish some degree of separation of ‘us’ from ‘them’, iv) status loss and discrimination experienced by labelled people that lead to unequal outcomes and v) unequal access to social, economic and political power that renders some more vulnerable than others to i) – iv).

According to Link and Phelan, stereotypes are social phenomena because they represent collectively agreed-upon ideas. They can automatically and quickly generate impressions and short-hand decisions about individuals who belong to a stereotyped group [13]. While social identity theorists focus on self-categorization and prototypical group evaluations in understanding health related stigma, American medical sociology and social psychology focus on the role of cultural stereotypes, and the role that medical diagnosis plays in triggering and generating them [15, 17, 18, 24-26].

**Chronic Illness and Stigma**

As mentioned earlier, sociological taxonomies include stigma as an important component of the lived experience of chronic illness. Jacoby (2005) from Division of Public Health United Kingdom,
reviewed the literature on the relation between stigma and the neurological disorder of epilepsy [27]. Using a multi-causal model incorporating neurological, psychosocial, demographic and treatment variables, stigma emerged as one of the seven key predictors variable for impaired self-esteem, low self efficacy, helpless, anxiety and depression, reduced life satisfaction and a predictor for psychopathology. Perceived stigma contributed to poorer quality of life along with psychological distress, loneliness and adjustment difficulties, with clinical variables associated with disease contributing less than expected.

In the case of chronic illness, the devaluing or discrediting may be due to a number of factors. Stigma is part of chronic illness because individuals who are chronically ill have less ‘social value’ than healthy individuals. In their investigation those unable to participate in the process of ‘reciprocal exchange’ because of ill health are considered to have less social value and so stigmatised [27]. Furthermore they propose that in order to simplify good and poor reciprocators, whole groups of people may be perceived to have poor social value, rather than individuals. According to Millen and Walker in their paper of stigma of chronic illness the greatest threat comes from self-labelling as sufferers internalise the lower status revealed to them by ‘normals’ in society including medical professionals. Sufferers of chronic illness can lose personal physical space as they are invaded by ‘normals’ with ‘probes and measures’ and who handle the ‘end products of their bodily functions’. The continuing need to explain one’s incapacities from a range of ‘normal’ social interactions helps generate a negative self-narrative that justifies exclusion. The stigma associated with chronic illness has also been attributed to perceived responsibility for the illness by individuals [28]

**Harmful alcohol use and stigma**

Alcohol disorders are among the most highly stigmatized of the psychiatric disorders [23, 29]. Research continues to show that the public perceives individuals with an alcohol problem as being responsible for their illness as well as being dangerous, blameworthy and immoral [2, 30-35]. While public health education campaigns have resulted in greater public understanding of alcohol use disorders as a medical or psychiatric condition, this has not markedly decreased public stigma or the maintenance of social distance by the general public [36, 37].

Recently, Schomerus (2011) conducted a systematic literature review exploring aspects of the stigma of alcoholism compared with other health problems. ‘Alcohol-dependent persons’, compared with people dealing with mental disorders, were perceived more negatively, less
frequently regarded as mentally ill, held more responsible for their condition, incited more social rejection and more negative emotions (anger, irritation, indifference), and were at risk for structural discrimination. According to Schomerus, the difference between the stigma of alcoholism and that of other health conditions, particularly mental health issues, was that it was used to enforce social norms, making ‘the deviant’ conform establishing acceptable behaviour.

Robin Room [30] in *Stigma, social inequality and alcohol and drug use* asserts that the most stigmatizing stereotype or attribute of ‘alcoholism’ is that the person has little or no will power to resist alcohol and this is a sign of moral and character weakness. He argues that character weakness is one of the most vivid and isolating distinctions which can be made by a society where attributes of success, morality and respectability are associated with self-discipline and will power. Alcohol use can serve as a demonstration of the extent of valued personal qualities such as self-control. Entering treatment for alcohol problems, as a result, is potentially humiliating evidence of failure in self-management.

**Stigma and alcohol treatment seeking**

Stigma has been found to be a major barrier to professional treatment-seeking reducing treatment compliance and participation [19, 38-45]. As previously discussed, despite the availability of effective alcohol treatments by health services, the majority of those in the general community with harmful alcohol use will not pursue treatment, with stigma being frequently identified as a major reason.

A recent national epidemiologic survey by Keyes and colleagues [2] involving 34,653 adults between 2004-2005 in the United States with alcohol abuse/dependence, and using the perceived devaluation-discrimination scale, examined whether perceived stigmatization of alcoholism was associated with less likelihood of using alcohol services. The study found that individuals with a lifetime diagnosis of an ‘alcohol use disorder’ were less likely to utilize alcohol services the greater their association of stigma with alcohol use disorders. Higher perceived stigma of harmful alcohol use among the participants was associated with male gender, lower income and education, being previously married and non-white.

High levels of stigma have been reported by individuals with substance use disorders receiving treatment. Luoma and colleagues (2007) examined stigma related experiences of 197 patients from 15
residential and outpatient substance abuse treatment facilitates. Patients were asked to complete a number of questionnaires regarding the experience of stigma whilst undergoing treatment [46]. The majority of individuals who entered substance abuse treatment believed that: most people held stigmatizing attitudes or behaviours; people would treat them unfairly on knowing about their substance use; others were afraid of them on finding about their substance use; and family and friends rejected them once they knew about their substance abuse. Elevated levels of enacted, perceived and self-stigma were reported by participants. Enacted stigma was defined as experiences of social discrimination (such as reduced access to housing, employment opportunities or social rejection); perceived stigma involved beliefs that members of a stigmatized group have about the degree of stigmatizing attitudes and reactions by others; and self-stigma as feelings of shame, negative self-evaluation and loss of confidence that arise from the identification with a stigmatized group. Secrecy coping (or concealment strategies), detrimental to recovery from addiction, were related to lower quality of life, experiences of stigma-related rejection in the past, higher internalized shame, and employment problems.

This study also showed that treatment systems were more likely to stigmatize people with a greater number of treatment episodes, a finding consistent with other studies [47]. According to the researchers, these findings support Link et al (1989) modified labelling theory which proposes that stigma begins to impact with an official label from a treatment establishment. This finding was confirmed by Sirey [43] who showed an increase in perceived stigma at the start of treatment resulting in poorer compliance with prescribed antidepressant regimens.

**Cognitive beliefs and utilizing professional services**

In both quantitative and qualitative studies, the most frequently endorsed reason for not using formal substance abuse treatment provided in both quantitative and qualitative studies involves ‘wanting to solve one’s drinking problem on one’s own’, without the need of professional help [39, 41, 48-51] (Chapter 4). Self-stigma may be a factor behind an individual’s preference for handling the problem without treatment, perhaps reflecting misplaced self-efficacy and fear of challenges to one’s self-esteem [50]. It is important to note that stigma is also a major reason cited by the general public for avoiding professional psychological help, apart from a desire to avoid discussing distressing or personal information. To be seen as seeking help from another is often internalized by the individual as a sign of weakness, or an acknowledgment of failure, inferiority or inadequacy and therefore treatment-seeking poses a threat to one’s self-esteem and self-efficacy [14, 52, 53]. Subsequently, not seeking professional help acts to protect one’s self-esteem [54]. Stigma has been found to contribute to loss of self esteem, resulting in depressive symptoms [14, 19, 23, 55-58]. The stigma associated
with seeking professional psychological help results in negative attitudes [52], a decrease in treatment adherence and termination of treatment [43, 44].

Social identity theory

Social identity theory is one of the most prolific contemporary theories approaches to explaining the relationship between self, group and intergroup behaviour, and addresses phenomena associated with stigma. The theory was first developed in Britain by Henri Tajfel in the 1970s and derived from his scientific and personal reflections in social perception, social categorization, and social comparison. According to Tajfel, large scale social behaviour cannot be adequately explained by personality traits or interpersonal interactions. Rather, he proposed, an individual’s self-concept and intergroup behaviour are derived from perceived membership in a relevant social group. He defined social identity as ‘the individual’s knowledge that he (sic) belongs to certain social groups together with some emotional and value significance to him (sic) of this group membership’ [59] (p. 292). Intergroup contexts drive people to make comparisons that maximize differences between self (as an in-group member) and other (as an out-group member) [60]. Over the last few decades, social identity theory has developed both conceptually and empirically with an extensive explanatory scope and range addressing stereotyping, self-conception, motivation, collective behaviour, norms and social influence, multiple categorization, and intragroup phenomena [61].

Social identity theory differs and progresses further than Goffman’s perspective of self and stigma. For Goffman stigma involved face to face interaction, ordinary social life rather than large scale social behaviour in a range of social contexts. Social identity theory elaborates in detail the operation of intergroup processes, the range of group behaviours, and contextual salience of specific social identity, and recognizes that individuals can differentiate into multiple identities.

According to social identity theory, a social group is defined as at least three people sharing the same social identity. According to Hogg

They identify and evaluate themselves in the same way and have the same definition of who they are, what attributes they have, and how they relate to and differ from people who are not in their group or who are in specific out-groups. Group membership is a matter of collective self-construal – ‘we’ and ‘us’ versus ‘them’. [61] (p.115)

Individuals can have many social and personal identities depending on the groups they affiliate with, the personal relationships they are involved in. Also, as the situation or context changes, the form that
the identity takes also changes. In any given situation, however, only one identity is psychologically salient to direct self-construal, social perception and social conduct.

Social categorization and prototypes

One of the key conceptual components of social identity theory, used to explain the relationship between self-conception and group processes, is social categorization [62, 63]. Social categorization is considered the cognitive basis of social identity processes, with categorization of self and others playing a pivotal role in social identification, group life and group membership. From a social identity perspective, groups are strongly associated with categories of people and social categories. Social categorization involves the establishment of a group as a prototype. Michael Hogg (2006) describes prototype as ‘a fuzzy set of attributes (perceptions, attitudes, feelings and behaviour) that are related to one another in a meaningful way and that simultaneously capture similarities within the group and differences between the group and other groups or people who are not in the group’ [61] (p. 118). Prototypes prescribe group membership, they graph the contours of social groups – the norms, characteristics, how people will behave and interact with one another, and how the group differs from other groups. Prototypes emphasize attributes that favour the in-group over the out-group, and tend to describe ideal, often hypothetical, in-group members.

The act of categorizing a person as a group member means that the idiosyncratic nature of individuals is seen and evaluated through the lens of the prototype and prototypical attributes. This is the means by which the self is assimilated to the in-group prototype and individual behaviour is transformed to correspond to the appropriate self-defining group prototype and in-group norms (normative behaviour) [62, 64, 65]. Once the norm has been established, it is internalized as the context-specific in-group prototype to which people conform through self-categorization. Group norms prescribe attitudes, perceptions and behaviour, and serve to express in-group similarities and in-group identity but also polarise the in–group from the out-group.

According to Hogg [61], social categorization depersonalizes and sorts out both in-group and out-group members:

Depersonalized perception of out-group members is more commonly called stereotyping – you view ‘them’ as being similar to one another and all having out-group attributes. When you categorize yourself, exactly the same depersonalization process applies – you view
you yourself in terms of the attributes of the in-group (self-stereotyping), and since prototypes also describe and prescribe group-appropriate ways to feel and behave, you feel and behave normatively. (p.119)

The categorization and depersonalization of group prototype has a number of advantages. It serves to create a positive self-concept, optimal distinctiveness (as attributes tend to be ideal and positive), a sense of belonging, uncertainty reduction, group cohesion, conformity and ‘patterns of in-group liking, trust, and solidarity’ (p.119). The darker side of categorization is that intergroup harmony and self-enhancement is dependent on polarizing and differentiating between group members and groups, a ‘we agree that we are like this and they are like that’.

If out-group attributes are highly negative and degrading, it may produce dehumanization, generating prejudice, discrimination, ethnocentrism, intergroup conflict, deviance and stereotyping. Out-group members, by being associated with undesirable attributes, tend to have to strive harder for self-distinctiveness, status, privilege, resources and social mobility. Also, less prototypical members, particularly those that are in-group rather than out-group members, are cast as deviants or marginalized, especially when they threaten the integrity of group norms [66-68]. It is important to note that social categorizations that affects identity and behaviour must be psychologically salient. People tend to draw on social categorization that are valued, important, easily linked to their self-concept and when situation favour an in-group membership [69].

**Honneth and mutual recognition**

A more recent and critical theoretical contribution to understanding stigma and social identity, has been made by German philosopher, Axel Honneth [70], whose work focuses on relations of power, recognition and respect. Honneth draws heavily on the phenomenology of recognition, as discussed by Georg W. Hegel and George Mead and on the object relations school of psychoanalysis, particularly the work of Winnicott. These schools of thought have long recognized the importance of interactive experiences or mutual social recognition in the formation of identity, self esteem and mental health. In Honneth’s view, intersubjective relations and mutual recognition in social relations are essential to an individual’s identity formation, self-confidence, self respect and social esteem: ‘the experience of being socially esteemed is accompanied by a felt confidence that one’s achievement or abilities will be recognized as ‘valuable’ by other members of society’ [45 (p33)].

Mutual recognition is acquired and maintained intersubjectively where each member of a society is
capable of experiencing social esteem, a self-respect whereby each individual acquires the sense of universal dignity of persons, morally responsible agents and something of value. The withholding of recognition and the lack of societal solidarity (in which every member is in a position to be valued) act to undermine an individual’s identity and self esteem. Consequently those who experience exclusion, insult and degradation will struggle for recognition in an effort to redeem identity and dignity. For Honneth, the importance of the social group can be seen in the significant role played by group pride or collective honour in social movements, such as in the homosexual gay rights or American black human rights movements.

For Honneth, self-esteem depends on a process of social inclusion based on mutual recognition, and therefore his theory proposes a means of correcting and responding to stigma. Unlike social identity theorists, Honneth provides a means of correcting and responding to stigma and associated processes of inclusion and exclusion. He emphasizes the importance of establishing supportive relations which involve social inclusion based on mutual recognition and community solidarity. Social identity theory, by contrast, does not offer a foundation for challenging stigma. It is largely descriptive, arguing the necessity of processes of devaluation and exclusion of others in the establishment of social identity. To a significant extent, it is functionalist in its approach insofar as it suggests that the splitting and othering it identifies are requisites of social identity. Honneth’s approach is demonstrably critical of this putative necessity. Anderson, in his preamble to Honneth’s book, makes an important point about members of marginalized groups: they ‘have been systematically denied recognition for the worth of their culture or way of life, the dignity of their status as persons, and the inviolability of their physical integrity and of their worth’ [45(p1)].

Honneth’s theorisation is supported by a growing body of evidence on the social and environmental determinants of health and disease. Social processes and circumstances determine the extent to which a person possesses the physical, social, and personal resources to identify and achieve personal aspirations, satisfy needs, and cope with the environment (a broader definition of health). Research has consistently shown that quantitative and qualitative improvements in socioeconomic conditions in relation to early childhood, health and social services, housing, education, nutrition, employment security and working conditions contribute to better health and longevity [71, 72]. Sociological research has also demonstrated that exposure to stressful experiences (such as death of a spouse, trauma or abuse, unemployment, divorce, poor education, financial limitations, or living in dangerous neighbourhoods) has a strongly negative impact on the physical and mental health of certain groups [73].

It is powerfully evident that supporting social relationships benefit health: adults who are more socially connected live healthier and longer lives than their more isolated peers [73]. Unmarried
individuals (particularly those who experience stressors such as separation, divorce and widowhood) have more illnesses and disabilities, shorter lives and more psychiatric disorders than do married persons [73]. Marriage stress has been associated with compromised immune and endocrine function, depression [74].

According to Honneth, it is the symbolic dimension of social life – involving the processes that accord value and esteem for individuals’ specificity and include them as integral members of collective life – that is foundational to people’s sense of self-worth and efficacy. From such a perspective, stigma can be understood as a pervasive feature of culture that consistently dishonours, humiliates, marginalizes and excludes those who are not valued for their individual specificity or for their contribution to and inclusion in collective or group life. Honneth’s approach suggests that recognition and respect, operationalized through social participation and social inclusion, is the answer to stigma.

**Self-management and self-transcendence**

In-depth interviews of those with chronic illness, involving a range of disabilities, have provided insights into how individuals adjust to chronic illness and illness-related stigma. This is a growing literature and beyond the scope of this thesis however a brief summary will be provided. Self-management is a dynamic process central to actively managing a chronic illness. According Kralick [75] self-management creates order, discipline and control in their lives, manage the shift in self-identity and enjoy a better quality of life. While the processes have not been clearly delineated optimal self-management consists of an ability to monitor illness and to use cognitive, behavioural and emotional strategies to maintain quality of life [76].

Two processes appear critical firstly, acknowledging the self as ‘changed’ and ‘sick’ and secondly, a purposeful search for meaning, normalisation and self-validation with entry back into usual social life despite limitations. Bury[77] referred termed this process ‘legitimation’ whereby Individuals come to construct meaningful explanations making sense of their life circumstances and biographies, and thereby gaining perspective in order to re-establish credibility in the face of the assault on self-hood. According to Bury normalisation plays an important role in coping with illness as it is the ‘psychological bracketing off’ of the impact of the illness, so that its effects on the person’s identity is not too distressing. Normalisation acts as means of protecting individuals from stigma in order to preserve the social and emotion self. Royer (1995) identifies a number of strategies where avoidance assists to ‘normalise’ and therefore adjust to chronic illness by engaging in usual activities,
maintaining normal appearance, avoiding embarrassing situations, limiting contact with persons in similar circumstances and engaging in denial [78].

Self-transcendence, while not developed by sociologists is theory developed by Reed (1991) found in nursing research literature. Self-transcendence is a complex, developmental process precipitated by life challenging events [79]. It has been associated with positive life outcomes including a high quality of life, emotional well-being and lower levels of illness distress [80]. Self-transcendence is a growth process especially high during ‘end-of-own-life experiences’ in which individuals broaden their personal perspective, and activities beyond physical psychological and social boundaries to find meaning and purpose during a challenging life experience [79, 81] It is considered to be a dimension of spirituality precipitated by a spiritual emergency as individual face their mortality. Outcomes described by participants include a renewed sense of purpose and meaning in life, acceptance of personal circumstance, connectedness with self and others [81]. Liver transplant patients have been found to have a higher liver of self-transcendence than other patient population. Bean [80] using a mixed method design found self-transcendence to be positively correlated with lower levels of illness distress, being employed, high perceived quality of life, strengthening of interpersonal relationships as a result of the informants’ transplant experience.

**Medicine, stigma and harmful alcohol use: the way forward**

According to Link [19] the findings of stigma research poses a key challenge for medicine and health care providers:

> Stigma has important effects, effects that remain even when people improve while participating in treatment programs. Health care providers are therefore faced with the challenge of how to address stigma in its own right if they want to maximize the quality of life for those they treat and maintain the benefits of treatment beyond the short term. (p.187).

Research has revealed the diverse negative effects of stigma including diminished social network size [30], restricted employment opportunities [82, 83], lowered self esteem, and increased depressive symptoms [14, 19, 23, 55-58], discrimination [23, 58, 73], limited social opportunities [73, 84], increased reliance on a counter-culture [30], and stress-related illness and impairment in daily functioning and relapse [45, 73, 85].
As previously mentioned, stigma has also been found to be embedded in health systems [18]. For example, health care professionals may hold stereotypical attitudes that substance use is within the control of the individual. Accordingly, they may blame them for their condition resulting in inferior service provision. Brener et al [86] found that staff attitudes can influence the quality of care provided to those in substance abuse treatment affecting treatment retention. Staff who have developed skills in establishing a therapeutic collaborative working alliance, are non-threatening and supportive, retain clients in treatment. Many can hold unconscious negative attitudes towards their clients but may report no awareness of such attitudes. A number of studies show that general practitioners and health professionals experience discomfort, lack confidence or try to avoid patient disclosures about alcohol use [87]. They report fears that questions about drinking may harm the patient-provider relationship [88-90] or contribute to stigmatization [91, 92].

Some have suggested that medicine has sought to protect individuals from the societal stigma associated with ‘alcoholism’, by emphasizing that alcohol dependence is a medical condition that requires treatment [93]. Yet, in a critical essay by Williamson [94], it has been argued that despite the availability of public education and neurobiological data over the years, and enduring negative attitudes by the public, medicine has not succeeded in reducing the stigmatization of those with addictive disorders. According to Williamson, even if alcohol use disorders were regarded as illness rather than bad behaviour, the public would continue to have legitimate concerns about the medical costs, violent behaviour, and reluctance of patients to participate in treatment and take responsibility [37].

In response to this situation, sociologists have proposed that medicine needs to incorporate a social model of health, which focuses on reducing stigma and improving the quality of life and well-being of those vulnerable to stigma, reducing its adverse effects [18, 95]. Williamson proposes an integrated medical-ethical approach:

One task of an integrated medio-ethical approach to alcohol dependence must be to disabuse the public (and professionals) of the notion that the condition can be addressed by focusing on the behaviour of individual drinkers. Science has long acknowledged the role that social environment plays in the development of dependence and its remedy.....Responsibility for preventing and controlling dependence also exists at a community level and the work is required to assess the extent to which and in what ways individuals and organisations might be accountable for alcohol misuse and the dependence of others. Together biomedical and ethical arguments for affording more detailed attention to social environment and social responsibilities in debates on alcohol dependence can help to dissipate the blame that falls on individual drinkers and that lies at the heart of stigma. (p e7)
Similarly Schomerus [96] posits that

.. stigma could be quite a dysfunctional way of pursuing the goal of keeping someone within the in-group of those able to control their drinking…..Here, the social purpose of the stigma of alcoholism can directly be addressed: to recover from alcohol dependence, people need personal strength and help from others. A stigma is downright contrary to these needs, because it weakens and isolates those affected, and it thus aggravates a problem it was probably intended to control. (p.110).

Conclusion

Medical practice has enhanced the health and quality of life for individuals, families and community. The experience of end-stage liver disease and transplantation has many physiologic, psychological, social and spiritual manifestations contributing to the potential for illness distress, requiring the transplant recipient to continuously adjust to the chronic aspects of living with transplantation. Individuals may have to adjust to the changes in identity, self-worth and social relationships.

