BETWIXT AND IN-BETWEEN STATE AND COMMUNITY:

Illness identities and the distinct expertise of a health-orientated community-based organisation within the contemporary socio-political environment

Paul Leslie Simpson

This thesis is presented in fulfilment of the requirements for the degree of

Doctor of Philosophy

University of Technology, Sydney

2013

CERTIFICATE OF ORIGINAL AUTHORSHIP

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Student:

Production Note:
Signature removed prior to publication.

Date: 5th March 2013

ACKNOWLEDGEMENTS

Firstly, I would like to thank my supervisory team: Dr kylie valentine and Professor Carla Treloar for their support through the earlier years of my candidature. A big thanks especially goes to Professor Jenny Onyx. Without Jenny's guidance, insights and passionate encouragement, I would not have gotten over the line. Thankyou also goes to Associate Professor Judy Johnston for her support and friendship.

I wish to extend many thanks to those who gave their time to be interviewed for this study. I would particularly like to thank Hepatitis New South Wales for their assistance. I would also like to acknowledge that I have been a grateful recipient of a scholarship from the Consortium for Social and Policy Research on HIV, Hepatitis C and Related Diseases.

On a more personal note, there are many friends and colleagues who provided many words and acts of support and kindness along the way. To name a few I would like to thank Kata, Nassim, Lee, Jaye, Karen, Tanya, Kate, Wayne, Annette and the Justice Health Research team at the Kirby Institute.

Above all, I am grateful for the patience and loyal, if sardonic, support of my partner Dudi and my loving family.

TABLE OF CONTENTS

PART ONE: BACKGROUND AND THEORY

PART TWO: METHODOLOGY

PART THREE: FINDINGS AND CONCLUSION

LIST OF FIGURES AND TABLES

List of figures

List of tables

ABSTRACT

This thesis is concerned with the critical potentials and challenges of a health-orientated community-based organisation within the contemporary socio-political environment. Hepatitis C (HCV) community-based organisations (CBOs) are reported by government to be a fundamental component of Australia's national response to the HCV epidemic. This is said to be due to a "specific" expertise that mark them distinct from public (health) sector sites. Traditional thinking on what marks civil society organisations like CBOs as distinct is commonly presented in terms of rationalist/utilitarian human service models. This thesis contends that health-orientated CBOs complicate this thinking as people who engage with HCV CBOs do so not only for service access, but also for social and identity reasons to help, and learn from, others to gain answers to questions such as; "who I am?", "whom am I connected to?" and "who can I hope to become?" as a result of HCV.

Drawing from HCV CBO text and interviews with key informants and people affected by HCV, this thesis investigates and links questions of illness experience and distinct expertise of a HCV CBO. Findings are assessed and articulated according to the model developed. Particularly, Victor Turner's work on liminality, which underpins the model, is used to interpret findings. Liminality, referring to a position or status that is "betwixt and in-between" (Turner, 1969), is applied in two different ways: as a negative effect when viewed in the context of illness identities and productively in terms of CBOs.

It is illustrated how HCV lived experience can represent a liminal identity fostered by dominant narratives of HCV that encourage people to adopt medicalised and health consumer identities. The study also explores how a HCV CBO's relational position in-between state and "community" endows it with a liminal quality that is expressed through the multiple and at times opposing HCV narratives that a HCV CBO (re)produces. Some of these narratives correspond to dominant medicalised and health consumer identities; others present as alternative identities whereby social, cultural and political contexts emerge. The critical potential of a CBO's liminal position, which is purported to underpin its distinct expertise, is discussed by presenting how participants affected by HCV scrutinise and draw from both dominant and alternative HCV narratives in ways that construct identities that are responsive to an individual's particular social circumstances and for some, more "community" minded. However, findings also suggest a CBO tendency to "manage" and marginalise alternative narratives and identities thus threatening its distinct expertise. This tendency is interpreted by discussing the contemporary socio-political climate which CBOs find themselves. This thesis contributes to new understandings of health-orientated CBOs based on a capacity to mediate illness identities in responsive ways, ways that may also give rise to health related social and political understandings and influence.

CHAPTER ONE

INTRODUCTION

Hepatitis C (HCV) community-based organisations (CBOs) are reported by government to be a fundamental component of Australia's national response to the HCV epidemic (CoA, 2000, 2005, 2010). This is said to be due to a "specific" expertise these organisations hold. The term "specific" denotes a type of knowledge and/or value CBOs hold that is not generally or prevalently available elsewhere. This expertise is typically inferred to be somehow connected to experiential knowledge - derived from the lived experience of individuals affected by HCV who engage with HCV CBOs (CoA, 2000, 2005, 2010), and as such helps construct HCV CBOs as distinct from other institutional sites such as the public (health) sector that predominantly attend to HCV.

Despite this well-rehearsed expertise claim with its connection to HCV lived experience, there is a paucity of research examining HCV CBOs, in particular research that examines this idea of HCV CBO "specific" expertise or, as I will call it from here on, "distinct expertise". Furthermore, the lack of social research on the lived experience of HCV that is well documented (Southgate, Kippax & Owler, 2002; Hopwood & Treloar, 2003; Hopwood & Southgate, 2003; Treloar & Rhodes, 2009) similarly applies to research looking at how engagement with a HCV CBO may inform the lived experience of HCV.

Community-based organisations typically emerge out of civil society and conceptually have become known to occupy the third or civil society sector, separate from public and business sectors (Sending & Neumann, 2006; Lyons, 2001; Van Til, 2000). Traditional thinking on what marks CBOs as distinct from their business and public sector counterparts is commonly presented in terms of rationalist utilitarian models. Such understandings primarily focus on legal classifications and/or service delivery dynamics in response to market or state failure, seeing those who engage with such organisations positioned as service consumers (Salamon & Anheier, 1994, 1996; Defourny, Develtere & Fonteneau, 1999; Lyons, 2000, 2001; Moulaert & Ailenei, 2005; Van Til, 2000, 2009; Anheier, 2009). Similarly, literature on health-orientated CBOs predominantly views such organisations as service organisations providing auxiliary support to mainstream medical/health services (Roberts, Salem, Rappaport, Toro, Luke, & Seidman ,1999; Rappaport, 1993).

Importantly, whereas traditional approaches have provided valuable insight into organisations like CBOs, some have criticised their tendency to overlook the user or member side of such organisations (Lyons & Simpson, 2009; Billis & Glennerster, 1998; Rappaport, 1993, Allsop et al., 2004; Short & Mutch, 2001). This neglect, and the privileging of rationalist utilitarian understandings, relates to what Lehman (2007) terms an 'assimilating logic' whereby social values are reduced to economic and utilitarian conceptions and calculations. Such logics overlook collective and social processes attached to personal subjectivity and limit the conditions for individuals to address concerns attached to the social system (Lehman, 2007, p. 653-656).

Government claims of HCV CBO distinct expertise sit alongside growing scholarly debate concerning how the contemporary socio-political environment compel many CBOs to increasingly mediate relations between the state and the “community” they represent and support. A prevailing issue here, which speaks to Lehman’s (2007) idea of an assimilation logic, concerns how such relations may affect CBO practices in ways that may constrain their defining distinction(s) or distinct expertise (Lyons, 2001; Lyons & Hocking, 2000; McDonald & Marston, 2002; Pugh, 2006; Carey, 2007, 2008; Onyx, Dalton, Melville, Casey & Banks, 2008; Onyx, Armitage, Dalton, Melville, Casey & Banks 2010). This debate is relevant to a HCV context because state-led National Hepatitis C Strategies implicate HCV CBOs within state governance relations (CoA, 2000, 2005, 2010). Despite such relevance, there are no studies to date that look at the potential impact of state governance relations on HCV CBOs and their members.

Scope of thesis

A central premise of this thesis concerns how health-orientated CBOs complicate and challenge traditional utilitarian/rationalist understandings of CBOs as people who engage with health CBOs do so not only for service access, but also for social and identity reasons in order to help, and learn from, others to understand answers to questions such as: “who I am?”; “whom am I connected to?” and; “who can I hope to become” as a result of living with an illness (Rappaport, 1993).

This identity mediation premise is used in this study to develop a preliminary model of HCV CBO distinct expertise that links questions of illness experience and a HCV CBO’s relational position between the state and HCV “community”. This model provides a framework to investigate how a HCV CBO could realise, or could be realising, the specific elements and processes that underpin its distinct expertise. The model postulates that a HCV CBO’s distinct expertise lies in a critical capacity to facilitate particular types of “narrative communities” that in turn help mediate responsive HCV identities among members, identities that are considerate of individual and social particularities and difference. Importantly, the model considers how a HCV CBO’s relational position between the state and HCV “community” may both facilitate and constrain its distinct expertise and thus constrain responsive identity mediations among its members.

Accordingly, this thesis aims to investigate the notion of distinct expertise in a HCV CBO and the factors that help express and constrain this distinct expertise and further asks, in what ways does a HCV CBO facilitate the construction of responsive HCV identities among those who engage with it?

To address this research aim and question a qualitative research approach is selected. Qualitative research often involves multi-, inter- or trans-disciplinary approaches employing various theoretical perspectives and categories in order to develop a theoretical approach and to analyse, articulate and interpret findings (Choi et al., 2006; Denzin & Lincoln, 2000). Drawing upon such disciplines as psychology, social theory, social anthropology, management/organisational studies and civil society sector research, the theoretical model developed and findings presented are articulated in terms of HCV narratives and the identity formations they construct. The “narrative turn” within the social sciences has permeated organisational studies reflecting a growing interest in stories and narratives within organisations, ‘especially as they are linked to issues of knowledge, sense-making, communication, power and identities’ (Brown, Gabriel & Gherardi, 2009, p. 324). Narrative approaches also feature in many studies examining health, illness and HCV and are seen as tools that are sensitive and respectful to the voices of research participants (Riessman, 1994, 2002; Viney &

Bousfield, 1991; Hurwitz, Greenhalgh & Skultans, 2004; Sutton & Treloar, 2007; Harris, 2009; Pugh, 2006).

By privileging the mediation of members lived experience or identities within ideas of health CBO distinct expertise, this study extends rationalist/utilitarian understandings of CBOs towards an expressive and social ontological approach, and thus contributes to new understandings of health CBOs.

Outline of thesis

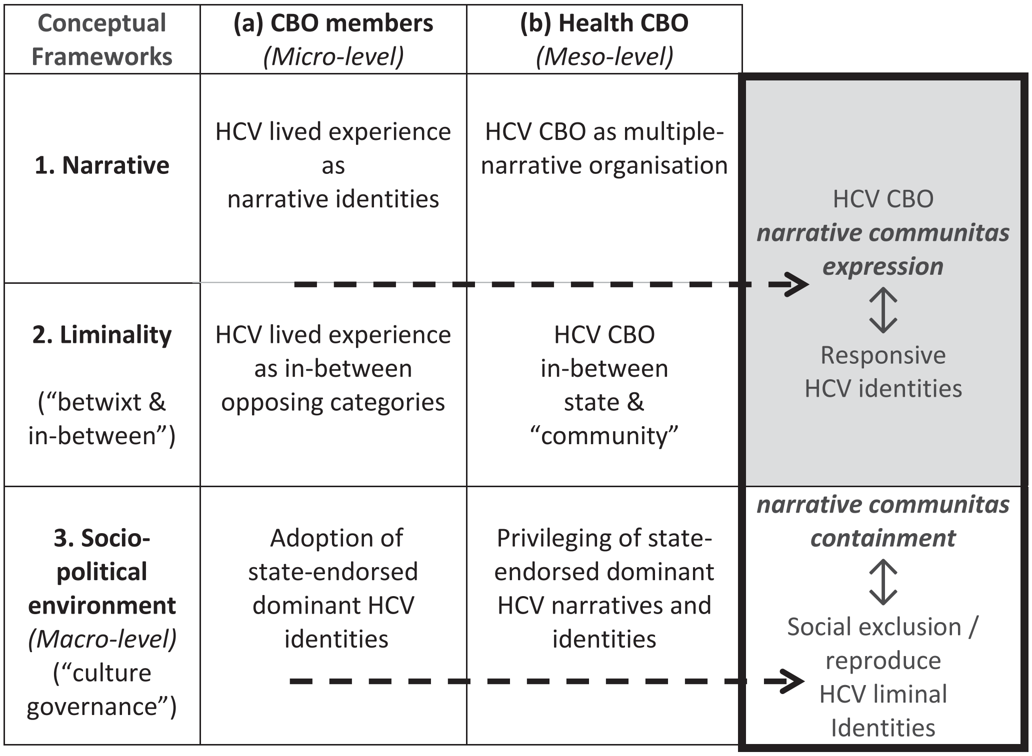
Part One: Background and theory

Part One presents the relevant background to this thesis and the theoretical model developed to investigate CBO distinct expertise. Chapter Two begins by presenting an overview of HCV in terms of its natural history, prevalence rates and social responses within Australia. A review of the literature on the lived experience of HCV is then presented. By focusing on the concepts of social stigma (Scrambler, 1998; Hopwood, Treloar & Redsull, 2006; Treloar & Fraser, 2007) and biographical adaptations (Bury, 1982; Carricaburu & Pierret, 1995; Sutton & Treloar 2007), attention is drawn to how HCV lived experience can be understood through the lens of identity formations as mediated by interweaving individual and collective interpretations of HCV and illness. Such interpretations implicate identity formations as temporally, relationally and discursively constituted. Said differently, attempts to accommodate HCV within one's life story are seen as being shaped by examining one's past, present and future to develop some sense of identity continuity, reinforcement and/or renewal. Importantly, it is illustrated how these attempts are mediated by a repertoire of publicly available narratives of HCV which have been produced and circulated within various social and cultural settings and institutions (Somers, 1992, 1994; Williams, 1984). These settings are examined employing a sectoral lens in terms of the public and civil society sector responses to HCV.

In discussing public sector responses, although appearing comprehensive in terms of a reported "partnership" approach between government, health experts and HCV CBOs, questions arise in relation to how state-led conformity issues impact on the kinds of practices and narratives HCV CBOs undertake and produce and what this may mean to the identity formations among those who engage with a HCV CBO. These questions point to a challenge HCV CBOs face in terms of negotiating relations between the state and the people or "community" they are said to represent. This challenge is of central concern to this thesis in the context of examining and understanding HCV CBO distinct expertise in relation to the constitution of HCV identity (re)formations among its members.

Chapters Three and Four consider these questions and challenges within the context of developing a model of heath CBO distinct expertise thereby considering the interactive relationship between micro- (member experience/identities), meso- (HCV CBO position and practices) and macro-level (wider socio-political climate) factors.

Figure 1: ‘Narrative communitas’ model of HCV CBO distinct expertise



Conceptual Frameworks	**(a) CBO members** *(Micro-level)*	**(b) Health CBO** *(Meso-level)*	
1. Narrative	HCV lived experience as narrative identities	HCV CBO as multiple-narrative organisation	HCV CBO ***narrative communitas expression*** ↕ Responsive HCV identities
2. Liminality (“betwixt & in-between”)	HCV lived experience as in-between opposing categories	HCV CBO in-between state & “community”	
3. Socio-political environment *(Macro-level)* (“culture governance”)	Adoption of state-endorsed dominant HCV identities	Privileging of state-endorsed dominant HCV narratives and identities	***narrative communitas containment*** ↕ Social exclusion / reproduce HCV liminal Identities

This model of CBO distinct expertise (see Figure 1) is articulated firstly in Chapter Three according to “two-by-two” intersecting conceptual levels: (1) *narrative* (Somers, 1992, 1994; Boje, 1994, 1995, 2001, 2008) and (2) *liminality* (Turner, 1969, 1974) by (a) *member experiences* (micro-level) and (b) *health CBOs* (meso-level). Beginning with level (1) a narrative approach is presented in order to conceive of: 1(a) member HCV experiences as narrative identities (Somers, 1992, 1994); and 1(b) HCV CBOs as multiple-narrative organisations (Boje, 1994, 1995, 2001, 2008). Following this, level (2) is presented in terms of Victor Turner’s (1969) concept of liminality, referring to a ‘betwixt and in-between’ position, in order to characterise: 2(a) HCV experience as occupying, or *in between*, two opposing categories (e.g. in-between illness and wellness); and 2 (b) HCV CBOs relational position *in-between* the state and "community". As such Turner's concept of liminality is applied differently according to micro- and meso-level factors within the model.

These "two-by-two" intersecting levels are then drawn from to articulate CBO expertise in terms of prospective "narrative communitas" spaces. This is achieved by firstly illustrating how CBOs' relational and liminal position between state and "community" is expressed narratively through the multiple organisation stories it produces whereby some of these stories or narratives (and consequent identities constructed within these narratives) align to *dominant* state narratives of HCV and others to *alternative* experientially derived narratives of HCV. Secondly, it is argued that exposure to these multiple dominant and alternative narratives allows CBO members, particularly those who experience HCV as a liminal experience, to recognise and *scrutinise* various stories about the factors and processes that play their part in the construction of their HCV identities. This in turn can lead to experimenting with new factors and stories as they emerge and resonate with the individual, leading to possibilities of *responsive* HCV narratives and identities that are considerate of personal and social particularities. The concept of 'narrative communitas' here represents a reconfiguration of Rappaport's (1993) idea of "narrative communities" due to the difficulties of defining community as well as the conceptual connection communitas has with liminality (Turner, 1969) as will be detailed in Chapter Three.

In Chapter Four, a final conceptual level (macro-level) is introduced to the model by presenting how CBO-state governance relations, as a result of contemporary socio-political forces, may be constraining CBO capacities to develop narrative communitas spaces and thus threaten CBOs' ability to facilitate responsive HCV identity formations among their members. I articulate this by drawing upon the concept of "culture governance" (Bang, 2004, 2003a, 2003b, 2003c) which has been used to understand how this contemporary context may be impacting on CBO practices and their constituents. Culture governance is discussed in terms of how state and CBO governance structures and processes are rearticulating the relationship between political authorities and lay people. This is achieved through state-CBOs relations that encourage members to adopt particular identities that instantiate ethical membership to particular groups, "communities" or to draw from Rose (2000, p. 1402) 'ethopolitical communities'. The aim of culture governance is to 'get individuals to freely and willingly employ their self-governing powers to help the systems connect' and deliver effective outcomes (Bang, 2003c, p 247). Culture governance within HCV CBO-state relations, it is argued, may see the privileging of public sector/state endorsed HCV narratives and identities at the expense of marginalising alternative experiential narratives and identities. The impact of such marginalisation is discussed in terms of social exclusionary effects.

Part Two: Methodology

Part Two outlines the methodological principles and approach this thesis takes. It is shown that the research aim and question, to be explored through the narrative communitas model, informs the following research objectives:

1. Illustrate HCV narratives that construct *dominant HCV identities* and the kinds of assumptions these identities imply about HCV and the individuals affected by HCV.

2. Illustrate HCV narratives that construct *alternative HCV identities* and the kinds of assumptions these identities imply about HCV and the individuals affected by HCV.
3. Illustrate the *realisation* and *negotiation* of these dominant and alternative HCV narratives and identities within a HCV CBO and its members.

Research objectives one and two are achieved by drawing from the analysis of: (i) the types of narratives a HCV CBO produces and circulates to its members through a HCV CBO publication called the *Hep C Review*; (ii) interviews with eleven HCV CBO members about what they value (or not) about their engagement with a HCV CBO in relation to negotiating HCV in their lives; and (iii) interviews with three key informants from a HCV CBO who talk about the benefits and challenges of a HCV CBO and the kinds of narratives they produce. Social research/literature on HCV, illness, public health and civil society is also drawn from to support the meeting of these research objectives.

These objectives help address the research aim and question. Meeting research objective three is particularly important as *realisation* and *negotiation* of dominant and alternative HCV narratives and identities within a HCV CBO and by its members provides an opportunity to assess and articulate the expression and containment of prospective narrative communitas elements within a HCV CBO.

Chapter Five also discusses the field site, the HCV CBO this study examines - Hepatitis New South Wales (HNSW) - in terms of its history, roles and organisational structure.

Part Three: Findings and conclusion

Findings are organised and presented in Part Three according to each of the three research objectives. Chapter Six reports on dominant HCV identities and the kinds of assumptions these identities imply about individuals affected by HCV. Specifically, this Chapter reports on the medicalisation of the self in relation to HCV before articulating on the emergence and predominance of the HCV health consumer. It is demonstrated that, although derived and produced within the public (health) sector, such dominant HCV identities correspond to identities constructed in the *Hep C Review* as well as within member interviews. The Chapter goes on to examine how HCV health consumer identities, while providing productive potential among some, ultimately can represent and facilitate ‘representational silences’ among those affected by HCV that along with paradoxical elements inherent within the health consumer facilitate HCV lived experience as a liminal illness identity.

Alternative HCV identities, in terms of identities that diverge from the dominant identities, are then examined in Chapter seven. Alternative identities, termed ‘social advocacy’, ‘social liminal’ and ‘community-mutualist’, are shown to be constructed within the *Hep C Review* text and member interviews and how each of these identities draw from socially orientated understandings of HCV and the self that extend beyond medical models and consumer agency ideas. I discuss how such identities point to HNSW narratives and spaces that encourage “HCV biosocialities” that in some expressions hold productive potential in terms of: advocating an understanding of HCV through a variety of discourses; negotiating treatment related liminality and, for some mobilising a desire to help others and a “community” orientation.

In Chapter Eight these dominant and alternative HCV identities are interpreted against the narrative communitas model developed. Drawing from HNSW key informant interviews and the literature, HNSWs' liminal position between state and community is firstly discussed by way of negotiating or 'balancing' types of HCV knowledge and narratives within the *Hep C Review*. This idea of 'balance' introduces a discussion of the expression and containment of prospective narrative communitas elements as found within the *Hep C Review* and member interviews.

Expression of HNSW narrative communitas elements is presented in terms of the enactment of members' alternative social-liminal and community-mutualist identities. Such alternative identities, it is argued, represent responsive HCV identities in terms of: diverging from dominant state-endorsed identities; being (bio)socially orientated and being considerate of members' particular histories and social circumstances. By focusing on one particular member's interview or story about treatment experience, it is illustrated how the enactment of the social-liminal identity derives from a scrutiny of, and oscillation between, both dominant and alternative HCV treatment narratives found within the *Hep C Review*. As such this identity provides support for the narrative communitas model in terms of HNSW narrative spaces facilitating responsive member identity formation.

The containment of narrative communitas elements through the management and marginalisation of alternative HCV narratives and identities within the *Hep C Review* is then discussed. This containment is viewed through the lens of culture governance to argue that CBO-state relations encourage a HNSW tendency to privilege dominant state HCV identities within the *Hep C Review* for the strategic purposes of success and influence attached to state-HNSW "partnership" imperatives. Consequently, it is argued that culture governance processes are likely to threaten HNSW narrative communitas elements thus threatening what bestows HNSW with its distinct expertise.

In conclusion, Chapter Nine reports on the limitations of the study in order to qualify findings and their interpretations. Implications of this study are considered and attached to two interrelated directions for future research according to: 1) HCV identities; and 2) conceiving distinct expertise of health CBOs.

Part One

Background and theory

CHAPTER TWO

UNDERSTANDING HEPATITIS C

CHAPTER INTRODUCTION

This Chapter begins by presenting a background to HCV in terms of its natural history and prevalence rates. Following this I report on literature looking at the lived experience of HCV. Despite a paucity of social research on HCV, research reveals important social, cultural and political issues that inform the lived experience of HCV (Hopwood & Southgate, 2003; Treloar & Rhodes, 2009). Drawing from this and related literature, I outline the commonly reported themes of social stigma and biographical adaptation. In doing so, I draw attention to how HCV lived experiences can be understood through the lens of identity (re)formations as mediated by interweaving individual and collective interpretations of HCV and illness. I conclude by discussing the importance of civil society organisations like CBOs in mediating individual and collective interpretations of HCV and thus HCV-related identity formations.

HEPATITIS C BACKGROUND

Natural history

By 1989 a virus named 'non-A non-B hepatitis' came to be known as the hepatitis C virus (HCV) (Crofts et al., 1997). The HCV is classified as an RNA virus (ribonucleic acid) which are said to be more genetically unstable compared to viruses made of DNA (deoxyribonucleic acid) such as HIV and the other hepatitides A, B, D and E. Due to its reported genetic instability mutation can rapidly occur into various strains. Despite HCV existing in the blood in very low concentrations it is extremely infectious and is very difficult to eradicate once exposed (Borgia et al., 2003).

Physical symptoms of HCV exposure can include tiredness and lethargy, ‘abdominal discomfort, nausea, anorexia, abdominal swelling, headaches and signs of coagulation disorder’ (McNally et al., 2004, p. 10). Of those exposed to HCV around 25% experience acute hepatitis and will go on to clear the virus, while 75% develop chronic hepatitis with some 27% of this latter group not experiencing any noticeable symptoms (ANCHARD, 2002; HCVPWG, 2006). Most who remain with chronic hepatitis will experience some liver damage, with approximately 7% going on to develop long-term liver disease such as cirrhosis and primary liver cancer some 10 to 40 years (probably closer to 20 years) from the time of exposure (Crofts et al., 1997; Freeman et al., 2001). While the above statistics are generally accepted by practitioners and scholars, it should be noted that the development of knowledge regarding the natural history of HCV is potentially ‘confounded’ as a result of the difficulties in diagnosing HCV that informs ‘a lack of information about date and duration of infection’ (Bonkovsky, as cited in Fraser & Seear, 2011, p. 27).

Hepatitis C is transmitted via blood-to-blood contact. Blood transfusions and other blood procedures and products, as well as non-sterile skin penetrative practices (e.g. tattooing, body piercing, acupuncture and injecting drugs), are the most commonly reported vectors of transmission. The sharing of toothbrushes and razors is also said to provide adequate conditions for transmission. Patient-to-patient and surgeon-to-patient transmission have been established via contaminated anaesthetic instruments and percutaneous injury, respectively (Sladden et al., 1997). Sexual transmission of HCV is possible but uncommon. Scholars acknowledge that the risk of transmission during sex is increased when and if blood is present, for example during menstruation or anal sex, respectively (Terrault, 2002). Around 5-10% of HCV exposure comes from the use of blood products (for example, blood transfusions) prior to 1990 when screening was introduced (Dore et al., 2003). In the West, HCV transmission occurs mostly through sharing contaminated injecting equipment for drug use (ANCHARD, 2002; HCVPWG, 2006).

Prevalence

By the time HCV had been identified millions of people throughout the world were reported to be infected. Estimates by the World Health Organisation suggest there are approximately 150 million people living with chronic HCV; approximately 2% of the world population (WHO, 2012). A large degree of geographic variability in prevalence rates has been reported. Higher prevalence rates are reported in Africa and most parts of Asia. Lower prevalence rates are reported in the industrialised nations of Canada, USA, Western Europe and Australia (Shepherd et al., 2005).

Australian estimates indicate that in 2012 there were an estimated 304 000 people who had been exposed to hepatitis C, with over 226 000 estimated to have chronic hepatitis C (Kirby Institute, 2012). Ten thousand new infections are estimated to occur annually in Australia though this figure has decreased since 2001 (CoA, 2010). The population rate of HCV diagnosis fell by 12% in 2009 with 52 per 100 000 in the general Australian population diagnosed (NCHECR, 2010). New South Wales has the highest prevalence rate of all states accounting for approximately 40% of notifications (HCVPWG, 2006). In 2006 it was estimated that only 2000 people annually receive antiviral treatment for HCV (HCVPWG, 2006) though in 2009, 3969 people were prescribed antiviral treatments for chronic HCV infection (NCHECR, 2010). Reasons for this increase include 'the introduction of pegylated interferon and the removal of liver biopsy as criteria for accessing subsidised treatment' yet the 'number of people commencing therapy still remains low' (CoA, 2010, p. 5).

Compared to other groups and populations, HCV prevalence rates tend to be higher among those traditionally marginalised in the West such as, illicit drug users, people incarcerated, Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse backgrounds. In Australia approximately 80% of people exposed to HCV are current or past injecting drug users (IDUs) (ANCHARD, 2002; HCVPWG, 2006). Estimates concerning Australian prisoners indicate HCV prevalence rates of 40-60% of all those incarcerated between 1991 and 2004. Prevalence rates of incarcerated women are 50-100% higher than male prisoners (see HCVPWG, 2006; Butler et al., 2005; Hellard et al., 2004). A more recent survey report a 51% prevalence rate for prison entrants who inject drugs and 22% for all prison entrants (Butler et al., 2011).

Estimates indicate 8.3% of those living with chronic HCV are from an Aboriginal and Torres Strait Islander background. This prevalence figure illustrates an overrepresentation as Aboriginal and Torres Strait Islander people comprise 2.4 % of the total Australian population (HCVPWG, 2006; NCHECR, 2010). More recent estimates based on data from the Northern Territory, South Australia and Western Australia suggest a similar overrepresentation where the Indigenous population rate of HCV diagnosis between 2005-2009 was 127 per 100 000, compared to 47 per 100 000 in the non-Indigenous population (NCHECR, 2010). It is also estimated that 11% of those HCV positive are migrants from countries where HCV prevalence is high (HCVPWG, 2006).

Though estimate procedures are improving, most estimates cited here are derived from surveillance systems that monitor the incidence of HCV among people who are more likely to get tested for HCV that is, IDUs. There may be many people who are HCV positive but not identified in current estimation procedures, people who currently do not inject drugs and are thus less likely to present for HCV testing (CoA, 2005). Nevertheless, and despite recent evidence suggesting rates of HCV diagnosis have stabilised or declined (see NCHECR, 2010), reported estimates suggest projected health, social and economic costs are likely to be significant (ANCHARD, 2002; HCVPWG, 2006).

LIVED EXPERIENCE OF HEPATITIS C

> Although the contribution of qualitative and ethnographic research to understanding the lived experience of chronic illness and treatment is well established, there is a dearth of such research focused on the lived experience of hepatitis C…
>
> (Treloar & Rhodes, 2009, p. 1322)

A paucity of research on the lived experience of HCV is well documented (Southgate et al., 2002; Hopwood & Treloar, 2003; Hopwood & Southgate, 2003; Treloar & Rhodes, 2009). Most Australian and international HCV research tends to focus on the epidemiology of the virus and clinical randomised trials relating to medical treatments (Hopwood & Southgate, 2003; Treloar & Rhodes, 2009). While this research area is important, so too is social research as it can provide insight into such issues as, stigma, discrimination, treatment decisions and other factors that inform HCV lived experiences. Despite this paucity, publications by scholars, HCV-affected people, and public and civil society sector agencies point to some key social, cultural and political issues attached to HCV. In the academic literature these are commonly associated with the themes of social stigma and biographical adaptations (see Hopwood & Southgate, 2003; Treloar & Rhodes, 2009). Reviewing these themes leads me to discuss understanding lived experiences of HCV through the lens of narrative identity.

Social stigma

Links between infectious disease and social stigma are commonly reported (Williams, et al., 2011; Mak, et al., 2006). In the context of HIV/AIDS, Morrison discusses stigma through the idea of a ‘cyclical continuum’ noting how stigma, discrimination, and internal stigma’ are interrelated concepts: ‘stigma causes discrimination, discrimination leads to internal stigma, and internal stigma, in turn, reinforces and legitimizes stigma’ (2006, p. 4). Stigma is typically represented as negative perceptions and attitudes towards an individual or group. Discrimination ‘moves into acts and behaviour based on those negative attitudes’ while internal stigma is viewed as an internalisation and acceptance of these negative perceptions and acts (Morrison, 2006, p. 4). Drawing from Scrambler (1998), stigma has been conceptualised in the HCV literature dichotomously, seeing both ‘felt stigma’ - expectations of negative judgement and, ‘enacted stigma’ - experiences of negative judgement, reported (see Treloar & Rhodes, 2009, p. 1324). The term social stigma captures these reported elements.

Experiences of social stigma among people affected by HCV are well documented (Glacken, et al., 2001; Golden et al., 2005, 2006; ADBNSW, 2001; Hopwood & Treloar, 2003; Fraser & Treloar, 2006; Harris, 2009). Social, cultural and political forces associated with HCV social stigma are also reported (Hopwood & Southgate, 2003; Crocket & Gifford, 2004). Fraser and Treloar (2006) note three aspects informing HCV-related social stigma: 1) an infectious potentially incurable disease; 2) a disease associated with the practice of injecting illicit drugs and; 3) a disease whereby the person is believed to be to blame for its acquisition. Thus beyond contagion concerns, HCV-related social stigma can also be informed by social views relating to drug use, the political nature of particular drugs deemed illegal, and ideas of self-responsibility.

A report on HCV-related discrimination in NSW found that HCV is a highly stigmatised condition as a result of inadequate understandings of HCV transmission. However, ‘perhaps more powerful than’ this ‘is that hepatitis C infection is inextricably linked to illicit drug use, which is highly stigmatized behaviour’ (ADBNSW, 2001, p. 128). Internal stigma is a reported consequence of this link between HCV and IDU. Temple-Smith, Gifford, & Stoove (2004) state that judgments about HCV and IDU can be internalised by some IDUs who report that they “deserved” the assignment of deviant. Drawing from Goffman’s (1963) theory of stigma, internalisation of HCV-related stigma is reported by Fraser and Treloar (2006) to inform and reinforce the idea of a ‘spoiled identity’ among those affected by HCV.

Stigma and discrimination are recognised by government as two key areas that need to be addressed to create an effective and sustained response for HCV prevention, care, and treatment (ADBNSW, 2001). HCV related stigma and discrimination derive from and can be felt on many levels; governmental, institutional and interpersonal (Hopwodd & Treloar, 2003; Crofts, Louie & Loff, 1997; Burrow & Bassett, 1996). While reports among IDUs suggest that social stigma can be of lesser concern among drug-using social networks, due to, among other things, the “normalisation” of HCV (Harris, 2009), experiences of discrimination and stigmatisation towards those living with HCV have been repeatedly documented within public (health) sector and medical settings (see ADBNSW, 2001). Another reported element of stigma and discrimination comes from HCV being seen in relation to HIV (see Rhodes and Treloar, 2008) which is likely due to the limited public and media profile of HCV compared to HIV (Carrier, Laplante & Bruneau, 2005), as well as the linked ‘histories of identification and responses to the two diseases’ (Fraser & Seear, 2011, p. 68).

A related HCV discrimination and stigma issue is disclosure; many do not disclose their HCV status beyond close and trusted others (Crockett & Gifford, 2004; Harris, 2005; Fraser & Treloar, 2006; Sutton & Treloar, 2007). Disclosure decisions can be informed by fear of rejection (Faye & Irurita, 2003; Fraser & Treloar, 2006; Hopwood et al., 2006). Submissions reported in the aforementioned report on HCV discrimination indicate these fears are warranted, seeing disclosure leading to discriminatory behaviour, notably in healthcare settings (ADBNSW, 2001). Furthermore, disclosure decisions can be 'entwined with people's fear of transmission within families, particularly to partners and children' (see Hopwood & Southgate, 2003, p. 256). These reports suggest a resistance to the traditional view of disclosure as psychologically beneficial or even a moral imperative (Hepworth & Krug, 1999; Perrson & Richards, 2008). However, despite decisions of (non)disclosure being viewed as productive and strategic in managing the effects of social stigma, non-disclosure is commonly reported to imbue an arduous burden on individuals due to its connection to 'anxiety, constant vigilance, and a lack of social support' (see Treloar & Rhodes, 2009, p. 1325). Furthermore, if disclosure is enacted felt stigma can persist (Golden, Conroy, O'Dwyer, Golden, & Hardouin, 2006).

A small number of studies have looked at the role discourses play in (re)producing felt stigma. Fraser and Treloar (2006) report how Western discourses about the body as pure and closed underpin a binary logic that contributes to stigmatisation informing 'spoiled identities' of those affected by HCV. Binary oppositions cited by the authors include "clean/contaminated", "well/sick", "before/after", and "good/bad". Some participants were reported to employ strategies to 'manage' this spoiled identity but no participant resisted this identity suggesting participants quite readily accepted themselves negatively in binary logic terms. Carrier et al. (2005), looking at IDUs “uptake” of public health and health promotion narratives, also connects the binary logic of discourses found in these narratives (in terms of “sickness/health”, “virus/bacteria”, “HCV/non-HCV”) to IDUs evaluating their own behaviour in terms of “good/bad” distinctions. IDUs responded negatively to being instructed on what to do, or not to do, to their body. Furthermore, some felt risk avoidance advice ‘was being communicated in a childish manner’ and saw ‘such communications not as a useful resource to avoid risk but as a judgement on certain types of behaviour (Carrier et al., 2005, p. 130).

Fraser (2011, 2004) also reports how health promotional narratives can ‘construct already infected persons as having failed to behave responsibly and, more broadly, create a climate in which individuals are held responsible (and potentially blamed) for a crisis’ (2004, p.206). In reviewing 24 studies looking at over 1,000 IDUs perspectives of HCV ‘risk’, Rhodes and Treloar (2009, p. 1601) identified the theme ‘individualization of responsibility’. This theme reflects both the lived experience of negotiating HCV risk among IDUs and ‘neo-liberal notions of the healthy citizen and rational autonomous actor which frame contemporary public health responses, including harm reduction’. Treloar and Rhodes (2009, p. 1325) conclude: ‘the representations of hepatitis C in health promotion materials targeted at IDUs were seen as reproducing felt stigma or shame, largely as a consequence of an emphasis on individual responsibility for risk awareness and illness avoidance’. In a technical review of HCV health promotional resources, Winters, Fraser, Booker and Treloar recommend that HCV ‘prevention messages should seek to avoid blame, which can reinscribe stereotypes and stigma’ (2011, p. 4).

In sum, alongside the issues of HCV being seen as an infectious potentially incurable disease, a disease associated with illicit IDUs, and a disease that attracts blame for its acquisition among those infected, public narratives directed at HCV "risk groups" such as IDUs also help (re)produce individualised notions of blame and stigma. To counteract this, HCV scholars assert a need to promote an understanding of the interrelated individual, social, political and medical factors and responsibilities surrounding HCV-related care, prevention and transmission (Fraser, 2004; Treloar & Rhodes, 2009; Winters et al., 2011), highlighting the importance of understanding and negotiating the lived experience of HCV beyond simply medically derived models.

I now examine the concept of biographical adaptations. Social stigma, and its management, can play an important part in notions of biographical adaptation in negotiating potential feelings of contamination and illegitimacy within one's life story as a result of a HCV diagnosis.

Biographical adaptations

An important research area that has been applied to a HCV context relates to how the emergence of illness impacts on a person's life, sense of self and identity - terms which "biographical disruption" and its derivatives have attempted to capture. Within medical sociology, the emergence of this area of research reflected a major conceptual shift from Talcott Parsons' (1951) "sick role" and Irwin Rosenstock's (1966) "health belief" models (Lawton, 2009). Moving beyond interpretations of illness as social deviance (Parsons, 1951) and as rational actor-based (Rosenstock, 1966), biographically informed research typically reports on the interplay of social and psychological elements and responses associated with a chronic illness diagnosis. Two important contributions to this shift are noteworthy: Michael Bury's (1982) classic paper looking at chronic illness as biographical disruption and; Gareth Williams' (1984) paper on the genesis of chronic illness and narrative reconstruction.

Compared to Williams' (1984) ideas, Bury's (1982) biographical disruption framework has attracted considerable scrutiny seeing his theory challenged and/or expanded on by bringing emphasis to the contextual factors and ideas of 'identity (re)formation' (Charmaz, 1987, 1991, 1995; Carricaburu & Pierret, 1995; Gatter, 1995; Williams, 2000; Faircloth, Boylstein, Rittman, Young & Gubrium, 2004; Copeland, 2004; Taylor & Littleton, 2006; Harris, 2009). Both Williams' (1984) work and biographical adaptation-related literature inform the examination of HCV though a narrative identity framework within this thesis.

In reviewing studies looking at biographical disruption, the lived experiences of HCV can be viewed in terms of identity (re)formations that are temporally, relationally, and discursively constituted. Said differently, attempts to accommodate HCV within one's life story are shaped by looking over one's past, present and future to integrate various events, social positions and other contexts of lived experience in order to develop and enact a subjective sense of self-continuity. Importantly, such an endeavour is mediated by a repertoire of collective understandings of HCV transmitted through publicly available narratives of HCV produced and circulated in various social and cultural settings and institutions.

Michael Bury (1982) coined the term "biographical disruption" to refer to how a diagnosis invariably, despite illness or individual, creates certain physical, psychological, and social impacts on a person, challenging both the structure and meaning of one's life. Reports of shock, fear, feeling contaminated, "condemned", stigmatised and alienated followed by a reassessment of past, present and future ideas of the self and social relationships and positions in the world, are documented in earlier HCV studies (e.g. Burrows & Bassett, 1996; Hepworth & Krug, 1999; Glacken, Kernohan & Coates, 2001). Earlier studies also illustrate accounts of a sense of feeling different and being perceived differently by others as a result of a HCV diagnosis (Burrows & Bassett, 1996; Hepworth & Krug, 1999). As such a HCV diagnosis was largely seen to disrupt one's life or life story and thus aligned comfortably with biographical disruption ideas. However, more recent research, while reporting similar findings, also points to the contrary. These studies highlight a diversity of reactions to a diagnosis and in doing so problematise the notion of biographical disruption.

In a qualitative study Sutton and Treloar (2007) looked at the experiences of 36 people living with HCV (acquired through a variety of transmission modes) within two models of chronic illness experience: the "illness trajectory model" and the "shifting perspectives model". The former suggests that people experience an initial biographical disruption to their lives and self-concept. Following this they begin a process of transition from fear and denial towards acceptance, integrating the impacts of their illness into their lives. Alternatively, the shifting perspective model describes people involved in a nonlinear and complex dialectic with the world. A state of acceptance may occur but also may be temporary seeing the person shift back and forth between attitudes of wellness and illness (Paterson, 2001). Sutton and Treloar's (2007) data supported both models with some participant experiences reflecting the trajectory model while others reflected the shifting perspective model. The authors note the importance of social context or collective understandings of HCV in the various and shifting experiences of illness.

Sutton and Treloar (2007), while illustrating a variety of illness experiences, noted how some IDU accounts reflected minimal biographical disruption. Similarly, Faye and Irurita (2003) report IDUs experienced minimal impact from a HCV diagnosis. Harris (2009, p. 1028) also reports on ‘narratives of unconcern about hepatitis C diagnosis’ among IDUs while other studies looking at IDUs indicate a diversity of initial responses to a HCV diagnosis (see Crockett & Giffard, 2004). Treloar and Rhodes in reviewing qualitative studies of HCV lived experiences among IDUs between 2000 and 2008 state: ‘in general, drug injectors appear to be presented as a ‘negative case’ to studies hypothesising hepatitis C as a form of condemnation or major biographical disruption’ (2009, p. 1326).

Accordingly, and consistent with other (non-HCV) research (e.g. Pound, Gompertz & Ebrahim, 1998; Sanders, Donovan & Dieppe, 2002; Faircloth et al., 2004; Locock, Ziebland & Dumelow, 2009), HCV social research findings problematise Bury’s (1982) biographical disruption concept. Terms such as ‘biographical reinforcement’ (Carricaburu & Pierret, 1995), ‘biographical flow’ (Faircloth et al., 2004), ‘biographical abruption’ (Locock et al., 2009) and ‘biographical adaptation’ (Treloar & Rhodes, 2009) emerged to reflect a more appropriate framework for interpreting the variability of experiences of illness and diagnosis. These studies are distinct from Bury’s (1982) work due to their more comprehensive ideas of context that bring attention to particularities of an illness type and an individual’s personal, social and collective history.

Carricaburu and Pierret (1995) draw from Charmaz’s (1987) concept of an “identity hierarchy” to posit the occurrence of “biographical reinforcement” among people living with HIV (i.e. respondents living with haemophilia or identified as “gay”).

Biographical reinforcement is premised on an individual thinking over their past to reconstruct the present in order to reinforce a previous identity and thus help create continuity in their biographies (Carricaburu & Pierret, 1995). Faircloth et al. (2004, p. 242) employs the term 'biographical flow' when examining the narratives of people recovering from stroke stating that 'the lives of people who have a particular illness that is notably marked by sudden onset are not inevitably disrupted' (2004, p. 242). Consistent with earlier findings by Pound, Gompertz and Ebrahim (1998), age and previous life experience and illness were important in presenting stroke as being a "normal" and "inevitable" aspect of ageing. Sanders et al. (2002) also found participant accounts of osteoarthritis illustrated such a condition to be an 'inevitable' consequence of their history and older age however, disruption to their daily lives was reported. This suggested that for these participants osteoarthritis was experienced as both "normal" (reflecting biographical flow/reinforcement) and disruptive.

While Bury (1991) initially noted the importance to biographical disruption of context in terms of a person's available resources when illness emerges, the above studies illustrate context more comprehensively to include events, identifications and biographies previous to, or outside of, one's immediate illness and diagnosis. Such elements reflect a mediation of interweaving individual and collective interpretations of the particular illness that in turn help individuals reconstruct their life stories and identities. To elaborate, I report on Carricaburu and Pierret's (1995) work for three reasons relevant to the present study: 1) most biographical disruption studies have been concerned with the initial impact of a diagnosis - Carricaburu and Pierret's (1995) study looks beyond this; 2) HCV has more in common with HIV than other conditions reported in this research area and importantly; 3) they highlight how individuals' actively work at 'fitting' their biological/medical status into identity reconstructions via collective or public narratives attached to relational settings – a central idea taken up in the model developed in Chapter Three.

For Carricaburu and Pierret (1995) context involves two interconnected levels: individual and collective interpretations of illness that both inform ideas of biographical “disruption”, “flow” and “reinforcement”. Collective interpretations introduce social, cultural and political discursive elements to meanings of illness. For example, the authors report that “public discourse” surrounding HIV/AIDS constructs HIV/AIDS as a “social phenomenon”. Consequently, people’s private subjective and bodily experiences of living with HIV become entwined with the social phenomenon or collective interpretation of infectious disease, organised around public narratives of contagion and epidemics as implicated among imagined “others”. In the context of HIV in the West this “otherness” is mostly assigned to “gay” men, IDUs and people living with haemophilia.

The social construction and collective experience of gay men in the West has been constituted through positive representations largely stemming from a history of people coming together to fight for the rights of sexual minorities. Carricaburu and Pierret (1995) cite “AIDS activism” as substantially modifying society’s perceptions of gay men and HIV/AIDS thus contributing to the social phenomena and collective experience of “gay” and HIV/AIDS. These narratives and collective histories come to mediate a complex process triggered by an HIV-informed biographical disruption that in turn gives way for a gay identity to be rebuilt or reinforced, imparting a renewed special importance (Carricaburu & Pierret, 1995). All participants identifying as gay in Carricaburu and Pierret’s (1995) study reported biographical disruption that led to biographical reinforcement in terms of a renewed positive gay identity.

Participants living with haemophilia however, presented a different picture – a picture though that also points to the role publicly available narratives and discourses play in mediating illness/diagnosis experience. Carricaburu and Pierret (1995) report on two discursive settings that help produce haemophilia as a social phenomenon: the health sector with its “dominant medical model” and the civil society organisation Association Francaise des Hémophiles. The latter helped produce “normalising” discourses for those living with haemophilia. Before HIV/AIDS emerged, such normalising discourses tended to deny haemophilia on the premise that the haemophilic person could do everything similar to everybody else (Carricaburu & Pierret, 1995). While the merits of this discourse include combating “victimhood” and social stigma, it can also contribute to the silencing of particular and unique experiences, or “representational silences” (Somers, 1994) associated with haemophilia and thus work at eroding a collective sense of history (Carricaburu & Pierret, 1995). Consequently, Carricaburu and Pierret (1995) questioned whether a HIV diagnosis would represent a new illness, a new biographical disruption as an effect of this normalisation or whether a HIV diagnosis created no or minimal disruption - placed in the historical and collective experience of being haemophilic. Findings indicated that some participants reported biographical disruption while others did not; those who saw their previous condition as normalised experienced disruption while those who had not accepted normalisation discourses had minimal or no disruption seeing HIV as a new complication of their haemophilia.

The importance of publicly available narratives and an individual’s personal experience relating to their history and body, and how these elements intertwine, thus appear significant in accommodating illness into one’s life story and identity. This significance has been noted in HCV social research applying Carricaburu and Pierret’s

(1995) notion of biographical reinforcement/flow. For example, in a qualitative study with 40 IDUs in Sydney and Auckland, Harris (2009) problematises the applicability of a biographical disruption framework within a HCV context. Nineteen participants reported significant disruption while 21 participants presented narratives of unconcern regarding HCV diagnosis. The former group had previously never been IDUs while the latter group were current IDUs.

Harris (2009) reports on the mediating factors of "time of diagnosis", "normalisation of HCV", "HCVs' relation to HIV" and "dys-apperance" in shaping whether HCV represents biographical disruption or reinforcement. With the exception of dys-appearance (relating in this instance to when the body attracts attention to the individual due to drug withdrawal), these factors point to the role dominant and local public narratives and stories play in biographical adaptations to HCV. "Time of diagnosis" points to the role taken by available medical knowledge and narratives of HCV at the time of participants' diagnosis. Due to a paucity of such narratives when HCV was termed "non-A, non-B hepatitis", a diagnosis was seen as unconcerning (biographical flow). "Hepatitis C as normalised" refers to local experiences and stories among immediate (IDU) social networks that see a HCV diagnosis as a part of an existing drug user identity (thus HCV reinforced this identity). "Hepatitis C in relation to HIV" refers to how public narratives of HIV overshadow(ed) the paucity of HCV pubic narratives thus constructing HCV as of lesser concern than HIV.

This overshadowing or lack of public or collective narratives of HCV speaks to Orsini (2002), who using social movement theories examined "blood activism" among people in Canada who contracted HIV and HCV through *Red Cross* blood products. Orsini (2002) found that compared to individuals living with HIV and haemophilia, those affected by HCV experienced difficulty in constructing and mobilising a collective HCV identity for activist pursuits, as a result of the historical absence of HCV public narratives and social infrastructure such as HCV CBOs.

The ideas these studies illustrate is how participants are actively involved in fitting HIV or HCV into their biographies, be that for for personal and collective reasons, and importantly, how collective/public stories and narratives help mediate this "fitting". Such ideas resonate with Williams' (1984) work. In a sense Williams' (1984) approach pre-empts later work that reconfigures the concept of narrative towards the examination of how public and personal narratives, among other things, shape identity formations, as exemplified by the work of Margaret Somers (1992, 1993).

Narrative constitution of illness identity

Williams looks at how participants engage in a 'narrative reconstruction of their changing relationship to the world in which they live and the *genesis* of illness within it' (1984, p. 175). Specifically, this involves attempts to reconstitute and repair any 'ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams, 1984, p. 197). Williams (1984) sees narrative as having two aspects: the routine and the reconstructed.

> In its routine form ... narrative is a process of continuous accounting whereby the mundane incidents and events of daily life are given some kind of plausible order. ... The trouble is that sometimes the 'orderly sequence of facts' gets broken up. ... The routine narrative ... as it attends to the mundane details of daily life is pitched into disarray: a death in the family, serious illness, an unexpected redundancy and so forth. From such a situation narrative may have to be given some radical surgery and reconstructed so as to account for present disruptions. Narrative

> reconstruction, therefore, represents the workings of the discursive consciousness (1984, p. 178).

Thus, in the face of chronic illness one's routine narrative *may* need to be reconstructed. I emphasise "may" because as noted earlier, HCV may not, to a degree, disrupt the routine aspects of one's life due to relational and discursive settings normalising HCV. If illness evokes disruption then an individual's narrative may need to be reconstructed 'in order to understand the illness in terms of past social' and collective experiences and interpretations and 'to reaffirm the impression that life has a course and the self has a purpose or *telos*' (Williams, 1984, p. 179). Williams' (1984) use of the term "genesis" marks how such narrative (re)construction relies on the invention of stories or "factions" (i.e. a combination of fiction and fact) that in part derive from particular public narratives that circulate in various relational settings: social networks and institutions. For example, participants in Williams' (1984) study drew from political narratives of exploitation in the workforce, social psychological narratives of stress and, cosmological narratives concerning god, narratives that appeared to coexist with and/or supersede biomedical narratives in informing the lived experience of rheumatoid arthritis.

Williams' (1984) paper speaks to Paul Ricoeur's work on narrative identity wherein Ricoeur formed the synopsis 'that the constitution of narrative identity, whether of an individual or a historical community', is informed by a 'fusion between history and fiction' (1988, p. 73). These ideas provide a conceptual basis for this thesis through which to explore the parts played by time, relational/social setting, social positions, and public and personal narratives in mediating biographical identity work in the face of illness. This basis is developed in Chapter Three through the work of Margaret Somers (1992, 1994) who claims we may examine identity formations by exploring an individual's "ontological narratives" and their relationship to the public narratives that an individual mediates in various relational settings. Ontological narratives echo biographical adaptations and narrative reconstruction as they are constructed and enacted through text/talk by the individual, deployed to define *who we are* given our previous and current circumstances. They are temporally and spatially based, thus we are always becoming. Ontological narratives enact and influence beliefs, actions and consciousness itself. Somers (1994) states that ontological narratives exist interpersonally derived intersubjectively through interactions with public narratives stemming from social, cultural and structural formations. Such public narratives stem from one's family, workplace, CBO, church, legal/police system, medical system, government, and nation. Some of these narratives are heavily established and thus easily reproduced but they may also be countered, transformed depending on one's personal history, social position and/or relational setting.

Literature on biographical adaptations and narrative identity highlight the importance of examining the public narratives of HCV that circulate in relational or social settings that people engage with to help understand and negotiate HCV in their lives, such as public sector and civil society sector sites. Accordingly, I now briefly look at the social responses to HCV in order to provide a background to public sector and civil society settings that attend to HCV.

SOCIAL RESPONSES TO HEPATITIS C

In this section I report on social responses to HCV according to state/public sector and civil society responses. These relational or social settings are influential in producing and circulating collective interpretations, or public narratives, of HCV, interpretations/narratives that as illustrated above are important to the mediation of HCV-related identities.

Public sector responses to hepatitis C

Hepatitis C prevalence figures (reported earlier in this thesis) painted a concerning picture for public sector authorities resulting in the eventual development and launch of the first *National Hepatitis C Strategy 1999-2000 to 2003-2004* aimed at promoting and supporting prevention, treatment, support and care (CoA, 2000). The 10 year period between identification of HCV and this first national response indicates a slow response by the Australian federal government. The illegality of IDU and 'inadequate concern about the likelihood of hepatitis C crossing over into mainstream Australia are reasons given' for this slow government response (Hopwood, Treloar, & Redsull, 2006, p. 24). Since the first National Strategy (1999/2000 to 2004/2005), the second (2005 to 2008) and third (2010 to 2013) National Strategies have been launched, reported to strengthen the approaches developed by the first (CoA, 2000, 2005, 2010). A government review of the first National Strategy reported that a more effective collaborative and integrated approach is paramount in addressing HCV. The complexity of medical, psychological, social and political factors involved in addressing HCV are cited as constraining such efforts (Levy et al., 2002).

In New South Wales (NSW), the *NSW Hepatitis C Strategy 2007–2009* provided a state-wide strategic framework for the 'prevention and management of hepatitis C' with the goals to: 'minimise the transmission of hepatitis C; improve the health status of people with hepatitis C and; minimise the negative personal, social and economic impact of hepatitis C' (AIDB, 2008, p. 16). The NSW Department of Health 'through the AIDS/Infectious Diseases Branch (AIDB) is responsible for providing the overall strategic direction for the public health response to hepatitis C. Area Health Services (now named "Local Health Districts") are responsible for the planning, coordination and provision of local HCV health promotion, treatment, care and support services' (AIDB, 2008, p. 24). Additionally, there are public sector strategies to reduce infections and morbidity associated with HIV/AIDS, STIs and HCV among Aboriginal people in NSW. Such strategies fall under the *NSW HIV/AIDS, Sexually Transmissible Infections and Hepatitis C Strategies: Implementation Plan for Aboriginal People, 2006–2009* (see AIDB, 2008, p. 17).

According to Pugh, these National and State Strategies represent 'the official discourse of hepatitis C in Australia', and lay the foundations 'for subsequent population health strategies' (2006, p. 263). They 'formalise the language for talking about the virus and people affected by hepatitis C' and set 'the form for interactions between governments, medical, scientific and health care professionals, and between ... professional communities and people living with hepatitis C' (Pugh, 2006, p. 263). An important mechanism that contributes to these foundations and interactions relate to how texts within National and State Strategies provide links in the chain of "communicative events" and public sector practices about hepatitis C (Pugh, 2006). That is, textual practices within National and State Strategies are likely to be appropriated and embedded in subsequent public health sector policy documents which in turn inform public sector narratives and practices at a local level. For example, National Strategies have directed and informed state-based HCV strategies such as, the *NSW Hepatitis C Strategy 2007–2009* (AIDB, 2008, p. 16).

Civil society organisations like HCV CBOs are reported within National Strategies to be a fundamental component of Australia's national response to the HCV epidemic. As reported earlier, this is said to be due to a "specific" or "distinct" expertise these organisations hold, marking them distinct from public sector sites where HCV help and support is predominantly found. This expertise is somehow connected to the experiential knowledge that such organisations are said to hold or mediate. From the five guiding principles underlining the *Third National Hepatitis C Strategy 2010–2013*, two include the recognition 'that those living with, and at risk of, infection are experts in their own experience and are ... best placed to inform efforts that address their own education and support needs (CoA, 2010, p. 12).

National Strategy principles are in part informed by the 'Ottawa Charter for Health Promotion' (WHO, 1986) and articulate a state-initiated partnership approach between 'governments, affected communities, researchers and health professionals' as 'characterised by consultation, cooperative effort, respectful discussion and action' (CoA, 2010, p. 12). Civil society and HCV CBOs are thus positioned as an important component of Australia's national "partnership" response to HCV and as such give HCV CBOs, to draw from Krug (1995), a "social authority' in addressing the issues attached to HCV.

Civil society responses to hepatitis C

Civil society responses to HCV emerged in the early 1990s, well before federal state responses materialised. Similar to circumstances relating to the HIV epidemic some 10 years earlier, government inactivity, contradictory medical information and aetiological uncertainty set the scene for small groups of HCV-affected people to come together to help counteract fear and confusion among those affected by HCV, health professionals and the wider public (Krug, 1995; Loveday & Wallace, 2001; Carey, 2007). Many of these groups evolved into civil society organisations (CSOs) or CBOs called Hepatitis C Councils, some as general Hepatitis Councils and others combined with existing HIV/AIDS organisations. By 1995 all Australian capital cities had one of these HCV CSOs. The following year saw the national or "peak" representative body, the Australian Hepatitis C Council form (Loveday & Wallace, 2001), today known as Hepatitis Australia. Other CSOs that have emerged in response to, or have responded to, HCV concerns include: NSW Users and AIDS Association (NUAA); Transfusion Related AIDS and Infectious Diseases Service (TRAIDS); Aboriginal Community Controlled Health Service (ACCHS); and Haemophilia Foundation Australia (HFA) (AIDB, 2008).

While remaining small relative to the public sector sites where HCV-related help is predominantly located, today most Australian HCV CBOs have grown in size, employ paid staff and attract and rely on state funding. They typically exhibit a mixture of elements indicative of mutual aid/help groups, advocacy groups, service provider organisations, and play a role as an expert reference group for government and media (Carey, 2007). Hepatitis New South Wales, the HCV CBO studied in this thesis, reflects a typical case for this growth and mixture of elements.

In acknowledging HCV CBOs' expansion, Loveday and Wallace (2001) claim many Australian HCV CBOs have retained their original features such as the participation of those affected by HCV and the use of volunteers. This claim sits alongside reports that, coinciding with the expansion of HCV CBOs' their 'core business' has 'become intertwined with the objectives of the State and Federal Government' (Carey, 2007, p. 44) as opposed to "community" priorities (Orsini, 2006). This interpretation finds resonance with Pugh who presents questions concerning state expectations for HCV CBOs 'to conform to the professional practices of public health' (2006, p. 267). Further, Krug (1995) reports that narratives within HCV CBOs typically appropriate medical and scientific discourses in ways that make them accessible to people not versed in such knowledge. They also look to 'construct discourses having sufficient social authority and credibility to be taken up by their constituents against politicians and unsympathetic health care workers' (Krug, 1995, p. 308). Hepatitis C CBO narratives thus arguably rely on public (health) sector knowledge and as such align well with state-led conformity issues of which Pugh (2006) and Carey (2007) speak. Although this is important in a strategic and social sense, the place members or volunteers who convey experiential knowledge have in such discourses and narratives - those who are reported to somehow help provide CBOs with their distinct expertise - is largely unexplored.

Hopwood and Southgate, drawing from Hepworth and Krug (1999), state that stories and narratives 'which give back a sense of meaning to life are needed most, more so than medical and scientific information' (2003, p. 260). Narratives of this kind are widely recognised for those living with chronic illness (Kleinman, 1988; Frank, 1995) and for those in marginalised positions (Somers, 1994; Violi, 1992). Hepatitis C CBOs are well positioned to provide such narratives alongside other scientific and public health-based narratives. Pugh notes that despite the prevalence and 'authority of scientific and biomedical discourses about HCV, in which professionals speak for and about hepatitis C positive people', there is scope for CBOs 'to critique such texts to shift the discursive practices of public health and the media to construct a less skewed perspective on hepatitis C, and effect social change' (2006, p. 264). Thus it is important for HCV CBOs 'to consider if, and in what way, the voices of those living with hepatitis C are represented in and by' publicly circulating texts (Pugh, 2006, p. 45) and I would add, HCV CBOs' own texts. Given that Carey (2007) reports that HCV CBOs provide opportunities for those who are HCV-affected to express their voices and stories, it is reasonable to imagine that HCV CBOs should nurture and foster such opportunities in order for their members to not only learn and inspect expert-based narratives but also to help reconcile individual and collective interpretations of HCV that are important to the social particularities of members.