Stigma is a central concern for those with a stigmatized chronic condition and remains a major barrier to treatment seeking and treatment participation. A review of the sociological literature has revealed the complexities of stigma as a social process. In the health field, researchers have identified a number of critical processes involved in stigmatization including: medical diagnosis, labelling, stereotyping, discrimination and ensuing adverse health and social effects. Those with harmful alcohol use continue to attract considerable negative public attitudes which serve to undermine their motivation for treatment. Attitudinal, organisational and policy changes are required by medicine and other health care services in order to make treatment of harmful alcohol use less stigmatized and treatment more accessible. Recognizing those who use alcohol in harmful way, as agents who can participate constructively with service providers in treating their alcohol use, and including them in the planning, provision and follow-up of such treatment, appear to counteract practices that result in stigma. Precisely how such recognition and inclusion might work in a medical setting such as that associated with ESALD is an issue that requires further investigation. Chapters 11 and 12 discuss these issues further.
References


CHAPTER 9
IN-DEPTH INTERVIEW STUDY
METHODOLOGY

As outlined in the literature review, international studies have shown that ESALD transplant participants are reluctant to participate in specialty alcohol treatment involving both pharmacotherapy and/or psychotherapeutic interventions, especially when this is offered within a liver transplantation program [1-3]. Treatment avoidance and treatment seeking amongst those with alcohol use disorders has been investigated using both qualitative and quantitative research methods, but no previous research has examined barriers to treatment seeking amongst ESALD transplant participants. Accordingly, an exploratory, qualitative research design was adopted in this part of the study.

The broad aim was to explore the experiences and understandings of alcoholic liver disease transplant participants in liver transplant management programs. The following specific questions were addressed:

What are the intrapsychic, social and organisational social factors contributing to a lack of treatment seeking?

What are the social factors that contribute to a lack of treatment seeking?

What are the organizational or program factors that contribute to lack of treatment seeking?

This chapter explains the methodology used to generate relevant data using a in-depth interview study involving semi-structured interviews with 42 ESALD transplant participants.

Research paradigm
A research paradigm provides a philosophical framework that generates knowledge and informs the strategies, criteria and techniques on which research practice is based [6-8]. According to Guba and Lincoln (1994: 105), a paradigm is ‘the belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways’ [9]. A paradigm may be considered as consisting of four elements: ethics (study of moral principles that guide right conduct); epistemology (theory of knowledge); ontology (theory of the nature of reality and of human beings in the world); and methodology (best means for gaining knowledge about the world) [6]. Thus the paradigm and its associated concepts and practices are important to the design, conduct and implementation of a research project, since it determines what knowledge is, how it is generated and how it is verified [8]. The research paradigm informs the selection of appropriate methods of data collection [9].

Commonly used research paradigms include the empirico-analytical paradigm (quantitative scientific approach), the interpretive paradigm and the critical research paradigm. These are based on the theoretical positions of positivism, idealism and realism respectively [8]. This study is a qualitative research project informed by the interpretive paradigm. Qualitative research can employ a number of data collection techniques, such as semi- or minimally structured interviews, participant/non-participant observation and document analysis.

The interpretive research paradigm is based on the proposition that there are multiple realities and that these can differ across time and place. The interpretive paradigm is philosophically different from positivism, which holds that knowledge is objective, generalisable, collected and analyzed from parts of phenomena, capable of generating a single truth, and universal [7].

While interpretivism can embrace a number of theoretical perspectives [7], this study is informed by symbolic interactionism, an approach derived from the American pragmatism of George Herbert Mead and Charles Cooley. Herbert Blumer, a student and interpreter of Mead, coined the term and argued that individuals continually reflect on and interpret the symbolic meanings of their environment or social world and that human action is mediated by the ascribed meanings derived from social interaction and modified through interpretation [10]. The symbolic interactionist assumption of the indeterminacy of action rests on the human capacity to objectify self and to ascribe meanings to self, as to any other object. Human beings are not passive recipients of meaning, but construct meaning from their interaction with the world; even when they encounter
the same objects, people experience them in different ways [11]. Therefore human knowledge and action are contingent on interpretation that is constructed in and out of interaction with the social world [7].

According to Blumer (1969: 188), the aim of the researcher working from an interpretive symbolic interactionist perspective is to ‘catch the process of interpretation through which people construct their actions’ [10]. The focus of research is on the subjective experience or interpretive process of the individual in dealing with others and with the environment. Furthermore, the subjective world of the researcher is itself important, as the interpretation emerges from the interaction between the researcher and the participants. The research is influenced by the questions being asked and by the values of the researcher, as well as how the findings are analyzed.

**Research design**

A complex set of factors is associated with the action of treatment seeking or non-treatment seeking by ESALD transplant participants within the specific organizational world of the liver transplant program. The interpretive paradigm with its associated qualitative methodology was best suited to capturing this complexity. In-depth interviews can reveal details of participants’ experiences, understandings (beliefs and attitudes) and feelings in relation to their engagement in the liver transplant program. Such an approach is ‘open-ended’ because it allows participants the opportunity to speak freely and to recount their experiences without being forced to choose between specific, pre-determined answers. It also allows the researcher to probe for additional information or otherwise explore responses in more depth [13].

In contrast, the methodology generally associated with the empirico-analytic paradigm proceeds from hypotheses about the reasons for human behaviour that are established at the outset. Using statistical techniques, the researcher measures the frequency or intensity of a phenomenon and the relationship between variables. Such an approach imposes significant limitations, because the researcher is required to identify in advance what variables will be tested using quantitative instruments such as standardized questionnaires [14].
Qualitative methods are increasingly used in health services research [15-16] to generate detailed accounts of health-related issues [17]. Such methods can provide in-depth information about how something is experienced (such as illness or a treatment approach), how things are done (such as how wards operate), how something is represented by people (relationships between doctors and nurses) or how to bring about change [12]. Qualitative methodology has been used to examine physician-patient relationships, primary care, and novel interventions, and to conduct clinical evaluations.

According to Daly (2007: 44), qualitative studies ‘may illuminate treatment issues, for example, indicating why some patients respond in a particular way to treatment, it is also common for a qualitative study to generate critique of current practice, indicating where standard practice may not be beneficial to one or more groups of people’ [5]. Qualitative research has been widely used to investigate compliance and treatment adherence and a number of specialised approaches, such as ‘post-positivism’ [18], ‘ethno-epidemiology’ and ‘qualitative epidemiology’ have been applied in the drug and alcohol field [19-20] and in the liver transplant area [21-24].

The interpretive paradigm underpins a number of research methodologies, including phenomenology ethnography, case studies, biographical methodology, ethnography and grounded theory (Figure 9.1).
Thematic analysis and theoretical orientation

This study utilized in-depth interview study using thematic analysis to analyze the data. In epistemological terms, thematic analysis leans towards many of the features of phenomenology and grounded theory, making it suitable for both interpretive and positivist approaches [26]. Thematic analysis does not reflect any particular theoretical or epistemological perspective, and no single text or author represents thematic analysis. According to Guest et al. [26], thematic analysis comprises ‘a bit of everything—grounded theory, positivism, interpretivism, and phenomenology—synthesized into one methodological framework. The approach borrows what we feel are the more useful techniques from each theoretical and methodological camp and adapts them to an applied research context’ (p.15). Thematic analysis has been used to organise and ‘make sense’ of unstructured data within a number of paradigms. Lodged between the two poles of essentialism and constructionism, it acknowledges individual meaning, social context and the limits of reality [25].

The theoretical freedom of thematic analysis, therefore, provides researchers with a flexible and
effective means of organising and interpreting unstructured (qualitative) data. It is essential, however, that the theoretical position from which the analysis is developed be made transparent, since each theoretical framework brings with it a number of assumptions about the nature of the data and what they are claimed to represent [25].

In this study the epistemological leaning was towards the interpretive paradigm of phenomenology (which seek to understand the meanings that people give to lived experiences) and to the positivism of grounded theory (in which interpretations are seen to be ‘grounded in’ the data, and which insists that techniques of collecting and analysing data should be systematic and transparent).

Selection and recruitment

Participants were recruited from the Australian National Liver Transplant Unit (ANLTU) at the Royal Prince Alfred Hospital in Sydney, Australia, between September 2009 and May 2011. Participants included those selected for the case control study (Study 1) of this research project and included two extra participants (total 42 participants). It was an ethical requirement that the researcher not directly recruit potential participants. Rather, they were to be referred by the Nursing Unit Manager or medical personnel. Thus the study relied on opportunistic recruitment to some degree but a diverse sample was sought including pre- and post-transplant participants; men and women; those with a diagnosis of ALD and of ALD and Hepatitis C virus; attendees and non-attendees of the outpatient liver clinic; and those who had relapsed.

The student researcher chose to tread carefully and commenced the study with less intensive semi-structured interviews based on the broad topic areas (see below). There were a number of reasons for this. First, the student researcher lacked clinical experience with this patient population, so familiarity had not had a chance to develop. Secondly, the transplant literature had clearly identified the reluctance—even irritation—among alcoholic liver disease transplant participants at the prospect of participating in alcohol interventions and their denial of any problem with alcohol. Thirdly, the majority of patients were dealing with serious health problems, a time consuming and complex medical regime, and time restrictions. Many had to travel from outside the Sydney metropolitan area to attend three monthly appointments. I was conscious of the demands of this
study on the participants and the confronting nature of the subject. Accordingly, data collection was arranged in one session.

Halfway through the recruitment phase, when I had had enough time to become immersed in the ESALD transplant community and gained familiarity with the context and the population [4] more intensive semi-structured interviews were conducted with key-informants and those who had relapsed. Key informants, included those who demonstrated a need to communicate further and elaborate on their experiences in more detail. Participants who had relapsed were purposely sought for another interview. Relapsers who had dropped out of the liver transplant program were specifically recruited for a semi-structured interview which occurred over the phone.

**Data collection and recording**

Interviews are the primary data gathering tool in qualitative research. They allow participants to recall, reflect, and reveal aspects of their subjective experiences and interpretations [40]. There are various forms of research interview (structured, semi-structured and unstructured). In the present study, semi-structured interviews were used. For most participants the interview occurred in the one session for some participants this may have included a two-stage process due to them being key informants or the decision to interview relapsers further.

The interview protocol included a number of open-ended questions about participants’ experiences of alcohol issues and the alcohol management program. It was important to approach the subject of any alcohol use cautiously, especially with pre-transplant participants, who would not feel comfortable reporting any alcohol use as this could jeopardise their place on the waiting list. To overcome this obstacle, potentially sensitive questions were phrased in the third person or in relation to hypothetical situations (e.g. ‘What do you think leads to people relapsing either before or after transplantation?’ rather than ‘What would make you relapse?’). Appendix Interview Guide shows the questions asked in the semi-structured interview, followed by questions utilized in the more in-depth semi-structured interview and exploratory probing questions.
As previously mentioned, a second round of more in-depth semi-structured interviews was conducted with selected participants. Participants were free to respond in any way they chose. Thus the process was more open-ended and free-flowing one, commensurate with participant comfort levels and time constraints. The researcher used listening and mirroring statements to encourage participants to reflect and to elicit additional detail or clarification of issues [20, 40-41]. Following Van Manen’s [42] recommendation, my role during the interview was to keep myself and the participant oriented to the phenomenon at hand and to maintain focus on the participant’s lived experiences.

Participants could choose the location of the interview—either at the transplant unit or at a room in the nearby Drug Health services building. The majority of participants preferred to have their interview at the transplant unit and for it to coincide with their outpatient clinic appointment. A quiet, private room located just outside the busy outpatient clinic was made available for this purpose. One participant, who was known to the nursing unit manager as a patient who did not attend any clinic appointments, preferred to meet at a nearby club.

All interviews were recorded, with the participant’s consent, using a cassette recorder. Written notes were also taken as backup. Interviews were audio-taped and transcribed by the student researcher. After each interview, field notes and preliminary analysis of the participant’s responses to particular questions were recorded [40, 42].

The initial round of interviews lasted between 15 and 30 minutes. As most participants were dealing with health problems and time constraints due to their complex medical regimens, attempts were made to complete the interview tasks for both Study 1 and Study 2 in one sitting and to keep the session as brief as possible. The duration of the second set of interviews was between 30 minutes and one hour. A total of 42 interviews were conducted of these 10 involved more in-depth interviewing.

The student researcher’s lack of direct clinical involvement in the liver transplant program helped to create a neutral environment in which participants were comfortable speaking as freely as they wished. The student researcher was also comfortable with the interviewing process due to her.
extensive experience in assessing and counselling individuals with alcohol use disorders, including situations involving denial, fear of stigma and resistance.

Data handling and analysis

All interviews were transcribed verbatim and all transcripts were then checked for accuracy against the original recordings. A master copy of the interview transcript was kept in the participant’s research file. Another copy, formatted with double spacing, wide margins, and page numbers, was used for analysis.

Throughout the project I also used a research diary to record my observations and reflections on the research process and emerging ideas. The transcript file contained raw data from the interviews. Memos or field notes were not typed but were available for review in hard copy when needed during the analysis. All data belonging to a particular participant were stored in a folder labelled with the relevant pseudonym. All folders and audiotapes were stored in a locked filing cabinet. A folder was created for each participant on a password-protected computer, and all data belonging to that participant were stored there.

Thematic analysis is the most widely used method of analysing qualitative data within the fields of sociology, psychology and public health. According to Braun and Clarke (2006), it is a technique for: ‘identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic’ [25] (p.79).

There is no clear agreement about what thematic analysis is and how it should be implemented [25]. Some of the phases and tasks of thematic data analysis are similar to the phases of other qualitative research. In broad terms, the process of thematic analysis involves: familiarising oneself with the data, identifying possible codes, generating themes, reviewing, comparing and contrasting themes and constantly checking these constructs against the data [25-26]. The endpoint is a report
of the content and meaning of patterns (themes) in the data.

The present study followed the analytic procedures outlined by Strauss and Corbin [14]. These comprise: data immersion, coding (open and axial), creating categories and identifying themes. It did not, however, fully conform to the methodological requirements of grounded theory. It was an exploratory study conducted with limited time and resources, so theoretical saturation was not attempted. At the same time, the thematic analysis did not involve merely a semantic content analysis of data. I used a latent approach that sought to identify the underlying ideas, assumptions, and conceptualisations that informed the semantic content of the data [25]. Therefore the development of themes did involve interpretative work, and the analysis moved beyond description towards theory development.

Data immersion involved listening to and transcribing the interview recordings, reading and re-reading the interview transcripts, diary keeping, memos, discussions with staff, and engagement in follow-up counselling with some participants who requested it after they had completed the study.

Coding is a formal process of examining and organizing the data from each interview and for the whole data set. Coding involves sorting and tagging data ‘bits’ (paragraphs, sentences or words) with descriptive labels (codes). In this way, key concepts can be identified while the context in which these concepts occur is taken into account [15, 35]. Two steps are involved in this process—open and axial coding.

Open coding was conducted on four transcripts to get an idea of the range and scope of codes that were present in the data. The coding process was undertaken independently by both the researcher and academic supervisor. Both read the transcripts and developed the code and came together to consult and discuss the agreed codes.

Coding involved examining, breaking down, comparing, conceptualizing and, eventually, categorizing the data. The transcripts were examined line by line, sentence by sentence, and paragraph by paragraph and codes of two to four words were attached to relevant segments. The codes, which were written beside the content in the margin area, provided a descriptive label for
what was being said, or for incidents, ideas or events. Loosely conceptualized, general categories 
were also identified at this point.

In axial coding, the main tasks are to locate the codes within subcategories and relate subcategories 
under a single category. According to Strauss and Corbin [14], open coding fractures the data and 
allows the researcher to identify some categories, their properties and dimensional locations. Axial 
coding puts the data back together in new ways by making connections between a category and its 
subcategories. It is at this stage of data analysis that descriptive labels or codes are raised to a 
conceptual level. The model proposed by Strauss and Corbin was used to identify the conditions, 
context, action/interactional strategies and consequences inherent in the codes. From this, 
subcategories can be formed and these begin to specify the features of a category, giving it 
precision and allowing for variation and depth of understanding. According to Strauss and Corbin 
(1990: 90), ‘The discovery and specification of differences among and within categories, as well as similarities, is crucially important and at the heart of grounded theory’.

The next step was to examine how codes can be linked in order to create coherent categories [35]. Categories were formed from codes that were logically related, that is, based on similar events, properties, attributes or consequences. The name of the category or subcategory came either from 
key words in the literature or from expressions used by the participants themselves (so-called in vivo codes). Once the scope and details of the codes and categories were identified, all transcripts were then open coded in this fashion.

Each category was examined in terms of its conditions, consequences, processes and relationship to other conceptual categories. The core category was selected on the grounds that it was sufficiently abstract to encompass and relate systematically to all the other categories in terms of conditions, context, strategies, and consequences. The core category has the following features: it frequently recurs in the data; it is linked with other data; it has explanatory capacity; it has verification in the literature; and it allows for variation in the experiences of most participants. After the core category had been identified, other categories were related at the dimensional level and relationships between categories were validated against the data. Categories needing further refinement or development were identified [14].
The final step was to identify themes. According to Braun and Clarke:

A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set. Furthermore, the ‘keyness’ of a theme is not necessarily dependent on quantifiable measures – but in terms of whether it captures something important in relation to the overall research question. [25] (P.82).

Themes are general propositions that emerge from the diverse and detail-rich experiences of participants. They evolve from the conceptual codes and sub-codes and are suggestive of a relationship between codes [15]. The generation of themes is not purely a process of describing a range of categories; it involves shifting to an interpretation of the issue under investigation [35]. The generation of themes requires testing the explanation both with the data and with the theory, with specific reference to the theoretical concepts relevant to the study.

**Ethical considerations**

The main ethical considerations in the study were those of informed consent and participant privacy and confidentiality. Informed consent is defined by Sim [38] as the ‘voluntary and revocable agreement of a competent individual to participate in a therapeutic or research procedure, based on an adequate understanding of its nature, purpose and implications’ (p.584). In this study, the key elements of informed consent were: providing information about the research; ensuring comprehension of the information; voluntary participation; and the freedom to withdraw at any time without adverse consequences [39].

All participants were given a flyer (Appendix X) introducing the study by referring transplant staff. If they agreed to be contacted, they were provided with an information sheet (Appendix Y) that explained the aim of the research and what their participation would involve. The information sheet was written in a simple, jargon-free style and provided the researcher's contact details. I ensured that all participants had the opportunity
to ask questions and that they were fully aware of their right to withdraw at any time. Written consent (Appendix Z) was obtained from each participant before data collection commenced. There was no special relationship or power imbalance between the researcher and participants that could be perceived as coercion. Participants received a $20 gift voucher at the end of the interview as a token of appreciation.

Patients were excluded if they declined or were unable to give consent (for example, if they were suffering from encephalopathy) or if they indicated a belief that participation would improve their place on the waiting list. At the time of interview, participants were reminded that they could ask for the audio-tape recording to be switched off at any time.

Confidentiality and anonymity were maintained through the use of pseudonyms on all files and by changing any potentially identifying contextual details in the final report. Data were stored in a locked filing cabinet in a locked office at the Drug Health Services Research Department. Data will be stored for seven years before being disposed of, in accordance with the requirements set out by the University of Sydney's ethical guidelines for research involving humans.

**Quality assurance**

Many qualitative researchers have been reluctant to provide prescriptive criteria for judging the quality of their research. As a result, evidence from qualitative studies is not routinely incorporated into systematic reviews in the health field [5, 35]. A team of Australian researchers has developed a set of criteria for assessing the capacity of four different qualitative research methods to provide evidence for practice or policy in health and medicine [5]. This is displayed in Figure 9.2 and Table 9.1
Figure 9.2. A hierarchy of evidence-for-practice in qualitative research study types and levels [5].
Table 9.1 A hierarchy of evidence-for-practice in qualitative research – summary features [5].

<table>
<thead>
<tr>
<th>Study type</th>
<th>Features</th>
<th>Limitations</th>
<th>Evidence for practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generalizable studies (level I)</td>
<td>Sampling focused by theory and the literature, extended as a result of analysis to capture diversity of experience. Analytic procedures comprehensive and clear. Located in the literature to assess relevance to other settings.</td>
<td>Main limitations are in reporting when the word length of articles does not allow a comprehensive account of complex procedures.</td>
<td>Clear indications for practice or policy may offer support for current practice, or critique with indicated directions for change.</td>
</tr>
<tr>
<td>Conceptual studies (level II)</td>
<td>Theoretical concepts guide sample selection, based on analysis of literature. May be limited to one group about which little is known or a number of important subgroups. Conceptual analysis recognizes diversity in participants’ views.</td>
<td>Theoretical concepts and minority or divergent views that emerge during analysis do not lead to further sampling. Categories for analysis may not be saturated.</td>
<td>Weaker designs identify the need for further research on other groups, or urge caution in practice. Well-developed studies can provide good evidence if residual uncertainties are clearly identified.</td>
</tr>
<tr>
<td>Descriptive studies (level III)</td>
<td>Sample selected to illustrate practical rather than theoretical issues. Record a range of illustrative quotes including themes from the accounts of “many,” “most,” or “some” study participants.</td>
<td>Do not report full range of responses. Sample not diversified to analyze how or why differences occur.</td>
<td>Demonstrate that a phenomenon exists in a defined group. Identify practice issues for further consideration.</td>
</tr>
<tr>
<td>Single case study (level IV)</td>
<td>Provides rich data on the views or experiences of one person. Can provide insights in unexplored contexts.</td>
<td>Does not analyze applicability to other contexts.</td>
<td>Alerts practitioners to the existence of an unusual phenomenon.</td>
</tr>
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These and other qualitative researchers in the health field have described the standards and practices that are required for a high quality, well-developed, generalizable interview-based qualitative study [4-5, 16, 35-36]. These can be summarized as follows:

i. A comprehensive literature review is essential. This provides the conceptual framework for the research problem structures the study design and informs the process of sampling and data collection.

ii. A grounding in sociological concepts and theory is required because human action takes place in a social context.

iii. Diversification and intensification of sampling and data collection is necessary in order to explore the diversity of the sample, to search for cases that do not fit the developing conceptual understanding and to identify the analytical point at which additional conceptual categories are required.

iv. Data analysis should involve a rigorous, systematic and essentially taxonomic process of sorting and classifying data. At the same time, the researcher should maintain a focus on understanding the meanings in the data based on the full range of accounts and explaining the conditions under which exceptions occur.

v. Relying on de-contextualized illustrative quotations that are not embedded in the overall analysis of the data set reduces the quality of a research study. It is important to provide the methodological detail necessary to exclude bias or impressionistic description and to demonstrate how well the identified issue/s are represented in the whole data set.

vi. Generalizability of the findings is determined with reference to the pertinent literature (i.e. how the study’s findings relate to other settings or groups). Qualitative studies identify themes by linking the observed categories with social theory until an overriding explanation is reached. This justifies the application of the study’s conclusions to other social contexts and groups.

Daly [5] points out that not all qualitative research can reach this standard, given the demands involved in an ‘ideal’ study. Many health-related studies fall short of the ideal processes for
producing generalizable results. This may be due to poor research practice, poor reporting of well-designed studies, lack of funding for data saturation, accessibility of participants, and/or a lack of understanding of social theory or of the literature so that theories and concepts do not fully frame the research process.