Pugh's thesis concludes by stating that the 'impact of governance by public health institutions on the operations of' HCV CBOs is an area of importance that future research should examine (2006, p. 272). This governance issue highlights a challenge HCV CBOs like HNSW face in terms of negotiating relations between the state and the people or "community" they are said to support and represent. This challenge, and the governance issue highlighted by Pugh (2006), is considered in the next Chapter in developing a model of HCV CBO distinct expertise.

CONCLUSION

In this chapter I presented a background to HCV in terms of its natural history and prevalence rates, followed by a review of the literature on the lived experience of HCV and related literature. I outlined the commonly reported HCV themes of social stigma and biographical adaptation. In doing so, I drew attention to how HCV lived experiences can be understood through the lens of identity (re)formations as mediated through interweaving individual and collective interpretations of HCV and illness. This interpretation implicates HCV identity formations as temporally, relationally, and discursively constituted. I drew on the work of Carricaburu and Pierret (1995), Williams (1984) and Somers (1994) to emphasise how such biographical/identity work is mediated by a repertoire of publicly available narratives of HCV as produced and circulated in various social and cultural settings. This led me to discuss social responses to HCV by way of public sector and civil society settings.

I reported that public sector responses to HCV were slow compared to those of civil society, and although government strategies appear comprehensive in terms of a reported 'partnership' approach between government, health experts and HCV CBOs, questions remain regarding state-led conformity issues in relation to the kinds of practices and narratives HCV CBOs undertake and produce and what this means to the identity formations among those who engage with HCV CBOs. These question points to a challenge HCV CBOs like HNSW face in terms of negotiating relations between the state and the people or "community" they are said to represent. This challenge is of central concern to this thesis in the context of examining and understanding HCV CBO distinct expertise in relation to the constitution of HCV identity (re)formations among its members.

In the following chapter, I develop a theoretical model of CBO distinct expertise that links questions of illness experience and CBOs' relational position between the state and the "HCV community" by combining the concepts of "narrative" and "liminality" to present the notion of "narrative communitas".

CHAPTER THREE

UNDERSTANDING THE DISTINCT EXPERTISE OF HEALTH-ORIENTATED COMMUNITY-BASED ORGANISATIONS

> Community-based and non-government organisations are the subject of increasing academic debate. Although they are now understood to be an integral part of our social and political system as the third sector, separate from the government and market sectors, how these organisations will realise their critical potential and overcome practical and theoretical challenges is largely unexplored.
>
> (Carey, 2007, p. 7)

CHAPTER INTRODUCTION

In Chapter Two I presented a background to HCV in terms of its natural history, prevalence rates, and discussed literature on the lived experience of illness and HCV. I drew attention to how HCV lived experiences can be understood through the lens of identity (re)formations as mediated by interweaving individual and collective interpretations of illness. Following this, I looked at public sector and civil society responses to HCV, responses and sites that play an important role in mediating individual and collective interpretations of HCV. This raised questions regarding CBO-state relations and conformity issues in relation to the kinds of practices and narratives HCV CBOs undertake and produce and what this means to the identity formations of those who engage with HCV CBOs.

In this chapter and Chapter Four I consider these questions further, together with the narrative constitution of identity within the context of developing a model of health CBO distinct expertise: a model that links questions of HCV lived experience and HCV CBOs' relational position between the state and the "community". This is primarily achieved through combining the concepts of "narrative" and "liminality" to present the idea that CBO distinct expertise lies with their capacity to facilitate what I term "narrative communitas" spaces that in turn provide productive potential in mediating responsive HCV identities among their members. This model is used to assess and investigate how health CBOs could realise, or could be realising, the specific elements and processes that underlie their distinct expertise.

UNDERSTANDING CIVIL SOCIETY ORGANISATIONS AND THEIR DEFINING DISTINCTION

As diverse as the people, purposes, and organisations that compose it, the civil society sector has come to be known by many terms: non-profit sector; voluntary sector; social economy; third sector; non-statutory sector; non-government organisation/NGO sector; independent sector; and solidarity economy. Such a sector has emerged in numerous forms in both ancient and contemporary societies speaking to a variety of political philosophies from guild socialism and anarcho-communism to more recently communitasrianism and associationalism (Walzer, 1995; Gough, Eisenschitz & McCulloch, 2006). However, the formal study of this sector is relatively new, and scholars are contending with theories pieced together from various disciplines. While the disciplines of economics and political science dominated theories in the 1980s and 1990s, more recently, and before the focus of "non-profit organisation/management" began to eclipse "voluntary action" as a research pursuit, scholars from sociology, social work, geography and community psychology, among others, have also contributed to the growing body of civil society sector literature. The complexity, size and definitional variations have seen the sector termed "a loose and baggy monster" (Kendall & Knapp 1995).

Attempts to define the civil society sector and its unique capacities or distinct expertise have a long and notable history and a full review is beyond the confines of this thesis. Nevertheless, a brief examination of some of the common approaches provides a necessary introduction before outlining how this thesis conceives CSOs like CBOs. Different understandings of the civil society sector in terms of definition, why it exists and what are its roles, distinct elements and processes have been largely shaped by differences between Europe and North America in historical circumstances, theories and practices. I present a brief overview of these understandings according to three interrelated approaches: institutional/legal; normative; and comparative advantage.

The institutional and legal approach

The institutional and legal approach 'consists in identifying the main legal and institutional forms through which most' civil society initiatives materialise (Defourny et al., 1999, p. 11). During the last 100 years three major institutional types of organisations are said to have constituted the civil society sector in industrialised countries: co-operatives; mutual benefit societies; and non-profit organisations or associations. Often the lines separating these institutional types are 'neither sharp nor immovable, especially in countries where such distinctions are not legally recognised' (Defourny et al., 1999, p. 13; also Lyons, 2001; Barraket & Crozier, 2008). It is the latter institutional type that is of interest to this study.

Associations are expressed in varied legal forms with a variety of names including non-profit/not-for-profit organisations, third, social and civil society sector organisations, voluntary organisations, community-based organisations, member-based associations, NGOs, and charities. Further, there are definitional differences concerning what types of associations constitute the civil society sector based on French/Italian and US/British differences in traditions of practice. This is where the legal approach to the civil society sector becomes salient (Lyons, 2001). The Comparative Non-profit Project (CNP), headed by Lester Salamon and Helmut Anheier at the Johns Hopkins University, examined the non-profit sector in over 22 countries and has become significantly influential in providing a US-led legal approach to defining the sector (Lyons, 2001; Van Til, 2001, 2009). Salamon and Anheier define non-profit organisations according to 'a legal concept called the *nondistribution constraint*, a principle that asserts that members cannot divide up the assets of an association upon its demise' 'what is left when the organizational lights go out, rather, becomes the property of other non-profit organizations' (Van Til, 2009, p. 1073).

This legal approach has become one of the most influential definitions of the civil society sector 'establishing both the centrality of the non-profit metaphor and its acceptance as an analytic category throughout the literature of both non-profit organization studies and public policy studies' (Van Til, 2009, p. 1070; see also Defourny et al., 1999). However, defining distinctions of the civil society sector according to this approach affords both costs and benefit. The largest 'gain involves conformance to governmental certification of non-profit standing and the associated ability then to count organizations and measure their size' (Van Til, 2009, p. 1073), staff and volunteer numbers (Defourny et al., 1999). Furthermore, the CNP allows comparative snapshots of the sector across many countries, and more precise dimensional comparisons against the public and business sectors (Lyons, 2003; Van Til, 2009).

On the down side, this legal definition follows governmental guidelines in defining the sector and in doing so constructs a sector that privileges larger organisations and excludes co-operatives, mutual benefit societies and many small associations that pay 'attention to culture, values and traditions of voluntary social action and service' (Van Til, 2009, p. 1074; see also Dobkin Hall, 1992; Horton-Smith, 1997; Defourny et al., 1999; Halfpenny & Reid, 2002; Lyons, 2001). In response, and within the context of renewed attention towards the social economy and civil society studies, the normative approach to defining the sector has gained currency. The normative approach also restores the place of co-operatives and mutual benefit societies within sector definitions.

The normative approach

The normative approach consists of highlighting the common principles of CSOs' various elements. From this approach it can be shown 'why we can give the same designation to organisations which, in the final analysis, are very diverse, and how as a group they differ from' business and public sectors (Defourny et al., 1999, p. 15). There are many ways to formulate such characteristics but generally they relate to particular values, principles and processes that instantiate and govern the sector. In more instrumental terms the normative approach sits within the wide consensus that in order to demonstrate the shared characteristics of CSOs we must examine organisational aims, objectives and methods in relation to service production, provision and decision making processes (Defourny et al., 1999).

Influential in this approach is Roger Lohmann's (1992) work on "the commons". The idea of the commons reveals how diverse organisations with different and at times conflicting purposes all share the basic components of the commons: uncoerced voluntary participation, a common purpose and shared resources, and social relations attached to an ethos of fairness and mutuality among participants. Van Til (2009) also uses a normative approach to define the sector based on: processes of sustained dialogue and democratic deliberation; and tasks that construct and reconstruct society's commons, which are aimed toward constructing a politics of relationship.

Other scholars adopting normative approaches include Defourny et al. define the sector to include 'all social and organisational formations ... whose ethics convey: 1) placing service to … members or to the community ahead of profit; 2) autonomous management; 3) a democratic decision-making process and; 4) the primacy of people and work over capital in the distribution of revenues' (1999, p. 16). Lyons claims that the third sector consists of 'organisations that: 1) are formed and sustained by groups of people (members) acting voluntarily and without seeking personal profit to provide benefits for themselves and others; 2) are democratically controlled and; 3) where any material benefit gained by a member is proportionate to their use of the organisation' (2001, p. 5; 2003). Within this approach the author states that "centrality of values" plays a distinctive and central role. The institutional/legal and normative approaches help inform the "comparative advantages approach".

The comparative advantage approach

The comparative advantage approach largely derives from the negative view of the business and public sectors' perceived inadequacies in providing for citizens. Comparative advantages of CSOs 'relate to generalized understandings of their organisational form, agendas and practices' (Teamey, 2007, p. 5) in terms of: being less hierarchical and more democratic (Lewis, 1997, Sood, 2000; Welle, 2001; Wamai, 2004); generating greater public trust (due to an absence of profit-seeking motives) (Lyons, 2001); and having a greater commitment than business and public sector counterparts to working with, and delivering services to, the poor and other marginalised groups (Lewis, 1997, 2003; Sood, 2000; Welle, 2001; Wamai, 2004; Haque, 2004; Billis & Glennerster, 1998).

This approach stems from economic and political science theories (Dollery et al., 2002) that commonly articulate the notion that CSOs exist to 'fill a gap' (Crampton, Woodward & Dowell, 2001) as a result of market and state failure (Gunn, 2004; Moulaert & Ailenei, 2005; Lyons & Simpson, 2009; Anheier, 2009), as well as bureaucratic failure, legislative failure (Dollery & Wallis, 2002) and political failure (Brinkerhoff & Brinkerhoff, 2002). In essence, these types of theories attempt to explain the genesis of CSOs 'characterized as the inability of a market or system of markets to provide goods and services in an economically optimal manner, or government failure, defined as the inability of public agencies to achieve their intended objectives' (Dollery & Wallis, 2002, p. 5).

The capacity of CSOs to "fill the gap" rests on CSO structure and values as articulated within institutional/legal and normative approaches, respectively. The purported flexible organisational forms and committed agenda of CSOs inform the view that CSOs are more ‘innovative, accountable, and effective in terms of cost and delivery’ and have ‘greater local and community knowledge’ than their business and public sector counterparts (Teamey, 2007, p. 4; see also Lewis, 1997, 2003; Billis & Glennerster, 1998; Sood, 2000; Wamai, 2004). Furthermore, CSOs are reported to “pluralise” the institutional arena by bringing more actors, voices, discourses, and networks towards working with, and for, the poor and marginalised (Mercer, 2002) and by challenging or securing support and recognition from local and national authorities through advocacy work (Brinkerhoff, 1999; Sood, 2000; Mercer, 2002).

Elements within the comparative advantage approach have been challenged by Salamon’s (1987) notion of civil society failure or “voluntary failure”. This view notes that the voluntary sector often cannot generate adequate resources and thus becomes ‘vulnerable to particularism and favouritism of the wealthy, paternalism and amateurism – hence voluntary failure’ (Billis & Glennerster, 1998, p. 83). Further criticisms concerning CSOs’ ability to respond to state or market failure include: their tendency to rigid hierarchal and bureaucratic elements especially as they grow (“creeping formalisation”); their ability to be cost effective; their ability to involve or reach those who need their services the most (i.e. the poor and marginalised); they may not challenge state authority or oppressive power relations within communities and local elites; their tendency to alleviate the symptoms not the causes of personal and social concerns and; their potential for diminished autonomy from donors/funders, leading to depoliticisation (Kramer, 1981; Salamon, 1987; Stone, 1996; Robinson, 1997; Fowler, 2000; Sood, 2000; Hilhorst, 2003; Lewis, 2003; Abrahamsen, 2004; MacDonald & Marston, 2005).

Although I do not argue that any particular sector has a monopoly of virtues, I do posit that there are particular organisational and relational processes and characteristics within the civil society sector that respond considerately and sensitively to different people according to different concerns of living. Importantly, whereas the above approaches have provided valuable insight into CSOs, some have criticised the tendency of such research to overlook the user or member side of CSOs (Lyons & Simpson, 2009; Short & Mutch, 2001; Billis & Glennerster, 1998; Rappaport, 1993). Billis and Glennerster (1998) for example, argue that consideration of user/members perspectives, and their relation to the structure of CSOs which differentiates them from their business and public sector counterparts, is particularly important to health-orientated CSOs. Privileging use/member perspectives within understandings of CSO distinct expertise is particularly relevant for CBO scholarship due the central place the idea of "community" has in defining CBOs. Through considering member perspectives and experiences within CBO-defining distinctions, scope is also afforded to contribute to new understandings of CBOs that move beyond dominant rationalist/utilitarian approaches.

UNDERSTANDING HEALTH COMMUNITY-BASED ORGANISATIONS BEYOND RATIONAL AND UTILITARIAN TERMS: THE IMPORTANCE OF PERSONAL EXPERIENCE

> Certainly any idea of 'community-based' must involve some sense that the organisation represents the community in question, and how this is done is one of the major theoretical problems facing … community-based organisations.
>
> (Altman, 1994, p. 7)

Health-orientated CSOs in Australia encompass a wide variety of organisations from public-serving non-profit hospitals, and blood product services (e.g. the Red Cross) to member-serving and public-serving non-profits (and combinations of both) that deal with specific concerns of living (Lyons, 2001), typically termed CBOs. These latter types of CSOs have experienced remarkable growth since they emerged from the health-related social movements of the 1960s and 1970s (Allsop, Jones, & Baggott, 2004). Health CBOs are recognised within civil society literature to have important social and political value for individuals and groups, providing pertinent services, education and representation to those marginalised from public and business sectors (Lyons, 2001; Carey, 2007). Importantly, such provisions are not only made available *to* CBO members but can derive *from* CBO members as well, making them relevant to, and representative of, members and their lives. Many health CBOs provide volunteer opportunities for people to apply their individual and shared experiences with others towards such areas as service and information development and delivery, peer-based activities, advocacy and organisational governance (e.g. becoming a board member) (Lyons, 2001). Generally such CBOs are understood to form 'in response to dissatisfaction with government efforts and funding contributions towards an area of concern' to a group of individuals (Carey, 2007, p. 32) thus speaking to "filling the gap" interpretations.

An additional interpretation concerning the formation and distinct qualities of health CBOs relates to personal experience. Allsop et al (2004), looking at 123 health CBOs in the UK, found that in recent years health CBOs have been increasingly formed by people with personal experiences of a specific condition. Common personal experience themes by founding members include: 'anger about what had happened to them; the perception that the condition was not well understood; a belief that service provision was inappropriate and a deep concern about the lack of information available for patients' (Allsop et al., 2004, p. 741-742) – similar to themes that informed the birth of HNSW (HNSW, 2011). Further, members 'wanted to support others and to draw attention to shortcomings at a number of levels, such as changing the perceptions of professionals and the public and influencing national and local providers' (Allsop et al., 2004, p.742). People representing health CBOs 'may themselves speak from personal experience but they also legitimate their position through drawing on the experience of their members' (Allsop et al., 2004, p. 753; see also Schubert & Borkman, 1991).

Experiential knowledge via personal experience represents an important element within health CBOs in terms of constituting an organisational power/authority base that positions such CBOs as distinct from their public and business sector counterparts (who rely on expert/professional and rational/legal expertise as their power/authority base: see Schubert & Borkman, 1991). Experiential knowledge is deployed, manifests, and produces "effect" in many ways among health CBOs and their constituents. Yet typically the literature reports that experiential knowledge is understood to develop and meet particular organisational goals of a rational or utilitarian nature such as effective service delivery (Schubert & Borkman, 1991). Consequently, despite the reported importance of personal experience in some studies a recurrent tendency remains to understand CBOs in terms of rational, economic and utilitarian means, understandings that primarily implicate the dynamics of service provision in terms of (decision-useful) information provision, and treatment support.

Roberts et al (1999) and Rappaport (1993) suggest that most research comes to understand health CBOs as alternative or complimentary service groups/organisations.

This understanding is derived from medical and human service models and informs many professionals and researchers orientations and positions people as service users (Rappaport, 1993) or consumers/customers. Consequently, a hierarchical relationship is set up, with professionals seen as power-deploying producers of a service or product, and members seen as having "no choice but to choose" what is offered or exit the service. Within a HCV CBO context, effects from "professional centrism" (Rappaport, 1993) potentially operates within the context of state-HCV CBO partnerships (under the National Strategies) whereby 'the professional practices of public health - particularly evidence-based practice and performance measurement' potentially work to (re)configure understandings of HCV CBOs in terms of delivering measureable outcomes (Pugh, 2006, p. 267). Keever, in examining how the 'knowing-in-practice' of CBOs contests state-led accountability and performance measurement apparatus, calls for reconfiguring understandings of CBOs 'beyond a narrow discourse of measurable outputs, outcomes and efficiencies' that emphasise service provision (2009, p. 257).

These understandings of CBOs relate to what Lehman (2007) terms an "assimilating logic" that he connects to "commodity fetishism", referring to the reduction of social values and relations to economic, rationalists and utilitarian calculations. Such economic and utilitarian logics 'deny the existence of collective, social as the fabric of intuitions and personal subjectivity', 'divorce us from creative thought processes' and limit the 'conditions fully conducive to the involvement of citizens in addressing and developing the tensions in the social system' (Lehman, 2007, p. 653). Kennedy in his examination of social policy and social exclusion states that commodity fetishism 'establishes the basis for the development of key economic categories that work at attempts to exert control over citizens (2005, p.109).

Lehman (2007) and Keever (2009, 2012) point to an alternative approach to understand CBOs that centrally considers knowledge and its relationship to practice, personal experience and subjectivity within CBO constituents – an approach that finds currency within social movement literature. For example, Bloomfield (1994) and Touraine (1985) note how new social movements, and CSOs within such movements, position themselves against the modern metasocial principle of utilitarianism. The importance of personal experience and subjectivity/identity within health CBOs extends; CBO understandings towards more expressive and social ontological concerns which are underscored by findings concerning identity reconstructions and biographical adaptations that illness conditions can invoke (Bury, 1982; Carricaburu & Pierret, 1995; Treloar & Rhodes, 2009). Further, CBOs have been noted to benefit 'people who evaluate themselves, or who have been evaluated by others as having troubled identities in need of repair' (Loseke, 2007, p. 670).

While research adopting rational, utilitarian understandings has provided many benefits, Rappaport states that a 'deeper understanding of', and 'a need for work that uses theories and methods consistent with, the experiences of members and the ethos of the organizations is required' (1993, p. 239). Rappaport (1993) and Roberts et al. (1999) propose that understanding such organisations in terms of member identity transformation contexts, or identity-shaping communities, can carry productive potential for researchers. Such an approach according to Rappaport has the advantages of: forcing us 'to listen to the personal stories people tell about their lives'; reducing professional hegemony and; forges links between individual lives and "community"/collective formations and processes (1993, p. 239 & 244).

Considering the significant increase in health CBOs over the last 20-30 years and the growth of CSO-related scholarship, it is somewhat perplexing that theoretical attention towards members' experiences and identities is lacking. Where attention is paid to CSO/CBO members and participants, it is commonly in the form of descriptive analyses, volunteer behaviour and motives and marketing or managerial objectives to increase membership numbers and retention (see Lyons & Simpson, 2009). A database search of the words "identity" and "subjectivity" in prominent third sector, non-profit and voluntary studies journals reveals scant attention paid to members and participants in terms of identity formation capacities. Where identity is addressed, it is largely in terms of a examining a "sector-based identity", or 'identity-based organisations', as typically defined by the ethnic or sexual minority status of their participants, and the "managerial/professional identities" of staff. However, the idea that settings like CBOs somehow mediate the identities of their participants is not new.

The large body of literature concerning political pluralism and "associationalism" often implicate plural identities as mediated though different CSOs (Walzer, 1995; Etzioni, 1995; Vertovec, 1999; Connolly, 2002; Gough et al., 2006, Tyler, 2011). Within social movement scholarship, social movement organisations are examined in terms of making sense of their interface with social movements and identity formations/mobilisations (Melucci, 1995; Stryker, Owens, & White, 2000; Dugan, 2008; Walder, 2009). There are a number of studies examining how mutual-help groups/organisations transform identity. These studies largely speak to small and particularly regimented CSOs such as Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and mental health-related groups (e.g. GROW) (Rappaport, 1993; Pollner & Stein, 1996, 2001; Rafalovich, 1999; Arminen, 1996, 2004). Other literature speaks to similar themes. For example, some HIV/AIDS studies (Kayal, 1993; Gatter, 1995; Maguire, Phillips, & Hardy, 2001) and ‘biosociality’ literature speak of relations between CSOs, identity and ideas of citizenship (Rabinow, 1996; Petryna, 2002; Orsini, 2008; Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Rose & Novas, 2004). In the following section I extend legal/institutional, normative and comparative advantage approaches and draw upon some of this other literature to develop a theoretical model on HCV CBO distinct expertise that links personal illness experience and HCV CBOs’ relational position between state and “community”.

A NARRATIVE COMMUNITAS MODEL OF DISTINCT EXPERTISE

This section presents a theoretical model of health CBO distinct expertise in terms of a capacity to produce what are termed “narrative communitas” spaces: spaces that help mediate responsive HCV identities among members. By responsive I mean identities that are meaningful and relevant and considerate of “difference” - considerate of an individual’s particular circumstances and social position. In developing this framework I draw from narrative identity theorist Margaret Somers (1992, 1994), organisational theorist David Boje’s (1994, 1995, 2001, 2008) work on the multi-story telling organisation, and social anthropologist Victor Turner’s (1969) ideas of liminality (and communitas).

The model is represented in figure 2 and is articulated firstly according to “two-by-two” intersecting conceptual levels: (1) *narrative* and (2) *liminality* by (a) *member experiences* (micro-level) and (b) *health CBOs* (meso-level). I begin with level (1) by locating the narrative approach I undertake within the wider literature on narrative in order to conceive of: 1(a) members' HCV experience as *narrative identity* and; 1(b) HCV CBOs as *multiple-narrative organisations*. Then, in relation to level (2), I discuss the concept of liminality ("betwixt and in-between") to represent: 2(a) HCV experience as occupying, or *in between*, two opposing categories; and 2 (b) HCV CBOs relational position *in between* the state and "community".

Following this, I draw from these "two-by-two" intersecting levels to articulate CBO expertise in terms of "narrative communitas" spaces. This is done by firstly illustrating how CBOs' relational position between state and "community" reflects an institutional liminality as expressed through the multiple organisation narratives it (re)produces whereby some narratives (and consequent identities constructed within these narratives) align to dominant state narratives of HCV and others to alternative and counter-narratives of HCV. Secondly, I present the potentiality of CBO members to scrutinise these multiple dominant and alternative narratives against their own experiences and social position giving way to the formation of responsive HCV identities. It is this member engagement of multiple narrative spaces that represents the productive potential of a narrative communitas space.

Figure 2. “Narrative communitas” model of HCV CBO distinct expertise (Two-by-two level model)

Conceptual Frameworks	**(a) CBO members** (Micro-level)	**(b) Health CBO** (Meso-level)	
1. Narrative	1 (a) HCV lived experience as narrative identities	1 (b) HCV CBO as multiple-narrative organisation	HCV CBO ***‘narrative communitas’*** ↕ Responsive HCV identities
2. Liminality (‘betwixt & in-between’)	2 (a) HCV lived experience as in-between illness/wellness	2 (b) HCV CBO in-between state & “community”	

Level 1 – Narrative

The theoretical model presented locates language as a central idea behind identity formations, which in turn implicates social arenas, such as organisations, in the mediation of identities. As such, I apply the concept of narrative within two different contexts (micro- and meso-levels):

1. (a) *Members’ hepatitis C lived experience as narrative identities (micro-level)*
1. (b) *Hepatitis C community-based organisation as multiple-narrative organisations (meso-level)*

Before doing so, a brief overview of the narrative field is provided in order to locate the conceptualisation of narrative identity and organisations utilised in this thesis.

The concept of narrative has become contested in recent decades (Bruner 1991; Brockmeier & Harré 2001; Somers, 1994) - successfully permeating the disciplines of psychology, education, the social sciences, political science, organisational studies, policy analysis, health research, law and cognitive science (Hyvärinen, 2006). The idea of identity conceived through narrative stems from a conceptual history of narrative informed by multiple sources (Hyvärinen, 2006; Heinen & Sommer, 2009; Spector-Mersel, 2010). However, two main distinctions can be made between "literary narratological theory" and "narrative-turn theory" (Hyvärinen, 2006). This thesis is located within the "narrative-turn" field. One key characteristic of the narrative-turn field is its metaphorical reconfiguration of the literary theory approach to narrative. Influential scholars concerning this narrative reconfiguration were Barbara Hardy (1968) and Louis Mink (1987), whose work extended beyond their literary theory fields to introduce discussions connecting ideas of "lived life" and "narrative" (Hyvärinen, 2006).

MacIntyre appeared the first to appropriate such discussions to explicitly present the metaphorical use of narrative in terms of 'living out narrative' giving us the now well-known proposition that 'man (sic) is in his actions and practice, as well as in fictions, is essentially a story-telling animal' (1984, p. 216). Other works that have been influential in consolidating the metaphorical/narrative-turn include psychologists Jerome Bruner's (1986) *Life as Narrative* essay as well as, philosopher Paul Riceour's (1983, 1984, 1985) three-volume *Time and Narrative*. According to Ryan (2005), the interest in the new metaphors of narrative and stories emerges in part from the epistemological crisis in the human and social sciences. The narrative-turn appeared to provide scholars with a new set of tools that allowed for more complex and less positivist forms of knowing than previous laws, experiments and abstract theories.

Narrative-turn approaches have been utilised in various ways, from attempts to understand human experience (including illness experience) and memory to identity performance and transformation from the point of view of a person in social and cultural contexts (e.g., Gergen & Gergen, 1988; Ross, 1989; McAdams, 1993; Rappaport, 1993; Skultans, 2000). Some regard narrative as a root metaphor for psychology (Sarbin, 1986) while others view narrative as the community (Bruner & Gofrain, 1984; Goldberg, 1987). Despite these various orientations, central to the narrative-turn is the bringing of experience and identity to language.

Narrative-turn approaches begin with the assumption that language and talk are constitutive. Meanings do not come from the stable properties of objects in the world but are constituted and negotiated through talk and interactions within relational settings. Following this premise, the articulation of experience has come to be understood for many as performance, constructed through language, enacting identities. Of importance here is the recursive relationship between a person's agency in constructing identities and the larger social and cultural forces which help constitute these identities (De Fina, Schiffrin, & Bamberg, 2006, Somer, 1994; Taylor & Littleton, 2006).

One of the first scholars to develop this approach to narrative was Margaret Somers. Somers (1992, 1994) reconfigured the notion of narrative identity by drawing upon Ricoeur's (1988) early works, amongst others. Somers' work asserts that scholars must avoid the deployment of categorical identities and view identities as narratively constituted embedded in overlapping networks of relations shifting over time. The key elements within this narrative identity (re)conceptualisation are *time* and *space.* By considering temporal and spatial relationships within the processes of identity formations, Somers claims that narrativity addresses the particularities that constitute an individual's identity while avoiding the totality of categorisation. In essence, time and space (within relational settings) destabilises the work of categories. With these temporal and spatial elements of narrative premised, Somers (1994) claims we may examine identity formations by examining an individual's "ontological narratives".

Ontological narratives are the stories we tell about who we are (and then what can we do) and enact and influence beliefs, actions and consciousness itself. Ontological narratives are constructed and enacted through text/talk by the individual, deployed to define who we are given our current circumstance. Because they are temporally and spatially based we are always becoming. They exist interpersonally and through interactions with other narratives stemming from social, cultural and structural formations (Somers, 1994). Narratives of this sort have been termed "traditions" (MacIntyre, 1984) or "webs of interlocution" (Taylor, 1989) - Somers (1994) terms them "public narratives".

Public narratives have been considered "grand" or "metanarratives" as well as everyday "official" culture narratives. Grand/metanarratives 'take issue with the narratives which have come down to us as part of the culture of the Enlightenment' which 'gained their legitimacy from foundational myths concerning' the Western 'evolutionary ideal of progress' as mediated though economic, scientific and technological means (Giroux, 1996, p. 2). Official narratives refer to the 'hegemonic narratives of everyday life: those legitimating stories propagated for specific political purposes to manipulate consciousness by heralding a … set of common cultural ideals' (Giroux, 1996, p. 2). They tend to be more localised and contextual than metanarratives and include, for example: the "official" narrative of the Afghanistan war; official narratives of classroom and pedagogy; and official narratives of what constitutes good health (Giroux et al., 1996). Thus, meta- and official public narratives can stem from one's family, workplace, CBO, church, legal/police system, medical system, government, nation and historical period. Such narratives can be well-rehearsed or deeply established and thus can be easily reproduced, but they may also be resisted and transformed depending on one's personal history, resources and social position and/or relational setting. Consequently, individuals do not always enact identities that are predictable through established narratives, rather they may 'read the context in which they are placed and can react according to their own set of concerns or meanings or that of their communities' (Toman, 2011, p. 8; see also Ricoeur, 1983, 1984, 1985).

From this perspective, understanding and identity both consist of and are shaped by the interaction between the individual and their relationship to collective histories and culture as mediated within present societal or relational settings via the reproduction, appropriation and/or resistance of public narratives that circulate within such settings. Somers' (1992, 1994) narrative identity approach provides a sophisticated theoretical and analytical way of linking, and examining the links between, the social and cultural and the personal through relations between public and ontological narratives within a relational setting framework. It is through this narrative identity approach that illness experience is conceptualised.