Verification in qualitative studies is dependent on the rigorous use of systematic methods of data collection and analysis. Throughout the present study, the student researcher strove to maintain rigour and validity by systematically following the grounded theory approach. This involved detailing the philosophical underpinnings of the chosen paradigm and approach and aligning this with the chosen methods of data collection and analysis. Proposed relationships were supported over and over again in the data even though the particulars of each participant’s experience may have differed. Theory development was limited to the categories, their properties and dimensions and statements of relationships that existed in the data. The researcher engaged in a constant interplay between proposing and checking. The use of an independent analyst and feedback from those working in the field helped to validate the applicability of findings to the wider context of liver transplantation and the experiences of alcoholic liver transplant participants.

In qualitative research, credibility refers to the trustworthiness of the findings [6] and the extent to which they vividly and faithfully describe the phenomena [37]. The strategies used to ensure the credibility of the study included rigorous and systematic data collection and analysis through which the voices of participants emerged in all their complexity and were sensitively interpreted in relation to the developing theory. The researcher was also alert to the possibility that theoretical frameworks derived from conventional drug and alcohol settings could affect one’s interpretation in the setting of a transplant unit.

Credibility in qualitative research is also enhanced by authenticity. Authenticity is evident when the theory demonstrates a range of realities, thus presenting a fair and consistent view of the patient population. This is strengthened when the multiple constructions and interpretations of events and experiences show consistency with the philosophical underpinnings of the interpretive paradigm [7]. Transferability is also indicative of credibility. This means that findings can be applicable to similar settings and contexts [37].
Reflections on using a mixed method approach.

As described earlier a gulf appears to exist between qualitative and quantitative research, with each belonging to distinctly different paradigms thus the movement between the paradigms can be difficult throughout different phases of a research project. For example data collection and analysis using a quantitative approach relies on the use of questionnaires and scale using deductive reasoning, and more descriptive analysis of incidence and frequency. While qualitative involves the self as instrument involving flexible and reflexive practice, participant observation, and reflexivity. Data analysis consists looking for patterns of inter-relationships, dealing with concepts and categories

For the researcher a great deal of flexibility was required and a number of pragmatic consideration, and practical constraints. The tension that that a mixed method project can induce was also alleviated by maintaining very clear boundaries regarding the differences between the research approaches in order to avoid confusion and contamination of the processes and equal weight given to both projects. Being organized as a research and diligent to each project individually was important. Knowing that in the study of psychosocial experience there is no one truth and human experience is multi-faceted helped deal with the theoretical divide. All data captures the subjective perspective whether one uses questionnaires or interviews which are not the objective neutral and scientific instruments they claim to be. Therefore the two approaches integrate at this level At the level of data analysis and discussion there are different explanations and flexibility is required. Daly would argue that there is a place for post-positivist elements in qualitative studies as diversification and intensification of sampling and data collection is necessary in order to explore the diversity of the sample. Certainly the political perspectives and values which drew upon sociological theory was challenging especially when the project was set within a medical setting, organization of the research team, and the subject was considerably controversial. A mixed method approach certainly makes the researcher work hard at understanding the relationship between theory, methods and data and to consider the relationships between the data sets created by different methods.

Conclusion

A qualitative in-depth interview study was selected in order to capture the lived experiences, attitudes and interpretations of ESALD transplant participants of the alcohol management program. The aim of this study was to identity factors contributing to resistance to alcohol treatment by ESALD transplant participants. Semi-structured interviews were conducted among 42 participants exploring
broad topic areas to do with abstinence, relapse, treatment seeking and the alcohol management program provided by the liver transplant program. A diverse population of ESALD transplant participants contributed to the study. Method of data analysis consisted of thematic analysis outlined by Strauss and Corbin whereby themes were identified within the data set.

The following chapter will present the data collected from this in-depth interview study.
REFERENCES


CHAPTER 10
Management programs for ESALD transplant candidates patient experiences

‘Alcoholism is a disorder of remission and relapse, and some recurrence of drinking by alcoholics who have undergone liver transplantation is to be expected, no matter how stringent the selection process…. Abstinent patients with alcoholic cirrhosis often resume drinking, even after a life-threatening decompensation or liver transplantation.’ Dureja & Lucey [1] (p.761-762)

‘These data suggest a powerful urge to drink exists in some patients with alcohol-related cirrhosis at risk of life-threatening decompensation. Apparently, neither variceal hemorrhage, distal splenorenal shunt, transjugular intrahepatic portal systematic shunt or risk of losing access to liver transplantation are sufficient of themselves to induce and sustain abstinence.’ Weinreib [2] (p.545)

‘Although undergoing liver transplantation can be viewed as a traumatic learning experience for the patient with ESALD, it is clearly insufficient to promote abstinence and the risk of returning to alcohol consumption remains.’ Tang [3] P.144

The current study interviewed 42 ESALD transplant patients. Of these, 30 were interviewed using a structured interview and 12 using a semi-structured, more in-depth interview. The qualitative data obtained from the combination of structured and semi-structured interviews are discussed in this chapter.

Characteristics of the participants

The majority of participants were men (35/42), the average age was 57 years, with more than half of the
group (26/42) married or in a stable de-facto relationship at the time of the interview. Virtually all (40/42) reported stable housing for more than 2 years. In terms of educational background, 22/42 had the equivalent of the School Certificate, 7/42 Higher School Certificate, 5/42 TAFE qualification and 8/42 had University education. Of the participants, 29/42 had a diagnosis of ALD, 13/42 had a diagnosis of ESALD/HCV and of these 11 had a history of intravenous drug use.

Of the total participants, 16/42 were pre-transplant participants and 26/42 were post- transplant participants. Post-transplant participants ranged from three months to sixteen years post transplant with the median number of years being five. The median time on the waiting list for both pre- and a post-transplant candidate was 8.5 months with a range of two months to 3 years. The majority of participants (27/42) reported being able to abstain but over one third (15/42) returned to alcohol use, with 10 of these relapsing to heavy drinking (over 6 standard drinks per day).
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Mean age : 57</td>
</tr>
<tr>
<td></td>
<td>Range : 45-70</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Males : 83% (35)</td>
</tr>
<tr>
<td></td>
<td>Females 17% (7)</td>
</tr>
<tr>
<td><strong>Number of pre-transplant participants</strong></td>
<td>16 (38%)</td>
</tr>
<tr>
<td><strong>Number of post-transplant participants</strong></td>
<td>26 (62%)</td>
</tr>
<tr>
<td><strong>Median years post-transplant</strong></td>
<td>5 years</td>
</tr>
<tr>
<td></td>
<td>Range (3 months – 16 years)</td>
</tr>
<tr>
<td><strong>Median period on waiting list</strong></td>
<td>8.5 months</td>
</tr>
<tr>
<td></td>
<td>Range (2 months to 3 years)</td>
</tr>
<tr>
<td><strong>Diagnosis of ESALD</strong></td>
<td>29 (69%)</td>
</tr>
<tr>
<td><strong>Diagnosis of ESALD/HCV</strong></td>
<td>13 (31%)</td>
</tr>
<tr>
<td><strong>Number reporting abstinence (including the occasional celebratory drink)</strong></td>
<td>27 (64%)</td>
</tr>
<tr>
<td><strong>Number reporting return to any alcohol use</strong></td>
<td>14 (33%)</td>
</tr>
<tr>
<td><strong>Number reporting relapse to harmful drinking (above 140g ethanol/week)</strong></td>
<td>10 (23%)</td>
</tr>
<tr>
<td><strong>Years post-transplant abstinence before relapse</strong></td>
<td>Average 1 year and 10 months</td>
</tr>
</tbody>
</table>
Participants who had relapsed to heavy alcohol use, compared with abstainers (Table 10.2), were significantly less likely to have a partner and a social support network, and more likely to have had a formal psychiatric history or current psychiatric problem. There were no significant differences between relapsers and abstainers related to familial history of alcohol problems, housing stability and education level.

Table 10.2. Socio-economic and psychiatric history of successful abstainers and relapsers

<table>
<thead>
<tr>
<th></th>
<th>Family history of alcohol problems</th>
<th>Housing Stability</th>
<th>Presence of Partner</th>
<th>Past or present psychiatric history</th>
<th>Social Support network</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstainers*</td>
<td>22 (66%)</td>
<td>31 (94%)</td>
<td>23 (70%)</td>
<td>5 (15%)</td>
<td>30 (91%)</td>
<td>22 (69%) SC</td>
</tr>
<tr>
<td>(n = 32)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapsers</td>
<td>7 (70%)</td>
<td>9 (90%)</td>
<td>3 (30%)</td>
<td>6 (60%)</td>
<td>6 (60%)</td>
<td>5 (50%) SC</td>
</tr>
<tr>
<td>(n=10)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

Thematic analysis of interview data

The essence of the ESALD transplant participant’s experience of the alcohol management and liver transplant program is expressed in five themes which include:
The contract: ‘a gift with conditions’

Subthemes included:

Conformity to the contract – degree of conformity, degree of difficulty, degree of disclosure, breach of contract, participant response to breach, awareness of contract.

Participant attitude to contract – ethics, gratitude, personal responsibility and critique of contract.

Staff attitude and influence regarding the contract and breach of contract

Abstinence: a do-it-yourself process

Subthemes:

Motivation facilitating abstinence – self-motivation, personal responsibility, reward of life, contract, end-stage liver disease

Maintenance of abstinence – degree of difficulty, family support, staff monitoring, relapse prevention skills, self-transcendence, mobilising social resources

Resistance to alcohol treatment

Denial of relapse

Relapse

Subthemes – personal responsibility, triggers to relapse, guilt, family and social support, public opinion and staff reaction, personal choice and the contract

Fear of stigma

Subthemes – label of ‘alcoholic’, personal shame, failure and responsibility, alcohol treatment, fear of disappointing staff, fear of penalty
No available and suitable alcohol support program-

Subthemes – ‘gap in the program’, lack of candor, living with chronic illness, wholistic perspective, ‘wanting to talk to someone’

Each of these themes is discussed below and key subthemes are selected. All of themes and sub-themes were in some way connected with the theme of ‘the contract’.

Appendix F contains Table 10.3 which provides a quantitative table showing the number and percentages of ESALD transplant participants (abstainers, relapsers and total group) and their responses to the semi-structured interview questions.

i) The contract – ‘a gift with conditions’

‘The contract’ was the most influential factor in participants’ experience of the management programs for transplant patients with alcohol-related liver disease. It involved a verbal agreement or understanding made with transplant staff for a period of abstinence (as a condition of candidacy for a liver transplant) followed by long term stable abstinence (apart from the special and occasional celebratory drink which was an agreed part of the contract). It was a covert category which was only indirectly referred to in the structured interviews and more explicit in semi-structured interviews. This category was intricately linked to other categories and themes. The contract is in force throughout the pre and post-transplant period. Participants noted that it was referred to and spoken about by transplant staff. Compliance with the contract was regularly monitored by staff who monitored compliance with it regularly. Participants referred to it as being written in the ‘blue book’ (the liver transplant patient information booklet). One participant reported a written contract although this was not a practice adopted by the Australian National Liver Transplant Unit (ANLTU) where the study was conducted.

The majority of participants interviewed (40/42) were aware of the contract of abstinence. They stated explicitly that they understood the importance of long term abstinence as a condition for transplantation in order to ensure positive transplantation outcomes and to preserve the healthy functioning of the new liver.
Participants were aware of the contract not only in terms of its important medical function and utility but also the social or ethical responsibility associated with receiving a scarce and life giving public resource.

The management of patients’ alcohol use by transplant staff revolved around compliance with the contract. The majority of participants referred to methods used by staff to monitor their drinking and ensure their compliance, including regular blood analysis (20/42) and questions by staff at clinic appointments regarding their alcohol use (18/42).

The following quotes illustrate the program’s emphasis on strict abstinence:

*Every time I go there they ask me if I have been drinking. It is a recurring theme. You are constantly mindful of the fact that they do not want you to drink. I think they have a duty of care to the organ donor family to make sure that the organ is treated with respect.*

Daniel

*Staff were totally against alcohol. It was always in the air that it (drinking) was frowned upon*

Bruce

*They have mainly been interested in me staying on the straight and narrow (abstinence)*

Pat

*There is pressure to not drink. Everyone I know would give me a kick up the backside. It is not an easy thing to hide anymore. Everyone would have a go at me. The pressure is positive though*

Matthew

A strong sense of moral and social obligation was associated with the theme of the contract. As participants (25/42) felt an obligation for being selected or for having received the ‘gift of life’. This obligation involved a number of relationships: the donor’s family, the deceased donor, transplant staff who worked tirelessly to preserve the patient’s life, the hospital, the patient’s own family and finally, the participant him/herself. Maintaining abstinence was seen as a way of repaying the gift. The shame or self-disgust for not being able to abide by the contract was evident in the transcripts of relapsers.
The following extracts illustrate the moral and social obligation expressed by participants for having received organ transplantation:

*If you give in (relapse), it is a breakdown of your whole moral fibre, to me. 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 behaviour. There are stressful things you go through when you have a transplant. There are times when you think about going back to drinking. The obligation stops you from drinking. It is a gift with conditions and I have accepted those conditions.*

Daniel

*They said you were not to drink. I signed a thing that said I would not drink but that went through the roof, but when I woke up after the transplant I recognized I do have a responsibility and that is when I did take it seriously*

Douglas

*The expectation is lifelong abstinence and I think this is stressed because of the donation rate being very low. 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.*

Natalie

*A lot goes into this investment in doctors, nurses, psychologists, psychiatrists. Someone has given an organ up for me and you yourself have gone through so much to get to that point. If that is not motivation enough I don’t get it. If you fail you feel that you have let so many people down not just yourself. RPAH transplant staff, your own medical people, your family, you have disappointed all of them and I am sure they would say something about it. Even though you don’t know them the donor and their family you have let them down. If you fall over you go back to alcohol or drugs because you have let so many people down ...I wouldn’t have the strength to come back and ask for help because you would be basically saying you are not worthy that’s all....* 

Mathew

For the majority of relapsers this moral and social obligation surfaced as intense guilt for having failed to abide by the contract – a theme which will be discussed further on in this chapter.

**ii) Abstinence as a do-it-yourself process**
End-stage liver disease is a powerful motivator for behavioural change with all participants reporting the decision to abstain from alcohol with the diagnosis of end-stage liver disease. Participants tended to recall an immediate heightening of their consciousness when their transplant doctor informed them about the terminal nature of their condition and the necessity for abstinence and transplantation. The experience of pain and illness, the threat of death and the desire to live and connect to others resulted in a powerful and focal incentive to stop drinking.

Many participants spoke about the importance of living longer and maintaining good health in order to see their grandchildren or children grow up. When participants became fully aware that further drinking would lead to their mortality, they described having to seriously and swiftly weigh up whether they were prepared to fully commit to an abstinent lifestyle. This change was also solidified and supported by the medical demands of transplantation and ‘the contract’ with transplant staff.

The following extracts describe the motivation for change:

*The specialist told me if I was to have another drink I would be dead so I didn’t have any more to drink. I believed him because I was crook as a dog at the time.... It wasn’t difficult for me. They (the doctor) said don’t drink. So I didn’t drink*  
Geoff

*My health was suffering and I lost the urge to drink and to self-medicate. I was concerned about my liver and general health; my bout of encephalopathy and waking up in hospital scared me. I had passed out; it was disturbing, a crisis for me and then I found out I had liver disease..... However having an 11 year old daughter is worth living for and to have a father who dies on her is a prime reason for trying to continue to live and not drink. My attitude now is I am not interested in drinking ever again because it has been quite a while since I have stopped*  
Miles

*Well that really woke me up because if someone tells you, ‘If you don’t stop what you are doing, you are going to be dead’. Well that sort of puts everything in perspective; it was like being wacked in the chin’. I just thought about my grandchildren and what I would be missing out on*  
George
I think it finally sunk in how much damage I was doing. They could tell me until I was blue in the face before but I think I thought I was invincible...but I had so many blackouts in a row and put in intensive care and that wasn’t very nice because most of my life was in hospital. I think the day when the doctor told me I would be lucky to see another Christmas it was then that it sunk in. That it was bad enough (liver) that I would die and that was when it sunk it....it was only until he came in and blurted out like that. That gave me real quick wakeup call and you never look back after that. I wrote that doctor a letter and told him I was grateful to the team and that I was thankful to him because he scared the daylights out of me.

Erica

For 27/42 participants there were no difficulties in achieving total abstinence as requested by the liver transplant unit. (This included pre transplant candidates). These participants reported no need for treatment due to their sobriety, motivation and self-efficacy. The majority also reported not having experienced any cravings or compelling urges for alcohol and related the lack of cravings to being too sick and preoccupied with the medical demands of transplantation. For many, past drinking behaviour was seen as a result of habit and socially learnt behaviour.

Successful abstainers reported some difficulty in the beginning with the initial change to a non-drinking lifestyle when having to deal with social situations however many persisted in establishing a normal life as much as possible. Once over this initial hurdle, abstinence was felt to be achievable.

I gave up drinking four years ago due to liver problems. I had no problems stopping for the liver transplant and after. I still go out and socialise with friends but I drink soft drink. There are times when I think about drinking but I can’t do it, I have a strong will. Not drinking is part of my life and I have stopped drinking with mates. Abstinence has not been difficult. I didn’t drink to get a high, just to relax after work. It is harder for my friends to go along with my change than for me, so it can be hard in social situations.

Ken

The majority of abstainers demonstrated individual responsibility and competency in being able to successfully change and used relapse prevention principles and skills (see below) maintained over a long period of time. Participants emphasized the use of will power, firm decision making, and the strength of personal resolve to maintain change. This was reported by 23/27 abstainers. This approach is characteristic of the cognitive processes found to be essential in the stages of change resulting in positive and enduring behavioral change. Most participants quietly acknowledged the role of alcohol in contributing to ESALD. Some spoke about their
propensity for rapid dependence if they were to drink and expressed regrets for not having realized the health risks associated with harmful drinking before the development of cirrhosis.

**Relapse prevention skills**

Relapse prevention skills used in initiating and maintaining abstinence by those who had not relapsed to heavy drinking included avoiding or learning to adapt to high risk social situations in 21/32 abstainers and adopting consequential thinking to managing cravings or thoughts of drinking in 18/32. Again these skills show how ESALD transplant participants adjusted to their chronic illness and self-managed.

The following examples illustrate the effective use of relapse prevention skills

*I approached stopping drinking the same way I stopped smoking.... I said I will never have another drink. I have an addiction and if I give in to the temptation I would likely have another drink and become addicted. I would lose all the health benefits I have gained. Everyone in my family has been supportive and understanding. They know I can’t drink.*  

_—Gavin_

*I don’t think the challenge ever goes away but some days are easier than others... I could be fine but then I don’t know what triggers it off (cravings). But I think about what I have put people through, my wife, my daughters and the transplant. I don’t want to throw this away (the new liver). The hepatitis C is still in my liver and I am going to fight that sort of thing. But if this liver goes or deteriorates it is because of a disease I can’t beat not because I am sitting in a hotel chair throwing schooners down my throat because I can’t handle society, or I can’t handle the cards I have been dealt. And that is what is making me strong.*  

_—Douglas_

Many drew on their moral obligation to ‘the contract’, transplant staff and family as a way of combating cravings and this was endorsed by 16/32 of participants as a method of maintaining abstinence. Life threatening illness and transplantation triggered a strong moral and social connection to others which had meaning and value, different to their pre-transplant life.
I stopped at the bottle shop and I looked in and I thought ‘will I, won’t I, should I, should I not have it?’ I stood there and said ‘No, you have been given this wonderful opportunity and I am straight now and I am not going to do it. I can’t hurt anybody and not myself. I feel obligated to the hospital, to the doctors; to everybody that has helped me; to my partner the kids who have put up with me Pat

Apart from occasionally you smell a beer and you would love one, but, as I say someone lost their life for me.... you can’t get rid of having thoughts or urges they are in there, but I think I always think about the person that lost their life for me; there is no greater gift than life for anyone to give. I am not going to jeopardize that. Douglas

(by drinking)...I would be disrespecting the person who has done this for me. I feel very strongly about this. This person has died and the family has given me this precious gift and that would be a slap in the face if I turned around and starting drinking. You have no idea how I feel towards them. I wrote a letter and wrote a beautiful letter and cried all the way through it and I said to them all the happiness that they had given us we know the heartache they have been through and Christmas day I cried for them. And wondered what they were going thorough. They have given my kids a mother and one day they will have a grandmother. Every day I used go out and see other people with their grandchildren and I thought I will not be there for this. I feel so grateful and I would not do anything to disrespect that gift I have been given. It is a pretty amazing gift. People say what is your best Christmas present and what do you think I say it was being given life. And my kids were so grateful. Well someone up there is watching over them. Erica

Self-transcendence

Many participants described the experience of self-transcendence as they adjusted to their life-threatening crisis. Of the abstainers, 9/32 referred to the positive benefits derived from abstinence. They spoke of an epiphany they experienced as a result of transplantation and their near death experience which positively reinforced their resolve to abstain. The epiphany consisted of a change in their world-view, attitude to life and personal relationships, and could occur either in the pre- or post-transplant period. In this psychological state, participants were able to process their existential anxieties, gained relief from the physical pain, illness and even any distress associated with transplantation. After transplantation, participants described finding greater fulfillment in personal relationships, a greater vitality for living, empathy for others, relief from negative behaviors such as
overworking, and finding satisfaction in alternative life activities which had replaced drinking. The following extracts give examples of the epiphany and its positive role in enhancing the quality of life of some participants

*I now look forward to the time I have with the family. I became a grandfather three weeks ago and all these things I would not have seen. There is another driving force. My granddaughter has just been born I hold her in my arms I don’t want to drink. I want to hold her in my arms until I can’t hold her anymore. I appreciate my life more now than I ever did*  

George

*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. Like a baby is born again you see life in totally different eyes*  

Anthony

*I have never tried to explain it, it is very surreal.... Once you get over the majority of the physical pain and discomfort then you have this spark of life and get back into it and you want to get into it......I was just ready to jump out and tackle the world and they said just be careful if you have a downer just take it easy.*  

Mathew

This experience of self-transcendence also involved a change in self-identity and self-renewal.