1(a) Members' hepatitis C lived experience as narrative identity

The investigation of illness experience through narrative has flourished in recent decades (see Hyden & Brockmeier, 2008; Skultans, 2000). As reported in Chapter Two, one approach that has emerged concerns how a diagnostic event may force individuals to reassess their life story via available cultural and public narratives and how this reassessment may impact on who they are within this story (Williams, 1984; Corbin & Strauss, 1987; Charmaz, 1987, 1999; Carricaburu & Pierret, 1995; Gatter, 1995; Williams, 2000; Sanders, et al., 2002; Faircloth et al., 2004; Copeland, 2004; Taylor & Littleton, 2006; Harris, 2009; Hyden & Brockmeier, 2008; Skultans, 2000). Such an approach aligns to Somers' (1994) use of ontological narratives and their mediation via public narratives.

Linking the work of Somers' (1992, 1994) and these other studies, in terms of (ontological) narrative reconstruction in the face of illness, compels an examination of the public narratives of illness which circulate in relational or social settings. Besides informal social networks, settings that produce and circulate public narratives of HCV are located predominantly in the public (health) sector and civil society spaces such as HCV CBOs. In this sense, understanding the constitution and enactment of identity through the inter-mediation of ontological and public narratives instructs us to understand and examine formalised social settings such as sectors, institutions and organisations through the lens of (public) narrative. In the next section I draw from David Boje's (1994, 1995, 2004, 2008) work on the multiple story-telling organisation to achieve this. Importantly, Boje's ideas provide direction in underpinning how multiple organisational narratives can provide a potentiality that mark CBO distinct expertise.

1(b) Hepatitis C community-based organisation as multiple-narrative organisations

The narrative-turn across the social sciences has permeated organisation studies seeing a growing interest in stories and narratives within organisations, 'especially as they are linked to issues of knowledge, sense-making, communication, power and identities' (Brown et al., 2009, p. 324). Emerging within organisational research has been the well-established genre of what Boje (1994, 1995, 2001, 2008) calls "storytelling organisations", in 'which the performance of stories is a key aspect of members' lives (Brown et al., 2009, p. 324; Brown & Humphreys, 2006). According to Brown et al., "[s]torytelling is now widely regarded as a currency (maybe, the currency) in which communities of practice trade, the means through which they exchange experiences and learn from each other's foils". The concepts attached to the storytelling organisation are contested. For example, there is no consensus on distinguishing stories from narratives, nor on how stories and narratives are distinct from 'definitions, proverbs, myths, chronologies and other forms of oral and written texts' (Brown et al., 2009, p. 324). As this thesis is not charged with reconciling such contestations, I choose to take the approach of Brown et al. in terms of referring to stories and narrative interchangeably, noting that:

> What is clear … is that while their [stories and narratives] structural features and relation to any kind of putatively objective 'truth' is often uncertain, stories are always replete with meaning, often contain moral judgements and frequently elicit strong emotional reactions. Moreover, whether they are conceived as aspects of organizations or constitutive of processes of organizing, stories are integral to any complete analysis of organizational becoming (2009, p. 325).

The proposition concerning organisations as storytelling arenas rests on conceiving of organisations as socially constructed from networks of conversations, dialogues, stories, and narratives (Humphreys & Brown, 2002; Rhodes, 2000a; Ford, 1999; Loseke, 2007), reflecting processes that promote, or attempt to promote, shared understandings and negotiated realities that are typically seen to allow some 'degree of collective consistency, coherence and continuity (Humpheys & Brown, 2002, p. 422).

Organisational stories and narratives within health CBOs are characteristically created by many, including board members, advisory committee members, workers, volunteers and members (Loseke, 2007). The many voices and stakeholders within such organisations are consistent with viewing organisations as multi-voiced, non-linear, and preliminary stemming from practices that occur simultaneously over time (Boje, 2001; Humphreys & Brown, 2002; Ford, 1999).

In presenting organisations as multiple "storytelling" organisations, Boje (2001) introduced the concept of "ante-narrative" to represent how the stories produced and circulated within and by the organisation are not only multiple stories but also at times fragmented, prospective and incoherent. Some of these prospective stories go on to form well-rehearsed organisational narratives - hence "ante" as an adverb meaning "before" narrative. The term "ante" has a second meaning for Boje (2001); "to bet" referring to speculating on the possibilities of meaning and coherence that stories accrue upon entering the organisational landscape to become well-rehearsed narratives. While Boje (1995, 2000) discusses in depth the theoretical and methodological aspects of ante-narratives and their relationships to, and distinctions between, stories and narratives, ante-narrative in a broad sense can be seen to articulate how organisations like CBOs present a myriad of stories/narratives that facilitate sense-making and identity formations among their members.

In examining organisational stories and narratives, Loseke (2007), Humphreys and Brown (2002), Boje (1994, 1995, 2001, 2008) and others, refrain from differentiating between sector-based organisations. However, I contend that this is important as stories and narratives in health CBOs can play out differently to those in their sector counterparts. This difference relates to whether the multiple narratives of organisations can be considered to carry productive potential and thus whether such multiple narratives are promoted or suppressed within organisational practices. Available literature suggests organisational multiple narratives are not viewed as positive for, and by, business sector organisations (Clegg, 1989; Boje, 1995; Rhodes, 2000b; Humphreys & Brown, 2002; Brown, et al., 2005; Boje, Hansen, & Grace Ann, 2007) or their participants (Dutton & Dukerisch, 1991). Rhodes found that within business sector organisations dominant elites and groups mobilise shared meanings and identities in order 'to impose their own monological and unitary perceptions of truth' see also (2000, p. 227; Humphreys & Brown, 2002). However, it is acknowledged that within organisations 'individuals and groups have some latitude to author their own reality, though always in ways shaped by available social discourses' (Humphreys & Brown, 2002, p. 422). Thus, individuals may oppose such centralising narrative building subjectivities (Rhodes, 2000b) or hegemonic identities (Humphreys & Brown, 2002).

Although public sector sites that address HCV transmit many stories, these are arguably subsumed under strategic well-rehearsed expert narratives. In contrast I posit multiple narratives carry productive potentialities for health CBOs which help underpin their distinct expertise. To elaborate, I introduce the second conceptual level of the model which centres on the concept of liminality to illustrate how both member HCV identities and CBO narratives may be seen to express and represent a "betwixt and in-between" character that differs according to their micro- (individual experience) and meso-level (institutional position) qualities. Following this, I link conceptual levels 1 (narrative) and 2 (liminality) to articulate CBO expertise in terms of "narrative communitas" spaces.

Level 2 – Liminality

In this section I outline the concept of liminality and apply it in two different contexts:

2. (a) *Hepatitis C lived experience as a function of occupying, or being in between, opposing social and cultural categories (micro-level)*
2. (b) *Hepatitis C community-based organisations' relational position in between the state and "community" (meso-level)*

The term liminal derives from the Latin word *limen,* meaning "threshold" and has been used in various disciplines from psychology, anthropology and sociology to literary arts, media and religious scholarship. The second edition of the Oxford English Dictionary (2009) notes that the term "liminal" first appeared in publication in the field of psychology in 1884 and was later introduced in anthropology by Arnold Van Gennep in 1909 in his seminal work, *Les Rites de Passage'* (La Shure, 2005) which subsequently informed Victor Turner's work in *The Ritual Process* (1969).

The Ritual Process (Turner, 1969) heavily derives from Turner's fieldwork in central Africa where he studied the Ndembu. Turner's (1969) central thesis concerns the productive potentialities of participating in successive phases of socially organised liminal spaces and social structure. Being subject to social structure alone is said to create and/or exacerbate: concerns of living, crises; alienation; and stifle innovation and creativity. Due to Turner's extension of liminality to contemporary social and cultural contexts, it is his work that predominantly informs the application and expansion of liminality in subsequent literatures (deployed to investigate such diverse topics as Western counter- and subcultures, literary works, organisational studies and illness experience).

Rather than simply examining the structures of society, Turner focused on liminality from the perspective that one should examine the symbolic and emotive impacts of these structures and, more crucially, what happens in between them. In these “in-between” places outside of social structure and norms, arousal, activity and emotion become intensified; social life becomes “social drama”. Liminal individuals in these spaces are seen as isolated, their status suspended, they are ‘neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, ceremony’ and dominant discourse (Turner, 1969, p. 95). Thus, Turner’s liminality relates to three dimensions: a relation to social structure, norms and cultural classification; a transitional process; and subjective intensities - or spatial, temporal and subjective dimensions. This multi-dimensional aspect thus affords and implicates mico-, meso- and macro-level considerations within applications or appropriations of the concept of liminality.

These dimensions have particular relevance to identity (trans)formation as demonstrated by Turner’s (1969) tripartite ritual process framework: *separation*; *liminal*; and *incorporation*. This tripartite process represents the passing from one cultural state or identity to another. Separation refers to a detachment or stripping away of one’s culture and former self which can be signified in symbolic actions and rituals (Turner, 1969). Following the separation stage is liminality, which refers to a space ‘between cultural states and structures, making them an in-between place, between social roles, cultural expectations, and status’, a non-place (Kelly, 2008, p. 336). Liminal individuals may be deemed “impure”, “unclean”, “sick” or “dangerous”. Symbols, myths and rituals and metaphysical agents (e.g. shamans, priests) are viewed as important during the liminal phase in terms of providing guidance through liminality. The third phase, incorporation, entails the return to society/social structure, accomplished after having completed the assumption of a new identity (Turner, 1969). While 'Turner develops the concept of liminality through analyses of preindustrial societies, he clearly intended for its use to capture general social processes' and experiences within contemporary Western societies (Yang, 2000, p. 383, see also Tuner, 1974).

2 (a) Hepatitis C lived experience as in-between opposing categories

In the 1980s the use of the concept of liminality emerged to examine physical disability and illness experiences. Although no conceptual consensus exists in this literature (Molzahn, Bruce, & Shields, 2008), most studies formulate liminality in terms of individuals persistently occupying an in-between, ambiguous state, experience or identity (Martin-McDonald & Biernoff, 2002; Texter & Mariscotti, 1994; Hallstein, 1992). Thus negative evaluations of "sustained liminality", that is, a liminal identity devoid of incorporation, are typically presented within illness and disability contexts. Sustained liminality in these studies is commonly 'linked to uncertainties of disruption in self-identity or personal narrative' (Molzahn et al., 2000, p. 13) and to the condition being chronic and/or terminal (e.g. Little, Jordens, Paul, Montgomery, & Philipson, 1998). For example, Murphy et al. reports that people living with chronic disability are isolated and experience a persistent status-suspension; disability becomes a sustained 'in-between state, for the person is neither sick nor well, neither fully alive nor quite dead' (1988, p. 238). In most studies reaching incorporation is either deemed unachievable or challenging, or is not imagined.

Formulations of liminality as a sustained, ambiguous space or experience are commonly marked in the literature by changing social relations or subjective experiences, presented according to intersections of opposing categories or declassification, where reclassification is absent. For example, a study looking at chronic kidney disease reports participants positioned between contradictory categories: living/not living, independence/dependence, restrictions/freedom, normal/not normal and alone/connected (Molzahn et al., 2008). Similarly, a study on prostate cancer reports participants feeling: recovered/not well, a longing for intimacy/absence of libido, "maleness"/loss of masculinity, social/social distance, adjusted/no reconcilement (Navon & Morag, 2004). Similar liminal representations are also present in studies looking at inflammatory bowel disease, schizophrenia, arthritis, the aged and people living with brain injuries, comatose, Alzheimer's, and HIV (Barrett, 1998; Kaufman, 2000; Shield, 1990; Shalinsky & Glascock, 1988; Shomaker, 1989; Sandstrom, 1990; Bloom, 1997; Kelly, 2008).

More recently, the term liminality has appeared in HCV articles (e.g. Treloar & Rhodes, 2009; Rhodes & Treloar, 2008; Harris, 2009). Parallels can be found between the above literature and these HCV studies. Generally, both formulate liminality as a sustained experience marked by subjective experiences and informed by intersections of opposing categories. Such intersections are a function of biomedically derived discourses and everyday social relations within the public (health) sector. For example, Harris presents liminality in relation to when HCV was initially termed non-A, non-B hepatitis, stating this medical label 'specifies what it is not, or an expression of absence' (2009, p. 1031). This absence, claims Harris (2009), saw participants experience themselves 'as neither ill with a legitimate knowable disease, nor in full possession of disease-free health' (Harris, 2009, p. 1032).

In a literature synthesis of 25 articles on HCV lived and treatment experiences of IDUs, Treloar and Rhodes state that: ‘studies uphold a narrative of trivialization, normalization, and biographical reinforcement on the one hand, and of illness disruption on the other; and injectors accounts draw selectively on both’ (2009, p. 1329). This, the authors hypothesise, suggests HCV can be viewed as a persistent liminal identity.

> We have seen the presentation of hepatitis C identity oscillates between trivial and serious, normalized and stigmatized, public and personal. The ambiguous and indeterminate nature of what it means to be living with hepatitis C is arguably intensified by its chronic nature alongside a pervasive sense of biomedical expertise being uncertain and provisional in relation to health and treatment effects. By focusing on the physical effects rather than the experience, biomedicine reinforces a sense of “living in this gulf,” especially because “you’re not all that sick”. This suggests that living with hepatitis C might be characterized as a liminal experience. It is indeterminate—an experience between normalcy and a chronic illness that is physical, legitimized, serious, and disruptive (2009, p. 1328).

In discussing the ‘liminal status’ of HCV, Rhodes and Treloar highlight the fundamental role of symbolic knowledge in terms of individuals drawing on multiple ‘symbolic knowledge systems based upon the themes of hygiene and trust’ (2008, p. 1600). These knowledge systems emphasise ‘a dual role of affective as well as cognitive forms of risk assessment’ among IDUs at risk of HCV and draw ‘upon ideas of emotion, fate or faith as well as biomedical risk calculus’ (Rhodes & Treloar, 2008, p. 1600).

It may be stated that as modern societies lack the rituals or rites of passage originally studied by Van Gennep and Turner, other contemporary symbols, agents and discursive systems present mediation structures for the liminal initiate. Hepatitis C-affected individuals are likely to be initiated within public sector contexts, informed by biomedically derived discursive relations and agents. In this sense, biomedicine and its derivatives such as health promotion provide ritual and symbolic guidance while doctors and allied health professionals supplant Turner's shamans or priests to instruct the initiate in order to guide or mediate the "polluted", "sick" and "treated" (i.e. anti-viral treatment) towards some hope of renewal and incorporation. Such symbolic guidance as provided by the public sector (re)produces rather than capitalises upon HCV as a liminal identity as Treloar and Rhodes underscore:

> More importantly, we find that interactions with the health care system can reproduce, rather than resist, hepatitis C as a liminal illness experience, not only through concentration on its physical manifestation, but through other interactions that trivialize the seriousness of illness experience and stigmatize those in search of treatment, care, and a legitimizing illness identity (2009, p. 1329).

The above review not only highlights Turner's (1969) idea of liminality within an illness experience context but also points to how the meso-structural level, in this instance public (health) sector settings, is implicated in (re)producing liminality among HCV-affected individuals. In the following section I look at the meso-level of civil society organisation in terms of how the relational position between state and community CBOs hold, represents and expresses a liminal quality that provides a potentiality to mitigate rather than (re)produce liminality among individuals affected by HCV.

2. (b) Hepatitis C community-based organisations' in-between the state and "community"

In examining CBO liminal qualities, I outline Turner's (1969) thesis as presented in *The Ritual Process* and connect Turner's ideas of liminality and "communitas" with the work of David Boje (1994, 1995, 2001, 2008) concerning the story-telling organisation. This connection allows me to characterise CBO distinct expertise by way of “narrative communitas” spaces.

In *The Ritual Process*, Turner conceptualises society (societas) as ‘a process rather than a thing – a dialectical process with successive phases of structure and communitas’ and states that there seems to be a propensity for individuals ‘to participate in both modalities’ (1969, p. 203). Turner conceives social structure along the lines of ‘a more or less distinctive arrangement of specialised and mutually dependent institutions and the institutional organizations and positions and/or actors which they imply’ (1969; 125). Social structure has cognitive quality expressed in one sense as a prevalent ‘set of classifications, a model of thinking about culture and nature and ordering one’s public life’ (Turner, 1969, p. 127).

The other dimension of “society” according to Turner is more difficult to define: community, which the term “communitas” attempts to capture. Communitas is a Latin (singular) noun that, according to Turner, refers to an unstructured “community” emerging where social structure is lacking and it has an existential quality. Human interrelatedness within communitas aligns to what Martin Buber (1958) refers to as experiencing of the other *with* the other, or a flowing from *I* to *Thou*, rather than from *I* to *It* (‘It’ representing an objectified other who serves a technical/service function). Accordingly to Turner such ‘relations between total beings are generative of symbols and metaphors and comparisons; art and religion are examples of their products rather than legal and political structures’ (1969, p. 127-128).

Communitas break through the interstices of social structure occupied by the liminal, marginal and “inferior”, transgressing and dissolving ‘norms that govern structured and institutionalized relationships and is accompanied by experiences of unprecedented potency' and affective intensity (Turner, 1969, p. 128). Such intensity represents a liberating energy and is a 'product of peculiarly human faculties, which include rationality, volition and memory, and which develop with experience of life in society' - as opposed to the Freudian sense of releasing an instinctual drive when cultural constraints are removed (Turner, 1969, p. 128). Such logics of experienced intensity/energy provide the conditions whereby alternative socio-political and cultural paradigms or 'myths, symbols, rituals, philosophical systems, and works of art' are created reflecting a production and mediation of 'anti-structure' (Turner, 1969, p. 128). This production of alternative paradigms however, is dependent on the structure and the cultural mainstream for legitimacy and psycho-cultural impact. As Arnott underscores:

> It is important to recognize from the outset that communitas does not represent for Turner some ideal state of community which is only lost or subjugated through the prevalence of hierarchically organized social structures. The latter are patently necessary, and communitas as such only persists in their midst, au milieu….This is to say, it does not require the destruction or collapse of social organization, but takes place only within such a context and despite its hegemony (2001, para.8).

Although anti-structure and communitas takes place in relation to social structure, new social structures in turn can surface from anti-structure. As La Shure (2005) states, just as chaos is the source of order, anti-structure and communitas represent possibilities from which social structure can also emerge. As such oscillations between structure and anti-structure help constitute a communitas. Engaging in these structure and anti-structure oscillations facilitates a reconfiguration or revitalisation of one's relation to social structure. In Turner's words:

> These cultural forms [reflecting anti-structure] provide men with a set of templates or models which are, at one level, periodical reclassifications of reality and man's relationship to society, nature, and culture. But they

> are more than classifications, since they incite men to action as well as to thought. … There is a dialectic here, for the immediacy of communitas gives way to the mediacy of structure, while, in rites de passage, men are released from structure into communitas only to return to structure revitalized by their experience of communitas (1969, p. 129).

The civil society sector is well positioned to foster such communitas or communitas spaces where oscillations between structure and anti-structure manifest, and where liminal, marginal individuals are able to generate alternative cultural forms (in relation to ideas of health/illness/HCV) in order for a revitalised return to structure. This return may also create the conditions to change social structure. This revitalisation may manifests through new and responsive HCV-related identities. The following section develops this contention within a HCV CBO context by linking ideas presented under level 1 ("narrative") and level 2 ("liminality").

HEPATITIS C COMMUNITY-BASED ORGANISATIONS AND NARRATIVE COMMUNITAS SPACES

Connecting narrative and liminality to present CBO expertise in terms of "narrative communitas" spaces centres on articulating how CBO multiple narratives correspond to structure and anti-structure elements. In this sense Turner's (1969) notion of communitas is reconfigured in narrative terms. Specifically, I discuss how the production of dominant and alternative or counter-narratives (re)produced within CBOs: 1) corresponds to Turner's (1969) concepts of structure and anti-structure and; 2) reflects its liminal position between state and community.

Turner (1969) emphasises symbolic and ritual devices within relations of, or oscillations between, structure and anti-structure in the generation of communitas. Community-based organisations represent contexts wherein the interplay of multiple symbolic devices transpires. That is, the stories and narratives that CBOs produce and circulate represent symbolic devices by way of the linguistic mechanisms and social practices attached to organisational storytelling. It is from this premise I substitute Turner's more traditional understanding of symbols, myths and rituals for the linguistic devices and social practices attached to contemporary language.

Similarities and connections between ritual and language have been documented in various ways: ritual theory and standardised language (Deumert, 2003), reading as a ritual process (Dressman, 1997), and reported speech as ritual discourse where Glenister-Roberts (2004) connects liminality to epideictic rhetoric. Further, Cook-Sather (2006) looking at liminality in a teacher preparation program supplants Turner's symbols and myths with the textual exchange space of electronic mail ("e-mail"). Viewing language and narratives as a ritual process of sorts, allows for Turnerian concepts to be more readily applied to contemporary contexts. The paucity of explicit symbolic rituals to mediate self-transformations in Western cultures has coincided with the development of a discourse heavy world directed towards identity (trans)formations. Further, St John states that 'Turner's "liminal ritual" was a pure, ideal category' and that 'inflexible application tends to disregard complicated performative spaces' (2001, p. 48). Substitution of such ritual ideals for story and narrative allows a more apt discussion concerning complex social spaces within the contemporary world.

Linking multiple narratives of hepatitis C community-based organisations to structure and anti-structure

Narratives produced by health and HCV CBOs can be seen to draw from public narratives and discourses that align to Turnerian notions of structure and anti-structure. That is, on the one hand some CBO narratives draw from dominant public narratives considered "meta"/"grand" or "expert"/"official" and thus correspond to structure in terms of dominant systems of knowledge and 'classifications that provide a model of thinking about culture and nature and ordering one's … life' (Turner, 1969, p. 127). On the other hand some CBO narratives may appropriate or transform dominant public narratives in subtle ways while others may more forcefully counter dominant narratives offering alternative symbols or ways of understandings events and the "self", thus reflecting anti-structure. Therefore when an individual engages in such a CBO environment, they contend with multiple organisational stories and narratives whose constitution represents relations to structure or anti-structure. In this sense, CBOs can be seen as "narrative ecologies".

The idea of multiple CBO narratives or narrative ecologies finds relevance in the multiple sources of stories (re)produced and circulated by HNSW and its participants and members. Taking as an example the most accessible HNSW narrative space, the publication *Hep C Review*, we see at first glance that some stories appear to correspond to or reproduce dominant expert narratives (e.g. news and medical research articles), while others correspond to the experiential narratives of those affected by HCV (e.g. reader stories). Such narrative ecologies are conceivably informed from the multiple stakeholders attached to CBOs like HNSW. Two central stakeholders that HNSW must consider, which instantiate the liminal quality of HNSW, are its state funders and those affected by HCV; HNSW must therefore negotiate and manage voices and narratives that come from the public sector as well as the people or "community" the CBO is said to represent. In simple terms, the state-based public sector and its priorities and narratives can be seen to correspond to structure while the HCV experiential or "community-based" voices and narratives correspond to the potentiality of anti-structure.

Hepatitis C community-based organisations and the production of state endorsed dominant narratives

It is well documented that the retraction of the welfare state has resulted in many CBOs taking up roles and responsibilities previously undertaken by the state (Vertovec, 1999; McDonald & Marston, 2005; Gough et al., 2006; Woolford & Curran, 2012). As reported earlier, within a HCV CBO context this retraction has seen HCV CBOs' 'core business' increasingly 'become intertwined with the objectives of the State and Federal Government' (Carey, 2007, p. 44) seeing HCV CBO services 'expected to conform to the professional practices of public health – particularly, evidence-based practice and performance measurement associated with the strategic-orientated model utilised by the public sector' (Pugh, 2006, p. 267). As such state and CBO relations can be seen to reiterate social structure within the CBO.

Examining the effects of state and CSO relations has attracted much scholarly attention. Researchers have coined terms such as "third-party government" (Salamon 1987), "enabling state" (Gilbert & Gilbert 1989), "the shadow state" (Wolch 1990) and the "contracting regime" (Smith & Lipsky 1993) to articulate the institutional shift toward publicly funded but CSO-delivered human services (Middleton Stone, Hager, & Griffin, 2001). In an article examining emerging trends in understandings of government–nonprofit relations, Brinkerhoff and Brinkerhoff (2002) discuss isomorphism. Isomorphism ‘relates to how nonprofits structure themselves to interact with governments’ and how they ‘increasingly organize themselves to mirror and imitate characteristics of how their public sector counterparts operate and are structured’ (Brinkerhoff & Brinkerhoff, 2002, p. 11). At times such isomorphism is a ‘function of traditional versus more radical objectives’, where CBOs ‘pursuing more traditional paths exhibit higher degrees of similarity with their’ (Brinkerhoff & Brinkerhoff, 2002, p. 11) state funders, as demonstrated by Brainard and Siplon’s (2002) analysis of health sector Internet-based nonprofits.

Techniques and processes within isomorphism are textual in nature as well. That is, CBOs are likely to (re)produce dominant public narratives that correspond to state narratives which articulate state priorities and agendas. As Pugh (2006) indicates, state-led national HCV strategies inform social practices within HCV CBOs and by extension this is likely to include textual practices concerning the narratives (re)produced by HCV CBOs. These dominant narratives of HCV are informed by a combination of biomedical and public health discourses and encourage members to adopt particular kinds of illness identities (Krug, 1995), as I explore in detail in Chapter Six. However, such effects in relation to isomorphism sit beside CBO capacities to produce and circulate stories and narratives of an anti-structure nature, which diverge from dominant state narratives, reflecting an alternative or counter-position to state priorities.

Hepatitis C community-based organisations and the production of alternative and counter-narratives

> While some academics believe that it is not yet clear how NGOs and CBOs will fulfil their objectives, it is clear that third sector organisations have an important socio-political role in offering discourses, knowledge, services and support, which differ from that of the government and market sectors.
>
> (Carey, 2007, p. 178)

Consistent with understandings of anti-structure presented earlier (Turner, 1969; Arnott, 2001), counter-narratives 'only make sense in relation to something else, that which they are countering. The very name identifies it as a positional category, in tension with another category' (Bamberg & Andrews, 2004, p. x). Counter-narratives mark the existence of anti-structure by way of the creation of alternative symbolic devices manifest through text. Counter-narratives represent a resistance or countering of "dominant" or "master" narratives (Bamberg & Andrews, 2004) or "official culture" narratives as Giroux's (1996) underscores:

> …even in a postmodern age, where citizens retain some sense of the critical exhibiting a characteristic "incredulity towards meta-narratives" there remain "official" narratives whether grand or otherwise. Counter-narratives, then…counter not merely (or even necessarily) the grand narratives, but also (or instead) the "official" and "hegemonic" narratives of everyday life: those legitimating stories propagated for specific political purposes to manipulate consciousness by heralding a national set of common cultural ideals (1996, p. 2).

While the term counter-narrative has been applied in civil society contexts (Tabar, 2007; Harter, Berquist, Titsworth, Novak, & Brokaw, 2005; Harter, Scott, Novak, Leeman, & Morris, 2006) and approaches to identity (Somers, 1994; Violi, 1992), it has been largely neglected in theoretical considerations of CBO distinction. One attempt to do so, which provides particular relevance for this research, is Carey's (2007) thesis looking at a HCV CBO. Carey argues that 'counter-discourse offers a tool for conceptualizing the role of' CBOs (2007, p. 181). Drawing on Foucauldian notions of resistance and counter-memory Carey states that counter-discourse is 'concerned with how individuals may interrupt the regulatory nature of power' stemming from dominant discourses (2007, p. 179). Hepatitis C CBOs, the author claims, can be understood 'as intermediaries for the creation of counter-discourses' (2007, p. 181). This follows Moussa and Scapp (1996) who refer to the creation of counter-discourses as "Foucauldian activism", whereby those typically voiceless, seen as facing representational silences, begin to speak a unique language of their own. This supports the critical place experiential knowledge has within CBOs.

As reported earlier, experiential knowledge represents an important element within health CBOs in terms of constituting an organisational power/authority base which helps position CBOs as distinct from their public and business sector counterparts (see Schubert & Borkman, 1991). The importance of personal experience within health CBOs extends beyond rational and utilitarian means towards more expressive and social ontological concerns, and manifests within CBO spaces as part of alternative/counter-discourse. Carey states that counter-discourse is created through 'arming marginalised and stigmatised individuals with the skills and knowledge to speak for themselves' (2007, p. 181). This is achieved through CBOs creating a 'political space for individuals affected by hepatitis C to speak for themselves' (Carey, 2007, p. 181). The HCV CBO examined by Carey (2007) produced this space through projects that aim to increase individuals' skills and knowledge around HCV; and by encouraging 'affected community members to take part in political forums' (Carey, 2008, p. 18) - work that similarly occurs at HNSW. However, the specific processes involved in this “arming” are not examined, subsumed under the broad skill-development activity of CBO program participation. In a sense, the current thesis considers the specific processes involved in the production of counter-discourse as conceptualised through the relations between liminality and structure and anti-structure processes that constitute CBO narrative communitas spaces.

Consistent with Carey’s (2007) position, this thesis contends that the notion of counter-discourse is an important part of conceptualising CBOs. However, the term counter-narrative is preferred, as it is more conducive to examining local narrative identity formations. Importantly, it offers a more inclusive approach to CBOs in terms of exploring the experiences of member engagement. That is, a very small minority of HNSW members typically participate in the programs/activities Carey (2007) describes as fostering counter-discourse (HNSW, 2007, 2008; HNSW key informant Alice, personal communication, December 15, 2011) possibly due to a number of reasons from time and resource restraints to issues of social stigma, among others. The present study contends that counter-narratives are likely to be implicated in more diverse, local and nuanced CBO spaces such as the *Hep C Review* and consequently, given that more people engage with the newsletter than specific skill training programs, suggests that a majority of CBO members have the opportunity to engage in, and create, counter-narratives and maintain anonymity if desired. Thus my emphasis is on the way stories facilitate such spaces rather than on notions of “skill development” (which may for some come after engaging in the former). Although counter-discourse and counter-narratives conceptually overlap, their differences come from the specifics they emphasise. Counter-narrative emphasise stories in a local sense:

> The notion of counter-narratives in this sense carries with it Foucault's "counter-memory" and the idea of counter-practices, but in a specific and local sense. Such counter-narratives are … quintessentially "little stories" – the little stories of those individuals and groups whose knowledge's and histories have been marginalized, excluded, subjugated or forgotten in the telling of official narratives. (Giroux, 1996, p. 2)

Counter-narratives are, in essence, about redressing representational or narrative silences, to cultivate or give back meaning in relation to one's experiences, social history and position thus speaking to Hepworth and Krug's (1999) claim that stories which give back a sense of meaning to people affected by HCV are needed more so than medical and scientific information. Carey argues that 'one can only ensure that a discourse is counter when the broad socio-political picture has been revealed' (2007, p. 181). Similarly, relations between structure and anti-structure see alternative/counter-narratives rely on and reveal dominant narratives and social structure. Community-based organisations viewed as containing both structure and anti-structure spaces facilitate this socio-political uncovering allowing, as Krug (1996) recommends, a repositioning of oneself in relation to dominant narratives. In a sense this also speaks to Fraser and Seear's call to reiterate the meaning and materialisation of HCV through posing the questions: 1) 'where are the options?'; 2) 'what is at stake?'; 3) 'are there really options?; and 4) 'how should we choose?' (2001, p. 80). While Fraser and Seear (2011) modestly acknowledge the concerns answering these from a particular discursive position, narrative communitas spaces within HCV CBOs may have the potential to present a starting place in addressing these questions.