*I have changed a lot. I think I am a much better person. I am much happier with myself. I am sure there is a long way to go.*  

Miles

*Your whole attitude is changed and your attitude to life is changed. Your values are different things; I used to take things for granted you don’t take for granted anymore. I used to be cranky and irritable but that was just the alcohol. I think I am a lot calmer now and I am a lot more at ease with myself.*  

Daniel

*The whole world has opened up. I am like a new person in my life. I used to look terrible, all skinny and sunken with a big stomach. I hated going out.. Everything is so good I keep getting all this good karma coming to me. Everybody has said I am like a new person. They say to me you look ten years younger you are so much more outgoing. The kids have said ‘you have come out mum, you are such a better person’. ....Now I do everything with them (children) I go to coffee with friends, I go out to*
Whilst successful abstainers talked at great length about the use of will power and individual responsibility required for the change, it was apparent - and acknowledged by participants - that social support, especially of a partner and that of the transplant team was critical in their success. Reaching out for support from family or friends occurred among 21/32 of participants while 7/32 relied solely on friends and NA/AA support. This issue is explored further below in this chapter under the heading psychosocial resources.

**Relationship with transplant staff**

The development of a strong rehabilitative relationship with transplant staff was also helpful in maintaining abstinence. The large majority of participants described a ‘special’, ‘positive’ and ‘helpful’ relationship, especially at those times when they were in extreme pain and distress. This was a two way process characterized by intensive support by staff and specialized medical care throughout transplantation, and unconditional trust by patients in staff. Staff provided ongoing support, encouragement and motivation for patients’ abstinence. Participants referred to staff as almost like family:

*They were fantastic down here, the aftercare I got in that ward was absolutely fantastic, the nursing staff they were so beautiful... I was crying all the time and when they took the catheter out I was having a spasm in my bladder from a urinary infection that was there all the time. I was just at breaking point and they got me through it, Dr. I was so grateful to him he came and saw me and put me on three lots of medication and then I slept from then on. And got better and better. The team here are fantastic and if I have any worries I can just ask could I see a doctor.*

_Erica_

*The staff here are brilliant. The whole Royal Prince Alfred Hospital (RPA) is a wonderful organisation, ....run by caring people. You don’t call the doctor ‘doctor’, it is Simone. They are part of your family as well. I trust this place. They see the worst of you and then they see the best of you. Everyone cares. Margaret and Simone are brilliant, they are my family.*

_Douglas_

*There has been nothing but pure excellence from all staff.*

_Ron_
Mobilizing social resources

As mentioned previously (see Chapter 2), there is some evidence to suggest that those able to mobilize and harness social resources over the course of liver transplantation experienced greater self-efficacy and immunity to relapse, making them the ideal candidates for liver transplantation. As noted in Table 10.2 and based on thematic analysis, abstainers described good social support throughout both the pre- and post-transplant periods, more likely to have a supportive partner compared to relapsers and less likely to have had a formal psychiatric history or current psychiatric problem. ESALD transplant participants when asked which factors could contribute to relapse 21/42 reported personal problems, life stressors and depression to be a key factor.

Treatment resistance amongst successful abstainers

Amongst abstainers, 22/32 stated that they believed that alcohol treatment was unnecessary or unwarranted due to the fact that they had successfully achieved abstinence through their own individual efforts. Many participants spoke about needing a medical rationale for alcohol treatment from their transplant physician before they would consider compliance or engaging in treatment. The retrospective account of relapsers also described their early confidence that they would never return to drinking. These quotes reflect the personal confidence of successful abstainers:

... 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 that myself. I don’t need treatment I have managed to stop drinking on my own

Gavin

Those that are not drinking ....what would they be treated for?

Lisa

If people have solved the problem themselves, then obviously they don’t need help. 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. If you don’t have a broken leg why put a splint on it?

Ron

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.  

Jennifer

Many successful abstainers reported that they would comply with a medical prescribed alcohol treatment program if it was necessitated by their transplant physician.

**Denial of relapse**

One of the major concerns observed whilst interviewing ESALD transplant participants was the lack of acknowledgement that relapse could be possible. When asked how they would deal with the possibility of a relapse, virtually all abstainers hesitated and paused for a considerable period, being unable to provide an answer or possible strategy. Many reiterated that they strongly believed they would never relapse.

**iii) Relapse**

As mentioned earlier, successful compliance with the contract of strict or stable abstinence was not the experience for all ESALD transplant participants. Of the total number of participants, 15/42 could not adhere fully to the contract reporting some alcohol use with 10 of these relapsing to harmful alcohol use (4/15 relapsing during the pre-transplant and 11/15 during the post-transplant period). Post-transplant relapsers, in reflecting on their history, believed that they had made a strong commitment to abstinence and remained dismayed by their relapse.

The reasons provided by ESALD transplant candidates for their relapse to harmful drinking tended to involve a combination of physical and psychosocial difficulties. The majority of relapsers (6/10) experienced the loss of a support network after transplantation. This generally involved the loss of a partner due to divorce 4/10, the experience of marital difficulties 1/10; 5/10 had relied on AA or NA and friends. Reference was also made to the difference in staff attention once the transplant was over and having to rely on one’s own resources. The lack of a support network after the transplant and the need to be ‘alive again’ and to belong, contributed to a return to a social life associated with heavy drinking. Even successful abstainers, when asked what could contribute to a
relapse, identified a lack of family support, psychological and personal problems and social pressure to drink as a main trigger for relapse.

Mental health problems, specifically depression in the post-transplant period and anxiety in the pre-transplant period, were described by 9/10 of relapsers as a factor associated with their relapse. The experience of depression and relapse was associated with: ongoing medical problems, difficulties adjusting to changes and stressors associated with transplantation, loss of confidence about one’s health, longevity and self-efficacy in the world. Some participants reported the experience of financial difficulties and role loss as a breadwinner, wanting to return to the old social network and difficulties coping with negative life events.

The following extracts exemplify the ‘biographical disruption’ created by a stigmatizing chronic condition and the difficulties adjusting. Relapsers unlike abstainers describe a number of life events and experiences which coincide with their relapse. These included: lack of social resources, mental health issues, illness distress, the need to be like ‘normal’ people or society, problems mobilizing resources such as finances, employment.

Before the transplant I never let up. I continued to work and did everything I needed to do even whilst attending hospital appointment. You think I have a second go at life but there are times when you think ‘Why did I bother’. You feel better after the transplant then you want to feel like how you were before the operation and to be doing what you were doing. I think I am dead lucky if I make it to 70 especially when both parents died in their 60s. When you think like this you say, ‘Bugger it. Might as well drink. What am I going to do, live like a Trappist monk until something good comes along?’ 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. Perhaps you get more dependent. No one understands that the transplant changes your life and you don’t want your life changed.

Rick

The risk of relapse is always on my mind, it never goes away. Hardest thing is finding a way to get things off my chest. Before you could talk to your mates: with drinking came a sense of camaraderie...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

Daniel

Ever since the aftermath of the transplant I had a lot of personal problems involving finances, work
problems, anxiety, my daughter started having problems with depression. It has been an unsettling time. I got back into the drinking 18 months after the transplant. I also returned to smoking again due to the stress. Alcohol had a stress relieving effect and as the pressures got greater the dependence got worse. After a transplant you think that you can have a party but you feel left out whilst everyone else can enjoy a drink and you think ‘What have I got to do?’. You miss out on being gregarious. You are dealing with depression and the alcohol gives you a big lift. You have survived a big operation and you think you can move at the same pace you were at before the liver disease. No one shows you or assists you through that period

Peter

Triggers to drinking in particular may be that one cannot underestimate the power of ‘what now’. All the energy around you is about, am I going to live. Am I going to die? The waiting for the phone call (from transplant unit with offer of a donor organ). What do I do when I get the phone call? What do I do now that life is given back? It is scary... So to have gone through that period totally sober, I may have gone through a lot more fear and loathing than I already did. I was hospitalized on occasions. I was in excruciating pain and had to call an ambulance and felt terrible and it was just overwhelming.

Bill

One woman who died during the study and who found it difficult to express herself said:

There was support in the beginning from family and friends but then it dropped after the transplant.

Katherine

Pre-transplant participants described the psychological distress waiting for life saving surgery with the threat of death and physical pain.

Before the transplant I was crook from the liver disease and I was given a death threat. I thought, ‘what have I got to lose?’, because I didn’t think I would be given a transplant. The drinking helped with the pain and the depression. It was medicinal. It made me feel better ...I hid grog everywhere. 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. The issue of dying was hard and I was so crook and the only thing that gives you relief was the alcohol.

Douglas
I do not want to go through liver disease again it is a shocking thing, it is a dreadful thing. The transplant was a difficult experience I did not know what I was in for. There are stressful things you go through when you have a transplant.

Daniel

Relapsers describe the difficulty adjusting after transplantation being left lost and unsure regarding their life purpose and direction.

There was something missing in your life. You are not really physically well but feeling much better, you need a bit of a boost.

Lisa

After the transplant my new wife of four years left me. All the drugs I had been taking prior to the transplant were fine but post transplant the drugs made me depressed and my mind went back onto the alcohol. I tried to go to AA but I just wasn’t interested. The drinking slowly increased over time. Call it arrogance, lack of will power whatever. I had no support.

James

Personal choice, the contract and relapse

Of the 14/15 who had returned to alcohol use, 4 did not want to remain abstinent and abide by the contract. Two participants emphasized the importance of free choice, autonomy and taking personal responsibility for their drinking as opposed to strict adherence to ‘the contract’. One 58 year old woman who returned to drinking a glass of wine per week, two months after her transplant, said:

I want to be able to drink a half to one glass of wine per week and when I choose to. I would be disappointed with myself if I didn’t, as I would like to think I have control over my drinking and my health. I would make sure that if or when if it did start affecting my liver results, I would stop. I would not agree with lifelong absolute abstinence. I feel it is important for people to make their own decisions. I am very strong about personal control and power within yours elf over what you are doing, having the freedom to do what you think whilst considering the impact of that decision. Jennifer
Another added that he preferred a harm minimization approach:

One is told that your life will be taken away, then it is given back, and I can't put that experience into words. It (offer of a transplant) is a gift, a responsibility, a challenge and an invitation to live your life the way you truly want to live it. I wrestled with abstinence. I eventually didn't stay clean..... I don't want to live in recovery. Recovery (12 step abstinence) has given me a lot but I don't want to live my life that way. I spent my time in sobriety doing the right things so I have seen both sides I know how I want to live. Bill

Others referred to how the ‘authoritarian’ experience of ‘the contract’ triggered a type of adolescent regression and resistance:

It feels a bit authoritarian and that is something I would resist at all times. It is part of my personality. Jennifer

You might be too scared to mention it which is sort of unfortunate. In a way it is like being too scared to talk to your parents because you think they are going to bite your head off as you would be hoping for some understanding. Miles

I presume they know I have an adolescent relationship with authority figures. I feel I am going to get into trouble if I tell them I am drinking now. Bill

Two participants denied the existence of a ‘contract’ requiring stable abstinence. One of these participants presented an inconsistent story describing how he only reduced his drinking during the pre-transplant period by drinking only low alcohol drinks and only due to the pressure from friends, ‘mates’, doctors and the transplant staff. He quickly returned to heavy alcohol use one month after the transplant.

This short extract from the interview describes his view of the contract:
Client: *I don’t remember that (contract). I would not be surprised if it was a condition and I may have well have lied if it was a condition. I may have forgotten about it. I was never told about a contract. I don’t think I was ill at the time or overwhelmed by things. I purely can’t remember any contract or condition.*

Int: What do you think if there was such a contract of abstinence?

Client: *That would be a form of blackmail. Are they giving me a liver or lending me one. Who is going to monitor if you are not drinking. They are coercing you or forcing someone to do what they don’t want to do. Taking away their choice to have a couple of drinks and if they want to drink heavily that is their choice. I was going to take control of my life again and I did not want someone else to determine what I do.*

Int: Blackmail?

Client: *That is when you take away a person’s free choice.*

Int: From your side there was no need to change your drinking at all. So you went through the waiting list without having to change your drinking?

Client: *It was always in the air that it was frowned upon but I don’t remember anyone specifically saying ‘if you don’t stop drinking you will not remain on the transplant list’. I don’t remember that being said.*

Int: What made you decide to cut down?

Client: *I suppose the demeanour of the medicos in there inferred that. That was what you were supposed to do, without me actually remembering that they had put it in black and white. It was inferred that drinking was not a clever thing to do and I wanted to get the transplant. I thought it was an unfair*
situation to be in as I say most of my mates drank just as much and did not have the same problem so it was down to the luck of the draw. That is what I put it down to. I did say it has taken me 45 years to stuff up one liver and if I get 20 years out of the next one I am laughing. They did not seem to think that was humorous and left it at that.

..but I can say to you can quote me that a comment made by one of the staff, ‘a few drinks won’t hurt you’. I think they are totally paranoid about wasting a liver by giving you a donor’s liver and if you set out to destroy that they are not happy chappies. I can understand their point of view but my attitude is that I went through enough pain and grief with the transplant that I want to resume a normal life as normal as I possibly can.

Two participants had mentioned knowing a small group of ESALD transplant candidates who had no genuine intention to abstain and who were waiting to receive their transplant then return to heavy drinking.

We come down here to the clinic and talk to people who are going to have transplants. There was one bloke there who talked about going to the transplant Olympics and that they will get on the grog after the transplant. That was a bad message for me because it outweighs all the good things.

Douglas

### iv) Fear of stigma

The fear of stigmatization was the strongest deterrent to alcohol treatment seeking amongst ESALD transplant candidates. A total of 26/42 actually used the word, stigma, and referred to it as being the primary barrier to treatment seeking within the OLT context. Relapsing or being unable to manage one’s urge to drink and comply with the contract was seen as a sign of personal weakness and a behaviour which would attract criticism and disapproval.

Participants who were abstinent said that they would be embarrassed or offended by the idea of seeking professional help due to a strong personal desire to handle the problem themselves to demonstrate self-competency. They described the potential for embarrassment, shame, sense of failure, loss of privacy and the fear of being labelled ‘an alcoholic’. Those who relapsed described a strong abstinence violation effect,
especially guilt, which contributed to further drinking and for some, their alcohol consumption was greater than their pre-transplant consumption.

These quotes illustrate the stigma, personal devaluing, moral obligation and reproach that would or could be evoked by failing to comply with the contract:

*I would be very ashamed because I did not keep my promise and I would be very unhappy with myself that I had given my word and let them down. The shame would be worse than the drink*  

Nick

*They asked me whether I needed to see a counsellor or do I feel comfortable going to AA or that. I said ‘no’ because I am not the sort of person ... I am not a person who could get up in a room and say my problems because I just have to deal with them. If I can’t deal with them no one can help me deal with them. That is the way I sort of feel ....I think in our era men used to deal with their problems on their own. You don’t go and express yourself or push your problems to someone else, you have to deal with it yourself*  

Geoff

*I think it is very hard to give people advice, but it is important to have a doctor who you can talk to. You need private discussion because people might think of you as an alcoholic*  

Katherine

*It would be embarrassing to let them know you are having problems.*  

Natalie

*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 (if referred to treatment)*  

David

*I think people don’t want to be labelled as an alcoholic and put in a group with other alcoholics who have worse problems than you do.*  

Greg
As discussed in Chapter 8, chronic illness invariably can create a sense of moral obligation and responsibility to be a good patient. Those with ill-health are expected to reciprocate as they can be perceived as having less social value. In this study participants described a strong obligation to reciprocate in some way.

‘I would disappoint them (transplant staff). They have given me everything. If I went to the grog I would be giving them nothing. It is my responsibility to look after this. If I was thinking about relapse this would be the first place I would ring because it is a lifeline. But I think I would be a failure if I relapsed. If I relapsed I don’t think I could walk back in here because I would have let people down so badly and they have so much faith in me. The time and money spent on me... it would have been cheaper to let me go. I would feel quite ashamed. I didn’t live up to my end of it. I come here every 3 months. It is my security bond. To me morally if I let them down I do not deserve a second chance it is up to me to preserve what I have got and look after what I have got and I could not walk back into that door if I had another drink. No way in the world could I do that because I will be on my back the other way (relapse).

Douglas

You wouldn’t want to let them know that you relapsed and let them down. It would be a kick in the teeth for them. That is how I would feel. I would feel guilty and ashamed. I felt ashamed when I first came here I told my doctor about what I had done. I would disappoint them they have given me everything. If I went to the grog I would be giving them nothing....I think it would be difficult to tell staff. I wonder if people do let them know. They do check your blood tests. I am sure people would find it hard to let them know. I would hope I would get it early before it became a problem

Erica

There was a lot of guilt for going back to the grog. Once you are educated about what alcohol does to you and the lengths you take to stay abstinent with the 12 step program and transplant. 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’.

James

‘I will always be indebted. I always appreciate what I have been given however it gives you a great deal of guilt (relapse)’

Rick

The diagnosis of ESALD itself before transplantation was reported to create stigma for some participants:
I coped with it when I was first diagnosed with it (ESALD) 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? 

Miles

Fear of disappointing staff

Again the need to reciprocate for receiving transplantation was strongly expressed. Of all the participants interviewed 27/42 confidently asserted that staff would be ‘extremely disappointed’, ‘hurt’ or ‘disapproving’ if they were to relapse or to be seen as having problems with abstinence. This is evident in the following extracts:

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. They don’t want to see you fall off the rails as they go through a lot of work. Doctors and nurses work hard to give you a transplant.

Ken

I can understand any disappointment staff may have. I got a good liver I got a good one and I am destroying it

Wayne

…it (relapse) would be undoing all the good work they have done so far. I would feel bad.

Ron

They would see it (problems with abstinence) as a sign of weakness.

Jennifer

When asked about whether they would let transplant staff know about any alcohol use, about half answered confidently that they would let staff know and would be willing to comply with treatment. This response was generally amongst those who were successful abstainers and who had no problem abiding by the contract. At least a third of successful abstainers recognized the potential for stigma and how the experience of stigma would be a major barrier to reaching out for help but they reported they would attempt to inform staff. One participant described how difficult it would be, in practice, to let transplant staff know about alcohol use in the event of a relapse.
I probably wouldn’t want to tell staff. …a lot goes into this investment in that I have the right thoughts behind not drinking. If I did relapse I would feel a bit of a loser…I would feel weak. I would be thinking that I had failed…. I wouldn’t have the strength to come back and ask for help because you would be basically saying you are not worthy that’s all .. I have gone through a lot and I wouldn’t like to let others down. You hope you are smart enough and brave enough to do something about it by approaching transplant staff for help. I would like to think I could do this, as there is that personal devious behaviour to try and hide it. 

Mathew

Amongst the participants who had relapsed 9/10 did not openly inform staff about their drinking and felt totally to blame or responsible for their relapse. Three participants described how their doctors only became aware of their drinking once they were admitted to an emergency ward:

I had not been asked about my drinking. They did not know I was drinking. I was in the causality ward after three suicide attempts. My psychiatrist was annoyed as he couldn't have made a proper diagnosis. I was editing myself for very good reasons. If I had told them I was drinking I would not get a liver and when I spoke to Dr. I was told if they had known I had been drinking they wouldn't have given me a liver’…..I feel like I am being an ungrateful wretch for not disclosing. 

Wayne

Some participants reported deterioration in the rehabilitative relationship with staff. This deterioration appeared to be a combination of staff being disappointed by the patient’s relapse and the patient’s own guilt and shame for relapsing. A post-transplant participant who had relapsed for a short period, and then returned to abstinence, spoke about the consequences of relapsing:

There are a number of consequences that follow from not following through. The loss of respect from friends and family, loss of respect from medical staff and then having to deal with the action they may choose to take. There are consequences you need to consider if you return to drinking. 

Daniel

The guilt and shame of relapse, especially when mixed with depression, was mentioned by participants as the primary reason for not attending clinic appointments:

I couldn’t criticize the transplant staff. I feel guilty about letting people down. For years I have put off
going to the clinic and seeing the staff for that reason. I think about going then I think ‘I can’t handle it, I can’t go through the guilt’ and ‘what they are going to think?’.

Rick

Fear of penalty

Of the pre-transplant participants, 3/16 believed that to disclose any alcohol related problems with liver transplant staff could or would result in penalties or unwanted consequences. They expressed their concern about being de-listed or moved down the waiting list if they were to report any alcohol use. At the same time they felt it was important to let staff know about their drinking as it could negatively impact on their medical care. One participant’s family was extremely nervous and cautious about the interview and documented the session. The following quotes describe the fear of penalty:

I don’t know because I don’t know how they are going to react. Are they going to over-react and take you off the list? But that is the thing, so maybe you try and keep it to yourself and try and deal with it yourself or get outside help. You might be too scared to mention it, which is sort of unfortunate in a way. It is like being too scared to talk to your parents because you think they are going to bite your head off, as you would be hoping for some understanding. But then I don’t know if you would get the understanding, maybe you would.

Mathew

There would be concerns but then I would tell them anyway. The concern would be that I would be shuffled down the transplant list...I am not certain that it would be a real concern to tell you the truth because I have been totally honest with them and they would probably recommend that I seek some counselling.

Steve

v) No available and suitable alcohol support program

‘The gap in the program’ and lack of candour

Participants referred to a ‘gap’ in the transplant program involving a silence between staff and participants concerning alcohol related matters and the lack of on-site drug and alcohol services. The absence of a drug and
alcohol service within the transplant program was evident in that 26/42 participants openly stated that staff did not discuss alcohol related matters apart from monitoring, advice and referral. Some participants wanted an open and honest working relationship with transplant staff, wanting to be able to inform staff about all issues which could impact on their medical care during transplantation if required. For relapsers, the lack of communication or candour about alcohol related matters acted as a barrier to candour and to support from staff with whom they had a rehabilitative relationship:

Staff don't talk about it. They don't approach the subject...they could be more initiating and elicit some discussion. Perhaps having a drug and alcohol person on staff would help. However not sure about how honest people are prepared to be because if you are drinking, you don't want to tell people as you won't get a liver.

Bill

They really didn’t do a lot. I had a chat to one or two people about it. It never came up. I don’t recall any monitoring or bringing the subject up. As I said it was mentioned on the odd occasion. Prior to liver transplantation it was brought up along the lines of 'have you had a drink?’. Nothing pushed past that. It was never a discussion point. I suppose if I presented as having an issue they would have brought it up. It suited me that the issue was not brought up

Mathew

The lack of discussion about alcohol related matters appeared to generate uncertainty in the minds of most participants about what would happen if such issues were raised. Some participants openly believed that to disclose any alcohol related problems with liver transplant staff could or would result in penalties or unwanted outcomes. Pre-transplant participants expressed their concern about being de-listed or moved down the waiting list if they were to report any alcohol use. This issue was relevant to pre-transplant participants as described in the following quotes:

I don’t know how they would react if I told them I was drinking or what they would do as I said they don’t talk about the subject.

Ron.

There would be concerns but then I would tell them anyway. The concern would be that I would be shuffled down the transplant list...I am not certain that it would be a real concern to tell you the truth because I have been totally honest with them and they would probably recommend that I seek some counselling

Steve
Some participants, especially those that had relapsed, noticed the ‘the gap’ or lack of an on-site drug and alcohol services and were not aware of any treatment pathway in the event of a relapse.

‘Staff did not tell you who to see when you have problems with alcohol or having stressful changes in your life’
Daniel

It seems strange that they would have to farm it (alcohol treatment) out to someone else and that there is no service here.
Miles.

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. I would gladly be happy to talk to someone here. They should have a drug and alcohol (service) here.
Pat

Living with the chronic illness of harmful alcohol use

Three participants believed that the contract of strict abstinence was ‘unrealistic’ as it does not account for the fact that addiction is a relapsing disorder and a therefore an ongoing chronic condition which a recipient has to live with prior to and after transplantation.

There has to be consideration and support for people who go through transplantation and who had a drinking problem... Alcohol is a big part of their life and if you get a liver transplant, you think it has to be understood and realised that there will be a strong likelihood that people will go back to alcohol. That is why I think Dr X, (drug and alcohol physician) and Dr Y (liver transplant psychiatrist) should be more involved. I would have thought that part of the program would have involved Dr X. coming into the picture, telling you have had a history of heavy drinking and what the processes are and working with him in the post transplant time. That is a time you would work with anyone. It is the time when you are in the frame of mind to consider help
Rick

Now just as an opening remark it seems to me that if it is true that the majority of liver transplant candidates are suffering from Hepatitis C. Then a high proportion of people seeking a liver transplant would have a history of intravenous drug use. Therefore it seems to me that if the intention is to
transplant these people, it is somewhat unrealistic to expect them all to be drug free. So that is the conundrum which exercises my mind. The idea that the person who needs a liver transplant due to intravenous 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 and that this is sufficient in order for them to change their lifestyle, I think that is ridiculous quite frankly.

**Wholistic perspective**

Participants referred to the limitations of medicine which focuses on the disease and it’s management but how it does not take seriously the human experience behind chronic illness and transplantation (as discussed in Chapter 8. Medical practice disregards the impact on human experience as medicine is conducted and the psychological and social aspects of a living with a chronic illness. 

Staff are very clinical, scientific, interested in blood analysis and tests, analyzing. I felt like a piece of meat. .....There is a gap between the clinical side of the transplant and the emotional difficulties of going through a transplant. Things could be improved in this area. Daniel

If someone like myself does make an attempt and is clean and sober for nine years, and then has a slip I think that should be taken into consideration because people are not machines. They are not perfect. Certainly that was my experience. It was a large period of time, about 9 years, where I had been sober and in the last of those 3 years when I was told I had to have a transplant and I was doing recovery and all the intentions were good and the actions were great and then some personal traumas happened around 1999 and I relapsed , I pulled myself out of relapse and then I relapsed again, just as I was put on the transplant list. So in my mind, because I’d been told abstinence was mandatory, I was not going to tell them about my past relapse. I was told I would not be given a transplant. I felt that this was unfair on the balance of my behaviour over a period of time. Bill

Whilst the majority were open to some degree of discussion regarding alcohol related matters, some participants who were successful abstainers never felt the need to discuss the subject and some mentioned how they preferred the subject not to be mentioned as it felt confronting or embarrassing.
‘Wanting to talk to someone’

The preferred choice of treatment by all participants, including relapsers 24/42, was being able to talk to someone without any risk, penalty, shame or discomfort. The need to talk (‘wanting to talk’) was evident among a further 14/42 who mentioned the value of a support group where patients could listen and learn from each other. Three participants proposed that access to a phone line, if they needed to speak to someone about alcohol related matters would be useful. There was a willingness and desire to reach out for assistance from their transplant doctor, transplant psychiatrist and nursing staff who they felt they could trust and who would understand their addiction or situation. This was strongly endorsed by 14/32 of the abstainers. However it was stressed that treatment seeking needed to be client driven, non-confronting and appropriate:

If I had enough trust, I probably would disclose and ask things about drinking more. I think it would be quite useful post-transplant to discuss things with someone. Where you can receive really good information about alcohol and your liver, what was ok and what was not ok. Jennifer

I think that you should have easy accessibility to a counsellor or someone when you feel something is amiss personally... I think the one-on-one counselling is important for when you feel that things are getting away from you, also that you feel that you are not being singled out and that there is a choice. After the single informal chat, then a person could be informed that ‘we do have a group with like minded people like yourself who do appreciate more support and who have already given up but don’t want to slip up along the way.

Steve

For me I had to make the decision (seek treatment). It is a personal decision whether you are going to indulge or not and that decision is influenced by some external forces but a lot of internal stuff too. Lisa

Pre-transplant patients could be helped by seeing those people who have gone through the transplant so they know what it is like when you finally get over a transplant. Daniel

I think it important for staff to understand what causes you to drink and the pressures who have to deal with. Something like you are doing now it starting to understand the issues once you understand the issues then you can work out how to give that support and understand what drives that person to drink.
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. Current staff are not able to do this, you need staff specialised in that area

Ron

I would like to be directed to people to whom I am supposed to speak to. After all these years of speaking at AA and rehab I don’t want to speak to every Tom, Dick and Harry on the street about my alcoholism. Sometimes I have to work out to whom I should speak…discussing it with just anybody is not always very easy because at times it is wanting to discuss it with someone who can understand and relate to what you are talking about. I guess for me I would search for someone who had knowledge of the subject, who was empathic about it and someone I would trust.

Andrew

Participants who had relapsed described experiencing unhelpful, at times distressing, alcohol treatment approaches designed to encourage their compliance with the contract. These approaches were felt as stigmatizing especially due to personal feelings of shame and failure for having relapsed. These approaches included: being coerced or strongly advised to attend off-site drug and alcohol treatment, being given simplistic professional advice, and being referred to Alcoholics Anonymous. One transplant recipient described how he felt when he was approached by alcohol transplant staff and how he would prefer to be approached:

I did have pancreatitis due to a lapse. The drug and alcohol squad got called in. I felt like a criminal, six people descended on me. I felt bad that I had disappointed the staff. I knew I did wrong, that I had fucked up, let them down; the very people who meant something to me. They understood but I felt bad. The drug and alcohol squad tried to reform me. Staff did not tell you who to see when you have problems with alcohol or having stressful changes in your life. You need something less clinical, a presence to help you get through it, something friendlier, a drug and alcohol support worker would help, something not so Gestapo like the drug and alcohol team.

Daniel

If I had said I don’t drink but gee I feel like one , that would have led to a different response I am sure. They would have asked a lot more questions and probably gone more fully into what was happening and we support you with this and do you really think you are going to lapse and you know how important it is not to drink when you have liver problems and all that sort of stuff....

Lisa
I would not go to AA, it is not my personality to get into that. It is a great program but I would not go to it.

John

There is the social barrier. Also no one likes to be pushed upon, interrogated about what they have been doing. I am not a person for AA groups prefer a one on one situation or a group of people going through the same boat. Questionnaires may be helpful but they need to be subtle and non judgemental, as they would help people get some more knowledge and insight into things they may not be thinking about....More information in the right environment would be helpful. You need an environment where you can talk to people and have a chat, a non aggressive environment and one that allows them to come out and talk about things and drinking could be mentioned

Alan

Two participants who clearly understood the dilemma of not wanting to seek treatment because of stigma and knowing that treatment would be useful, provided specific recommendations about how treatment could be conducted. This involved a non-confronting appointment with a drug and alcohol professional as part of the post-transplant outpatient clinic visits of the liver transplant program:

There is a window of opportunity where you might be able to capture and prevent people from going back on the grog. This is after you are discharged. It should be mandatory to have alcohol treatment. Dr. X and Dr.Y (addiction specialists) need to come into the situation. Recommending people to go to AA is not everybody’s bag. ..People don’t like to admit that they are dependent on grog. The word ‘alcoholic’ has stigma to it and people don’t like to talk about the problem. In that window of opportunity, perhaps in the blue book which people read so carefully, it should be pointed out that alcohol treatment is mandatory in the first 18 months after a transplant

Rick

It scares people off (alcohol treatment). It is like so many other things, smokers get confronted by campaigns as it is putting it into people’s face, makes them jump back rather than engaging with people in an open environment. It would make me feel I failed whereas an open easy approach would invite me to talk. Perhaps having regular appointments alongside your outpatient appointments as part of the visit where you have a catch up with someone about how you are going. It would like how I have appointments at the clinic every 6 months. Somewhere to be able to discuss things like going back to work, finances and life after transplant.

Michael
The contract and other key themes

The theme of the contract as explained earlier was closely connected to all the major themes. It was linked to abstinence as a do-it-yourself process as the contract of abstinence provided motivation for long-term abstinence, stressed the importance of self-management, and connected the recipient with transplant staff, family, friends and the public. Relapse was indelibly linked to the contract as it was a breach of the contract resulting in a number of consequences and significance. The contract acted to preserve and protect against self-stigma yet when breached contributed to self-stigma. The theme of the ‘gap in the program’ was due to the policy associated with the contract as recipients of transplantation are expected to abstain though their own efforts despite being in the transplant program and the stressors transplantation can create.

Preferred treatment

The results of a short survey about preferred treatment options (Table 10.3) suggested a dislike for direct alcohol interventions, independent of the liver transplant program. Most participants (30/42) preferred an approach that integrated an individual or group program during the post-transplant period and that focused on recovery and lifestyle issues, including alcohol use. A group program focused solely on alcohol was only endorsed by one participant.
Table 10.3 Preferred treatment survey

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Number (n=42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual alcohol counseling</td>
<td>8</td>
</tr>
<tr>
<td>Group program addressing alcohol issues</td>
<td>1</td>
</tr>
<tr>
<td>Individual post-transplant counseling including alcohol and lifestyle issues</td>
<td>15</td>
</tr>
<tr>
<td>Group program post-transplant recovery including alcohol and lifestyle issues</td>
<td>15</td>
</tr>
<tr>
<td>Written workbook addressing alcohol issues</td>
<td>1</td>
</tr>
<tr>
<td>None of these options</td>
<td>2</td>
</tr>
<tr>
<td>Other suggestions</td>
<td>0</td>
</tr>
</tbody>
</table>

Conclusion

Self-management was important to ESALD transplant participants who attributed their lengthy abstinence to
their own efforts and therefore felt no need for alcohol treatment. Yet it is evident that a number of factors, besides self efficacy, will-power, consequential decision making, relapse prevention skills and avoidance of high risk situations contributed to the initiation and maintenance of abstinence. One of the most significant was the power of the medical, moral and social obligation imposed by ‘the contract’. Furthermore, abstainers had greater access to psychosocial resources than their relapsing counterparts. The vast majority of abstainers had a partner or spouse who played a pivotal role in their recovery, and they also tended to have good family and social networks. Establishing close, rehabilitative relationships with transplant staff was also a critical feature. The experience of transplantation for abstainers was not marked by psychological stressors, psychiatric difficulties and unwelcomed life events.

By contrast, those who had relapsed to harmful drinking reported fewer psychosocial resources. Many had lost the support of a partner after transplantation due to divorce or interpersonal conflict. Many lacked a social support network, feeling the enticement of the company of drinking peers. Relapse triggered a strong abstinence violation effect associated with increasing guilt and shame and further alcohol consumption. It contributed to: deterioration in the rehabilitative relationship with transplant staff, secrecy coping, avoidance of outpatient and other health care services, the need for re-transplantation and, finally, mortality. Most participants described relapse happening after this social collapse however it also appeared that relapse undermined their ability to access or enhance their psychosocial reserves.

Stigma was the major deterrent to seeking or utilizing alcohol treatment. Alcohol treatment was associated with the label ‘alcoholic’ and the negative attributes associated with the stereotype. For many participants, treatment suggested a failure to self-manage and therefore a personal weakness. It was also a failure to abide by one’s moral and social responsibility to the contract.

The study findings suggest that participants were open to alcohol treatment and were critical of the absence of a suitable alcohol support program that was an integral feature of the liver transplant process. Independent alcohol interventions, such as AA, were not favoured with participants suggesting integration of an alcohol support program with the medical program, particularly in the post-transplant recovery period. They preferred an approach which maintained their personal dignity and right to solve their problems, simultaneously it needed to be medically prescribed and integrated with the liver transplant program. It is worth noting the difficulties ESALD transplant patients may experience in accessing outside services due to the burden of illness, lack of knowledge of services, stigmatization, inconvenience, the energy and motivation involved in engaging with another service, transportation problems, geographical barriers and time constraints.
References


CHAPTER 11
In-depth interview study - Discussion

This study followed the experiences of end-stage alcoholic liver disease transplant participants. The aim of the study was to explore the barriers to and reasons for resistance to treatment for alcohol use among ESALD transplant candidates before and after liver transplantation. Two main reasons for treatment resistance were identified in the thematic analysis. Firstly, most ESALD transplant participants wanted to avoid alcohol treatment due to the fear of stigma. Secondly, ESALD transplant participants who were abstinent felt they didn’t need alcohol treatment. A barrier to alcohol treatment reported by most participants was the lack of a suitable alcohol support program that was integrated with the liver transplant program. Each of these findings will be discussed in this chapter, along with limitations of the study and directions for future research.

Fear of stigma associated with alcohol treatment

Stigma is rarely ever mentioned in the liver transplant literature, despite its frequent reference in alcohol treatment and medical sociological literature. One of the primary findings of the current study suggests that resistance to alcohol treatment by ESALD transplant patients acts as a defence against stigma. When ESALD transplant participants were asked an open-ended question about what would prevent them from seeking alcohol treatment, the majority replied, ‘stigma’. The present study found that the fear of stigma experienced by ESALD transplant participants involved self-stigma rather than enacted or perceived stigma. Self-stigma constitutes negative thoughts and feelings that emerge from identification with a stigmatized group, which leads to internalized shame, fear, and negative self-evaluation associated with behavioural impacts including treatment avoidance [1]

As discussed in previous chapters, stigma has been theorized in a number of ways. Goffman defined stigma as an ‘attribute that is deeply discrediting’ and occurring within social interactions. Proponents of the modified labelling theory, as previously discussed (see Chapter 8) argue that stigma is activated once an individual enters treatment and is diagnosed, activating stereotypes which can become internalized as self-stigma. A further
advancement of modified labelling theory (Link and colleagues) also previously discussed defines stigma as the anticipation or experience of labelling, stereotyping, blame or devaluation or discrimination (structural) in a situation characterized by unequal access to power and social resources. Social identity theory postulates that stigma is the result of polarization and differentiation in group membership, creating a positive in-group prototype and a negative out-group prototype. Individuals who become affiliated or categorized as an out-group member and the undesirable attributes associated with it, are subject to depersonalization, dehumanization and discrimination. Honneth’s theoretical perspective on the significance of mutual recognition and respect among individuals and groups in social life suggests that stigma is one of the mechanisms by which respect and recognition are withheld resulting in the denial of social inclusion and self-esteem. We can understand the fear of stigma among ESALD by drawing on the explanatory power of these theoretical perspectives.

ESALD transplant participants did not want to be referred to alcohol treatment independent of the liver unit as this inferred the label ‘alcoholic’. The label ‘alcoholic’ and alcohol treatment were associated with a failure of self-management and personal weakness. Furthermore, to be perceived as needing professional help was associated with a failure to abide by the social and moral contract of abstinence and, therefore, a failure to meet social obligations to family, friends and transplant staff. ESALD transplant participants reported that for alcohol treatment to be warranted and legitimate, it needed to be medically justified by their transplant physician. As significantly, the preferred intervention survey revealed, it needed to be intrinsic and integral to the general liver transplant program of recovery in the form of a post-transplant recovery intervention.

The avoidance of the label ‘alcoholic’ and alcohol treatment can be understood from the perspective of the modified labelling theory which, as mentioned earlier, posits that once an individual enters treatment and is officially diagnosed, powerful stereotypes are activated [2]. If the individual accepts the label, s/he may internalize the stigmatized images and stereotypes associated with it, resulting in a range of adverse effects, including treatment avoidance.

From a social identity perspective, the stigma reported by participants in seeking and attending external or independent alcohol treatment services, was related to the possibility of being designated a member of a negative out-group – in this case, those unable to abstain from using alcohol. As discussed in Chapter 2, liver transplant candidacy is dependent on rigorous selection criteria and donor organs are offered to a highly selected group, considered to be the best candidates amongst a cohort of better prognosis patients. Apart from the medical considerations for transplantation, candidacy requires the ability to demonstrate a commitment to abstinence, medical compliance, psychological resilience and a stable social support network, among other factors. Liver transplant candidacy for ESALD transplant participants, therefore, inescapably involves the establishment and operation of an in-group prototype where normative behaviour, ideal patient attributes and formation of rehabilitative relationships with staff are essential to medical outcomes. According to social
identity theory, individuals in group life seek a positive self-concept, solidarity, reduction in uncertainty and to maximise their access to important resources. To be seen by the transplant team as having ‘alcoholic’ attributes (even needing treatment) would render liver transplant patients as possible ‘out-group’ members. Membership of the ‘out-group’ would be life-threatening, increase uncertainty, undermine medical compliance and staff relationships. Micheal Lucey [3] refers to these processes when he states:

This resistance to treatment may reflect the fear that a declaration of a desire for alcohol will be interpreted by the transplant team as a sign of poor candidacy or a lack of commitment to sobriety (p.757).

The in-group prototype, as revealed by thematic analysis, involved attributes of: self-efficacy, moral responsibility to the contract of abstinence, will-power, strength of commitment, and invincibility to relapse to match the heroic medicine provided by transplant staff. To need alcohol treatment simultaneously and intrinsically signified membership of the out-group, which was linked to the label ‘alcoholic’ and which suggested failure of self-management and an inability to meet moral, social and public responsibilities. The importance of being valued and respected by transplant staff was evident in that the majority of participants asserted that staff would be ‘extremely disappointed’, ‘hurt’ or ‘disapproving’ if they were to relapse or to be seen as having problems with abstinence and needing treatment.

An ‘us’ and ‘them’, in-group and out-group membership was evident amongst ESALD transplant participants, who displayed a lack of interest and even revulsion at the idea of being referred to, or being seen as needing, alcohol treatment. For many participants, even the formation of a support group evoked the fear of being in an out-group of ‘alcoholics’ and so they actively avoided being identified with this group. Research has shown that avoidance from a potentially stigmatizing group is a common response amongst individuals whose social identity is under threat [4]. It is important to note that there was a small subgroup of participants representing in-between and out-group members who specifically requested an alcohol support group, had no problems identifying as ‘alcoholic’ and who tended to be affiliated with AA.

Using Honneth’s perspective, ESALD transplant patients can be understood as striving to maintain mutual recognition (with staff, family, and friends) by being seen as morally responsible agents and valuable contributors in a shared project through abstaining and preserving the ‘gift of life’. For some this was a new life role associated with an epiphany. In order to preserve self-esteem, it was important to disaffiliate from a
denigrated social group (‘alcoholics’) to prevent social patterns of humiliation and marginalization. As significantly disaffiliation was understood as critical to securing a place as a donor recipient.

The qualities required to join the in-group prototype of ideal transplant candidates ignore the fact that alcohol dependence can be a relapsing condition. Therefore those who do not meet the criteria for membership of this ideal group prototype by relapsing are more likely to experience stigma. The presence of stigma and its adverse effects were described by relapsers, effects that were consistent with research identifying the negative cognitive, affective, behavioural and health impacts of stigma [5, 6]. Relapsing participants described guilt and shame, negative self evaluation, depressive symptoms, secrecy coping, loss of employment, deterioration in quality of life, social avoidance, re-affiliation drinking peers, liver disease requiring re-transplantation and mortality. Treatment dropout from the transplant program and lack of alcohol treatment seeking were also reported by relapsers, both strongly associated with health-related stigma. Goffman’s work including the research in health-related stigma, has identified how stigma can lead to exclusionary social processes that limit the individual’s ability to fully participate in everyday life, including social relationships. Self-critical and devaluing thoughts in reaction to relapse have been found to increase the likelihood of substance use as a means of suppressing negative emotions [7]. Also, while substances are used to avoid and suppress shame associated with stigma, they reduce access to the useful regulatory function of the emotions of shame in order to regain self-control [8], with shame contributing to treatment dropout [9] and poor social functioning [10].

Stigma as a deterrent to participation in alcohol treatment is not unique to the ESALD transplant population. A large body of alcohol research has found stigma to be a major barrier to treatment seeking by the majority of those with harmful alcohol use in the general population [11-19]. Similarly, in these studies treatment was associated with social disapproval, low self esteem and being labelled an ‘alcoholic’ with a strong preference to handle one’s own problems [11-14, 20-22]. Treatment avoidance acts to preserve self-esteem, as seeking professional treatment can trigger feelings of inferiority, inadequacy, a sign of weakness or failure [23]. However the limitations of these studies is there is little sociological and social psychological theory and analysis to explain these findings.

The transplant literature has frequently referred to denial as a distinguishing feature of ESALD transplant participants and one of the main reasons for resisting alcohol treatment. This present study suggests that ESALD transplant participants reject the diagnosis or past alcohol problems, and alcohol treatment, to protect dignity and self-worth. Denial and stigma, however, can be closely connected as they both function to protect a person’s self-esteem and his or her interpersonal relationships. Like stigma, maladaptive denial manifests in non-compliance, rejection of a diagnosis, interpersonal difficulties and, importantly, refusal to participate in
treatment [24]. Research has shown that persons with an alcohol dependence problem are afraid of openly admitting their condition, fearing adverse reactions from others while privately recognising their problems with alcohol [25]. Considering these processes, it appears that alcohol treatment for ESALD transplant participants that do not trigger stigma need to meet certain conditions in their provision. On the basis of the data from this study, two key conditions have been identified. One is the integration of an alcohol treatment program with the liver transplant program. The second involves the orientation of such a program towards the enhancement of self-management in a collaborative and respectful context, rather than in a context in which the person or client is seen as a failure because of alcohol use. It is also important to appreciate that denial in relation to a life-threatening chronic illness assists in managing the challenges associated with chronic illness, maintain social roles, facilitates being a ‘good patient’ and acts to normalise [26]. Anger and denial has been found among patients recently referred for transplant [27].

The fact that men make up the large proportion of the ESALD transplant patients may also be important when examining denial and stigma. Males invest more energy keeping their illness contained and disability invisible in order to maintain their masculinity while maintaining another identity at home (Chapter8).