The above sections illustrate how multiple CBO narratives correspond to structure and anti-structure elements – a critical basis for narrative communitas spaces.

The following section focuses on how these narrative communitas spaces may generate a productive potential towards new and responsive identity formations among CBO members.

Productive potential of narrative communitas spaces within a hepatitis C community-based organisations

Liminal individuals engaging with liminal social fields or institutions are a central idea behind the productive potential of CBOs. In articulating this idea, the interactive dynamic between liminal individuals and communitas spaces and the potentiality of productive consequence from such a dynamic, is considered.

Taylor, Durant and Boje (2007) point to productively working with multiple preliminary stories and liminality in a crisis context but rather than contemplating CBO capacities to facilitate this, researchers are posited (as the article is directed at enhancing crisis inquiry). Multiple preliminary stories here are located within individuals in terms of their attempt to construct stories (thus preliminary, incipient) as a way to seek ways out of a state of crisis. For Taylor et al. these personal narratives reflect a 'crisis of language and communication' often corresponding to a liminal experience (2007, p.5). In examining this communication crisis, the authors advocate for the strategic use of "invitational rhetoric". Invitational rhetoric uses language to express a desire to understand the other, 'admits the inadequacy of language to express such an understanding' at times, 'and indicates a willingness to learn from the other in order to build new relationships, new structures, and new metaphors' (Taylor et al., 2007, p. 6).

In presenting a background for such rhetorical devices, Taylor et al. could be writing about narrative communitas elements within CBOs as proposed in this study:

> The crisis of language and communication [stemming from crisis/trauma/illness] can therefore be imagined to be "betwixt and between", a state which has potential to call forth new structures, new symbols, and new metaphors: in other words, new relationships and new understandings. In seeking ways out of the state of crisis, language strategies available lead towards either a reassertion of standardization or an embrace of the new, which in turn requires trust, a sense of humility and/or humor, and faith that an opportunity for creativity lies in the crisis. It also usually requires interaction with others, interaction mediated by inadequate language …the strategy of mutual problem solving and the tactics of persuasion, openness, and mutual enhancement elicit, and also are elicited by, a cooperative orientation. (2007, p. 5).

In more simplistic terms the above passage suggests that crisis provokes liminality and communication problems expressed through personal (preliminary) narratives. To address this, discursive interactions are proposed which in turn can lead to standardization (social structure) or something new (indicative of anti-structure). The latter requires trust, mutuality, openness, cooperation and interactions with others who express ante-narratives. While such processes and elements are not the monopoly of CBOs, a community or peer-based relational setting is feasibly conducive to such processes as reported in normative and comparative advantage approaches to CSOs.

Fostering narrative communitas spaces whereby liminality and personal narratives interplay with other multiple (public) narratives carries potential. However, I would like to again underscore that it is structure and anti-structure oscillations and liminality which furnish this potential. As Arnott (2001) highlights; it is the oscillation between anti-structure and structure that can provide a dynamic and creative force behind the production of new potentialities, understandings and identities by liminal individuals - a dynamic and creative force with potential "revolutionary effect". In linking liminality and communitas to Guattari's (1989, 1995) aesthetic paradigm, Arnott (2001) claims liminality can be viewed as, a logic of affective intensities. Logics of intensities are, as Guattari states, ‘concerned only with the movement and intensity of evolutive processes’ which ‘oppose here to system or to structure (1989, p. 136). What Guattari (1989) and Arnott (2001) are asserting is that the productive potential of liminality is bound up in how the affective intensities attached to liminality direct individuals away from the conservatism that is required to preserve abstract and universal systems of knowledge. This de-privileging of dominant social structures can accompany an embracing of alternative knowledge in the production of subjectivity – alternative knowledge and narratives interpreted as “authentic”. To reiterate, such alternatives or counter-positions felt as “authentic” are conditional on dominant structures and paradigms functioning to test or “check” the latter, as Arnott states:

> … an aesthetic paradigm that places emphasis on liminality and its creative potentialities … pays less heed to the stratifications of science and rationalist principles. It is not of course that the products or effects of these latter paradigms can somehow be extracted or abstracted from the production of subjectivity, it is rather that their acceptance or dominance will be checked against an underlying aesthetic sensibility capable of resisting or problematizing, if necessary, their prescriptions (2001, para.18).

Liminality within communitas spaces allows finite assemblages, dominant narratives, structured systems of knowledge and discursive sets that surround us on a day-to-day basis (and in this instance within CBOs), to become open to scrutiny through an ethico-aesthetic experimental process (Toscano, 2003). Srinivas, employing a critical perspective on NGO action, links this position to ensuring an epistemic openness in order ‘to avoid formulating an over-determined subject’ (2009, p. 618). Scrutiny and experimentation within epistemic openness through communitas engagement, can give way to ideas, practices and identities of a different and singular manner conducive to an individual’s personal and social particularities (Toscano, 2003). Guattari (1989) terms this ”re-singularization” and points to the civil society (“third”) sector as a potential site to develop communitas or ‘ecologies of re-singularization’ to use his terms. In the *Three Ecologies*, Guattari (1989) suggests that we must look at domains where new value systems can flourish such as the value of social and aesthetic (liminal-inspired creativity) “profit”, rather than market or state-based utilitarian values.

> Until now, of course, domains of value not governed by capitalist profit have been dominated by the state ... We have, however, reached a point where new social associations - with charitable foundations, for example - should be drawn upon to expand the financing of a more flexible third sector which is neither private nor public. The third sector will in any case constantly be forced to expand as human labour gives way to machine technology; and the question posed by its expansion is not only that of how to achieve recognition of a universal minimum income - recognized as a right, not a means of reintegrating individuals into the workforce. It begs the question, too, of how to stimulate the individual and collective organization of a developing ecology of re-singularization (Guattari, 1989, p. 146).

In a sense, re-singularisation is about the mediation of identities responsive to the individual and rests on the engagement of both dominant (structure) and alternative/counter (anti-structure) narratives within CBOs. The mediation of identity here resembles a “restorying” by retracing relations between dominant and counter-stories (White & Epston, 1990), seeing ‘dominant and counter-narratives ‘in-interaction being both made use of to bring off, and more intelligibly manage, emergent identities’ (Bamberg & Andrews, 2004, p. 351). This narrative communitas dynamic thus allow liminal individuals to recognise and scrutinise various stories about the factors and processes that play their part in the construction of their HCV-related identities. This in turn can lead to experimention with new factors and stories as they emerge and resonate with the individual, leading to the possibility of new HCV narratives and identities that are considerate to personal and social particularities.

CONCLUSION

This chapter presented a theoretical model of health CBO distinct expertise that extended traditional approaches to understanding CSOs/CBOs towards an expressive and social ontological understanding of CBOs. Such a model is based on the premise that health CBOs complicate traditional understandings of CBO distinction as people who engage with health CBOs do so not only for service access and skill development, but also for social and identity reasons to help, and learn from, others to understand answers to questions such as; “who I am” and “who can I and we hope to become” as a result of illness.

A central component of the model linked member (illness) experience and CBOs’ relational position between the state and “community” by combining the concepts of “narrative” and “liminality” to present the idea of CBO distinct expertise in terms of a capacity to generate “narrative communitas” spaces. It was argued that such spaces allow liminal individuals to recognise and scrutinise various dominant and alternative/counter narratives and stories about the factors and processes that play their part in the construction of their illness/HCV identities. This in turn can lead to experimentation with new factors and stories as they emerge and resonate with the individual, leading to possibilities of new illness or HCV narratives and identities that are responsive to a member’s personal and social particularities. Consequently, the narrative communitas model of CBO distinct expertise provides a new lens which helps to examine how health CBOs could be, or are, realising the specific elements and processes that underlie their distinct expertise.

In the following Chapter I look at how the potential for CBO narrative communitas spaces might be challenged as a result of contemporary socio-political forces. In doing so another conceptual (macro) level is included in the narrative communitas model.

CHAPTER FOUR

SOCIO-POLITICAL ENVIRONMENT AND THE CONTAINMENT OF NARRATIVE COMMUNITAS SPACES

> It is less a question of predicting how things might turn out, but instead a matter of identifying the sites where potentiality has opened and is opening up, and of discovering how these might facilitate creative enterprises … of all kinds. At the same time, we must strive to be vigilant regarding new mechanisms of control which seek to channel creative energies along predefined and "acceptable" paths, and also struggle against reductionist tendencies bent on effective subjective homogenization.
>
> (Arnott, 2001, para.24)

CHAPTER INTRODUCTION

In the previous chapter I presented a "narrative communitas" model of health CBO distinct expertise which linked member (illness) experience and CBOs' relational position between the state and "community". It was proposed that CBOs harbour a productive potential to facilitate narrative communitas spaces that allow liminal individuals to experiment with new factors and narratives which resonate with the individual, leading to more responsive HCV narratives and identities. In this chapter I consider the role wider macro forces may play in the productive potential of CBO narrative communitas spaces. These wider macro forces stem from the contemporary socio-political environment to which CBOs are subject to.

I begin with a brief overview of recent historical changes within Western political systems towards so-called “Third Way” politics, and how this has seen CSOs increasingly contend with complex relations with the state. I consider what these CSO-state relations might mean for health CBOs in terms of CBOs’ potential to facilitate narrative communitas spaces. By drawing on Henrik Paul Bang’s (2003, 2004) work on governance as social and political communication, I argue that increasing relations between health CBOs and the state may not only have effects on explicit and particular service and advocacy roles that health CBOs might undertake, but also the kinds of narratives and identities they produce - seeing a tendency to privilege public sector/state-endorsed illness narratives and identities and suppress alternative/counter narratives and identities. Consequently, this is likely to compromise CBO distinct expertise in terms of containing narrative communitas spaces.

Emergence of “Third Way” centralist ideology

Poor socio-economic indicators documented over recent decades have been interpreted by many, appropriately or not, as a failure of both collectivist (Marxist, welfarist) and individualist (liberal, neo-liberal) political systems (Gough et al., 2006; Vertovec, 1999). Similarly, social approaches of the state have been increasingly challenged from all sides of the political spectrum resulting in increasing signs of rapprochement, or merging, between collectivist and individualist political models (Vertovec, 1990; McDonald & Marston, 2005). The political philosophies of “communitasrianism” and “associationalism” point to such fusions (Vertovec, 1999; Gough et al., 2006). Both philosophies reject liberal individualism as being overly atomistic and instrumental (Etzioni, 1995; Vertovec, 1999) and rework ‘social democratic themes in opposition to neoliberalism', although associationalism puts forth a 'deeper and [more] radical critique' (Gough et al., 2006, p. 209).

Communitasrianism and associationalism models are said to inform, to various degrees, ideas of the "Third Way" (Gough et al., 2006) and coincide with the retraction of the welfare state which has seen many CSOs adopt roles and responsibilities previously undertaken by the state (McDonald & Marston, 2002, 2005). Since the early 1990s 'welfare reform has been at the heart of the Centre-Left's search for a new political middle way between post war social democracy and Thatcherite Conservatism' (Driver, 2004, p. 31). The Third Way frames these reforms and became popularised in Western political circles in the late 1990s particularly through Tony Blair's "New Labour" policies (Gough et al, 2006; Driver, 2004). One of the key attributes of the Third Way involves advocating for notions of "social inclusion" and "community" participation – the latter said to facilitate the former (Gough et al., 20006). Civil society organisations have become important vehicles for this agenda (McDonald & Marston, 2002, 2005; Gough et al., 2006), as highlighted by the then Australian Federal Minister for Social Inclusion Julia Gillard, in a speech at the ACOSS National Conference in April 2008:

> From the Government's perspective, [social inclusion] means coordinating policies across national, state and local governments and with the community sector to ensure no Australian is excluded from meaningful participation in the mainstream economic and social life of the country. It won't be an easy task. Especially as many of the socially excluded suffer serious and multiple disadvantages that are difficult to address, and have specific problems which do not always command public sympathy (2008, p.12).

Australian politicians have not mobilised the term "Third Way" to the same extent as their counterparts in the UK. However, the idea (and newly created ministerial position) of “social inclusion” indicates the appropriation of Third Way ideas. Gillard’s statement regarding “coordination of policies” across public and civil society sectors in a sense has become one hallmark of this new centralist political landscape and coincides with new public health approaches towards “partnerships” with expert and community sectors; approaches with which the HCV field has become familiar via state-led national hepatitis C strategies (see Pugh, 2007).

This contemporary context of CSOs has been subject to growing scholarly debate, particularly in relation to the challenges CSOs face as a result of increasing relations with the state and how this is affecting CSO roles and participants (Carey, 2007; Lyons, 2001; McDonald & Marston, 2002; Rose, 2000). As Salamon and Anheier (1997) note, the civil society sector has an expanding role in today’s climate, which is distinct from public and business sectors but also connected in many ways. Such connected relations with the public sector are referred to in the literature as “government-nonprofit” relations and have been examined from multiple perspectives (see Brinkerhoff & Brinkerhoff, 2002).

Impacts of state and civil society organisation relations

As reported in Chapter Three, in examining the effects of state-CSO relations researchers have coined various terms such as “third-party government” (Salamon 1987), “enabling state” (Gilbert & Gilbert 1989), “the shadow state” (Wolch 1990) and, the "contracting regime" (Smith & Lipsky 1993) to articulate the institutional shift toward publicly funded but CSO-delivered human services (Middelton Stone et al., 2001). Orsini (2008), in looking at “community” as a locality, articulates upon this shift in terms of the transformation of these localities and their services from “community-run" to "community-based". Brandsen, van de Donk and Putters state that boundaries between the state and CSOs have become 'blurred' and 'fuzzy', and argue for the idea of the 'hybrid' organisation seeing hybridity as a 'permanent and inevitable characteristic of the third sector' (2005, p. 749-750).

Reported impacts of this institutional shift include isomorphism (Brinkerhoff & Brinkerhoff, 2002) and a reduction in political activity among non-profits (Alexander et al., 1999; Smith 1993; Matthews 1994). Other studies report on punishment or fear of punishment for political activity (Monsma, 1996; Stone, 1996; Reid, 1999). Australian studies by Onyx et al. (2008, 2010) indicate that advocacy-related impacts are not easily categorised since some CSOs report "mature relationships" with state departments and others report difficult relations. Regardless of such findings, the consequence of increasing state-CSO relations, assert Chaves, Galaskiewicz and Stephens, is 'enhanced caution about political activity in the presence of government funding' which results from 'what non-profit leaders (who weight the costs and benefits of political activity) believe about the negative consequences of such action for their organisations, and it will operate even if those beliefs are unfounded or alarmist' (2004, p. 299).

Organisational activities in these studies are conceived as overt and traditional political practices, such as lobbying governments, mobilising members to demonstrate and advocating for a political party/candidate. However, Chaves et al. (2004) note that state resource dependency operates on other levels in more nuanced ways, such as changes in organisational structures, board composition and increases in formalisation, bureaucratisation and professionalisation. These are viewed as necessary changes in order to secure, manage and sustain funding which can eventually take time and attention away from political activities (Chaves et al., 2004). However, the authors and others do not consider other more subtle effects that can occur on a discursive level through the negotiation and provision of systems of knowledge and meaning which in turn impact on the mediation of identity (re)formations of those who engage with them.

Two key conditions implicate HNSW in state-CSO relations. One condition is that HNSWs' current primary funder is the NSW state government, which has helped HNSW expand over the years. The other, less tangible, condition relates to the health-orientated nature of the HNSW. This 'means it is also subject to the influences of medical institutions that in turn have their own complex relationships with the state' (Carey, 2007, p. 134). This premise of resource and medical expertise dependency introduces 'power in an institutional and discursive sense within' state-CSO partnership approaches to HCV (Pugh, 2006, p. iii). In terms of the traditional political activity of advocacy, the ability of HCV CBOs and their members' to affect state-led policy development may be constrained under state-CSO relations as Pugh, in critically examining the partnership approach underpinning the first national HCV strategy, underscores:

> Community representatives remain on the periphery of networks (including social networks) that influence hepatitis C public health policymaking such that any consensus reached can be regarded as "selective". In this model of policy development and implementation NGOs are required to conform to professional practices. Moreover, the complex that constitutes the partnership has adopted the professional voice with which to express itself, pushing the lay voice further to the margin (2006, p. 111).

The public sector conformity issue highlighted by Pugh (2006) is likely to impact on techniques and processes of a textual nature as well, by way of (re)producing public narratives that correspond to state HCV priorities and agendas. As Pugh (2006) notes, state led national HCV strategies inform social practices within HCV CBOs - and by extension this is likely to include textual practices concerning the narratives that HCV CBOs produce. One explicit example of this concerns the development of HCV CBO educational resources financed by state funding which 'is required to meet prescribed specifications under [state] departmental guidelines' (Winter et al., 2011, p. 7). Although this can carry benefit in terms of the requirement to focus-test and evaluate educational materials, it can also 'place considerable constraints on their content including imagery, messages and language' (Winter et al., 2011, p. 7.). This is likely due to political populist forces, as is touched on by the extract below:

> There are examples of occasions where resources have ended up in the hands of an unintended audience and caused public consternation due to the perceived graphical nature of the content and lack of understanding of its public health relevance. Further, producers may be restricted by the perceived moral implications of providing considerable detail in directing the (safest) preparation and consumption of illicit drugs (Winter et al., 2011, p. 7).

The above extract also sits at odds with the earlier extract presented by Julia Gillard regarding the need to address 'specific problems which do not always command public sympathy' (2008, p. 12). The "perceived moral implications" present a complicated dynamic for HCV CBOs in terms of dealing with any potential conservative and/or populist state political orientation, while mediating relevant and responsive HCV narratives and identities to drug users' at risk of or affected by HCV. This complicated dynamic brings me to discuss the issue of governance within state-CSO relations and the prospect of how governance processes impact on HCV CBO narratives as well as the identity (re)formations of HCV CBO members.

The idea of governance presented does 'not merely include the actions of government, but extends beyond government to address the role of citizens, both individually and organized in various forms of association' (Brinkerhoff & Brinkerhoff, 2002, p. 4-5). Many contemporary governance studies indicate that the dominant governance paradigm derives from "new public management" discourses that privilege a utilitarian or instrumentalist/efficiency-orientated view of state-CSO relations, whereby 'market forces are relied upon to solve most societal problems' (Brinkerhoff & Brinkerhoff, 2002, p. 5). According to the authors, this dominant view of governance misses other aspects of state-CSO relations, such as the reconfiguring of CSO values and identities towards instrumental means to achieve 'social and political objectives, as well as economic efficiency' (2002, p. 10). These "missed aspects" are considered by Bang (2003) and Dean (2003), with consideration also given to the identities of CSO constituents.

Culture governance

> In governance…empowering and ruling together with lay people and civil society in dialogical and co-operative relationships become the new criterion for success. In the same fashion governance can fertilize the ground for new, moral practices in society, where the exercise of political freedom is expressed by every individual, as an existential and ethical project linked with the pursuit of identity.
>
> (Bang, 2003b, p. 7)

In developing this idea of governance presented in the above extract, Bang (2003c, p. 241) and Dean (2003, p. 117) present the term 'culture governance' to broadly refer to a rearticulation of the relationship between political authorities and lay people. Bang states that the study of 'governance must connect with more macro-sociological views of 'meta-governance', 'governmentality', 'governance as interaction', 'bottom-up institutionalism' and the 'micropolitics of becoming' (2003b, p.

14). This is ‘in order to complement the decentred view of authority with one that allows for its recentering as regime and community governance’ (Hang, 2005, p. 14). Such a decentred view of authority refers to how ‘political authorities (at whatever level) can no longer act for the whole or control that whole directly’ (Hang, 2005, p. 14). As such, an increasing reliance on connecting and enabling citizens to ‘partake in the system’s governing processes on their own terms *but* with a commitment to’ fulfilling political authorities ‘need for effectiveness, wholeness and coherence’ is emerging as a new steering imperative (Hang, 2005, p. 14, italics my own).

The goal of culture governance relates to the homogenisation of actors and processes within governance relations in order to achieve “effective outcomes” as configured by political authorities. As such, this stands in contrast to more recent ideas about CSOs reconfiguring on their own terms what constitutes effective outcomes – to which recent discussions of “social impact” express (Edwards et al., 2012; Zappala & Lyons 2009). This culture governance goal is achieved through elites (be they political, CSO, class, public sector elites) and their attempts

> to socialize and regulate people’s conduct in an indirect manner by working on their identities and thereby their values, feelings, attitudes and beliefs via a variety of new interactive modes of dialogue and co-operation. The aim is to get individuals freely and willing to employ their self-governing powers to help the systems connect and deliver in an effective manner (Bang, 2003c, p. 247).

Despite noting culture governance’s similarity to Foucault’s governmentality, Dean (1999; 2003) suggests there is more to it than this. Rather than being an invisible force or hand of the government, culture governance is constructed only through understanding its own operations and intentions.

Civil society is a critical component of effective culture governance and speaks to Ilcan and Basok's notion of "community government", referring to how communities are targeted through 'programmes or schemes that seek to direct and shape the actions of others' (2004, p. 131). Effective culture governance, via (de)'politicising individuals in civil society by empowering them for the sake of getting them more actively involved in the political rule of the social, is today articulated as "good" governance' (Bang, 2003b, p. 14). Key individuals within CSOs, who facilitate the culture governance process, or "culture 'governors", are typically leaders and managers who tend to mobilise and privilege particular identities and practices of CSO participants for the strategic purposes of success and influence within the configurations of the system, political regime and its governance imperatives (Hang, 2003c, p. 251).

In the context of HCV CBOs, this may suggests that particular HCV CBO narratives such as alternative or counter-narratives may be suppressed in such a way that maintains the grip of other privileged dominant identities and practices – identities and practices endorsed within state-initiated partnership and network systems approaches to addressing the HCV epidemic (e.g. the National Hepatitis C Strategies – CoA, 2000, 2005, 2010). This suggestion finds support from Pugh who asserts, that CBOs 'are to conform to professional practices of the public health sector and help produce "responsible IDUs", thereby perpetuating the dominant health paradigm with its treatment imperative to contain the disease' (2006, p. iii). This potential to suppress alternative and counter-narratives is likely to affect the productive potential of HCV CBO narrative communitas in terms of members' construction and enactment of HCV identities that are novel and responsive to their individual and social particularities – as opposed to dominant state-endorsed identities whose enacted logics indicate strategic and network/partnership success.

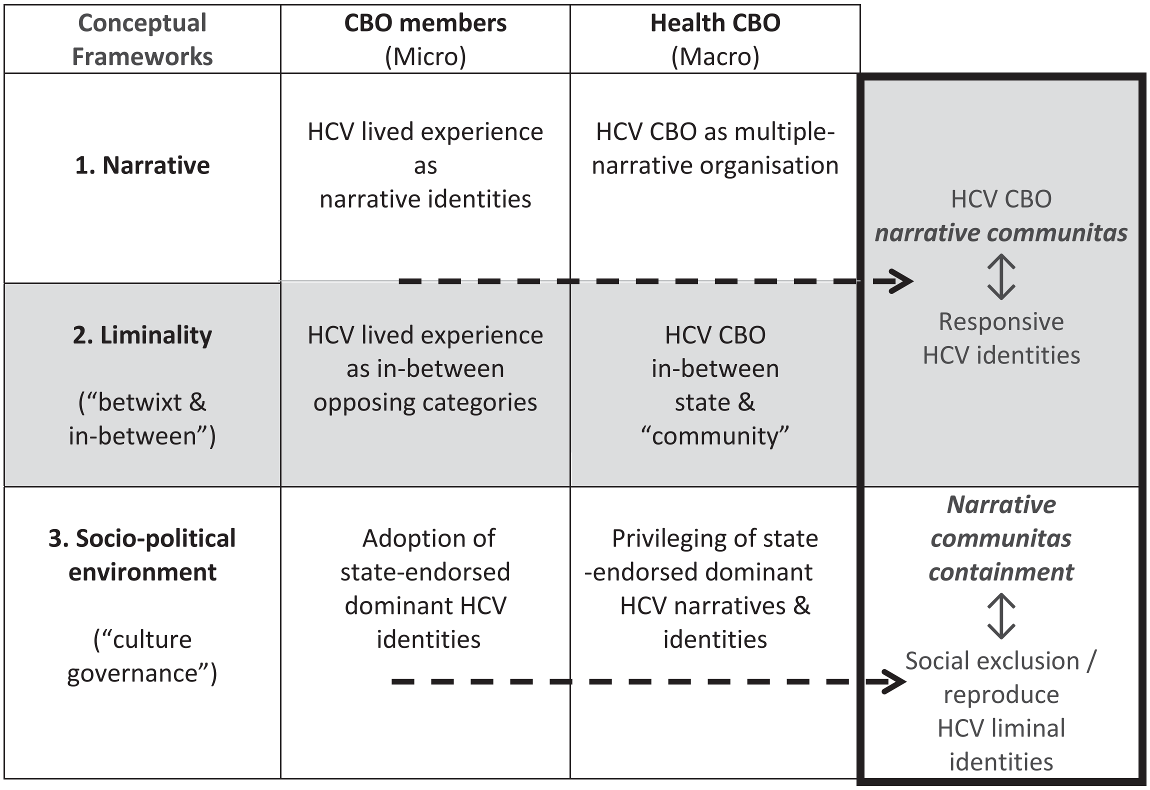
Culture governance imperatives that relate to the privileging of dominant identities within CBOs to facilitate systems success, speaks to Rose's commentary on the Third Way's incitement of the terms "community" and 'responsibility' (2000, p. 1398). According to Rose, such incitements work towards fostering:

> … a double movement of autonomization and responsibilization. Populations that were once under the tutelage of the social state are to be set free to find their own destiny. Yet, at the same time, they are to be made responsible for their destiny and for that of society as a whole. Politics is to be returned to society itself, but no longer in a social form: in the form of individual morality, organizational responsibility, and ethical community (2000, p. 1400).

Culture governance can been viewed as a Third Way technology, operationalised in one sense through CSOs like CBOs, organisations which are touted as sites where ideas of individual morality, organisational responsibility and ethical community can be fostered (McDonald & Marston, 2002; Boyle & Rodgerson, 2006). To draw from Rose (2000), such an 'ethopolitical community" within a health or HCV CBO context, is likely to privilege HCV narratives and identities that align to, or presume, this double movement of autonomization and responsibilization. The imperative to mediate such ethopolitical communities and identities is arguably compounded by hostile social and political forces directed at drug users.

At its worst, those who cannot, or 'refuse to become responsible and govern themselves ethically have also refused the offer to become members of our moral community' (Rose, 2000, p. 1402). Ironically then, the Third Way's logic of social inclusion may instead implicate a new type of exclusion. For some affected by HCV, such social exclusion may likely reinforce HCV as a liminal identity through the experience of being further isolated. Therefore, in presenting a narrative communitaa model of CBO distinct expertise, culture governance as an expression of contemporary socio-political forces, should be considered (see figure 3).

Figure 3. "Narrative communitas" model of HCV CBO distinct expertise



Conceptual Frameworks	**CBO members** (Micro)	**Health CBO** (Macro)	
1. Narrative	HCV lived experience as narrative identities	HCV CBO as multiple-narrative organisation	HCV CBO ***narrative communitas*** ↕ Responsive HCV identities
2. Liminality ("betwixt & in-between")	HCV lived experience as in-between opposing categories	HCV CBO in-between state & "community"	
3. Socio-political environment ("culture governance")	Adoption of state-endorsed dominant HCV identities	Privileging of state -endorsed dominant HCV narratives & identities	***Narrative communitas containment*** ↕ Social exclusion / reproduce HCV liminal identities

CONCLUSION

The contemporary socio-political environment to which CBOs are subject is informed by changes within Western political systems towards so-called "Third Way" politics which has seen CBOs increasingly contending with complex relations with the state. Such relations, viewed through the lens of culture governance, can see CBO leaders and managers adopt a tendency to mobilise and privilege particular narratives and identity formations within CBO practices and among CBO members for the strategic purposes of success and influence within the configurations of the system, the political regime and its governance imperatives. In terms of a narrative communitas framework, this may result in the privileging of public sector/state-endorsed illness narratives and identities and the suppression of alternative or counter-narratives and identities. Consequently, this is likely to compromise CBO distinct expertise in terms of containing narrative communitas spaces at the cost of reinforcing social exclusion and delimiting responsive HCV identity formations among members.

In the following Chapter I outline the methodology employed to investigate the distinct expertise of a HCV CBO according to the narrative communitas model.

Part Two

Methodology

CHAPTER FIVE

METHODOLOGY

CHAPTER INTRODUCTION

This chapter outlines the methodological principles and approaches undertaken in this thesis. I report that the research is premised on a social constructionist epistemology, employing a theoretical and methodological framework that locates narrative as a central idea behind identity and relational settings (e.g. organisations). This chapter also outlines the research goal, aim, question and objectives and describes the qualitative research methods employed to gather data as well as the analytical approaches undertaken.

Research goal

The goal of this thesis is to contribute to new understandings of health-orientated CBOs by investigating connections between CBOs' relational position between the state and "community" and the lived experience of illness of those who engage with them. Maxwell (1996) states that when formulating a qualitative research design, it is useful to distinguish among personal goals, practical goals and intellectual goals for doing a study - goals which are likely to be interrelated. As such, it is a combination of my personal and professional history that has steered my interest in and commitment towards two important issues: the theoretical and socio-political potentials of civil society formations and illness identities among marginalised individuals and groups.

Hepatitis C provides a fertile path to these issues. Although nearly all kinds of illness present affliction and degrees of social stigma, HCV is arguably the first infectious disease to emerge since HIV that can place exceptional burden on those affected due to issues of stigma and discrimination connected to the idea of the marginalised and “deviant body”. The deviant body, be it due to the connections produced between gay, queer or transgender/gender variant identified individuals and HIV or illicit drug users and HCV, can challenge and efface what it is to be “normal” and healthy and bring to surface the social and political aspects of health and illness more saliently (Terry and Urla, 1995). Community-based organisations that address specific illnesses contend with these issues to various degrees. This is particularly so for HCV CBOs as discrimination, meaninglessness and alienation are commonly reported among those affected by HCV who engage with the public health system (Treloar and Rhodes, 2009).

Conceptual framework

This research employs a qualitative approach premised on a social constructionist epistemology. Social constructionism informs an ‘expressivist-constructivist theory of language, in which broadly conceived, language is understood as a range of activities’ in which we encourage, claim, express and realise ‘a certain way of being in the world’ (Schwandt, 2000, p. 198). Language conceived through narrative lends itself to an “inter”- or “transdisciplinary” approach to theory building (Somers, 1994) and methodological and analytical frameworks (Sommer, 2004).

Drawing from Fairclough (2007) and Choi and Pak (2006), I consider a transdisciplinary approach to be one that engages in a dialogue with other disciplines: theories and categories as sources for theoretical and methodological development. Accordingly, the theoretical model presented in Chapter Four drew from various disciplines; community psychology, social theory, political science, social anthropology and organisational and civil society studies. Within this model the conceptual underpinnings of narrative identity provide bridges between conceptual levels, categories and associated disciplines.

Narrative approaches feature in many studies examining health, illness and HCV and are seen as tools that are sensitive and respectful to the voices of research participants (Riessman, 1994, 2002; Enosh & Buchbinder, 2002; Hurwitz et. al., 2004; Sutton & Treloar, 2007). For example, Arthur Frank's (1995) illness narrative typology of restitution, chaos and quest have been commonly used to analyse and interpret illness experience. In using a narrative identity framework, this research rejects positivist or essentialist notions of identity and in favouring a social constructionist perspective, views identities as providing a subjective sense of self-continuity to a person as they symbolically integrate various events, public narratives, social positions and other contexts of lived experience in the plot of the story they tell about their self or life (Ricoeur, 1988; Somers, 1994; Ezzy, 1998).

Research aim and question

The aim of this thesis is to investigate the notion of distinct expertise of a HCV CBO and the factors that help express and constrain this distinct expertise. To achieve this, a narrative communitas model of CBO distinct expertise is developed, which provides a framework to examine how a HCV CBO could realise, or could be realising, the specific elements and processes that underlie its distinct expertise. As the narrative communitas model presented implicates the mediation of HCV identities among HCV CBO members, this thesis also examines whether and in what ways does a HCV CBO facilitates the construction of responsive HCV identities among those who engage with it. The term "responsive" refers to understandings of HCV that point to identity formations which diverge from the dominant HCV identities produced and circulated within the public (health) sector – identities that are considerate of an individual's personal and social particularities and difference.

Research objectives

To address the research aim and question the following research objectives will be met.

1. Illustrate HCV narratives that construct *dominant HCV identities* and the kinds of assumptions these identities imply about HCV and individuals affected by HCV.
2. Illustrate HCV narratives that construct *alternative HCV identities* and the kinds of assumptions these identities imply about HCV and individuals affected by HCV.
3. Illustrate the realisation and negotiation of dominant (objective 1) and alternative (objective 2) HCV narratives and identities by a HCV CBO and its members.

Research objectives will be met by drawing from the analysis of:

(i) The kinds of narratives a HCV CBO produces and circulates to its members and the wider public and how these narratives construct and encourage particular identities in relation to HCV and the HCV CBO;

(ii) The stories of members who are affected by HCV in terms of what they value (or not) about their engagement with HNSW in relation to negotiating HCV in their lives and how these stories construct and enact ontological narratives that point to HCV informed identities;

(iii) What key informants from a HCV CBO see as the benefits and challenges of a HCV CBO and;

(iv) Social research/literature on HCV, health and illness, public health and civil society, among other literature.

Meeting research objective three is particularly important as the *realisation* and *negotiation* of dominant and alternative HCV narratives and identities within a HCV CBO and its members provide an opportunity to assess and articulate upon the expression and containment of prospective narrative communitas elements within a HCV CBO.

Field site

Given the significant impacts deriving from the emergence of HCV in the last two decades, it is somewhat perplexing that HCV CBOs have received so little scholarly attention. With the exception of Carey (2007), who in her thesis examined how understandings of community and spatiality inform complexities and challenges among those who work at a HCV CBO in South Australia, there is no research of which I am currently aware that has specifically examined HCV CBOs.

One interpretation of such a paucity is that scholarship directed at community-based organisations might be subject to similar academic and disciplinary resistance as historically experienced by qualitative research – a resistance that implicates power and political discourse within maintaining a 'distinction between hard science and soft scholarship' (Denzin & Lincoln, 2000, p. 7-8). On another level, the civil society sector tends to offer poorer salary packages, job security and, promotional opportunities compared to other sectors (Onyx & Maclean, 1996), highlighting that the sector is under-resourced and undervalued within the wider culture of capitalism. Elements within these interpretations, among others, are likely to contribute to a lack of scholarly interest in CBOs.

Regardless of these potential social forces and realities, the agreement among political authorities, academics and HCV CBO practitioners that HCV CBOs are important in addressing the HCV epidemic suggests that research into HCV CBOs is needed to generate knowledge that can assist them in effectively addressing any challenges they face in meeting their organisational aims and goals.

Hepatitis New South Wales

Recognising a need to address the confusion and ignorance faced by HCV-affected people, Ms Audrey Lamb and Dr Geoffrey Farrell of Westmead Hospital created the first Australian HCV support group in 1991. An information telephone service was established, but, lacking an office space, calls were directed to Lamb's residential home, 'where she stayed up all hours answering calls providing information' (Hepatitis Australia, 2011, para.8). With the help of Dr Farrell and others, Lamb wrote the first HCV information booklet in Australia and became instrumental in developing similar groups and HCV resources nationally. Lamb

> coordinated a national network of volunteers from the affected communities and organised a 4,000 signature petition to NSW Health Minister, delivered in May 1993, calling for the NSW Government to initiate an anti-discrimination focused community awareness campaign and for resourcing and support for the tens of thousands of people in NSW already living with hepatitis C (Hepatitis Australia, 2011, para.7).

Such a national coordination effort saw the group become incorporated in early 1993 as the 'Australian Hepatitis C Support Group'. However, symptomatic of the state's slow response to HCV (as reported earlier), applications for federal funding 'were rejected and the group could not function on a national level' (HNSW, 2011, p.1). With a successful application for funding from the NSW Health Department in 1994 the Australian Hepatitis C Support was reformed into the Hepatitis C Council of NSW, 'moving to its first offices at Belmore St, Surry Hills in Sydney' before relocating later that year 'to more suitable office accommodation in Crown St, Surry Hills' (HNSW, 2001, p. 1). In 2012 HNSW relocated once more to the fourth level of a building in Elizabeth St. Surry Hills, sharing tenancy in the building with the AIDS Council of NSW, SWOP (Sex Workers Outreach Project) and other groups.

State funding helped expand its roles to include advocacy work, public awareness campaigns and health care worker and peer-based education strategies. From the late 1990s onwards, the Hepatitis C Council of NSW was increasingly invited to participate in state-led initiatives looking at HCV including: the NSW Hepatitis Advisory Committee (later the Ministerial Advisory Committee on Hepatitis); the NSW

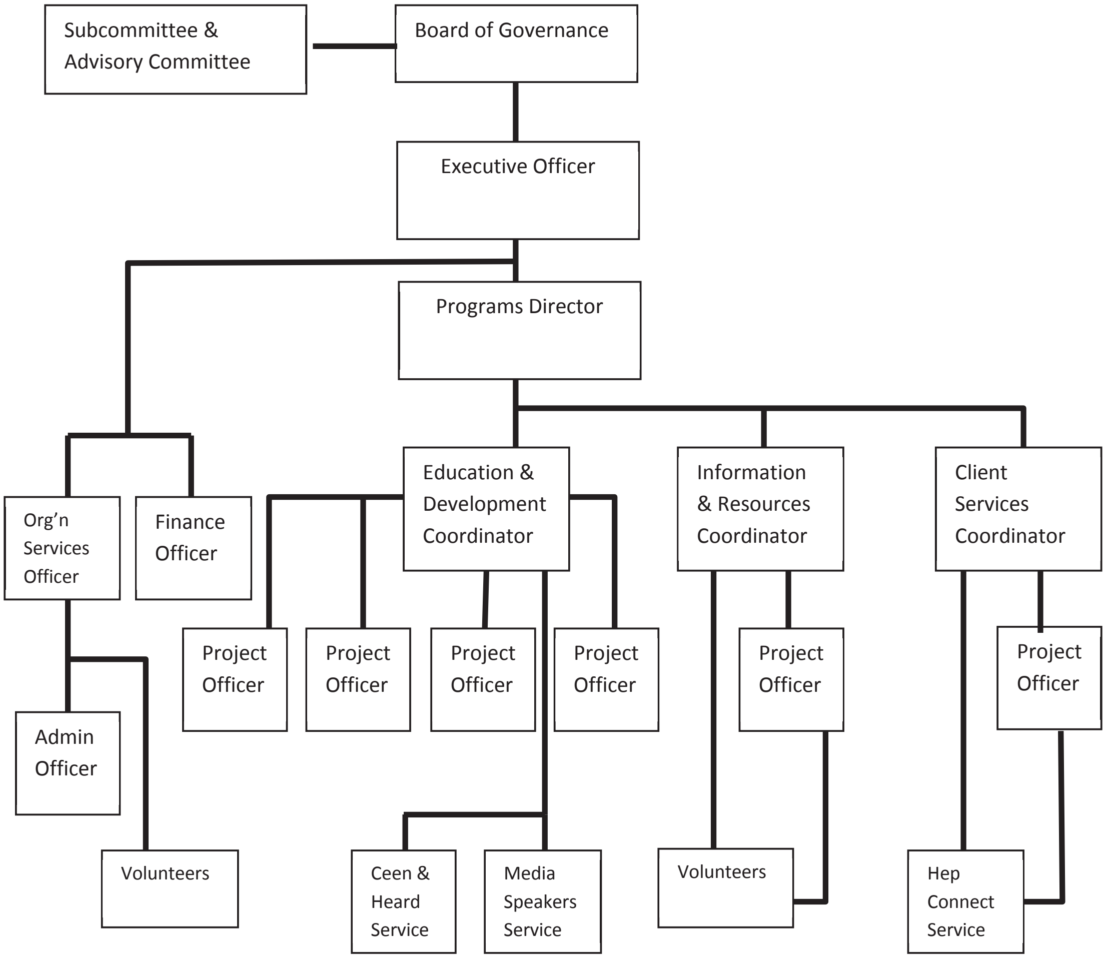
Parliament's Standing Committee on Social Issues Inquiry into hepatitis C - *Hepatitis C: The Neglected Epidemic*; National Hepatitis C Strategy-related committees; the world's first inquiry into hep C-related discrimination by the NSW Anti-Discrimination Board; a range of NSW Area Health Services' strategic planning committees; and various Federal government consultation groups (HNSW, 2011, p. 1-2).

During the course of this research the Hepatitis C Council of NSW changed its name to Hepatitis New South Wales reflecting its expansive agenda to provide support surrounding hepatitis B as well as HCV. Initially only for those living with HCV, HNSW now caters for a variety of people including: people living with HCV and hepatitis B, their partners, family and friends; healthcare and welfare professionals; peer organisations; state departments; private sector employers and the NSW public (HNSW, 2009). HNSW initiated and provided a range of resources, services and activities during the 2000s including:

- The *Hep C Review* publication: the HNSW major regular publication to members and the wider public.
- *Hepatitis Helpline*.
- World's first mass media HCV public awareness campaign.
- *Heplink*, HCV-related health care worker network.
- *C-een & Heard* positive speakers service: training people to tell their story about their experience of living with HCV to health professionals and community groups.
- *Prisons Hepatitis Helpline* (in collaboration with the NSW Department of Corrective Services).
- *HepCAustralasia* internet forum.
- Media Speakers Service: training people living with HCV to tell of their experiences to media.
- *Hep Connect*: a peer support program enabling people to speak by phone with trained volunteers who have experiences of living with HCV.

Despite the expansion of HNSW, Loveday and Wallace (2001) report that many Australian HCV CBOs have retained their original features such as the participation of those affected by HCV and the use of volunteers. On its website HNSW describes itself as 'an independent, charitable, community-based membership organisation offering assistance to people affected by the hepatitis C virus' (HNSW, 2009, para.1). The organisational structure of HNSW at the time data was collected for this thesis is presented in Figure 4 and illustrates the expansion of HNSW since its early days as a support group (HNSW, 2011).

Figure 4. Organisational structure of HNSW



METHODS

Data selection

Data selected are informed by the three research objectives and come from four different sources: HNSW texts; interviews with HCV-affected participants who engage with HNSW; interviews with HNSW key informants; and the social research/literature on HCV, health and illness, and public health, among other topics (see Table 1). Selection of specific data types from these sources, or the "data corpus", was informed by considerations provided by Fairclough (1992) who poses two important data related questions: *What is accessible?* and *Does the corpus reflect diversity of practice*?

Table 1. Types of data collected according to research objectives

Research objective	Types of data collected to meet research objective		
	Secondary data	Interviews	Wider literature
HCV narratives that construct *dominant HCV identities* and the kinds of assumptions these identities imply about individuals affected by HCV.	HNSW texts	HNSW member interviews HNSW key informant interviews	Social research/literature
HCV narratives that construct *alternative HCV identities* and the kinds of assumptions these identities imply about individuals affected by HCV.	HNSW texts	HNSW member interviews HNSW key informant interviews	Social research/literature
The *realisation* and *negotiation* of these dominant and alternative HCV narratives and identities HCV narratives by HNSW and its members.	HNSW texts	HNSW member interviews HNSW key informant interviews	Social research/literature

Accessibility to HNSW data was limited. Initially, two types of data collection were proposed: non-participant observation of HNSW board meetings and HNSW texts that are most commonly accessed by those HCV-affected. The intention to observe board meetings was for background briefing purposes in order to familiarise myself with the organisation and executive decision-making procedures. Upon developing my research proposal I was invited to a HNSW board meeting to present it to board members. A decision over my non-participant observation of board meetings was to be given after the board had seen my research proposal. The board denied this request. Concerns were expressed over board level discussions becoming public via the media. Such concerns were informed in part by sensitivities regarding researching issues of vector mode of transmission that were seen to relate to HNSWs position regarding compensation for those who through Red Cross blood products became HCV positive. My initial research proposal noted investigations regarding distinctions among research participants on the basis of their vector modes of HCV transmission. Given this restriction HNSW data collected were limited to HNSW secondary texts and interviews with key staff.

(1) Hepatitis NSW secondary text - Hep C Review

Hepatitis NSW secondary text derives from the publication the *Hep C Review*. Whether the *Hep C Review* represents an acceptable level of diversity of practice within HNSW warrants further deliberation. Accessing a "diversity of practice" relating to HNSW data means accessing data that reflects a diversity of HNSW narratives and consequent HCV identity constructions. However, HNSW practices targeting those HCV-affected extend beyond the publication of the *Hep C Review* to include the *C-een and Heard* program, the *Hepatitis Helpline* and *Hep C Factsheets*, to name but a few.

However, it was envisioned that the narratives and identities attached to these practices are likely to find expression and be circulated within the *Hep C Review* in the form of the reporting and promoting of HNSW services and programs to its readers. Therefore it was assessed that the *Hep C Review* represents an acceptable level of diversity of (narrative) practice relating to HCV and HCV-related help.

The *Hep C Review* and the HNSW website represent the most common means of engagement with the HNSW that people are likely to undertake (S. Loveday, personal communication, October 11, 2005). First published in 1992, the *Hep C Review* is produced quarterly in partnership with an editorial committee who advise on key issues. It is posted to HNSW members and made available at various NSW health and alcohol and drug agencies, among other locations. The *Hep C Review* 'is a 64 page publication aimed at a general readership of people who have an interest in hep C (and B)' and contains a mix of hepatitis news (i.e. medical/scientific and "human interest"), editorial comment, reader's stories, and information promoting "health messages" about hep C (and B) (HNSW, 2011d, p. 1). Aims and target populations of the *Hep C Review*, as stated in the *Call for Expressions of Interest, Hep Review magazine project evaluation* document (HNSW, 2011d, p. 1) include:

Aims:

- provide support and information to people affected by hep C (and B)
- encourage positive behaviour changes among readership
- build the capacity of the sector to deliver effective outcomes to the affected communities and to prevent transmission of hep C (and B)
- raise awareness of hep C (and B)

- advocate on behalf of affected communities and provide leadership in the hep C (and B) sectors
- build a strong, representative organisation as a foundation for our work.

Target populations:

- People living with hep C (or B) across NSW
- People in NSW whose work involves hep C (or B)
- Health policy decision makers in NSW whose work touches on hep C (or B)
- People in the general community who have an interest in viral hepatitis.

This diversity of content, aims and target populations suggests that the *Hep C Review* as data corpus reflects a diversity of HNSW practice in terms of providing multiple public narratives concerning HCV and HNSW.

Procedure

Selected texts come from the *Hep C Review* editions 51 to 54 published over a 12 month period (December 2005 to December 2006) prior to conducting participant interviews. These editions were selected on the basis of an "exposure likelihood" assumption. In examining any relations between participant narrative identities and HNSW narratives in the *Hep C Review*, it is assumed that participants would have been exposed to an edition, or editions, of the *Hep C Review* during a period not too distant from the time they are interviewed. If HNSW narratives, among other non-HNSW narratives, are taken up within participants' stories, then it is reasonable to presume that such narratives derive from *Hep C Review* editions falling within the 12 month period preceding the participant interview. Further, as it was not possible to determine when participants became affected by HCV before they were interviewed, consideration of participants who had recently been diagnosed with, or affected by, HCV meant they were unlikely to have begun engaging with HNSW until recently before the interview. The possibility of participants mediating HNSW narratives from more than 12 months prior to the interview is acknowledged. However, due to practical considerations, the period of 12 months of editions was selected.

Within the selected editions "editor's intro", "council keyholes", "reader stories" and other news and feature stories (e.g. *C-een and Heard* speaker program and other volunteer opportunities) that represent HNSWs' diversity of practice to some degree were selected. Consequently, these texts are different from one another, and are written by different authors – a fact acknowledged within their analyses. Such diverse texts are considered to make up HNSW narratives.

<u>Editor's intro</u>: An editorial is a writing style used to express an opinion or reaction to topical news, events or an issue of concern. Editorials usually aim to inform, promote, praise and/or entertain the reader or do all of these things. Sometimes the editorial can be used to persuade readers to think or act in a particular way (Rystrom 1999). An editorial piece can be presented with a personal narrative style and act as a representative voice of the publication in which it features. Accordingly, it can be said that the ""editor's intro"", signed by "Paul Harvey, Editor", represents a HNSW "voice" that may inform, promote and raise to readers particular and potential areas of interest, which said readers may find helpful in relation to HCV issues. As such the "editor's intro" flags the kinds of knowledge and experiences available to readers. In addition, as it would be exhausting and impractical to analyse all text found in the *Hep C Review*,

including the “editor’s intro” in the data corpus in a sense, provides a “snap shot” of the contents of the *Hep C Review* in terms of the kinds of knowledge and opportunities present.

Council keyholes: A “council keyhole” column is introduced in editions 53 and 53 and sits beside the “editor’s intro”. It presents to members/readers descriptions of the kinds of work that the HNSW undertakes. Authorship of this new column is not assigned to an individual author but to “HNSW”. It is reported in edition 53 that the introduction of this column stems from a recent online *HepCAustralasia* discussion ‘about the place and role of Hep C Councils’ which as stated in the editorial, ‘has emphasised the importance of updating readers about’ the work HCCNSW does (*Hep C Review*, edition 53, p. 2). Thus this communicates directly to members the voice or narratives of the HNSW.

Reader stories: Given the importance of experiential knowledge in ideas of a CBO and mutual-help contexts (Schubert & Borkman, 1991, Rappaport, 1994; Carey, 2006), reader stories were selected as they provide an opportunity to examine how experiential knowledge is present in the *Hep C Review* and thus promoted by the HNSW. Reader stories represent elements of mutual help in that they represent a way readers can receive help from the HNSW by learning from, and potentially relating to, others affected by HCV; additionally they represent a way readers can give help to others by way of contributing stories to the publication which may be of benefit to others.

(2) Hepatitis NSW member data – Member Interviews

Hepatitis NSW member data comes from semi-structured interviews. Hepatitis NSW facilitated access to their members through research recruitment notifications published in three editions of the *Hep C Review*. Perhaps after the HNSW website (where the *Hep C Review* can also be accessed), the *Hep C Review*, which has a print circulation of 20 000 per edition, represents perhaps the most accessible HNSW resource for those affected by HCV; thus using it to access research participants potentially allows access to a diversity of individuals affected by HCV. As such, this represents the best available method for gaining access to participants and to be best assured that the corpus reflects diversity of practice in terms of recruiting participants with a diversity of HCV lived experience.

Procedure

Recruitment of participants:

Phase 1 - An initial recruitment notice was placed in the *Hep C Review* (edition 54) in September 2006 inviting members who were 'living with hepatitis C' and eighteen years of age or older to participate in an interview (see Appendix A). The aim of the study was briefly stated along with information about what was expected from participants. My contact telephone number and email address was provided if members required further information and/or elected to participate. When potential participants called to participate, their age and HNSW membership status was confirmed in order to fulfil study inclusion requirements. Eight people responded to the advertisement, however, three people were not subscribed HNSW members, and one person called on behalf of their partner. This left four people for study inclusion. These four participants were interviewed during November and December 2006 at a place of their preference.

During the interviews one participant reported that they had “cleared” HCV so did not consider themselves HCV positive. When participants originally called to participate in the study, only age and HNSW membership status was determined as I made the assumption that only people currently living with a HCV would respond to the recruitment notice (as the notice stated I was looking for people living with HCV). While in retrospect this stage of the recruitment process should have prevented this type of assumption, it also gave an indication of how HCV may impact people’s lives. In the case of the participant who had “cleared” HCV, HCV still informed their life in some ways. One expression of this was volunteering to participate in this study.

It was proposed earlier in the research planning stage that if difficulties were to arise in terms of poor recruitment rates due to study inclusion criteria, then the criteria would be reconsidered. Consequently, the study inclusion criterion was revised from participants being HCV positive to participants living with the impacts of HCV. This meant that participants who had been through antiviral treatment and had “cleared” HCV could participate. Consequently, the new criteria for study inclusion became: participants must be 18 years of age or older, HNSW members and living with the impacts of HCV.

Phase 2 - The participant recruitment notice was re-published in the *Hep C Review* (edition 57) for the second time in June 2007. Only three people called to participate, all fulfilling the revised study inclusion criteria. One of these participants had cleared HCV through antiviral treatment.

Phase 3 - As only eight participants had been recruited, the recruitment notice was published a third and final time in September 2007 (*Hep C Review,* edition 58) which saw four people respond. All four were included in the study. As such eleven HNSW members in total were interviewed. Demographics and reported HCV and treatment status, as well as mode of transmission of participants are presented in Table 2. Aliases are used to de-identify participants.

Table 2. Participant demographics, reported HCV and treatment status and mode of hepatitis C transmission

Participant	Demographics	Reported HCV and treatment status and mode of transmission
Aaron	Male 40-50 years Anglo-Australian Receiving a disability pension	HCV + Advised he cannot have treatment IDU
Andrew	Male 40-50 years Anglo-Australian Drug and alcohol counsellor HNSW volunteer	'Cleared" HCV through treatment IDU
Bree	Female 30-40 years Sri-Lankan-Australian Artist Receiving government benefits.	HCV+ Undergoing treatment IDU
Chris	Male 40-50 years Anglo-Australian Receiving a disability pension	HCV+ Not ready for treatment IDU
Gina	Female 70-80 years Anglo-Australian Retiree	HCV + Advised she cannot have treatment Blood products
Jacki	Female 30-40 years Anglo-Australian Receiving government benefits	HCV+ Undergoing treatment IDU
Jen	Female 30-40 years Greek-Australian	HCV+ Not ready for treatment IDU

	Receiving government benefits	
Josie	Female 40-50 years Anglo-Australian Tertiary educated Artist Health professional	HCV+ Not ready for treatment IDU
Kate	Female 50-60 years Anglo-Australian Home duties Hospital volunteer	HCV + Had treatment, now waiting for 'better' treatments to be developed Blood products
Nick	Male 30-40 years Anglo-Australian Tertiary educated Receiving government benefits HNSW volunteer,	'Cleared" HCV through treatment IDU
Pete	Male 40-50 years Anglo-Australian Receiving government benefits	HCV+ Not ready for treatment IDU

<u>The Interview</u>: Semi-structured interviews were conducted with recruited participants. Semi-structured interviews allow departure from and modification of interview questions. Additional related questions and non-directive probing were employed when any relevant or unidentified themes emerged (Pawar, 2004). Items for the semi-structured interviews follow. Questions were informed by the studies theoretical model and literature on HCV, illness experience and community-based organisations. The first section of the interview looked at how participants responded to a HCV-positive diagnosis and in what ways they sought to understand what a diagnosis would mean to their lives.

1. How did you first react or feel when you were diagnosed? What were your thoughts or thinking here? (prompt) Why?
2. After being diagnosed what ways did you try to work out what it meant for you to have hepatitis C? Did these ways help? How or why not do you think?
3. If you disclosed, how did your family/friends/partner(s) react?

4. How is your relationship with doctor/GP/other healthcare provider?
5. What benefits, if any, do you get or value (or don't value) from you doctor etc.?

The second section of the interview is intended to investigate what public narratives may have been drawn upon in order to construct the meaning of HCV in participants' lives.

6. What did you know of hepatitis C before you were diagnosed? Where did you get this perspective/knowledge from?
7. When you were first diagnosed, how do you think most of the general public think or would react about people affected by hepatitis C? Why?

The final section of the interview looked at participant involvement with HNSW and their thoughts today living with the impacts of HCV.

8. Why did you join, or become a member of HNSW?
9. What benefits, if any, do you get or value (or don't value) from your engagement of HNSW and/or its resources/services?
10. Why do you value (or do not value) these benefits do you think?
11. What are your current thoughts and feelings surrounding your HCV status? Any changes from when first diagnosed? How do you account for these changes (if any)?
12. How is your relationship with doctor/GP/other healthcare provider these days?
13. Many people mobilise(d) around HIV to address certain needs and rights. Could you see that happening around HCV? Why is that?

(3) Hepatitis NSW key informant interviews

To examine the contemporary climate in which HNSW finds itself, by way of the realisation and negotiation of any dominant and alternative HCV narratives produced by HNSW, interviews were conducted with HNSW key informants. Specifically, key informant views on HNSW distinct expertise and challenges were investigated, with a focus on relations between HNSW and their state funder. Key informant interviews are also used where relevant to discuss the place of dominant or alternative HCV identities within HNSW.

Procedure

Three key informants were selected for interview by the CEO of HNSW. Key informants were senior staff members of HNSW who had been working for HNSW for 18 months, six years and 20 years respectively. Key informants were interviewed at the office of HNSW. While informants may be identifiable due to the disclosure of their senior positions at HNSW, aliases are used in an effort to de-identify them. Informants were given extracts presented in this thesis in order to obtain their consent for the use of any information they provided for this study. Interview questions were again informed by the theoretical model presented in Chapter Four, literature on CSO and state relations as well as insights gained through conducting this research. The interview items include:

1. What do you think makes Hepatitis NSW unique in terms of the kinds of help HNSW provide to people affected by hepatitis C?
2. I wanted to ask about the *Hep C Review* and the kinds of knowledge and help it provides to people. HNSW has a policy concerning 'resource development and production' that does not apply to the *Hep C Review*. Can you tell me what informs or guides the production of the *Hep C Review*?
3. The *Hep C Review* presents various kinds of information, expertise and experiences regarding helping address the impacts of HCV. How does HNSW decide on the proportion or mix of such various kinds of HCV-related help and knowledge?
4. Some have noted the *Hep C Review* contains a lot of medical and scientific information and articles, compared to say the experiences, stories and views of those affected by HCV. Why do you think this is the perception among some?

5. Does HNSW provide spaces or opportunities where members or those affected by HCV can express alternative views to public health and medical experts regarding HCV?

6. How does HNSW manage or negotiate (or balance) public health and medical expert views with views of others who may contest such expert views?

7. Can you describe the Funding and Performance Agreement HNSW has had with NSW Health over the last 5 years?

8. What was HNSWs' experience in negotiating Performance Indicators under such agreement(s)?

9. Over the past 5 years, how did/does HNSW measure its effectiveness in terms of such performance indicators?

10. Can you describe the advantages and challenges of HNSW's PFA over the last 5 years?

11. Has HNSW been involved with any local AHSs or other local government agencies regarding such developing and delivering HCV-related programs or services? If so, can you describe what this was and the advantages and challenges of such a collaboration?

The most recent review of the NSW Health NGO Program saw HNSW partner up with other NGOs in the HIV, HCV and STI sector in making a submission to the review. The *NSW Health NGO Program Review Recommendations Report* published in July 2011 listed four recommendations.

I. Reduce red tape and improve NSW Health NGO Program Administration
II. Strengthen accountabilities & improve the performance monitoring & service evaluation of the NSW Health NGO Program
III. Strengthen partnerships and revise governance arrangements of the NSW Health NGO Program
IV. Implement the NGO Review recommendation

12. Can you tell me thoughts on the four recommendations and how they might impact the HNSW in terms of providing advantages and challenges to HNSW?

13. How was HNSW's experience working collaboratively with other NGOs in providing a submission to NSW Health NGO Program Review? And what reasons were behind such collaboration?
14. Has HNSW experienced or perceived any difficulties or pressures concerning any advocacy role it has undertaken?

(4) Literature

In explicating different kinds of HCV narrative identities I also draw from social science literature that critically engages with public health, civil society and public sectors, HCV, health/illness identities and related concepts. This allows me to strengthen the analysis and articulation of HCV identities presented.

Procedure

Literature was collected by conducting meta-searches in social science related databases with the keywords hepatitis C, public health, health identities or subjectivities, illness identities or subjectivities, medicalisation, among others.

Analysis

The different kinds of data collected require different kinds of analysis (see Table 3). Text-based analyses was chosen for HNSW text and HNSW member interviews due to the close link between object of inquiry and mode of inquiry (Riessman, 1994, 2002; Somers, 1994). However, because the these two kinds of data differ in terms of text production and audience (HNSW text being secondary text and member interviews being talk-in-interaction), and analysis of both types of data is used to articulate a similar phenomenon, in terms of the construction of HCV identities, I use different kinds of analysis which share some common theoretical and methodological ground. These different kinds of analysis are Fairclough's Critical Discourse Analysis (CDA) (1992, 2007) and Bamberg's Positioning Analysis (PA) (1997, 2004).

Both have been utilised to capture one of the central and overarching themes commonly found in research on identity and language; constructions of subject positions or identities (De Fina et al., 2006). While CDA has more traditionally been applied to secondary texts, PA provides more consideration to interview contexts in terms of "talk-in-interaction". PA considers both CDA and Communication Analysis (CA) elements and in doing so 'avoids the overly top-down trappings of CDA or the overly myopic technicalities of CA' (Korobov, 2001, p. 8). This is 'because it derives from neither orientation' (Korobov, 2001, p. 8). Instead, Positioning Analysis derives from Bamberg's (1997)

> concept of narrative positioning - a concept that results from a critical functionalist extension of what the concept narrative means, particularly as it involves the tension between 1) narrating as a way to simply refer to a world of past events (ordered in time) and 2) narrating as a way to establish perspective or point-of-view (Korobov, 2001, p. 8).