**Abstinence as a ‘do-it-yourself’ process**

Alcohol treatment was perceived by more than half of the study participants as unnecessary due to successful self-management having achieved abstinence without needing professional treatment. Weinrieb and colleagues, also noted that ESALD participants reject established alcohol therapies because they have already been abstinent for some time [28]. Also research shows that a large number of individuals can reduce or abstain from alcohol through self-initiated and not professionally facilitated change [12, 14, 29-32] [33-37].

Achieving and maintaining abstinence by ESALD transplant participants involved many of the cognitive and behavioural tasks associated with the stages of change as identified by Prochaska and DiClemente, and relapse prevention as reported by Marlatt. In the current study, participants described a cognitive appraisal process in response to the diagnosis of life threatening liver disease. Decision making and relapse prevention strategies included dealing with high risk situations, challenging cravings or thoughts about drinking and consequential thinking. Behavioural strategies included achieving lifestyle balance by focusing on rewarding, non-alcohol-related activities and a reliance on general and abstinence social support. Yet it is evident that a number of significant social factors, besides psychological techniques of managing cravings and self-regulation, contributed to the initiation and maintenance of abstinence.
Abstainers had greater access to close social relations and a sense of solidarity than their relapsing counterparts. One of the most significant factors was the role of the spouse and support of family and friends who supported abstinence. These factors were found to be lacking amongst relapers who were more likely to have lost the support of a close partner, to experience depressive symptoms, more stressful events and a poorer quality of life. The role of socio-economic factors, including educational background, in relation to stigma and relapse, was not confirmed by this study, perhaps due to methodology and the small number of relapse participants.

As discussed in Chapter 8, Honneth points to the important role of social connectedness, self-value and solidarity in the health and well-being of individuals, and how this is supported by sufficient evidence showing that social relationships and marriage benefit health and well-being [38] [39]. This is consistent with relapse research literature, both within the transplant research but also outside the transplant field, confirming the important role of a partner, and personal and social resources in alcohol relapse [40-42] (Chapter 2). Several clinical studies have reported that relapses may result from stressful life events, interpersonal conflict, affective/mood states and/or difficulties coping with stress [43-45]. Another factor which contributed to abstinence was the powerful social contract which has already been discussed.

The study findings suggest that abstainers unlike relapers were able to adjust to the ‘biographical disruption’ created by a stigmatizing chronic illness (Chapter 8.). Many described adapting to their illnesses through the use of self-management, positive determinism, self-transcendence, maintaining a sense of value and meaning in life setting realistic goals in order to maintain everyday life, maintaining support and coherence. Revealing the importance of self-management. Wainwright reported an overwhelming desire by liver transplant patients to regain lost independence and to live a normal life again [46].

Abstainers unlike relapers did not report painful emotional journeys involving loss of partner, financial vocational distress, mental health problems, and illness distress. These findings are consistent with a qualitative study by Newton [47]. The clinical themes suggest that liver transplantation, although life altering, does not necessarily transform one’s life in a positive way. The themes represent a spectrum of life-altering possibilities that range from the liver transplantation experience being very positive for some recipients to it being a taxing ordeal for others to endure. The data show that recipients who perceived their lives as full of afflictions had a higher likelihood of alcohol relapse after transplantation than did the recipients who described their lives in more positive terms, regardless of previous pathology or cause of liver failure. Newton (2003) reported that approximately 23% of ALTRs were assessed as having moderate to severe depression. Thus, it may be that the themes “impact of co-morbidities” and “life stinks” represents the views of ALTRs who are
clinically depressed after transplantation. It was found that alcohol relapse after liver transplantation was more likely when recipients identified with two of the themes: “impact of co-morbidities” and “life stinks.”[48]

**No available and suitable alcohol support program**

A barrier to alcohol treatment reported by most participants was the ‘gap in the program’ involving the lack of a suitable alcohol support program, described by participants as being integrated with the liver transplant program. Participants referred to a silence or lack of communication between patients and transplant staff around alcohol related issues, expressing a need for ‘someone to talk to’ in the event that they might need assistance with the psychological, social or health difficulties associated with transplantation and maintaining abstinence. At the same time they wanted an approach that was respectful of their personal achievement and self-efficacy.

Weinrieb has attributed the lack of open communication between patients and staff regarding alcohol issues due to the policy of mandatory abstinence. For Weinrieb this policy acts as a barrier to candour and for those seeking medical assistance for ‘their problem’ and, places patients in the position of having to conceal their alcohol use for fear of penalties [49]. Alternatively studies report that when patients are encouraged to discuss their alcohol use openly, without fear of judgement or penalty, they feel more comfortable about disclosing their alcohol use honestly [42, 50]. Such an approach is considered a more effective way of identifying alcohol use in the post-transplantation period [49, 51, 52].

Considering the important role of psychosocial resources and the negative impact of stigma associated with alcohol treatment seeking and relapse, it appears that liver transplant services are obliged to actively and directly support the social and interpersonal dimensions of transplantation. This approach to alcohol treatment is suggested by a combination of internationally recognised contributors to the field of social stigma and self-esteem, especially in relation to health care settings, and by research into the social and environmental determinants of health discussed in previous chapters. The latter emphasize the important role that social relationships and support play in positive identity, self-esteem and recovery from relapse and as an antidote to stigma. An onsite integrated program connected to their medical transplantation and addressing the social and emotional dimensions of post-transplant recovery would be seen more consistent with the reality of the challenges that participants face in managing their alcohol use and maintaining abstinence.
Limitations of the study

As this was an exploratory study, additional valuable insights into patients’ experiences, especially the experience of stigma, could have been obtained by adopting a more in-depth, life history or narrative interview approach. The experience of end-stage liver disease and transplantation has many physiologic, psychological, social and spiritual manifestation of illness distress requiring the transplant recipient to continuously adjust to the chronic aspects of living with transplantation. Illness narratives could have brought more of the person back into the discussion of illness, stigma and relapse. It would have been possible to explore how participants adjusted to the changes in identity, self-worth and social relationships, how they make sense of their illness experience, agency and resistance in the illness experience. Also it would have been interesting to explore the ‘biographical disruption’ between abstainers and relapsers.

Another limitation of the study was the small number of more in-depth interviews especially with those who had relapsed. Time restrictions, as well as consideration of the participants’ health status and medical regimen, limited the scope and depth of the interviews that were used to generate qualitative data.

The process of following up patients who had relapsed, proved difficult and time consuming, since they no longer attended the outpatient liver clinic. Some expressed willingness to participate in the study but, despite a number of scheduled appointments and telephone contacts, did not do so. It is also possible that participants were reluctant to give negative feedback about the alcohol management program due to their feelings of loyalty to and appreciation of the transplant program staff. The latter may have meant that participants were less than completely open and honest about their experiences. In future research, non–ESALD transplant participants could be included to address this concern.

As is the case in all research, findings emerge from the interaction between the researcher and the participants and are influenced by the questions being asked, the values of the researcher and the analytic techniques adopted. The student researcher brought to the research processes her own theoretical perspective, subculture, and unique psychosocial history. Participants may have been influenced either consciously or subconsciously, by my background in drug and alcohol counselling, and this may have affected the comments they made.

Through consultation with my academic supervisors, theoretical biases to the topic were identified by the researcher and these were considered but – as has been widely discussed in the methodological literature – no
research can ever be totally value-free. Ultimately, concepts derived from the psychology of addictive behaviour and models of treatment seeking, discussed earlier in the literature review, have been most influential in developing my theoretical perspective and interpretation of data.

**Directions for future research**

This study has identified a significant gap in our understanding of treatment resistance among ESALD transplant patients. It has highlighted the conceptual and empirical neglect of stigma as an explanatory tool. Further research is needed to identify the processes, mechanisms and antecedents of stigma, and whether ESALD transplant participants not only anticipate stigma but actually experience it during the course of their referral, evaluation and participation in the transplant program. Another fruitful area for future research is to explore whether some ESALD patients are more vulnerable to stigma by virtue of their socioeconomic status, gender and/or ethnicity. Such investigation should consider the chronicity of ESALD and liver transplantation as mentioned earlier and the interaction of social structural (gender, ethnicity and class) dimensions of the experience of liver transplantation with other significant features such as mental health, coping capacity and social support. It would also be worthwhile to investigate the attitudes and experiences of staff involved in the patient’s health care.

**Conclusion**

This study sought to better understand the barriers to, and reasons for, treatment resistance amongst ESALD transplant candidates before and after liver transplantation. Its findings suggest that ESALD transplant participants reject alcohol treatment for two main reasons: fear of self-stigma and the belief that treatment is not needed. The processes and mechanisms of stigma in the context of liver transplantation candidacy result in treatment being associated with the label ‘alcoholic’ and failing to live up to the group prototype of the ideal transplant candidate. The impact of stigma was evident among ESALD transplant participants who had relapsed to heavy drinking, contributing to the loss of self-esteem and treatment avoidance. ESALD transplant participants perceived no need for treatment because they believed they could undertake the process of remaining abstinent themselves, despite the fact that abstainers were strongly supported by intimate partners, social networks and ‘the contract’. For alcohol treatment to be attractive to ESALD transplant participants it evident that it needs to be medically integrated with the general transplant program. As importantly, such treatment of alcohol issues needs to be delivered as part of a post-transplant recovery program, and not as a stand-alone service.
The findings from this qualitative study can make an important contribution to the development of such an intervention, to be further outlined in the following chapter.
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CHAPTER 12

Conclusion and Recommendations

This study by adopting both quantitative and qualitative methods, demonstrated that ESALD transplant patients resist alcohol treatment due to stigma, self-initiated abstinence and high abstinence self-efficacy and, the lack of a suitable alcohol program tailored to the needs and clinical characteristics of this patient population. Study 1 utilized an empirical analytical paradigm involving a case control design as means of isolating, defining and measuring variables commonly associated with alcohol seeking treatment. This study design made it possible to compare alcohol treatment seekers with ESALD transplant patients, to determine why alcohol treatment is considered unwarranted by transplant participants. Study 2 used the interpretive paradigm using an interview-based thematic analysis study, uncovering the beliefs, meanings, experiences and actions of ESALD transplant participants to gain a participant’s perspective for treatment resistance.

An examination of the findings for both the case control and in-depth interview studies revealed more consistencies rather than discrepancies. Both studies confirmed three main factors to treatment resistance, and these factors will be discussed in this chapter, along with recommendations for the design and implementation of alcohol intervention, to reduce the risk of relapse amongst ESALD transplant patients.

Factors contributing to resistance to alcohol treatment

Firstly, the majority of ESALD transplant participants are likely to reject alcohol treatment as they accurately perceive no need for treatment as many will have achieved a lengthy abstinence without the use of professional services. Yet such an approach is contingent on the presence of particular and significant processes that operate in the livers of transplant participants. Both studies confirmed the presence of cognitive and behavioural processes and tasks that are critical in the process of change and maintenance of abstinence. The case control study measured the stages of change from the time of
probiemmatic drinking and transplant candidacy. A progressive- readiness- to- change profile marked by high action, was observed, suggesting that the early and latter tasks of changing addictive behaviour were incorporated (problem recognition, weighing pros and cons, decision making, use of cognitive-control and suppression of competing motivational tendencies). These results provide empirical evidence that ESALD transplant patients make genuine change as a result of a life-threatening illness disputing the proposal that denial is one of the main reasons for treatment resistance.

Study 2 actually described how participants achieved abstinence and how their experience was different to relapers. The in-depth interview study also found participants describing many of the cognitive and behavioural tasks associated with initiating and maintaining abstinence. ESALD transplant participants revealed the use of cognitive appraisal, self-control strategies, suppression of alcohol related cues and substitute activities in order to maintain abstinence. This study did however highlight the positive role of partnership, social support, psychological wellbeing and the moral and social obligation associated with the contract as critical to maintaining abstinence. The importance of self-management and self-transcendence as participants face a life-threatening illness and how this alters attitudes, values and behaviour. Tentative findings of the case control study, which compared abstainers with relapsers, also pointed to the benefits of marriage, social support and optimal quality of life in preventing relapse. Health beliefs and motivation were identified by the case control study as clinical variables that changed.

The second reason for resistance to alcohol treatment was stigma. Stigma was suggested in Study 1 findings showing an embarrassment and fear of disappointing transplant staff associated with seeking professional help. However Study 2 provided a more in-depth understanding of the both self and relational factors along with the role of candidacy to a fear of self-stigma by ESALD transplant participants. Alcohol treatment in this setting was perceived as a social identity threat and a threat to candidacy, and closely associated with the negative stereotype of ‘alcoholic’. Treatment seeking was perceived as a failure of self-management and a sign of personal weakness. Study 2 unlike Study 1 was able to provide some links to stigma especially the critical role of the ‘contract’, the role of social interpersonal relationships including transplant staff and public opinion in relation to the gift of life. Unlike Study 1, the qualitative study provided the opportunity for those who had relapsed to describe the contextual and psychological factors contributing to relapse. Study 1 did not find depression as a factor while in Study 2 relapers reported a range of psychologically distress including depression, pre-transplant anxiety, difficulties adjusting to chronic illness.
Thirdly, ESALD transplant patients will reject alcohol treatment as these programs are unsuitable for this clinical population. The case control study clearly demonstrated a difference in the clinical profile and characteristics of ESALD transplant patients to those who would typically utilize alcohol treatment. ESALD transplant patients, unlike ATS, had a less severe form of alcoholism, less psychiatric co-morbidity, better quality of life and more psychosocial resources. The clinical profile of ESALD transplant patients is closer to natural remitters than those with alcohol use disorders who seek specialty treatment. While the qualitative interview–based study was not equipped to systematically measure and confirm the suitability of alcohol treatment based on clinical characteristics using statistical tests. It did reveal that ESALD transplant patients perceive specialty alcohol treatment as an external service only for a marginalized group and therefore potentially stigmatizing. They preferred a less direct and on-site alcohol interventions integrated with the liver transplant program.

**Alcohol treatment recommendations**

Current alcohol management programs used by liver transplant programs worldwide are effective, as over half of ESALD transplant participants maintain stable abstinence. Furthermore relapse rates are significantly lower than those with alcohol use disorders who complete conventional alcohol treatment. However, relapse to heavy alcohol use occurs for at least one third of ESALD transplant patients with adverse health effects. Also relapse amongst donor organ recipients can undermine public confidence in transplant program and organ donation rates.

The results of this study suggest five key guidelines to the development, implementation and integration of alcohol intervention in this setting. Firstly, an on-site medically prescribed alcohol support program integrated with liver transplant treatment provided by experienced drug and alcohol clinician is suggested. Secondly, the alcohol management approach needs to support the psychosocial rehabilitative dimensions of transplantation. Thirdly, direct and intensive evidence-based alcohol interventions used in specialist settings such as motivational interviewing have not been suggested by this study for those who are abstinent. This is consistent with poor treatment participation and adherence found in use of direct alcohol interventions amongst ESALD transplant patients (Chapter 3). Fourthly, a relapse prevention approach needs to be integrated with the transplant program whilst still maintaining a
requirement for abstinence. The large majority of ESALD transplant patients minimised their risk of relapse and did not have a relapse prevention plan. Relapsers did not pursue treatment and experienced adverse physical and psychosocial effects as a result of harmful drinking. Finally, a case management/case monitoring approach will be required as relapse can be difficult to predict especially when slips and triggers for relapse are not being closely monitored.

The policy and goal of transplantation consisting of lifelong abstinence may need to be re-examined as it contributes to a fear of stigma and the lack of candour about alcohol related issues. The lack of candour and communication regarding alcohol issues whilst participating in the transplant program and difference in individual need and self-efficacy suggests that ESALD transplant population would benefit from the communication skills of experienced drug and alcohol professionals. Such clinicians are able to efficiently engage patients in a non-stigmatizing manner, assess relapse, and provide specialty alcohol treatment service when indicated. Interventions can be stepped up or stepped down in intensity, delivery and/or frequency depending on the individual’s clinical characteristics, presence of predictors for relapse and degree of perceived stigmatization.

**Program Components**

In order to tailor a program suitable to the needs and clinical characteristics of ESALD transplant patients and to minimize the potential for stigmatization, a three tiered stepped care is recommended (Figure 12.1).

**Pre-Transplant Phase**

The goal of pre-transplant alcohol treatment is assertive engagement and the promotion of treatment seeking by patients in the event of a lapse or relapse. Low intensity interventions are recommended such as information provided about alcohol support services in the ‘blue book’ or as part of transplant orientation program. Conversations between patients and their transplant physician regarding using alcohol services in order to maintain abstinence are also important.
The provision of an on-site abstinence support session with a drug and alcohol clinician for those being considered for candidacy and who need to enhance their abstinence self-efficacy. More intensive intervention is required for those who are drinking or who have relapsed.

**Post-Transplant Phase**

The aim of alcohol treatment in the post-transplant phase is to prevent relapse by addressing the physical, psychological, social and occupational adjustment difficulties that may be experienced after transplantation for some ALD patients. All ALD patients are advised to attend ‘Post-transplant recovery’ appointments scheduled in conjunction with outpatient transplant clinic appointments every 3 months during the first post-operative year to assess capacity to maintain abstinence and adjustment after transplantation.

‘Post-transplant recovery’ intervention is recommended for those at risk of relapse and who are experiencing significant psychological, social and occupational difficulties associated with their relapse. This intervention would address active coping, illness behaviour, building social networks, enhancing occupational performance (employment capacity, routine, life roles) and maintaining abstinence.

Standard on-site drug and alcohol treatment will be required for those who relapse. More intensive specialised intervention is required for those who relapse. Again this would involve assessment of relapse triggers, psychiatric co-morbidity, cognitions and motivation but also a more comprehensive psychosocial rehabilitation care program focusing on quality of life and building support network as recommended by number of key authors [1-4]. Referral to suitable medical, drug and alcohol, mental health and community providers may be required. Programs may need to consider a goal of controlled drinking after liver transplantation if relapse to heavy drinking is difficult to alter and motivation for abstinence has changed [3]. Follow up care via telephone will also be required. Key caregivers or significant people in the patient’s life may
need to be incorporated. Referral to specialist services would need to be considered such detoxification and residential rehabilitation services. A post-transplant peer based support group is indicated due to the special needs of those likely to experience stigma, may be marginalized and who lack psychosocial resources.

The use of broader interventions addressing the interpersonal dimensions of transplantation, quality of life and wellbeing is recommended. This is consistent with the higher acceptability and engagement by ESALD transplant patients to the use of social network therapy (Chapter 3). In terms of addressing self-stigma there a number of possible yet still not empirically verified interventions or strategies being proposed [5]. These have included psycho-education, CBT approach involving increasing stigma awareness, challenging stigmatizing thoughts and behaviours, empowering strategies such sharing personal experiences, enhancing coping skills increasing self esteem and finally acceptance and commitment therapy. These approaches may be incorporated in the interventions program to be discussed.
Figure 12.1. Alcohol treatment approach for ESALD transplant patients undergoing liver transplantation

**Pre-Transplant Phase**

Aim - Assertive engagement and promotion of treatment seeking focus on maintaining abstinence

- Blue book
- Transplant orientation sessions
- Communications between patient and transplant staff regarding on-site abstinence support services
- Individual assessment and alcohol treatment for those at risk of relapse or who are drinking

**Post-Transplant Phase**

Aim - to prevent relapse by promoting physical, psychological, social and occupational adjustment after transplantation

- Post-transplant recovery sessions every 3 months for the first post-operative year in conjunction with liver transplant clinic appointments, assessing risk of relapse
- Provision of ‘post-transplant recovery’ intervention as required.

Intensive intervention for those who lapse/relapse using

- On-site standard alcohol treatment
- Referral and Liaison
- Assertive follow-up
- Support group
Conclusion

High abstinence self-efficacy, the fear of stigma and the lack of suitability of specialty alcohol treatment were the key reasons for treatment resistance among ESALD transplant patients based on a quantitative and qualitative study. On the whole ESALD transplant candidates were not opposed to the idea of alcohol treatment as long as they perceived the need for treatment, experience it as non-stigmatising and integrated with the liver transplant program. The risk or rate of relapse may be minimised by providing a more suitable, non-stigmatizing and efficacious intervention, at the same time maintaining the confidence of donor families and the general public in the integrity of the transplantation process. The findings from both the qualitative and quantitative study add texture and depth to prior knowledge and should encourage liver transplant providers to develop and implement suitable alcohol treatment approaches within the transplant context.
REFERENCES


APPENDIX A- Models of treatment seeking

Figure 1  Becker et al (1977) Adapted Health Beliefs Model Health Beliefs Model. Reprinted from [220]
Figure 2 Goldberg and Huxley’s Pathways to Care Model. Reprinted from [34]
Figure 3: A Stress and Coping Model by Finney and Moos. Reprinted from [221]

REFERENCES


21 September 2009

Dr C Lennings
Gr- Ms C Hayes
Drug Health Services
Level 5, Building 14
Royal Prince Alfred Hospital

Dear Dr Lennings,

Re: Protocol No X09-0060 - “Barriers to alcohol treatment amongst patients with alcohol related liver disease undergoing liver transplantation”

HREC/09/RPAH/126  SGH/09/RPAH/341

Thank you for submitting a Site Specific Assessment Form for this study. I am pleased to inform you that authorisation has been granted for it to be undertaken at the Drug Health Services and Australian Liver Transplantation Unit, Royal Prince Alfred Hospital.

The approved information and consent documents for use at this site are:

- Information for Participants (RPAH Version 1, 24 July 2009)
- Participant Consent Form (RPAH Version 1, 24 July 2009)

The following conditions apply to this research study. These are additional to those conditions imposed by the human research ethics committee (HREC) that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research, which may affect the ethical acceptability of the study and which are submitted to the lead HREC for review, must be copied to me.
24 May, 2010

Ms Cathy Hayes
Drug Health Services
Level 5, Building 14
Royal Prince Alfred Hospital

Dear Cathy,

HREC Ref No.: HREC/09/RPAH/126
Project title: Barriers to alcohol treatment amongst patients with alcohol related liver disease undergoing liver transplantation

Thank you for your correspondence of 19 May 2010 requesting approval for access to participants, by distribution of a flyer at Concord Hospital.

I am pleased to advise that your request has been approved. The following document has been authorised for distribution at Concord Drug Health Services:

- Advertisement Version 1 dated 24 March 2010

Yours sincerely,

[Signature]

Virginia Turner
Research Governance Officer
SSWAHS Human Research Ethics Committee – CRGH
Recovery after Liver Transplantation – do people with a previous problem with alcohol benefit from additional assistance

A successful liver transplant is dependent on a person’s dedication to their medical regime, regular checkups and abstinence from high risk behaviors such as alcohol use. Giving up alcohol is a very difficult thing to achieve however you have managed to do that. We are very interested to know more about how you have managed to achieve this, and what things have helped you maintain your abstinence over such a long period.