Within PA, the concept of "indexicality" or how positioning is linked to interpretive repertoires (which I will return to shortly), connects CDA and CA, as Korobov outlines:

> Through an empirical focus on socio-linguistic variability for understanding *how* subject positions are indexed by the use of linguistic forms—which in turn index interpretive repertoires— Bamberg is able to use positioning analysis to connect CA and CDA. By trading on the multifunctionality of construction types, positioning analysis affords a multi-level analysis (between CA and CDA) of how language forms convey what the talk is about and how it is structured (CA), with an

> ideological and rhetorical discussion of how it works (conveying blame, taking responsibility, satirizing, demeaning, etc.) to establish various subject positions within a moral order. Said differently, positioning analysis analyzes the different linguistic forms used to position oneself within different topics, during different interactive situations, and for the management of certain ideological tensions in the overall establishment of "who I am" or "who I am becoming" (2001, p. 11, author's italics).

Thematic analysis is used to examine Hepatitis NSW key informant interview data. This type of analysis was chosen in order to identify themes that emerged from informants talk about HNSW distinct expertise and HNSW relations with the state and HCV "community". Relationships or disjunctions in themes across interviews are examined.

Table 3. Types of analysis according to data type

Data type	Analysis
HNSW text	Critical Discourse Analysis
HNSW member interviews	Positioning Analysis
HNSW key informant interviews	Thematic Analysis

Hepatitis NSW text analysis

In analysing HNSW text, a central interest is identifying narratives and the discourse practices and linguistic devices from which they draw that encourage particular HCV-related identities. Literature investigating the multiplicity of organisational narratives and discourses suggests that Critical Discourse Analysis (CDA) can be a worthwhile analytical tool (Grant & Iedema, 2005). Fairclough's (1992, 2007) approach to CDA stems from the work of those who have recognised the social importance of language to personal, social and cultural change (e.g. Antonio Gramsci;

Michel Foucault, Jürgen Habermas). Fairclough's (1992, 2007) CDA situates discourse and narrative within the contexts of mediating social relations and identities. This speaks to Somers (1992, 1994) theoretical thinking on narrative and identity. However, Fairclough's focus on social change and discourse more saliently unwraps the role ideology can have on concepts of self and social identities.

People approach discourse analysis in different ways depending on the focus of the research. In recognising this, Fairclough (1992) proposes not a blue print but some general guide-lines for researchers to take into account when conducting discourse analysis. These guide-lines outline the main elements and considerations that were taken into account when looking at HNSW text. The three (overlapping) dimensions considered in discourse analysis are:

1. Analysis of discourse practices
2. Analysis of text
3. Analysis of social practice in constructing identities

Step 1: Analysis of discourse practices

This stage of analysis explores the heterogeneity of discourse types within the narratives of HCV and related help. Firstly, discourse practices that help produce narratives surrounding particular HCV-related topics are identified and interpreted (and where relevant, a content analysis of topics is conducted first). The concept of intertextuality is an important component here and highlights the way narrative is built from texts from the past ("the insertion of history"). This building or production of narrative can transform past text and restructure discourse to generate new ones. Alternatively, it may also simply reproduce past discourse (and/or associated conventions and practices). The centrality of indexicality informs much of CDA, as well as CA and PA (as I will return to shortly).

Step 2: Analysis of text

Interpretations of discourse practices were substantiated by the analysis of text. Specifically argumentation, theme and modality were examined. These elements act as "traces" of discourse practice and "cues" for text interpreters (both myself as analyst and general text interpreters). Ultimately, the traces and cues that are reported here are derived from the way description and interpretations of texts merge together. Fairclough (1992, 2007) asserts that description and interpretation are not mutually exclusive concepts as often assumed. As analysts we are interpreting all the time when we select what to describe and by its subsequent description. What one analyses is always shaped and informed by one's relationship to discourse, social and political processes.

Step 3: Analysis of social practice in constituting identities

The final stage of analysis attempts to integrate the first two stages in a way that sheds light on the research question. That is, how do HNSW text and narratives as a social practice position those affected by HCV who engage with the HNSW? This final stage of analysis also highlights the interpretive role the researcher brings to the research project.

Member interview analysis

Respecting participant's experiences and reflecting them more richly and accurately are important issues in conducting research (Viney & Bousfield, 1991).

Analyses dealing with talk/text/narratives, as opposed to quantitative data, can be useful when researching topics that may harbour certain sensitivities among participants.

Member interviews were transcribed for analysis. No system of transcription can record all aspects of speech. Often the research aim will shape the focus of transcription; that is, it will affect what sort of features are recorded and in what detail (Fairclough, 1992). To remain close to all aspects of the research process I personally transcribed participant interviews. This enabled me to familiarise myself with the more precise details of talk-in-interaction I may have lost by "out sourcing" transcription. A fuller immersion in the data was achieved this way. Transcribed interviews were then analysed using PA.

PA stems from Bamberg and colleagues efforts at a conceptual and analytical integration of CA and CDA elements. The epistemological underpinnings of PA, conceives of talk-in-interaction as central to constructing and enacting identities (Bamberg, 1997, 2004; Bamberg & Georgakopoulou, 2005). As such this suits the investigation of participant interview text rather than HNSW text which is secondary text and not talk-in-interaction. PA provides a structure to analytically navigate between the two ends of micro and macro-analysis thus helping to account for the personal and social links in identity formations (Bamberg & Georgakopoulou, 2005). This can be achieved by focusing on "indexicality" and "intertextuality".

Indexicality connects utterances or text via linguistic signs to aspects of the wider social context (Defina et al., 2006; Bamberg, 2004; Bamberg & Georgakopoulou, 2005). An example is the use of pronouns which has been recognized by linguists, psychologists and anthropologists as an important way of anchoring speech to certain contexts. Pronouns can signal time and space arrangements within a narrative and reference relations with others (individuals, groups or institutions), which can result in the speakers construction of subject-positions/identities and elicit relations towards systems of knowledge and meaning, or discourse (Defina et al., 2006). In sum, indexicality point to acts of reference connecting the performance of speech to social and discursive understandings.

The concept of intertextuality is import in a critical enquiry sense and refers to, in a PA context, how utterances, talk and text are populated by parts of past utterances, talk and text. History (society and culture) becomes inserted into talk and text, and talk and text constitute history (Kristeva, 1986). While intertextuality points to how talk/text can transform prior talk/text and thus (re)create new texts, the scope and practice of this ability is not limitless. As such elements of previous narratives and discourses may feature in text/talk.

The guidelines I employ for PA are drawn from Bamberg (2004) and Bamberg and Georgakopoulou (2005) who propose, similar to Fairclough's (1992) guidelines, three levels in which the speaker participates in positioning to constitute identity enactment:

1. How characters are positioned within the story
2. How the speaker positions him/herself/their self (and is positioned) within the interactive situation
3. How the speaker positions a sense or idea of the self with regard to public narratives and the discourses that help constitute such narratives

Level one: How characters are positioned within the story

Level one explores self-reflection, self-criticism and agency perspectives. Bamberg suggests that we begin our analysis by paying close attention to the ways in which the represented world of characters and event sequences are drawn up (1997, p.

224). Here we attempt to spot descriptions and evaluations of the characters and analyse the time and space coordinates in the way that these relate to social categories and their action potential. Conversation units are important here, or more precisely how conversation units are positioned in relation to each other within the event being reported. Conversation units deal with the content of narrative and include; characters, topics, events and verbs. Focus is placed on how characters are constructed, for example “I” "she", "he", "they", "us", "them", "Rachel", "the Doctor", "my partner" etc. As such characters are linguistically marked in terms of either who or what is in control of the event or others, or who is a passive victim of outside forces, luck or fate.

Level two: How the speaker positions him/herself

This level looks at how the speaker positions him/herself to, or is positioned by, the audience (actual or imagined). Specifically, this level looks at what the conversation units are doing (interactively within the interview). Said differently, it examines how the content and structure of narrative have interactive effects. Discursive modalities are important here in indexing how characters and topics or events (from level 1 analysis) create subject positions in relation to social acts that are ideologically meaningful. Some social acts that may be of interest here include expressing that something/someone is unfair, attributing blame, making a denial, and justifying an action. This stage of the analysis, with its focus on discourse modes, introduces more of a CDA perspective.

Level three: How the speaker positions a sense or idea of the self with regard to public narratives

The final level addresses how the speaker positions him/herself in answering the question (specifically or generally) "who am I?" or "how do I want to be understood or seen?" This stage builds on the first two stages of analysis by looking at how both content and structure within the narrative point to identity work. Particularly, what (discursively derived) interpretive repertoires that relate to claims and enactment of identities are deployed by the narrator. Any ideological tensions produced here are highlighted and discussed.

PA can capture efforts at "resignification" by examining elements of participant's ontological narratives, which position themselves as "creditable" or not. It can identify elements of public narratives that have been drawn on within these ontological narratives be they derived from dominant, alternative or counter-narratives. Positioning Analysis captures multiple positions people construct thus conveying the idea of multiple identities. These may be informed by negotiations of past, present and desired future positions. Some of the positions may be more individualistically based and attempt to deal with morality concerns or may index notions of affinity (e.g. commonality elements) with others who live with the impacts of HCV. The latter may also indicate aspects of a shared or community narrative.

Hepatitis NSW key informant interview analysis

Thematic analysis was conducted on key informant interviews. Thematic analysis is a qualitative analytic method for 'identifying, analysing and reporting themes within data. It minimally organises and describes the data set in detail. However, frequently it goes further than this, and interprets various aspects of the research topic' (Braun & Clarke, 2006, p.79). Identified themes capture 'something important about the data in relation to the research question and [represent] some level of patterned response or meaning within the data set (Braun & Clarke, 2006, p.82). Themes may be identified at the 'manifest level', directly observable in the interview data, or at the 'latent level', underlying a phenomenon (Boyatzis, 1998, p. 4).

I draw from Braun and Clarke's (2006) six-phase guide to conducting thematic analysis which includes:

1. *Becoming familiar with the data*: This involves the researcher familiarizing themselves with the data in terms of transcribing data, reading and re-reading the data, and recording any initial ideas and thoughts.

2. *Generating initial codes*: This encompasses coding any interesting features or elements within the data. This is done systematically for the entire data set, collating data relevant to each code.

3. *Searching and generating themes*: This phase involves collating codes from phase 2 into potential or "candidate" themes.

4. *Reviewing themes*: Reviewing themes during this phase means that some candidate themes may not be considered "really themes" (i.e. 'there is not enough data to support them, or the data are too diverse), while others might collapse into each other' (i.e. 'two or three candidate themes might form one theme) while other themes might need to be broken down into separate themes' (Braun & Clarke, 2006, p. 91).

5. *Defining and naming themes*: This involves refining the specifics of each theme that can speak to the research question/aim.

6. *Writing up findings:* This entails selecting clear and compelling extract examples which relate to the research question/aim

Organising and presenting findings

The following chapters articulate and discuss findings and are organised and presented according research objective (refer to Table 4). Chapter Six firstly presents dominant HCV identity templates supported by the literature and HNSW text, HNSW key informant and member interview extracts. Chapter Seven does the same but for alternative HCV identities. In Chapter Eight I look to interpret dominant and alternative HCV identities presented in Chapters Six and Seven according to HNSWs' position between state and community in terms of negotiating or "balancing" types of HCV knowledge and narratives within HNSW textual spaces. This negotiation or "balance" is then discussed in terms of the expression and containment of narrative communitas elements within HNSW.

Table 4. Organising and presenting findings according to research objectives

Research objective	Chapter presenting & discussing findings
HCV narratives that construct *dominant HCV identities* and the kinds of assumptions these identities imply about individuals affected by HCV.	Chapter 6 - Dominant HCV identities
HCV narratives that construct *alternative HCV identities* and the kinds of assumptions these identities imply about individuals affected by HCV.	Chapter 7- Alternative HCV identities
The realisation and negotiation of these dominant and alternative HCV narratives by HNSW and its members.	Chapter 8 - Betwixt and in-between state and community: Expression and containment of prospective narrative communitas

Ethics approval was gained from the university's Human Research Ethics Committee.

Part Three

Findings and conclusion

CHAPTER SIX

DOMINANT HEPATITIS C IDENTITIES

CHAPTER INTRODUCTION

This chapter reports on dominant HCV identities. Drawing from the literature I look at the medicalisation of the self in relation to HCV before presenting the emergence of the HCV health consumer. I locate where these identities are produced illustrating that although derived and produced within public (health) sector settings, they also correspond to narrative identities produced in the HNSW publication the *Hep C Review* and HNSW member interviews. I present how HCV health consumer identities, although providing productive benefit for many by way of a sense of empowered agency, also instantiate a responsibilised, autonomous, (neo)liberal idea of the self that tends to overlook the social and cultural aspects of the individual and HCV. Consequently, I contend that health consumer identities reflect and facilitate "representational silences" among those affected by HCV. This leads me to consider how dominant identities encourage HCV lived experience as a liminal illness identity.

Public sector as hepatitis C relational setting

In NSW understanding and finding help in relation to HCV is predominantly mediated within relational settings located within the public sector. Local Health

Districts are ‘responsible for the planning, coordination and provision of local HCV health promotion, treatment, care and support services’ (AIDB, 2008, p. 24). Sites that provide these types of help largely include; hospitals, specialist clinics, sexual health services, allied health and mental health services, and alcohol and other drug (AoD) services. Aside from HCV CBOs like HNSW, other sites that provide HCV help include complementary and alternative medicine and private GP clinics, and are typically located in the business sector. However, these non-public sector sites occupy a much smaller position in overall HCV relational settings. By and large HCV help is located in the public sector. People engaging in the public sector commonly do so within the contexts of HCV diagnosis, liver function monitoring, anti-viral treatment, and health promotion strategies. Such contexts rely on medical and public health models and agents to develop and administer HCV understandings and help.

Hepatitis C is typically diagnosed by a medical practitioner (Hopwood & Treloar, 2003; Gifford, O’Brien, Bammer, Banwell, & Stoove 2003). Others are diagnosed within AoD, sexual health service settings and publicly or privately run detention centres (McNally, Temple-Smith, & Pitts 2004). AoD and sexual health services are generally staffed by medical practitioners, counsellors, nurse practitioners/educators, and some have gastroenterologists as joint appointments with hospitals. Anti-viral treatment is ‘typically administered by a multidisciplinary team of highly skilled clinicians and allied health professionals in a hospital liver clinic’ (Hopwood et al., 2006, p. 1). The period between diagnosis and commencing treatment (or not) can result in many subject to routine medical tests (Krug, 1995; Harris, 2005).

Health promotion materials and services (e.g. needle and syringe exchange programs) represent another common mode of HCV help engagement. Health promotion officers are typically attached to Local Health District sites (AIDB, 2008) and health promotion materials circulate in various public sector settings (Hopwood et al., 2006). Support groups are also provided at some public sector sites. A handful of NSW public hospital-based liver clinics provide support groups (AIDB, 2008). Typically, support groups are run by clinic nurses and social workers with the primary aim of treatment compliance (Hopwood et al., 2006; AIDB, 2008).

All these public sector sites, modalities and agents mediate particular public narratives about HCV. These narratives are constituted by particular discourses and linguistic devices that encourage and construct particular HCV understandings and identities.

Public sector narratives of hepatitis C

Public narratives of HCV in the public sector are typically about prevention, risk, detection (testing, diagnosis), measurement (monitoring), treatment, and “management” and predominantly draw upon biomedical and public health discourses (Krug, 1995; Carrier et al., 2005). This reflects historical relations between biomedicine and public health in Australia.

Lewis (2003), in discussing the historical trajectories of Public Health in Australia states that alongside ideological tenets directed at national efficiency and Indigenous race degeneration, public health discourses have been historically dominated by biomedical discourse. Biomedical discourse constitutes a system of knowledge that incorporates technological and scientific innovations through which the body, health, illness and disease are conceived, understood and intervened upon (Clarke et al., 2003).

Critics characterise biomedical discourse as overly mechanistic, viewing the body as an object to be repaired, resulting in a mind/body dualism and physical reductionism that overlook the psychological and socio-political constitution of individuals, health and illness (see Clarke et al., 2003). Consequently, the patient comes to be viewed simply as an illness or disease carrier while 'experts and practitioners monopolise medical knowledge leaving patients alienated from decision-making capacity' (Bologh, 2008, p. 200).

However, Lewis (2003) reports that from 1950 to 2003 public health in Australia has been approaching a crossroads. This crossroads is informed on the one hand by the emerging New Public Health (NPH) movement with its expansive agenda to introduce a human rights and social justice framework to ideas of health, and on the other hand by the continued importance and hegemony of science and medicine with its focus on treatment, risk factors, prevention and control/order (Lewis, 2003). This idea of a crossroads is embedded within wider cultural shifts in health consciousness and the rise of New Public Management (NPM), neoliberal and consumer discourses as I detail shortly.

The dominant HCV identities I present have, in a sense, emerged within this "embedded crossroad". In simple terms, such identities reflect ideas concerning the docile "medicalised patient" being remade as the involved and empowered "health consumer". Importantly in terms of this thesis, these identities can also be found beyond the public sector, and can be seen to be (re)produced and circulated by HNSW as will be illustrated.

MEDICALISATION OF HEPATITIS C IDENTITIES

Biomedical and scientific discourses inform dominant understandings of illness and disease and their impact on people's lives (Hopwood & Southgate, 2003) and identities (Whyte, 2009). A foundational concept in the literature that represents this relationship is "medicalisation". The concept of medicalisation emerged in the social sciences in the late 1960s focusing on 'the creation (or construction) of new medical categories with the subsequent expansion of medical jurisdiction' (Conrad, 2005, p. 3). Analysis was commonly and critically directed at the power and authority of the medical profession to medicalise experiences and social problems which had traditionally escaped the medical lens such as, hyperactivity, menopause, child abuse (Conrad, 2005) and homosexuality (Ballard & Elston, 2005). Chronic illness, infertility, ageing, traumatic experiences such as rape and torture (Whyte, 2009), and homelessness (Lyon-Callo, 2004) are further examples of the experiences that became subject to the expansion of medicalisation. As the discussion of medicalization expanded so too did its configuration towards a more complex and less critical stance as I will illustrate in regards to the health consumer.

References to medicalization are featured in the HCV literature (e.g. Krug, 1995; Hepworth & Krug, 1999; Hopwood & Southgate, 2003; Fraser, 2010, 2011). Hopwood and Southgate in reviewing international and Australian literature on living with HCV state: 'The dominance of medical discourses and a relative lack of alternative 'voices' around living with hepatitis C have material effects on the way people with the infection experience life' (2003, p. 259). Fraser and Seear (2011) also examine ideas of medicalisation in a HCV context by looking at the medicalisation of addiction, IDUs and the reiteration of HCV within medical practices and understandings that align with HIV discourse.

Krug in examining the social construction of HCV states: ‘Following the establishing of the person as a carrier and a patient, the subsequent medicalizations translate the processes of techne tou biou [craft/art of living] from an introspection and examination to an extroverted process of rewriting one’s self in terms of the medical discourse’ (1995, p. 316). Similarly, Hepworth and Krug (in extract 1 below) report those diagnosed with HCV tend to “fall prey” to medicalising discourses (psychological discourses included) ‘while looking for ways to ‘make sense of the new conditions in which the self exists’ (1999, p. 244).

Extract 1. Social research/literature and HCV medicalisation

> For a period of time following diagnosis, when people’s selves are placed in flux through the need to redefine and make sense of the new conditions in which the self exists, we may say that people are in a state of transition. The old selves have been disrupted and new constellations of meaning, derived from new stories and new relationships, require time to stabilize. During this transitional period, there is a great risk that the medical and psychological discourses may predominate, leading to the medicalization and pathologizing of selves.
>
> (Hepworth & Krug, 1999, p. 244)

Components of the *Hep C Review* correspond to narratives and constructions of a HCV-medicalised self. Many sections feature abridged articles from mainstream media and medical journal and news websites. Extracts 2, 3 and 4 (below) are abridged articles from the *Journal of Hepatology* (extracts 2 & 3) and the *Sydney Morning Herald* newspaper (extract 4). As such dominant narratives and discourses are largely unmediated in terms of their reproduction. While there are various markers that index and encourage a medicalised self, three interrelated markers can be seen in these extracts, markers I refer to as *names, nominalization* and *numbers*. By names I mean codified medical terms. Examples presented below that come from the *Hep C Review* are, “steatosis”, “fibrosis” (extract 2), “bioavailability” (extract 3) and, “autopsy” (extract 4). This type of language can be closely related to nominalisation.

Nominalization is a term used in CDA to describe words that become general purpose verbs and in doing so can act as an ideological function by way of deleting subject agency and context thus overlooking social, cultural and political elements that intercede and constitute who and what is being (re)presented (Billig, 2008). Medical, scientific and technical writers tend to isolate activities such as “experimenting”, “measuring” and “analysing” as abstract conceptual units creating passive constructions that reflect the traditional concern with ideas of objectivity, removing the individual and their complexities from the picture. This produces characteristic constructions surrounding for example, “testing”, “measuring” and “treating”. Markers of nominalisations in the below abstracts 2, 3 and 4 include: “nonresponse (to treatment)” (extract 2) and “(basing) doses” (extract 3), “(poor) response” (extract 4). Individuals in such extracts are reduced to medical interventions and/or responses to interventions.

Finally, by “numbers” I refer to measurement, a central practice of medical science. Examples include: “threshold body mass index” (extract 3); “low sustained viral response rates” (extract 3) and “hundreds of deceased addicts” (extract 4).

Extract 2. HNSW text: ‘nonresponse to treatment’.

> *OBESITY TIED TO HCV TREATMENT FAILURE*
>
> In HCV patients, they add, “obesity is associated with inflammation, insulin resistance, steatosis, progression of fibrosis, and nonresponse to treatment with interferon or peginterferon alpha and ribavirin.” Moreover, patients with both hepatitis C and obesity-related nonalcoholic fatty liver disease are at greater risk for more advanced liver disease…
>
> (HNSW, 2006d, *Hep C Review*, Edition 54, p. 47)

Extract 3. HNSW text: ‘low sustained viral response rates observed in obese patients infected’.

> Other approaches to enhance combination drug therapy may include longer duration of treatment and higher doses to counteract the decreased bioavailability. In addition, rather than basing doses on weight, use of peginterferon, for example, could be founded on a threshold body mass index. “Treatment strategies that focus on improving underlying metabolic factors associated with poor response to combination therapy,” conclude the researchers, are “more likely to overcome the low sustained viral response rates observed in obese patients infected with HCV”.
>
> (HNSW, 2006d, *Hep C Review*, Edition 54, p. 47)

Extract 4. HNSW text: “autopsy results of hundreds of deceased addicts”.

> *LIVER DISEASE MAY KILL HEROIN USERS*
>
> Australia - Chronic liver disease may be to blame for the increased number of older, more experienced heroin users dying from overdose in Australia, a new study has found. More than 350 heroin users die in Australia each year - typically older, unemployed men killed by an overdose. Puzzled as to why the most experienced are the most likely to die, researchers at the National Drug and Alcohol Research Centre (NDARC) carried out Australia's first study analysing the autopsy results of hundreds of deceased addicts.
>
> (HNSW, 2006d, *Hep C Review*, Edition 54, p. 10)

Names, nominalisation and numbers feature frequently in *Hep C Review* texts and, as the extracts above illustrate, render the identities of people living with HCV according to biological, metabolic processes and responses, exhibiting absent agency – subject to disease and medical interventions. Hepatitis NSW staff acknowledge the (re)production and place medicalised understandings of HCV have in the *Hep C Review*. For example, Carl who oversees the production of the *Hep C Review*, refers to the "inescapable" presence of medical language in the newsletter (in extract 5 below). The reason behind this claim understandably helps explain in part the dominance of biomedical discourse and practices in relation to understanding and living with HCV.

Extract 5. HNSW key informant interview: 'by our nature we can't escape it'.

Paul: Some I interviewed noted the *Hep C Review* contains a lot of medical and scientific information and articles, compared to say the experiences, stories and views of those affected by HCV. Why do you think this is the perception among some?

Carl: We've got particular sections of the magazine such as research updates which I think for most would be difficult to read. We carry research abstracts and although we cut or abridge out, I wouldn't call it jargon, but language like p scores and stuff like that. It's still a difficult read..…..I think that magazine has to carry a certain level of medical and clinical type articles because hep c is a medical condition – it's managed and treated by clinicians it's diagnosed by doctors – by our nature we can't escape that. I guess the balance is to try and have a magazine where the articles are amended down so that people aren't put off too much by dry, over clinical articles. I say that to the exception of the research updates we make no excuses, no apologies there is not much you can do with them yea.

(Carl, HNSW key informant interview)

Carl’s term “balance” indexes an acknowledgment that despite the medical nature of HCV, HNSW has a role in mediating such medicalised understandings in order to make such knowledge accessible and relevant. HNSW key informant Alice states that ‘the magazine is quite hefty’ in terms of the degree of expert medical information. When asked the same question as Carl in extract 5, key informant Michael, in extract 6, also talks about the issue of accessibility of, and the HNSW being responsive to, such language.

Extract 6. HNSW informant interview: HCV medicalisation

> I think part of that is to respond for us to look at the language used in the review. Quite clearly some of the articles I mean even I look at them and say we need to look at the language and tone that down as well.
>
> (Michael, HNSW key informant interview)

In turning to how types of medicalisation correspond to people’s lived experiences and identities, Krug (1995) notes a “fetishizing” of medical information within the project of understanding the self in relation to HCV. Again, numbers or measurement act as central markers of this HCV medicalised identity (see extract 7).

Extract 7. Social research/literature and HCV medicalisation

> One physician reported that a patient under his care insisted on monthly liver function tests (ALT tests). For some persons, these liver function test scores are a major marker of the disease process. Some people may compare scores to those of other HCV-positive persons, whereas others may discuss their conditions in terms of these numbers. Even though these numbers do not correlate closely with damage, they are for people an “objective” scale that tells them how sick they are even if they are not sick. One respondent said, “I was feeling tired all the time, I only found out later that my ALTs were three times normal”
>
> (Krug, 1995, p. 305)

Having an embodied affinity with medical measurements like ALTs can extend, according to Krug, to a 'general fascination with medical scientific information regarding HCV in general' (1995, p. 305). The author qualifies this medicalisation of the self through a common interest and concern among those affected by HCV that 'the condition *is* serious and is not recognized as such by those in power' (i.e., the state, most physicians, scientists, etc.) (1995, p. 305, italics my own).

Although HNSW members interviewed used medical terms and measurements to express their experience of and relationship to HCV and other people, such members presented a more complex relationship to medical discourse – a presentation that speaks to a more contemporary expression of medicalisation.

Contemporary expression of medicalisation

Over the last 20 years notions of medicalisation have moved from a traditional critical stance to more complex and productive expressions. Medical sociologists have increasingly questioned the idea of the empty and 'docile lay populace, in thrall to expansionist medicine' (Ballard & Elston, 2005, p. 229). The activities of social movements, CBOs and interest groups, as well as changing cultural dynamics, have challenged and complicated earlier conceptions and expressions of medicalisation. Increasing concerns over health risks, challenges to expert authority and scientific knowledge (Ballard & Elstyon, 2005), the growth of medical consumerism (Conrad, 2005) and rising personalised responsibility of health practices (Crawford, 1980, 2006), have led to individuals, groups and social movements becoming increasingly conceived of as consumers of healthcare 'seen as playing an active role in bringing about *or* resisting medicalisation' (Ballard & Elston, 2005, p. 229, italics my own). One example of the medicalisation concerns “alcoholism” (Conrad, 2005) and patterns of illicit drug use (Shiner, 2003). Gay and lesbian activism leading to the declassification of homosexuality as an illness provides example of resisting medicalisation (Conrad, 1992).

Medicalisation and demedicalisation can carry various processes and effects to different people in different contexts. This idea has led medical sociologists to examine ‘particular contexts and protagonist characteristics that are conducive (or not) to medicalisation and of the different forms that medicalisation might take, rather than assuming it to be the inexorable outcome of medical dominance’ (Ballard & Elston, 2005, p. 234). Lewis (1993) for example, states that the medicalisation of child birth and menopause, rather than being a matter of medical conspiracy, reflected a process of political claim-making by many women who wanted better care but who also at times resisted this medicalisation. Additionally, medicalisation in the face of conditions that impart biomedical uncertainty (e.g. cancer and HIV) is reported to empower individuals, connect them with others experiencing the same condition and help with political claim-making (Sulik, 2009; Marelich, Roberts, Murphy, & Callari, 2002; Borkman & Munn-Giddings, 2008).

The above literature, cultural events and forces have coincided with shifts within public health sector models (towards NPH) indicated by a moving away from more socialised health perspectives to more individualistic ones. Although these shifts are variously complex, what they share are efforts to instantiate lay experience in shaping healthcare practices and identities. A dominant contemporary expression of HCV medicalisation within these shifts is the health consumer identity.

HEPATITIS C HEALTH CONSUMER IDENTITIES

The public (health) sector (and beyond) has enthusiastically embraced and (re)produced ideas of the health consumer. An important premise behind this embrace lies within NPH efforts to represent and utilise lay experiences and agency in health care and to respond to earlier paternalistic practices of medicine. The rise of the concept of the health consumer within both NPH and wider society is linked to the growth of consumerism and healthism in Western societies.

Consumerism

Consumerism as a term attracts positive and negative evaluations. Positively, it can suggest personal empowerment connected to the idea of a 'social order that allows autonomous enterprising individuals to pursue their own goals without unnecessary constraint by or dependency on the state' (Shaw, 2003, p. 33). Negatively, it spells the death of the active and collectively orientated citizen in public affairs, replaced by 'the calculative gratification of individual material wants' (Shaw, 2003, p. 33). Consumerism is a concept with multiple definitions, meanings and usages. Notwithstanding this plurality, consumerism can be categorised under three broad approaches: as a cultural way of life, as social movement and as political ideology (Shaw & Aldridge, 2003; Shaw, 2003).

Consumerism as a cultural way of life is presented as a logic for self-transformation through the consumption of products and services. Consumerism as a set of social movements typically refers to user and pressure groups and organisations that assess goods and services, recommend best products, services and practices, and campaign for the rights of consumers (Shaw & Aldridge, 2003). Consumerism as political ideology is seen to legitimise economic and social reform (McDonald & Marston, 2005; Gough et al., 2006), social institutions and socio-cultural change in the broad pursuit of strengthening the performance of late capitalism (Shaw, 2003; Gough et al., 2006; Hopwood, 2007).