Re-establishing a normal life after transplant surgery is quite challenging as one has to face medical and health issues, returning to employment or other life roles and resuming social or family activities. People may find themselves having cravings or thoughts about alcohol as they try to cope with these issues. Our concern is whether there are other things we can do to assist people’s rehabilitation and strengthen their coping skills during the post-transplant period.

This study aims to determine the most effective approach to assisting patients with alcohol liver disease during and after liver transplantation. You will be offered the opportunity to contribute your ideas in order to improve our health service.

Please contact Cathy Heyes on Ph.9515 7328

If you are interested or require further information
Flyer for alcohol treatment seekers (controls)

Would you like to participate in a alcohol treatment research study?

We are looking for

- Males over the age of 50
- Good liver function
- Who started or returned to AA in the last month

This study is being run from Royal Prince Alfred Hospital, Drug Health Services in Camperdown. The study aims to determine the most effective approach to assisting patients with alcohol related liver disease during and after liver transplantation. You are invited to participate in this study as you have sought help or alcohol treatment and will act as a ‘control’ participant in the
study. A $20 Myers/Coles gift voucher will be provided for your time and contribution.

*If you are interested or require further information*

*Please contact Cathy Heyes on Ph. 9515 7328*
APPENDIX D Information for participants and consent form

*Barriers to Alcohol Treatment amongst patients with Alcohol related Liver Disease undergoing Liver Transplantation*

**INFORMATION FOR PARTICIPANTS**

**Introduction**

You are invited to take part in a research study to help us determine what kind of alcohol treatment services could be useful to patients with alcohol liver disease undergoing liver transplantation. A successful liver transplant is dependent on a patient's dedication to their medical regime, regular checkups and abstinence from high risk behaviours such as alcohol use. Abstaining from alcohol can be a very difficult thing to achieve and it is easy to slip back into old habits especially when motivation changes. We are concerned that some people can return to some kind of drinking within five years after a transplant which can lead to recurring liver disease, graft failure and health problems such as cardiovascular disease and cancer. Once the immediate demands of transplantation are over, people may find it difficult to maintain an abstinent lifestyle due to health problems, loss of employment or difficulties functioning and socializing without drinking.

The objective is to investigate whether patients could benefit from having more professional support either before or after their liver transplant and what approach would be useful. From this study we will be better able to make recommendations regarding an effective intervention for patients with alcohol liver disease undergoing liver transplantation, thus further developing our liver transplant services.

You are invited to take part in a research study because

i) You have been diagnosed with alcohol liver disease and are either on the transplant waiting list or have received a transplant over six months ago

OR

ii) You have sought help to overcome problem drinking and will act as a ‘control’ participant in the study.
The study is being conducted within this institution by Cathy Heyes, a Drug and Alcohol Clinician working at Drug Health Services at Royal Prince Alfred Hospital, and will form the basis for the degree of Doctor of Health Science at The University of Sydney under the supervision of Professor Paul Haber, Medical Head, Drug Health Services, Royal Prince Alfred Hospital and Dr Andrew Baillie Senior Lecturer, Psychology, Macquarie University.

**Study Procedures**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked to complete an interview and 10 questionnaires asking about your past alcohol use, quality of life, personal goals, treatment motivation, mood, treatment experiences and stage of change. This will take around one hour to complete. If you are a liver transplant recipient you will be asked to complete an interview (which will be audiotaped). If you are not an alcohol liver transplant recipient you will also be asked to provide a liver function test within the last three months either from your general practitioner or from recent hospital medical records.

In addition, the researchers would like to have access to your medical record to obtain information relevant to this study.

**Confidentiality**

All the information collected from you for the study will be treated confidentially, and only the investigators named above will have access to information on participants. No information provided will be reported to any staff associated with the Liver Transplant Unit or Drug Health Services at RPAH. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. The study information will be coded so that you cannot be identified. The clinic will not be given any information about you or your study test results.

**Voluntary Participation**
Participation in this study is entirely voluntary. You are in no way obliged to participate. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect your medical treatment or the staff involved in your treatment. Staff will not be directly informed about your participation or non-participation.

**Benefits**

Following on from this study, a treatment study will be conducted in which you will be offered the opportunity to receive further support to improve your physical and psychological coping mechanisms. While this study may not be of direct benefit to you in the short term, in the future it will further improve health services for those with alcohol liver disease undergoing transplantation.

**Costs**

Participation in this study will not cost you anything, however you will be reimbursed for your time to the value of $20.

**Further Information**

When you have read this information, Cathy Heyes will answer any questions you may have. If you would like to know more at any stage please feel free to contact her on 9515 7328.

This information sheet is for you to keep.

**Ethics Approval and Complaints**

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 and quote protocol number X09-0080.
Study identification code

Drug Health Services

SYDNEY SOUTH WEST
AREA HEALTH SERVICE
NSW HEALTH

Barriers to Alcohol Treatment amongst patients with Alcohol related Liver Disease undergoing Liver Transplantation

Principal Researcher: Dr Chris Lennings, University Sydney ph: 9351 9587

PARTICIPANT CONSENT FORM

I, ........................................................................................................... [name]
of...........................................................................................................[address]
have read and understood the Information Sheet on this research study
and have discussed the study with .................................................................................................................................................................

I have been told about what is involved in this study. I understand that the interview will be audio taped and I agree to this. I freely choose to take part in this study and understand that I can withdraw at any time.

I also understand that anything I say will be kept strictly confidential.

I understand that the research project will be carried out according to the principles in the National Statement on Ethical Conduct in Research Involving Humans.

I agree to participate in this study.

NAME: ...........................................................................................................
SIGNATURE: ............................................................................................... 
DATE: ...........................................................................................................
NAME OF WITNESS: .................................................................................... 
SIGNATURE OF WITNESS: ........................................................................

Version 1.2
SSWAHS Drug Health Services

Version 1.2
26/11/2009

26/11/2009
APPENDIX E Assessment Measures

Demographic and Clinical Data

Age: Gender:

Cases: Stage of Transplant: Pre: Post:

Length of abstinence after being placed on the waiting list:

Length of abstinence before being placed on waiting list:

Hepatitis C Virus □ Yes □ No

Ever IVDU □ Yes □ No

Has there been anyone in your close or extended family who had a marked problem with excessive alcohol use e.g. sibling, parent, uncle or aunt, grandparent?

□ Yes □ No

Have you lived in stable housing for the last two years? □ Yes □ No
Are you married or living in a committed cohabiting partner?

□ Yes □ No

Have you ever been diagnosed, received medical or psychological treatment or been prescribed medications for mental health problems such as depression, anxiety or other condition?

□ Yes □ No

Do you believe you have a good social support network consisting of family and/or close friends but also people who support your abstinence or need to change your alcohol use?

□ Yes □ No

Are you currently employed?

□ Yes □ No

What level of education did you reach? ≤SC ≤HSC ≤TAFE ≤UNI
## Lifetime Drinking History

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Frequency</th>
<th>Quantity</th>
<th>Type</th>
<th>Style</th>
<th>Life Events or Changes</th>
<th>Context</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger to Older</td>
<td>Daily</td>
<td>Average</td>
<td>Beer</td>
<td>1 Occasional</td>
<td>1 Family</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>To Older</td>
<td>1 Week</td>
<td>Maximum</td>
<td>Wine</td>
<td>2 Work</td>
<td>Alone</td>
<td>Morning</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3 Group</td>
<td>With</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4 Frequent</td>
<td>Afternoon</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 Residence</td>
<td>Evening</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6 Legal - Jail</td>
<td>Evening</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Additional Information

- **Gender:**
- **Race:**
- **Marital Status:**
- **Education Level:**
- **Occupation:**
- **Income Level:**
- **Religious Affiliation:**
- **Political Affiliation:**
- **Medications:**
- **Family History:**
- **Social Support:**
- **Financial Status:**
- **Housing:**
- **Legal History:**
- **Employment History:**
- **Type of Alcohol:**
- **Method of Consumption:**
- **Patterns of Use:**
- **Associated Activities:**
- **Environmental Factors:**

---

© Copyright 1978 by Harvey A. Skinner, Ph.D.
I’d now like to ask you some more detailed questions thinking about the time your drinking was the most problematic or at its heaviest. Answering yes or no!

<table>
<thead>
<tr>
<th>ALCOHOL DEPENDENCE</th>
<th>ALCOHOL DEPENDENCE CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did find that when you started drinking you ended up drinking much more than you were planning to?</td>
<td>? = inadequate info</td>
</tr>
<tr>
<td>Did you drink for a much longer period of time than you were planning to?</td>
<td>1 = absent</td>
</tr>
<tr>
<td>Did you try to cut down or stop drinking alcohol?</td>
<td>2 = sub threshold</td>
</tr>
<tr>
<td><strong>IF YES:</strong> Did you ever actually stop drinking altogether?</td>
<td>3 = true</td>
</tr>
<tr>
<td><strong>IF NO:</strong> Did you want to stop or cut down? (Is this something you keep worrying about?)</td>
<td></td>
</tr>
<tr>
<td>Did you spend a lot of time drinking, being high or tipsy, or hung over?</td>
<td></td>
</tr>
<tr>
<td><strong>(3) alcohol is often taken in larger amounts OR over a longer period than was intended</strong></td>
<td></td>
</tr>
<tr>
<td><strong>(4) there is a persistent desire OR unsuccessful efforts to cut down or control alcohol use</strong></td>
<td></td>
</tr>
<tr>
<td><strong>(5) a great deal of time is spent in activities necessary to obtain alcohol, use alcohol, or recover from its effects</strong></td>
<td></td>
</tr>
<tr>
<td>Did you have times when you would drink so often that you started to drink instead of working or spending time at es or with your family or friends, engaging in other important activities, such as sports, gardening, or playing music?</td>
<td>(6) important social, occupational, or recreational activities given up or reduced because of alcohol use</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Did your drinking ever cause any psychological problems like making you depressed or anxious, making it difficult to sleep, or causing ‘blackouts?’</td>
<td>(7) alcohol use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by alcohol (e.g., continued drinking despite recognition that an ulcer was made worse by alcohol consumption)</td>
</tr>
<tr>
<td>Did your drinking ever cause significant physical problems or made a physical problem worse?</td>
<td></td>
</tr>
<tr>
<td>IF YES TO EITHER OF ABOVE:</td>
<td></td>
</tr>
<tr>
<td>Did you keep on drinking anyway?</td>
<td></td>
</tr>
<tr>
<td><strong>Have you found that you needed to drink a lot more in order to get the feeling you wanted than you did when you first started drinking?</strong></td>
<td>(1) tolerance, as defined by either of the following:</td>
</tr>
<tr>
<td>IF YES: How much more?</td>
<td>(a) a need for markedly increased amounts of alcohol to achieve intoxication or desired effect</td>
</tr>
<tr>
<td>IF NO: What about finding that when you drank the same amount, it had much less effect than before?</td>
<td>(b) markedly diminished effect with continued use of the</td>
</tr>
</tbody>
</table>
Did you ever have any withdrawal symptoms when you cut down or stopped drinking like

... sweating or racing heart?
... hand shakes?
... trouble sleeping?
... feeling nauseated or vomiting?
... feeling agitated?
... or feeling anxious?
... having a seizure
... seeing, feeling, or hearing things that weren’t really there?

Get description of how much symptoms interfered with work social life or relationships.

(2) withdrawal, as manifested by either (a) or (b):

(a) at least TWO of the following:

- autonomic hyperactivity
  (e.g., sweating or pulse rate greater than 100)
- increased hand tremor
- insomnia
- nausea or vomiting
- psychomotor agitation
- anxiety
- grand mal seizures
- transient visual, tactile, auditory hallucinations or illusions

<table>
<thead>
<tr>
<th>?</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**IF NO:** Did you ever start the day with a drink, or did you often drink or take some other drug or medication to keep yourself from getting the shakes or becoming sick?

(b) alcohol (or a substance from the sedative / hypnotic / anxiolytic class) taken to relieve or avoid withdrawal symptoms

**When did (Symptoms CODED ‘3’ on previous pages) occur? Did they all happen around the same time?**

**AT LEAST 3 DEPENDENCE ITEMS CODED ‘3’ AND ITEMS OCCURRED WITHIN SAME 12 MONTH PERIOD**

**NO**

**YES**

**ALCOHOL DEPENDENCE GO TO CHRONOLOGY BELOW**

---

*CHRONOLOGY FOR DEPENDENCE*

**How old were you when you first had (list of symptoms coded 3 above)**

Age at onset of Alcohol Dependence (CODE 99 IF UNKNOWN)

---

**During the past month, have you had anything at all to drink?**

**Tell me more about it.**

**Has your drinking caused you any problems?**

Full criteria for Alcohol Dependence met at any time in past month (or never had a month without symptoms of Dependence or Abuse since last onset of Dependence)

**CURRENT DEPENDENCE**

*** this only depends on symptoms not on abstinence

?  NO  YES
Indicate if:

1 - **With Physiological Dependence** (current evidence of tolerance or withdrawal)

NOTE SEVERITY OF DEPENDENCE FOR WORST WEEK OF PAST MONTH

(Additional questions about the effect of alcohol on social and occupational functioning may be necessary)

1  **Mild:**  Few, if any, symptoms in excess of those required to make the diagnosis, **and** the symptoms result in no more than mild impairment in occupational functioning or in usual social activities or relationships with others (or criteria met for Dependence in the past and some current problems).

2  **Moderate:**  Symptoms or functional impairment between ‘mild’ and ‘severe.’

3  **Severe:**  Many symptoms in excess of those required to make the diagnosis, **and** the symptoms markedly interfere with occupational functioning or with usual social activities or relationships with others.

2 - **Without Physiological Dependence** (no current evidence of tolerance or withdrawal ***)
<table>
<thead>
<tr>
<th>ALCOHOL ABUSE CRITERIA</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A. A maladaptive pattern of alcohol use, leading to clinically significant impairment or distress, as manifested by one (or more) of the following occurring within a twelve month period:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>? = inadequate info</td>
</tr>
<tr>
<td></td>
<td>1 = absent</td>
</tr>
<tr>
<td></td>
<td>2 = sub threshold</td>
</tr>
<tr>
<td></td>
<td>3 = true</td>
</tr>
<tr>
<td>(1) Recurrent alcohol use resulting in a failure to fulfill major role obligations at work, school, or home (e.g., repeated absences or poor work performance related to alcohol use; alcohol-related absences, suspensions, or expulsions from school; neglect of children or household).</td>
<td></td>
</tr>
</tbody>
</table>

Did you ever miss work or school because you were intoxicated, high, or very hung over?  
Did you ever do a bad job at work or failed courses because of your drinking?  
What about not keeping your house clean or not taking proper care of your children because of your drinking?  

**IF YES**  
How often? (Over what period of time?)
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you ever drink in a situation in which it might have been dangerous to drink at all? Did you ever drive while you were really too drunk to drive?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF YES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How many times? (When?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) recurrent alcohol use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by alcohol use)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did your drinking get you into trouble with the law?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF YES How often? (Over what period of time?)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) recurrent alcohol-related legal problems (e.g., arrests for alcohol-related disorderly conduct)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SCID I
CHECK FOR ABUSE CHRONOLOGY BELOW

ALCOHOL ABUSE CHRONOLOGY

How old were you when you first had (any abuse symptom coded '3')?

Age at onset of Alcohol Abuse _____  _____
(CODE 99 IF UNKNOWN)
**During the past month, have you had anything at all to drink?**  
_Tell me more about it._  
_(Has your drinking caused you any problems?)_
SIP 2-R

INSTRUCTIONS: Here are a number of events that people sometimes experience. Read each one carefully, and indicate how often each one happened **DURING THE TIME YOUR DRINKING WAS THE MOST PROBLEMATIC OR HEAVIEST** (0=Never, 1=Once or a few times, etc.). If an item does not apply to you, circle zero (0).

<table>
<thead>
<tr>
<th>During your <strong>Heaviest period of drinking</strong> how often did this happen to you?</th>
<th>Never</th>
<th>Once or a few times</th>
<th>Once or twice a week</th>
<th>Daily or almost daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was unhappy because of my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Because of my drinking, I did not eat properly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. I failed to do what was expected of me because of my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. I felt guilty or ashamed because of my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. I took foolish risks when I had been drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. When drinking, I did impulsive things that I regretted later.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Now answer these questions about things that happened to you.

During your **Heaviest Drinking period**, how often did this happen? Circle one answer:

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. My physical health was harmed by my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. I had money problems because of my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. My physical appearance was harmed by my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. My family was hurt by my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. A friendship or close relationship was damaged by my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. My drinking got in the way of my growth as a person.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. My drinking damaged my social life, popularity or reputation.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. I spent too much or lost a lot of money because of my drinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Has this happened to you **During your heaviest drinking period**? Circle one answer:

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>Almost</th>
<th>Yes, once</th>
<th>Yes, more than once</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. I had an accident while drinking or intoxicated.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
**SADD**

Thinking about the time when you WERE DRINKING HEAVILY, answer each question by placing a tick under the MOST APPROPRIATE HEADING.

<table>
<thead>
<tr>
<th></th>
<th>NEVER</th>
<th>SOMETIMES</th>
<th>OFTEN</th>
<th>NEARLY ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Did you find it difficult to get thoughts of drinking out of your mind?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Was getting drunk more important than your next meal?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Did you plan your day around when and where you could drink?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>Did you drink in the morning, afternoon and evening?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>5</strong></td>
<td>Did you drink for the effect of alcohol without caring what the drink was?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>6</strong></td>
<td>Did you drink as much as you wanted irrespective of what you were doing the next day?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>7</strong></td>
<td>Given that many problems might have been caused by alcohol did you still drink too much?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>8</strong></td>
<td>Did you know that you wouldn’t be able to stop drinking once you started?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>9</strong></td>
<td>Did you try to control your drinking by giving it up completely for days or weeks at a time?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>10</strong></td>
<td>The morning after a heavy drinking session did you need to drink to get yourself going?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>11</strong></td>
<td>The morning after a heavy drinking session did you wake up with a definite shakiness of your hands?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>12</strong></td>
<td>Have a heavy drinking session did you wake up and retch or vomit?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>13</strong></td>
<td>The morning after a heavy drinking session did you go out of your way to avoid people?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>14</strong></td>
<td>After a heavy drinking session did you see frightening things that later you realised were imaginary?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>15</strong></td>
<td>Did you go drinking and the next day found that you had forgotten what happened the night before?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**SOCRATES 8 A (Restrospective)**

**Instructions:** Each one describes a way that you might (or might not) feel about your drinking. For each statement, circle one number from 1 to 5, to indicate how much you agree or disagree with it right now.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided or Unsure</th>
<th>Agree</th>
<th>Strong Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I really wanted to make changes to my drinking</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Sometimes I wondered if I was an alcoholic.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. If I didn’t change my drinking, my problems were going to get worse.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I started making some changes to my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I was drinking too much at that time, but I managed to change my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Sometimes I wondered if my drinking was hurting other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I was a problem drinker.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I was not just thinking about changing my drinking. I was already doing something about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. I changed my drinking and I was looking for ways to keep from slipping back to my old pattern.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I had a serious problem with drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Sometimes I wondered if I was in control of my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. My drinking was causing a lot of harm.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I was actively doing things to cut down or to stop drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I wanted help to keep myself from going back to the drinking problem that I had before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I knew that I had a drinking problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. There were times when I wondered if I drank too much.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I was an alcoholic.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I was working hard to change my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I made some changes in my drinking, and I wanted some help to keep myself from going back to the way I used to drink.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>
**SOCRATES 8A (Current)**

*Instructions:* Each one describes a way that you might (or might not) feel about your drinking. For each statement, circle one number from 1 to 5, to indicate how much you agree or disagree with it right now.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided or Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I really want to make changes in my drinking or continue with not drinking</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Sometimes I wonder if I am an alcoholic.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. If I don’t change my drinking soon or remain abstinent my problems can get worse.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I have already made changes or stopped my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I was drinking too much at one time, but I’ve managed to change or abstain from drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Sometimes I wonder whether returning to drinking could hurt other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I am or have been a problem drinker.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. I’m not just thinking about changing my drinking, I’m already doing or have done something about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. I have already changed my drinking. I am always considering ways to keep from slipping back to my old pattern.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I have or have had serious problems with drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Sometimes I wonder if I am in control of my drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. My drinking is or can cause a lot of harm.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I am actively doing things now to cut down, stop or abstain from drinking.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I want help or will consider help to keep myself from going back to the drinking problem that I had before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I know that I have or have had a drinking problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. There are times when I wonder if I drank too much.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I am an alcoholic.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. I am working hard to change my drinking or to keep my abstinence.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I have made changes in my drinking. I will want some help to keep myself from going back to the way I used to drink.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### HISTORY OF SUBSTANCE USE

**Code**: 0  
Never used or a few times only

- 1 Past non-problem
- 2 Past problem
- 3 Current non-problem
- 4 Current problem

<table>
<thead>
<tr>
<th>Substance</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannabis</td>
<td></td>
</tr>
<tr>
<td>Heroin</td>
<td></td>
</tr>
<tr>
<td>Methadone</td>
<td></td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td></td>
</tr>
<tr>
<td>Amphetamines</td>
<td></td>
</tr>
<tr>
<td>Cocaine</td>
<td></td>
</tr>
<tr>
<td>Ecstasy</td>
<td></td>
</tr>
</tbody>
</table>
## PREVIOUS ALCOHOL TREATMENT

1. Inpatient Detoxification

<table>
<thead>
<tr>
<th></th>
<th>Nil</th>
<th>1 time</th>
<th>2-3 times</th>
<th>4-5</th>
<th>5+</th>
</tr>
</thead>
</table>

2. Outpatient Detoxification

<table>
<thead>
<tr>
<th></th>
<th>Nil</th>
<th>1 time</th>
<th>2-3 times</th>
<th>4-5</th>
<th>5+</th>
</tr>
</thead>
</table>

3. Residential Treatment

<table>
<thead>
<tr>
<th></th>
<th>Nil</th>
<th>1 time</th>
<th>2-3 times</th>
<th>4-5</th>
<th>5+</th>
</tr>
</thead>
</table>

4. Day Program

<table>
<thead>
<tr>
<th></th>
<th>Nil</th>
<th>1 time</th>
<th>2-3 times</th>
<th>4-5</th>
<th>5+</th>
</tr>
</thead>
</table>

5. Outpatient Counselling

<table>
<thead>
<tr>
<th></th>
<th>Nil</th>
<th>1 episode</th>
<th>2-3 times</th>
<th>4-5</th>
<th>5+</th>
</tr>
</thead>
</table>

6. Alcoholics Anonymous or SMART

|   | 0 (< 12 occasions) | 1 (More than 12 occasions) |

Reasons for seeking current treatment (controls):
HEALTH BELIEFS TREATMENT BARRIERS QUESTIONNAIRE (CASES)

INSTRUCTIONS: Circle the answer that shows how much you agree or disagree with each item.

<table>
<thead>
<tr>
<th>DISAGREE</th>
<th>NOT</th>
<th>AGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>STRONGLY</td>
<td>......</td>
<td>SURE</td>
</tr>
</tbody>
</table>

PART 1

1. Liver disease can be caused by alcohol.

   1  2  3  4  5  6  7

2. Drinking after a transplant can lead to serious health problems.

   1  2  3  4  5  6  7

3. Abstinence is essential for a healthy liver.

   1  2  3  4  5  6  7

4. The health of my liver concerns me a great deal.

   1  2  3  4  5  6  7

5. It is likely that I will get sick if I return to drinking.

   1  2  3  4  5  6  7

6. Not drinking is more trouble than it is worth.

   1  2  3  4  5  6  7

7. Lifetime abstinence is worse than liver disease.

   1  2  3  4  5  6  7

8. Doctors have the best advice about alcohol and liver disease.

   1  2  3  4  5  6  7
<table>
<thead>
<tr>
<th>DISAGREE</th>
<th>NOT</th>
<th>AGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>STRONGLY</td>
<td>...</td>
<td>SURE</td>
</tr>
</tbody>
</table>

9. I do not let cravings or old drinking behaviour interfere with my life.  
1  2  3  4  5  6  7

10. Looking after my health is one of my major concerns.  
1  2  3  4  5  6  7

11. I worry about returning to drinking after my transplant.  
1  2  3  4  5  6  7

12. Drinking for me, can lead to health problems more than other people my age  
1  2  3  4  5  6  7

13. I am likely to get liver disease again if I return to drinking.  
1  2  3  4  5  6  7

14. I would consider professional help if I started to drink or crave alcohol  
1  2  3  4  5  6  7

15. I know how to socialize without drinking  
1  2  3  4  5  6  7

16. I am confident about coping with life problems without drinking  
1  2  3  4  5  6  7

17. My life is better for not drinking  
1  2  3  4  5  6  7

18. Not drinking and staying well is largely a matter of good luck.  
1  2  3  4  5  6  7
19. I have replaced my drinking lifestyle with people and activities.
HEALTH BELIEFS TREATMENT BARRIERS QUESTIONNAIRE (CONTROLS)

INSTRUCTIONS: Circle the answer that shows how much you agree or disagree with each item.

<table>
<thead>
<tr>
<th>DISAGREE</th>
<th>NOT</th>
<th>AGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>STRONGLY</td>
<td>....</td>
<td>SURE</td>
</tr>
</tbody>
</table>

PART 1

1. Liver disease can be caused by alcohol.  
1 2 3 4 5 6 7

2. Drinking after a liver transplant can lead to serious health problems.  
1 2 3 4 5 6 7

3. Abstinence is essential for a healthy liver.  
1 2 3 4 5 6 7

4. The health of my liver concerns me a great deal.  
1 2 3 4 5 6 7

5. It is likely that I will get sick if I return to drinking.  
1 2 3 4 5 6 7

6. Not drinking is more trouble than it is worth.  
1 2 3 4 5 6 7

7. Lifetime abstinence is worse than liver disease.  
1 2 3 4 5 6 7

8. Doctors have the best advice about alcohol and liver disease.  
1 2 3 4 5 6 7
9. I do not let cravings or old drinking behaviour interfere with my life.
   1  2  3  4  5  6  7

10. Looking after my health is one of my major concerns.
   1  2  3  4  5  6  7

11. I worry or would worry about returning to drinking after having been abstinent.
   1  2  3  4  5  6  7

12. Drinking for me, can lead to health problems more than other people my age.
   1  2  3  4  5  6  7

13. I am likely to get liver disease if I continue to drink.
   1  2  3  4  5  6  7

14. I would consider professional help if I started to drink or crave alcohol.
   1  2  3  4  5  6  7

15. I know how to socialize without drinking.
   1  2  3  4  5  6  7

16. I am confident about coping with life problems without drinking.
   1  2  3  4  5  6  7

17. My life is better for not drinking.
   1  2  3  4  5  6  7

18. Not drinking and staying well is largely a matter of good luck.
   1  2  3  4  5  6  7

19. I have replaced my drinking lifestyle with people and activities.
   1  2  3  4  5  6  7
**Ferrans and Powers**  
**QUALITY OF LIFE INDEX®**  
**GENERIC VERSION - III**

**PART 1.** For each of the following, please choose the answer that best describes how **satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>HOW Satisfied ARE YOU WITH:</th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. Your health care?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. The amount of pain that you have?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. The amount of energy you have for everyday activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. Your ability to take care of yourself without help?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. The amount of control you have over your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. Your chances of living as long as you would like?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>8. Your family’s health?</td>
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<td>9. Your children?</td>
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<td>10. Your family’s happiness?</td>
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<td>11. Your sex life?</td>
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<td>12. Your spouse, lover, or partner?</td>
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<td>13. Your friends?</td>
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<td>14. The emotional support you get from your family?</td>
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<td>15. The emotional support you get from people other than your family?</td>
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(Please Go To Next Page)  
© Copyright 1984 & 1998 Carol Estwing Ferrans and Marjorie J. Powers
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<th>Question</th>
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<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
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<td>17. How useful you are to others?</td>
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<td>18. The amount of worries in your life?</td>
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<td>19. Your neighborhood?</td>
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<td>20. Your home, apartment, or place where you live?</td>
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<td>21. Your job (if employed)?</td>
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<td>22. Not having a job (if unemployed, retired, or disabled)?</td>
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<td>24. How well you can take care of your financial needs?</td>
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<td>25. The things you do for fun?</td>
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<td>26. Your chances for a happy future?</td>
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<td>27. Your peace of mind?</td>
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<td>28. Your faith in God?</td>
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<td>29. Your achievement of personal goals?</td>
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<td>30. Your happiness in general?</td>
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<td>31. Your life in general?</td>
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<td>HOW IMPORTANT TO YOU IS:</td>
<td>Very Unimportant</td>
<td>Moderately Unimportant</td>
<td>Slightly Unimportant</td>
<td>Slightly Important</td>
<td>Moderately Important</td>
<td>Very Important</td>
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<td>16. Taking care of family responsibilities?</td>
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<td>17. Being useful to others?</td>
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<td>18. Having no worries?</td>
<td>1 2 3 4 5 6</td>
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<td>19. Your neighborhood?</td>
<td>1 2 3 4 5 6</td>
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<td>20. Your home, apartment, or place where you live?</td>
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<td>21. Your job (if employed)?</td>
<td>1 2 3 4 5 6</td>
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<td>22. Having a job (if unemployed, retired, or disabled)?</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>23. Your education?</td>
<td>1 2 3 4 5 6</td>
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<td>24. Being able to take care of your financial needs?</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>25. Doing things for fun?</td>
<td>1 2 3 4 5 6</td>
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<td>26. Having a happy future?</td>
<td>1 2 3 4 5 6</td>
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<td>27. Peace of mind?</td>
<td>1 2 3 4 5 6</td>
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<td>28. Your faith in God?</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>29. Achieving your personal goals?</td>
<td>1 2 3 4 5 6</td>
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<td>30. Your happiness in general?</td>
<td>1 2 3 4 5 6</td>
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<td>31. Being satisfied with life?</td>
<td>1 2 3 4 5 6</td>
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<td>32. Your personal appearance?</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>33. Are you to yourself?</td>
<td>1 2 3 4 5 6</td>
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</tbody>
</table>
Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

0  Did not apply to me at all

1  Applied to me to some degree, or some of the time

2  Applied to me to a considerable degree, or a good part of time

3  Applied to me very much, or most of the time

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down</td>
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<td>2</td>
<td>I was aware of dryness of my mouth</td>
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<td>3</td>
<td>I couldn't seem to experience any positive feeling at all</td>
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<td>4</td>
<td>I experienced breathing difficulty (eg, excessively rapid breathing,</td>
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<td></td>
<td>breathlessness in the absence of physical exertion)</td>
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<td>5</td>
<td>I found it difficult to work up the initiative to do things</td>
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<td>6</td>
<td>I tended to over-react to situations</td>
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<td>7</td>
<td>I experienced trembling (eg, in the hands)</td>
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<td>8</td>
<td>I felt that I was using a lot of nervous energy</td>
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<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of</td>
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<td></td>
<td>myself</td>
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<td>10</td>
<td>I felt that I had nothing to look forward to</td>
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<td>11</td>
<td>I found myself getting agitated</td>
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<td>12</td>
<td>I found it difficult to relax</td>
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<td>13</td>
<td>I felt down-hearted and blue</td>
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<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I</td>
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<td></td>
<td>was doing</td>
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<td>15</td>
<td>I felt I was close to panic</td>
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<td>16</td>
<td>I was unable to become enthusiastic about anything</td>
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<td>17</td>
<td>I felt I wasn't worth much as a person</td>
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<td>18</td>
<td>I felt that I was rather touchy</td>
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<td>19</td>
<td>I was aware of the action of my heart in the absence of physical</td>
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<td></td>
<td>exertion (eg, sense of heart rate increase, heart missing a beat)</td>
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<td>20</td>
<td>I felt scared without any good reason</td>
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<tr>
<td>21</td>
<td>I felt that life was meaningless</td>
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</table>
HIGH-RISK ALCOHOLISM RELAPSE SCALE

1. Duration of heavy drinking in years
   - □ Less than 11 years
   - □ 11-25 years
   - □ Over 25 years

2. Number of daily drinks when drinking
   - □ Less than 9 standard drinks
   - □ 9-17 standard drinks
   - □ More than 17

3. Number of prior alcoholism inpatient treatments
   - □ 0
   - □ 1
   - □ More than 1
HELP SEEKING SURVEY

These questions are about your experience of counselling and medical staff at this hospital

DISAGREE NOT AGREE
STRONGLY ... NOT ... STRONGLY

PART 2

1. I feel comfortable letting staff know about problems I may be having with drinking
   1 2 3 4 5 6 7

2. Staff would be very disappointed if I was to tell them about problems with drinking. 1 2 3 4 5 6 7

3. I would be embarrassed to let staff know about any problems with abstinence 1 2 3 4 5 6 7

4. If I let staff know about problems with alcohol they will see me as a failure. 1 2 3 4 5 6 7

5. If I talk about alcohol with staff it will affect the type of treatment I get. 1 2 3 4 5 6 7

6. Staff encourage patients to talk about their alcohol use. 1 2 3 4 5 6 7

7. Staff have provided help and advice with any alcohol related problems 1 2 3 4 5 6 7

8. I want alcohol treatment provided by this service (or if it was available) 1 2 3 4 5 6 7

9. There is a staff member available who you can discuss alcohol issues with. 1 2 3 4 5 6 7
<table>
<thead>
<tr>
<th>TASK</th>
<th>SCORE</th>
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</thead>
<tbody>
<tr>
<td>1. What is the year, season, date, day of week, and month?</td>
<td>/5</td>
</tr>
<tr>
<td>2. Where are we? Prompt for country, state, town, building (e.g. Hospital/home), and floor or room.</td>
<td>/5</td>
</tr>
<tr>
<td>3. Name three common objects slowly and clearly, e.g. ‘apple’, ‘table’, ‘penny’. Ask the patient to repeat them.</td>
<td>/3</td>
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<tr>
<td>4. Ask the patient to count backwards from 100 by 7. Stop after five answers. (Alternatively ask them to spell ‘world’ backwards.)</td>
<td>/5</td>
</tr>
<tr>
<td>5. Ask the patient to recall the objects learned earlier. (apple, table, penny)</td>
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<tr>
<td>6. Point to your watch and ask the patient, ‘what is this?’ Repeat with a pencil.</td>
<td>/2</td>
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<tr>
<td>7. Ask the patient to repeat this phrase after you ‘No ifs, ands, or buts.’</td>
<td>/1</td>
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</table>
| 8 | Give the patient a piece of paper and say: ‘Take this paper in your right hand, fold it in half, and put it on the floor.’  
   | One point for each correct action. | /3 |
| 9 | Show the patient a piece of paper with ‘CLOSE YOUR EYES’ printed on it.  
   | One point if the patient's eyes close. | /1 |
| 10 | Ask the patient to write a sentence.  
   | One point if sentence has a subject, a verb, and makes sense. | /1 |
| 11 | Ask the patient to copy a pair of intersecting pentagons onto a piece of paper.  
   | One point if the figure has ten corners and two intersecting lines. | /1 |
| TOTAL |   | /30 |

<table>
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<tr>
<th>Score Range</th>
<th>Cognitive Function</th>
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<tr>
<td>25 – 30</td>
<td>Normal cognitive function</td>
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<tr>
<td>21 – 24</td>
<td>Mild cognitive impairment</td>
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<tr>
<td>10 – 20</td>
<td>Moderate cognitive impairment</td>
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<tr>
<td>&lt; 10</td>
<td>Severe cognitive impairment</td>
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</table>
APPENDIX F Interview guide and table of themes

INTERVIEW GUIDE

Semi-structured interview

Q1. Abstinence
   a) What has it been like giving up drinking whilst going through liver transplantation?
   b) How did you manage to achieve abstinence?
   c) What support has been behind remaining abstinent?

Q2. Transplant Staff
   a) How have transplant staff helped you with alcohol related issues?
   b) Have staff discussed alcohol related matters, provided information or referred you to services?
   c) How would they react if you told them you were having cravings, needing treatment or that you had been drinking?

Q3. Relapse
   a) What do you think causes people to relapse either before or after a transplant?
   b) If you relapsed what would you do?

Q4. Preferred alcohol treatment approach
   a) What support do you think transplant staff could provide to assist people with maintaining long term abstinence?

Q5. Possible reasons for resistance to alcohol treatment
a) Why do you think ALD transplant patients may refuse to attend or participate in alcohol treatment programs when provided by liver transplant units?

**In-depth semi-structured interview**

What has it been like going through a liver transplant and giving up drinking?

Probing questions

- a) How difficult was it to achieve abstinence?
- b) What support was behind remaining abstinent?
- c) When has it been difficult?
- d) What prompted or motivated you to achieve abstinence?
- e) Have you been bothered by urges or cravings?

**Describe the relapse experience**

Probing questions

- a) Under what conditions do you think relapse is possible?
- b) What factors do you think may have influenced your lapse or relapse?
- c) Personal reaction to relapse?
- d) The reaction of others to your relapse?

**What has been their experience of transplant program and staff regarding alcohol and alcohol related problems?**

Probing questions

- a) What was your experience of how transplant staff deal with relapse?
- b) What is your view of the contract of lifelong abstinence?
Views regarding using alcohol treatment

Probing questions

a) Would you consider treatment?
b) If yes, when would you consider treatment?
c) What is your preferred choice of treatment?

Exploratory/probing questions for more in-depth semi-structured interviews

What has been your experience of liver transplantation?
Can you describe that situation or experience a bit more?
What was it like when….
If you could, what would you like to tell transplant staff?
What do you think they may need to know?
Tell me more about……
What are your thoughts about that?
What do you think was influencing you when … or at that time?
Reflect what they are saying …was that how it was…does that sound right?
What would you tell other people who are going to go through a transplant about the risk of relapse?
It seems to me that you are saying….did I get that right? Is that how it is or is there something I may be missing? Would you like to add more or clarify/elaborate?
What kind of advice would you give to others?
What will the future be like?
Is there anything you would like to add or say before I finish the interview?
Table 10.3 The number and percentages of ESALD transplant participants (abstainers, relapsers and total group) and their responses to the semi-structured interview questions.

<table>
<thead>
<tr>
<th>Motivation for abstinence</th>
<th>Abstainers (n=32)</th>
<th>Relapsers (n=10)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>End-stage liver disease and wanting to live</td>
<td>32 (100%)</td>
<td>10 (100%)</td>
<td>42 (100%)</td>
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<tr>
<td>Including other reason</td>
<td></td>
<td>2 (22%)</td>
<td>2 (6%)</td>
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</table>

<table>
<thead>
<tr>
<th>How abstinence was achieved and maintained</th>
<th></th>
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<tbody>
<tr>
<td>I weighed things up, made a decision, used my willpower</td>
<td>23 (72%)</td>
<td></td>
<td></td>
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<tr>
<td>The support of partner and family</td>
<td>21 (66%)</td>
<td></td>
<td></td>
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<tr>
<td>By avoiding or coping with social events</td>
<td>21 (66%)</td>
<td></td>
<td></td>
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<tr>
<td>I thought about why I shouldn’t drink</td>
<td>18 (56%)</td>
<td></td>
<td></td>
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<tr>
<td>Moral obligation</td>
<td>17 (53%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplant related epiphany</td>
<td>9 (28%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relying on friends only</td>
<td>4 (13%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AA/NA support</td>
<td>3 (9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relying on myself not a partner</td>
<td>4 (12%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being active</td>
<td>2 (6%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants experience of transplant staff/program</th>
<th>Abstainers (n=32)</th>
<th>Relapsers (n=10)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>The issue of alcohol was not discussed apart from monitoring</td>
<td>20 (63%)</td>
<td>6(60%)</td>
<td>26 (62%)</td>
</tr>
<tr>
<td>Staff look at your blood tests to see how you are going</td>
<td>15 (47%)</td>
<td>5 (50%)</td>
<td>20 (48%)</td>
</tr>
<tr>
<td>Staff provide medical advice, information and referral</td>
<td>12 (38%)</td>
<td>5 (50%)</td>
<td>17 (40%)</td>
</tr>
<tr>
<td>You are asked about your drinking and encouraged not to</td>
<td>11 (34%)</td>
<td>7 (70%)</td>
<td>18 (43%)</td>
</tr>
<tr>
<td>Don’t remember getting advice, referral or information</td>
<td>9 (28%)</td>
<td>0</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>You are expected to comply with staff recommendations</td>
<td>5 (16%)</td>
<td>6 (60%)</td>
<td>11 (26%)</td>
</tr>
<tr>
<td></td>
<td>Abstainers (n=32)</td>
<td>Relapsers (n=10)</td>
<td>Total</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------</td>
<td>------------------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>Participant perceptions regarding staff and relapse</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff would be very disappointed</td>
<td>21 (66%)</td>
<td>6 (60%)</td>
<td>27 (64%)</td>
</tr>
<tr>
<td>Staff would be supportive despite any problems</td>
<td>10 (24%)</td>
<td>3 (33%)</td>
<td>12 (32%)</td>
</tr>
<tr>
<td>May not get a liver or placed down the list if I report problems</td>
<td>2 (5%)</td>
<td>2 (22%)</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>4 (13%)</td>
<td>1 (11%)</td>
<td>5 (12%)</td>
</tr>
</tbody>
</table>

| **Participant views on reasons for relapse** |                   |                  |       |
| I feel fine now I have a new liver, I can return to drinking | 17 (56%)          | 2 (20%)          | 19 (45%) |
| Personal problems, stressors, depression, or trauma | 13 (41%)           | 8 (80%)          | 21 (50%) |
| Lack of family support | 9 (28%)           | 6 (66%)          | 15 (37%)  |
| Culture of social drinking | 6 (19%)           | 5 (50%)          | 11 (26%)  |
| Pre-transplant period-waiting (fear of death or unknown, pain) | 4 (13%)           | 3 (33%)          | 7 (17%)  |
| Denial (‘don’t see a problem’) | 3 (9%)           | 1 (10%)          | 4 (10%)  |
| Severity of dependence | 4 (13%)           | 1 (10%)          | 5 (12%)  |
| Lack of activity | 1 (3%)           | 0                | 1 (2%)  |
| No idea | 3 (9%)           | 0                | 2 (5%)  |

<p>| <strong>How participants would manage a relapse</strong> |                   |                  |       |
| I would tell my doctor or nursing staff | 14 (44%)           | 1 (11%)          | 15 (36%) |
| Handle it myself | 6 (19%)           | 6 (60%)          | 12 (29%) |
| Go to AA/NA | 4 (13%)           | 3 (30%)          | 7 (17%)  |
| Turn to my family for help first | 2 (6%)           | 0                | 2 (5%)  |
| Detox/rehab | 1 (3 %)           | 0                | 1 (2%)  |
| Another health professional/counselor off-site | 2 (6 %)           | 2 (20%)          | 4 (10%)  |</p>
<table>
<thead>
<tr>
<th></th>
<th>Abstainers (n=32)</th>
<th>Relapsers (n=10)</th>
<th>Total</th>
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<tbody>
<tr>
<td>How participants would manage a relapse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would tell my doctor or nursing staff</td>
<td>14 (44%)</td>
<td>1 (10%)</td>
<td>15 (36%)</td>
</tr>
<tr>
<td>Handle it myself</td>
<td>6 (19%)</td>
<td>6 (60%)</td>
<td>12 (29%)</td>
</tr>
<tr>
<td>Go to AA/NA</td>
<td>4 (13%)</td>
<td>3 (30%)</td>
<td>7 (17%)</td>
</tr>
<tr>
<td>Detox/rehab</td>
<td>1 (3%)</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Another health professional/counselor off-site</td>
<td>2 (6%)</td>
<td>2 (20%)</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>Turn to my family for help first</td>
<td>2 (6%)</td>
<td>0</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Possible reasons for resistance to alcohol treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I’m abstinent don’t need for treatment/I can work it out</td>
<td>22 (69%)</td>
<td>7 (60%)</td>
<td>29 (69%)</td>
</tr>
<tr>
<td>Stigma, sense of failure, guilt about letting staff down</td>
<td>18 (56%)</td>
<td>8 (80%)</td>
<td>26 (62%)</td>
</tr>
<tr>
<td>People may not see they have a problem with alcohol</td>
<td>4 (15%)</td>
<td>1 (10%)</td>
<td>5 (12%)</td>
</tr>
<tr>
<td>Don’t like professionals telling me what to do</td>
<td>5 (15%)</td>
<td>4 (13%)</td>
<td>5 (12%)</td>
</tr>
<tr>
<td>Staff too busy</td>
<td>2 (6%)</td>
<td>4 (44%)</td>
<td>6 (14%)</td>
</tr>
<tr>
<td>Some may be hiding their drinking</td>
<td>3 (11%)</td>
<td>0</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Don’t know where to go</td>
<td>1 (3%)</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Don’t want to stop my drinking</td>
<td>0</td>
<td>1 (13%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Being pressured into treatment</td>
<td>0</td>
<td>2 (25%)</td>
<td>2 (5%)</td>
</tr>
</tbody>
</table>