Elements within these approaches overlap. For example, all share a preoccupation with consumption to solve all life's problems (Shaw & Aldridge, 2003). Self-transformation is configured to "business" and market models. Assumptions about the consumer subject comfortably align to neoliberal and NPH ideas of the individual in terms of privileging notions of individualism, personal responsibility and autonomous, rational decision making. Smart (2003) asserts that the exemplary subject of neoliberalism is a calculating, rational and self-interested individual. Similarly, Lupton states: 'In all usages of the notion of the patient *qua* consumer, regardless of political orientation, the dominant and privileged representation is that of the dispassionate, thinking, calculating, autonomous subject' (1997, p. 374). Similarly, these subject positions align to popular psychological (e.g. the "health belief model") and sociological (e.g. the "reflexive actor") theories that underpin health promotional strategies (see Lupton, 1997) central to NPH models. These common presumptions can be explored further by examining the concept of "healthism".

Healthism

Healthism refers to 'a particular way of viewing the health problem' (Crawford, 1980, p. 365) in which the health consumer emerges. The concept of healthism has been drawn upon by many scholars, most notably political economist Robert Crawford

(1980), medical scholar Petr Skrabanek (1994) and social theorist Nickolas Rose (1999). Respective differences among these authors relate to the roles movements, medicine, the state and self-governance play in conceptions of healthism. Arguably, healthism is related to all three perspectives but to different degrees according to time and place. What all three perspectives share is their focus on neoliberal tenets of individualism and market led solutions to achieve health and wellbeing.

Healthism in essence ‘construes individual behaviour, attitudes and emotions as the factors which need attention for the realisation of health, and solutions to preventing illness are seen to lie in the realm of individual choice’ (Hopwood, 2007, p. 1). Making correct choices concerning particular behaviours, attitudes, information, products and services; or lifestyle generally, is paramount. Elements of lifestyle must be heavily subjected to self-regulated and disciplinary mechanisms. “Good” health becomes achievable ‘via an individual's determination to resist the temptations of culture, overcome institutional and environmental constraints, resist disease agents and refuse to succumb to lazy or poor personal habits’ (Hopwood, 2007, p. 2). Responsibility is fundamentally personalised; ‘individual responsibility is seen to be all that anyone ever needs’ (Hopwood, 2007, p. 2; see also Greener, 2008).

Becoming a health consumer is not just about achieving wellbeing, but extends to the expression of certain values such as ‘self-control, self-discipline, self-denial, [and] will power’ (Crawford, 1994, p. 1353). Subsequently, a ‘personal morality converging around the body claims public relevance and consequence, the body forming the site of a spectacular demonstration of personal economy’ (Race, 2005, p. 8). Failure of this responsibility towards personal economy can encourage “victim-blaming”, whereby the experiencing of illness by the individual is seen simply as a result of “bad” individual choices. Illness and any practice seen to lead to illness, ‘becomes an individual moral failing caused by personal deficits’ (Hopwood, 2007, p. 3) such as a weakness of will (Blaxter, 1997). In these scenarios, health (consumerism) becomes not a right but a (moral) duty (Galvin, 2002). Falling short of this duty exposes oneself to blame and felt stigma. Victim blaming and internalised stigma have been recognised among ‘those working with marginalised populations like people with HIV’ and HCV (Hopwood, 2007, p. 3).

Under healthism projects, human activities and by extension humans become ‘divided into approved and disapproved, healthy and unhealthy, prescribed and proscribed, responsible and irresponsible’ (Skrabanek, 1994, p. 15). Individuals or groups whose social and cultural practices ‘are deemed to constitute a personal or community health risk are understood to be a drain on resources and a threat to civilisation, and often both’ (Hopwood, 2007, p. 3). According to Skrabanek at its extreme, healthism can provide ‘justification for racism, segregation, and eugenic control since healthy means patriotic, pure, while unhealthy equals foreign, polluted’ (1994, p. 15).

In these darker contentions, Skrabanek (1994) claims healthism can represent an incipient totalitarianism. However, given that we are witnessing a retraction of the welfare state, or “farewell” state, and the work of healthism is increasingly mediated by relations between business and public sector health sites (Crawford, 1980), mass media and self-regulating individuals (Rose, 1999), perhaps a better way to represent this is in terms of a peculiar kind of liberal conservatism. This conservatism organises around a contradiction inherent in the consumer subject – a contradiction between the health consumer as a free-acting, autonomous subject and a subject who also must exercise responsibility, restraint and discipline (Race, 2009). Hepatitis C health consumers must thus wrestle with a ‘double movement of autonomization and responsibilization’ (Rose, 1999, p. 174). The public sector forms an important locus in fostering this double movement by and large through HCV-related health promotion narratives.

The hepatitis C expert health consumer

Two key HCV “priority action areas”, “steered” by public sector authorities, concern HCV prevention and HCV self-management (as reported in the three National Strategies – CoA, 2000, 2005, 2010). These goals rely in large part on health promotion discourses (see Hardwick, 2008, p. 16-17). Consequently, the responsibilised health consumer becomes incited at both poles of the HCV health promotion spectrum. At one end are harm reduction narratives that aim to *prevent* HCV and are largely presented in terms of reducing the harms or “risks” associated with IDU (Fraser, 2004; Carrier et al., 2005; Hopwood, 2007; Rhodes & Treloar, 2009). At the other end are self-management narratives for those *currently* HCV-positive: promoting HCV treatment, treatment adherence and symptom management, and behavioural, product and service choices for a “healthy lifestyle” (Krug, 1995; Jenner & Scott, 2008).

Both harm reduction and self-management narratives derive from biomedical and NPH discourses. Both assemble the complexities of public health priorities, biomedical science and derivative disciplines into visible and accessible directives to achieve health (Hughes, 1999). A clear overlap exists between assumptions behind the harm-reducing and the self-managing subject: the autonomous, responsible, rational decision-making individual who is primarily decontextualised from socio-political and cultural contexts. Such representations presume that risks can be calculated and avoided and health is maintained by choosing the “correct” services, information, products and practices (Fraser, 2004; Lawn, 2008). The notion of risk found in health promotion narratives is a key element in building health consumer identities; providing the premise for regulating consumption and behaviours deemed to threaten one’s health (Crawford, 2006).

Hopwood reports that the public sector has incited much ‘scientific calculation of risk based on large epidemiological data sets’ to create notions of individuals and communities at risk ‘with a purpose of developing harm reduction interventions that enculture’ responsible ‘self-regulation’ (2007, p. 4). For HCV prevention, IDU communities and individuals become targets for this enculturation (Hopwood, 2007), acting as a ‘moral curb’ for drug consumption practices (Race, 2009). Again, personalising responsibility is a central component of this enculturation (Hopwood, 2007). Fraser’s (2004) study of IDUs and HCV prevention examines harm reduction materials from two NSW drug user service organisations (one public sector-based and the other civil society sector-based). In discussing “personalised responsibility” as a common theme in these materials, Fraser (2004) notes that, in some of these resources personal responsibility is positioned as extending to preventing HCV infection among others (friends and the community) and even preventing the closure of health services that provided needle and syringe exchange programs (as one material source reported low used-syringe return rates may jeopardise the future of the health service organisation).

Hepatitis C self-management research is largely descriptive in terms of looking at the types of, and factors involved in, self-management practices (e.g. Stoller, Webster, Blixen, McCormick, Perzynski, Kanuch, & Dawson, 2009; Hopwood &

Treloar, 2006; Sladden, Hickey, Dunn, & Beard, 1998). Krug discusses how medical and public health discourses encourage the construction of an ideal ethical self in relation to HCV through self-administrative practices directed at "lifestyle" changes that range 'from diet to sexual activities to alcohol consumption' (1995, p. 315). The responsibility for constructing this ethical self, Krug (1995) notes, has shifted from institutions to the individual. Beyond HCV research, other scholars discuss how self-management narratives privilege 'a certain type of subject, an ethical subject who is self-regulated, health conscious, middle class, rational, civilised' (Lupton, 1995, p. 155, see also Hughes, 1999). Participating in a "healthy lifestyle" and "good" consumption practices is paramount for this subject, thus inscribing certain products, services and practices with a moral capital (Hughes, 1999).

Expert health consumer identities (re)produced within Hepatitis NSW

The *Hep C Review* extracts below feature the topics of biomedical research, treatment and self-management as ways of understanding and receiving HCV-related help - topics that commonly populate dominant public sector narratives about helping those deemed ill (Clarke et al., 2003). In the context of the *Hep C Review* these topics are tied to narratives about increasing treatment options, "clearing" the virus and how to "best" live with or manage the impacts of HCV. Accordingly, these topics and narratives draw from biomedical and NPH discourses and work at positioning those HCV-affected as both "expert patients" and "health consumers", or "expert health consumers".

Extract 8. HNSW text: Biomedical research representing new choices

> Within ED52, we also promote the Polymerase Inhibitor Trial. This trial is especially interesting as it tests a brand new medicine that is unrelated to the current interferon-ribavirin combination therapy. It would represent a new treatment option rather than a refinement of an existing medicine.
>
> (HNSW, 2006b, *Hep C Review*, Edition 52, p. 2)

Extract 8 comes from the editorial column, "editor's intro", and is an example of expert knowledge being promoted by HNSW. Similar to the technical language of biomedical discourse, the text depersonalises those affected by HCV; persons affected by HCV are largely absent from the text. The verb "tests" obscures agency among those being tested and thus consigns agency to biomedical agents who "test" this new medicine. However, the agency of those HCV-affected is also present albeit indirectly. The following sentence appropriates this active biomedical agency to those affected by HCV by proposing such biomedical practice "would represent a new treatment option" (HNSW, 2006b, p. 2). This implicitly positions those affected by HCV as treatment choice agents. Categorical modality use ("It would represent…") suggests a strong conviction of truth for this proposal, connecting research to increased consumer choices among those affected by HCV.

Increasing people's awareness of the treatment choices available to them is consistent with ideas that foster a health consumerism ethos (Cockerham, Rutten, & Abel, 1997). However, the text in extract 8 reaches further than this. It also works at positioning the health consumer as a biomedical expert, or expert patient. This is achieved by locating HCV-related help within biomedical "names" or technical knowledge. For example, biomedical terms, such as "polymerase inhibitor trial" and an article explaining such terms (HNSW, 2006b, p, 19) expose readers to biomedical research practices and knowledge. In a sense this encourages a “skilling up” of readers on the discursive terms and practices of biomedicine – fostering a medical expertise and potential empowerment among readers. Cumulatively, this helps position readers and those affected by HCV as “expert health consumers”.

Extract 9. HNSW text: Recurring self-management narratives encourage self-responsibility

> Articles related to self-management are regular inclusions in The *Hep C Review*. Recent articles have included articles about diet and exercise, alcohol, diabetes, complementary therapies, and symptoms and side effects management. An example of self-management promotion within our resources is our recent booklet, *I Have Hep C what might happen to me?* This 2005 resource is targeted at people with hepatitis C and includes a strong emphasis on the importance of teamwork between the individual and her/his health care providers. The resource also highlights the importance of the individual “owning” their health issues and taking a proactive, positive and informed approach to dealing with those issues
>
> (HNSW, 2006c, *Hep C Review*, Edition 53, p. 2).

Extract 9 comes from a “council keyhole” column which sees an editor/editorial team report on that the work HNSW undertakes. This extract establishes the regular presence of self-management narratives in the *Hep C Review*. Self-management narratives are typically narratives of self-transformation through consumer logics (Bandura, 2005; Hughes, 1999). Favoured by NPH pundits, they assemble, as previously reported, the complexities of medical science and derivative disciplines into visible and available directives and choices concerning health (Hughes, 1999). Extract 9 illustrates how HNSW has previously circulated such directives organised around the various topics of diet, exercise, alcohol, diabetes, complementary therapies, and symptoms and side effects management. Despite the idea of self-management narratives toning down expert language (Hughes, 1999), subjects of self-management/health promotion discourses are encouraged to become "experts" of consumption in relation to a myriad of particular products and services. Absent subject agency commonly found in biomedical discourse is reconfigured within health promotion narratives, resulting in the presumption of the active subject.

By referring to a self-management resource (i.e. *I have Hep C what might happen to me?*), the relationship in extract 9 posited between the self and one's health issues is one of ownership; individuals are encouraged towards recognising the importance of "owning" their health issues. Agency is thus imputed in terms of the individual bearing responsibility towards everyday choices in order to effectively manage (regardless of an individual's capacity to "manage") their condition.

Self-management narratives also feature in published reader's stories and thus provide example of dominant narrative identities being reproduced by those affected by HCV who engage with HNSW. Extract 10 demonstrates how HCV experiential knowledge can be informed by drawing from expert knowledge as derived from health promotion/self-management narratives. Dave, who wrote this story as an incarcerated person, illustrates the overwhelming amount of everyday directives to which individuals can become subject.

Extract 10. HNSW text (reader story): Self-management and multiple every day directives

> Smoking has to go too… I drink camomile tea instead of coffee. I have cut back to one 30gr White Ox per week from three packs. Next is a patch to stop smoking. I drink water and eat fruit every day; I brush and floss every time I eat so at least three times a day. I use sensodyne toothpaste that actually works; it has cut out the pain by 80%. Hep C can cause dry mouth, so if you are HCV you need water, water, water. If you cannot cop plain water put a couple of drops of pure lemon juice in it, not cordial. If you are on methadone, give up any sugar; swap over to

> honey, if you must sweeten things. Coke, pepsi, party mix, must all go, they cause dry mouth and the sugar attacks your dentures. Fibree is a must, natural muesli, sultana bran, weetbix with fruit is also necessary, you must go to the toilet everyday, not every third day, as it can cause colon cancer by baking your waste for three days at a time. It sounds like a lot but the health issues associated with your past drug use and methadone treatment is slowly stripping your system defences away and bad health just creeps in like a thief in the night, you don't even notice it
>
> (HNSW, 2006d, *Hep C Review*, Edition 54, p. 32).

The HNSW texts in extracts 8, 9 and 10 are examples of many in the *Hep C Review* that reproduce dominant biomedically derived public narratives, with extract 8 representing those affected by HCV with absent agency. However, at the same time this absent agency is recouped within the same text and elsewhere (e.g. extract 10) in such a way as to align with ideas of self-management, consumerism and healthism, where self-administration regimes are encouraged through knowledge acquisition of the technical aspects of biomedical research and the numerous choices people are encouraged to undertake concerning treatment and achieving "good" health. In this sense, biomedically derived discourses are reworked towards more of a consumer logic, pointing towards expert health consumer identities. Such identities thus correspond to HCV identities privileged in the public sector.

Hepatitis NSW members talk from the interviews conducted also corresponded to health consumer identities. Given the dominance of such identities within the relational settings of the public health sector and HNSW (newsletter), such correspondence is not surprising,

Expert health consumer identities (re)produced by Hepatitis NSW members

Ten of the eleven HNSW members interviewed spoke of joining HNSW to access expert knowledge. For most, stories of joining HNSW pointed towards, to various degrees, identity formations that corresponded with (expert) health consumer identities. This kind of identity formation was more apparent among those who could not, or who had decided not to, undertake medical treatment for HCV, or those who had undertaken treatment but had not "cleared" HCV. These participants also resisted other kinds of stories derived from experiential knowledge found in "reader stories", in a sense which helped "manage" expert health consumer identity formations.

Extracts 11 and 12 illustrate the value Josie and Kate receive from HNSW in relation to the provision of biomedical understandings of HCV. For Kate, receiving this kind of help is the only reason she is a HNSW member. Such dominant narratives of HCV provide Kate and Josie with expert knowledge which informs their decision-making process around if and when to have treatment. Accordingly, this kind of help provides a biomedical "skilling up" directed towards consumer agency around treatment agents and services. This agency appears important in terms of negotiating HCV in one's life.

<u>Extract 11. HNSW member interview: Biomedical research and consumer agency: 'I can take from that what I feel'.</u>

Paul: And what benefits if any do you value from your membership?

Josie: I guess it's just keeping a foot in what's going on. I've chosen not to have treatment but I do read about latest findings um some of the people's stories and just the global information as well and I feel that any new research and stuff they're gonna put in there and you find

> out stuff you know, because I’m living my life and I’m not living my life as like aw, I’ve got hep C and I’m not thinking about it every day you know what I mean. I’m conscious of being healthy. I’m not living being a victim of it and it's just good to have that and you know whenever I get the publication I can read it and I can see what's going on I go, “ok I’m up to date” and I can take from that what I feel.
>
> (Josie, HNSW member interview)

Extract 11 comes from Josie’s story. Josie is a 40 year old Anglo-Australian woman who resides in Melbourne. Josie is professionally employed in the health sector and is also an artist. Josie states she has “chosen not to have treatment”, stating later in the interview that this is because there would be no one to look after her child if she were to undergo treatment. This situation has left Josie waiting for new and improved treatments, in terms of effectiveness and a reduction in treatment side effects, in order to be able to undergo treatment while also taking care of her child. Despite this situation suggesting Josie has little agency surrounding treating HCV biomedically, her talk points to the contrary. Josie states categorically she is “not living being a victim”. This strong claim to truth draws from a consumer agency informed by expert knowledge. Expert knowledge is referenced twice. Once Josie is up to date with the “latest findings” and “any new research” she states, “I can take from that what I feel”. Other parts of the interview not reported here indicate these utterances relate to decisions about undertaking biomedical treatment.

Josie’s presented consumer agency allows her to resist elements of biomedical discourse that presume people universally as patients who must be treated. Such resistance and agency allows Josie to negotiate her particular circumstances, including currently being a sole parent. In the meantime Josie is not living life as a victim and by stating how she is not thinking about HCV every day, Josie is able to “background” her HCV world from her everyday world.

Extract 12. HNSW member interview: Biomedical research and consumer agency:

‘ … because then I can get onto my specialist’.

Paul: The next question I was going to ask was, I know the HNSW have a few different services from the *Hep C Review*, the website, the helpline, peer speakers, training and what not. I was going to ask you what would you think are the major benefit or benefits of being a member of the Hep C Council?

Kate: Probably the news, receiving information, yea because then I can get onto my specialist and say look is there any use in this for me, which I did recently. There was something in it, some guy down in Melbourne who was doing something with white cells and I got in touch with my specialists and said, “look where do you think this is gonna lead?” and he actually knew the bloke. He’d done some research work with him but at the moment it’s not for me, but yea things like that are useful.

Paul: You’ve probably answered my next question I was going to say what parts of the *Hep C Review* would you most read?

Kate: Treatment.

(Kate, HNSW member interview)

A connection between expert knowledge and consumer agency is also present in Kate’s story. Kate is a 58 year old Anglo-Australian woman who is married and a mother of three adult children. Kate resides in a regional city and is a volunteer at a local hospital, as well as undertaking home duties. Kate refers to biomedical research as what she values most from her HNSW engagement and talks about communicating this type of knowledge (e.g. research on white blood cells) to her specialist. As such this provides Kate with knowledge and agency when negotiating help with medical experts.

Like Josie, talk of agency and expert knowledge work towards presenting Kate as an empowered expert health consumer.

Similar to Josie, Kate elsewhere in the interview states that she is waiting for new and improved HCV treatments. Kate's last treatment episode resulted in HCV not being "cleared". Waiting for treatment is likely to relate to Kate's position as someone who welcomes the more dominant narrative of HCV as informed by biomedical research as this type of knowledge may create new treatments, new choices. Waiting for new treatments also speaks to Rose's (2007, p. 148) idea of biological citizens who draw from an 'ethos of hope' as organised through an alliance of various actors: public health experts, biomedical specialists and health-orientated CBOs. Hope in this contest is attached to recent discoveries in biomedicine that can see CBOs engage in 'new forms of political activism, seeking to act directly on the truths and technologies generated by biomedical research' (Rose, p. 148). CBO action here becomes reliant on the 'hopes that the science of the present will bring about cures or treatments in the near future' (Rose, p. 148).

Aaron also presents himself as someone who prefers HCV-related help as informed by dominant public narratives by way of his interest in medical information (presented elsewhere in the interview) but also by resisting other types of HCV narratives.

Extract 13. HNSW member interview: Resisting other HCV narratives : 'We're all serious about hep C cause it's a lethal disease'.

Paul: Right just mostly the *Hep C Review*. Can I ask what is it about the *Hep C Review* particularly that you or could you see anything more that you would like to see in there or ways to improve it?

Aaron: It's tryin to be a comic and tryin to be a reference article and it fails on both mainly I suppose. That's what I find I don't like but other than that it's quite good.

Paul: Um can I ask what do you mean, why does it fail do you think?

Aaron: When it tries to be a comic. It has comical stuff.

Paul: You don't find it comical or it's not comical or you don't think it's appropriate or?

Aaron: Well, no it's not. We're all serious about hep C because it's a lethal disease and it's trying to rationalise the whole thing like what's the word I can't find the word. Just make it easy and they're just trying to, aw, I can't find the word.

(Aaron, HNSW member interview)

Aaron is an Anglo-Australian single male in his early 40s who has been diagnosed with liver cancer. Aaron lives with a friend in an inner-city suburb of Sydney and receives a disability pension. Aaron like Josie has not under gone medical treatment for HCV, as he says his doctor will not allow it due to a diagnosis of bipolar disorder and his level of alcohol consumption. Aaron hopes that one day he can try treatment. In the meantime Aaron is preoccupied by his HCV-related health issues associated with liver cancer.

In extract 13, Aaron talk-indexes a health consumer position though the kinds of knowledge he sees as suitable or not for those affected by HCV. Aaron positions himself and all others HCV-affected as "serious" about HCV. The term "lethal disease" is invoked by Aaron to explain why. Aaron's understandable concern, regarding HCV-related death can be interpreted to impart this serious outlook, informing how Aaron feels one and others must approach HCV. Biomedical discourse aligns readily with this seriousness as presumed in biomedical underpinnings are scientific, objective and clinical perspectives which are commonly expressed through a genre indicative of formality. Other alternative or counter-narratives to biomedical ones which can be informed by other types of knowledge that deal with the social and political aspects of HCV, and which may be constructed using divergent genres and styles (e.g. the informal humour found in the *Hep C Review*), are contested by Aaron as disrespectful of his condition. This resistance to alternative or experiential narratives, also displayed by Kate elsewhere in her interview, helps in part to instantiate a participation in a health consumer-informed identity.

In sum, Kate and Josie's talk corresponds to dominant public narratives on HCV help as informed by biomedical-expert knowledge that are organised around issues of (future) treatment. The value attributed to receiving this type of knowledge brings in ideas of consumer agency and possibly an ethos of hope attached to a future biomedicine "cure" for HCV. As such Kate and Josie's talk points towards "expert health consumer" identity work. Aaron and Kate's (elsewhere in her story) stories featured resistance to narratives that were not informed by expert knowledge. This resistance in a sense works at maintaining a health consumer identity. These HNSW members were three among ten member participants whose talk corresponded to dominant HCV identities constructed in the public sector and HNSW newsletter.

LIMITATIONS OF DOMINANT HEPATITIS C IDENTITIES

A contagious and potentially fatal infection such as HCV, combined with its association with the "deviant body" of the drug user, sharpens the social and political constitution and implications of illness as reflected by the experiences of alienation, discrimination and stigmatization reported among those affected by HCV (Glacken et al., 2001; ADBNSW, 2001; Hopwood & Treloar, 2003; Fraser & Treloar, 2007). Health consumer identities while providing knowledge and productive consumer agency in relation to medical interventions, or waiting for medical interventions, as well as "lifestyle" choices, bypass a focus on these wider implications by encouraging the channelling of 'personal discontent into individualistic and narrow definitions of both the problem and the solution to physical and psychological disease' (Crawford, 1980, p. 365).

Hepatitis C health consumer identities can thus limit creating the conditions to challenge to the social production of HCV that is obscured by the rationalities of biomedicine and its derivatives. This limitation not only reduces the likelihood that stigma, discrimination and treatment adherence can be effectively addressed, but prevents changing the very conditions that have created HCV infection as a problem in the first place (Hopwood, 2007). Most interestingly, this ironically excludes many from becoming "successful" HCV health consumers. A central (neo)liberal-tenant here relates to how the health consumer comes to represent a decontextualised subject who must resourcefully and responsibly negotiate and avoid a web of "risk" factors (Hancock et al., 2000; Smart, 2003). Yet the various social conditions, structural deprivations, and histories of trauma that inform an individual's illness and capacity to excel at avoiding risk factors are overlooked.

In extract 14, Hopwood (2007) suggests that public sector harm reduction may be doing more harm than good, due to its focus on the individual rather than structural causes of illness and disadvantage. The author states that such discourses

Extract 14. Social research/literature: health consumer negating structural determinants

> … continue causing harm to people without accepting responsibility for or acknowledging the social, legal and economic source of those harms. By improving the immediate and worst short–term effects of illicit drug use, medical harm reduction circumvents the need for States to change drug laws or address other systemic impediments to health. Harm reduction as it is currently constituted relieves the institution of prohibition of its responsibility for exacerbating health issues such as viral epidemics and in so doing reduces the incentive to make fundamental changes to policy; harm reduction is non–judgemental of illicit drug users, yes, but equally non–judgemental of the system that creates them.
>
> (Hopwood, 2007, para.12)

Without consideration of these factors, HCV health consumer identities facilitate assumptions of equality and commonality between all individuals. This liberal perspective favours individuals who are equipped with adequate resources to undertake the "correct" health related choices and practices. Crawford states that the responsible (health) consumer reflects and reinforces 'defining features of middle-class culture' (2006, p. 410). Self-management practices have also been noted to be predominantly adopted by white middle-class populations (Rogers, Bower, Kennedy, Gately, Lee, Reeves, Gardner, Richardson, Morris, Jerrim, & Chandler, 2005; Paterson & Hopwood, 2010) and not by those who are likely to need them most: people who are socially and economically disadvantaged (Cockerham et al., 1986; Rogers et al., 2005; Griffiths, Motlib, Azad, Ramsay, Eldridge, Feder, Khanam, Munni, & Garrett, 2005; Wilson & Mayor, 2006). In privileging a middleclass liberal subjectivity, the HCV health consumer fails to consider and represent "others" – others who are marginalised socially and economically disadvantaged, the very social positions occupied by those most susceptible to being infecting with HCV. In this sense the complexities and particularities of these “others” are not represented, but become silenced (Somers, 1994).

(Re)producing hepatitis C as liminal identity

Understandably, HCV literature posits self-management as an important and significant component in providing help to those living with HCV and undergoing HCV anti-viral treatment. However, health promotion narratives arguably need to be more accessible, relevant to and representative of participant’s lived experiences (Koch et al., 2004; Lawn, 2008). Winter et al. (2011) stress the importance of relating HCV health promotion narratives to people’s lived experiences as information emphasising only personal responsibility is not enough when it does not consider the wider context of an individual’s life. Similar sentiments are echoed by Lawn who states that ‘the lack of inclusion of the person’s perspective and understanding is at the heart of the failed implementation’ of many self-management initiatives (2008, p. 23). Furthermore, self-management narratives do not challenge the way medically derived identity logics on the one hand universalise subjects yet at the same time stratify them according to dichotomies (e.g. healthy/unhealthy, “good” choice/”bad” choice, non-IDU/junkie, etc.).

Interestingly, representational silence sits alongside an almost extreme or prolific kind of visibility. With the notion of risk as a key element that builds the health consumer, comes an individual and collective incitement to auditing and profiling the body and its behaviours. Most HNSW members interviewed spoke of their acute awareness of addressing risks in terms of preventing transmission to others and some spoke of their bodies and behaviours coming to be made highly visible by others due to contagion fears. This presents the paradoxical position of people affected by HCV being both marked visible by risk and erased as individuals (Orsini, 2006a). One's health becomes trivialised and downplayed, and individual and social circumstances are erased, while risk and its related responsibilities become amplified (Orsini, 2006a; Treloar & Rhodes, 2009). This paradox speaks to Race's (2009) claims that expert and state power paradoxically comes across as both "saviour" and "punisher", with those affected by HCV caught between these two opposing social forces.

Health consumer identities that reflect and facilitate representational silence and associated paradoxical elements speak to HCV being viewed as a liminal identity. However, the stories of participants who were undergoing anti-viral treatment indexed a liminality not only in terms of occupying in-between categories (e.g. social invisibility/risk-based visibility and illness/wellness) but also a temporal and ontological suspension of identity representing a more intensive expression of liminality. Such liminal intensity is interpreted in terms of a re-centering of biomedical imperatives within the health consumer as a result of entering anti-viral treatment

Regardless of the advantages for some of consumer agency and empowerment within the subject of health consumer, when the individual undertakes anti-viral treatment, the hegemony of biomedicine that resides within the health consumer becomes reinstantiated, and with this the negation of the social becomes magnified. In a sense, this speaks to Lewis' (2003) statement about public health in Australia approaching a crossroads: a crossroads informed on the one hand by the emerging NPH movement with its expansive agenda to introduce a human rights and social justice framework to ideas of health; and on the other hand by the continued importance and hegemony of science and biomedicine. In a sense, social practices and impacts stemming from anti-viral treatment "dissolve" this crossroads for the health consumer, with biomedical imperatives thereby dominating. The biochemical nature of anti-viral treatment as well as the expert agents who dispense and monitor treatment clearly assists in this biomedical reinstantiation. The effects of this for members Bree and Jacqui are expressed through a liminality marked by being in-between opposing categories and a subjective suspension of one's life and identity.

Hepatitis NSW members: Bree and Jacqui

Jacqui is a 38 year old Anglo-Australian woman who lives in an inner-city suburb of Sydney and is currently not in paid employment. Bree is Jacqui's partner. She is approximately 30 years of age and also resides in an inner-city suburb of Sydney. Bree is Sri Lankan-Australian and identifies as an artist who is not currently in paid employment. Both Jacqui and Bree became members of HNSW and began reading the *Hep C Review* when they commenced anti-viral treatment. Bree and Jacqui were both days away from completing treatment when I interviewed them. Similarities between Bree and Jacqui's stories arguably relate to their close relationship with each other.

Extract 15. HNSW member interview: Treatment related liminality: 'I'm feeling quite frozen at the moment'.

Paul:	Would you label yourself or call yourself sick or how do you see yourself at the moment? How do you feel or see yourself?
Jacqui:	No, I wouldn't call myself or label myself a patient or a blah, blah, blah, blah, blah and I'm really trying to be aware of that. I'm trying not to put too much pressure on myself and kinda like post treatment it's like get on with. So I'm feeling quite frozen at the moment, what's wrong with my-self. I'm not labelling myself anything. I have to tell myself that I'm very much involved in the process and

> it’s very easy to just give yourself a really god dam hard time about it man. Even when you’re on treatment all the time you’re fighting with; “am I trying hard enough should I push myself more”. Then you push yourself then I think maybe I should just chill out...in terms of labelling myself I suppose I'm in a form of recovery.
>
> (Jacqui, HNSW member interview)

In the above extract Jacqui’s reference to occupying the liminal position of recovery (being neither a “patient” of being well) is connected to self-berating. Jacqui refers to the adjective ‘hard’ twice in relation to the process and work she has undertaken to ‘get through’ treatment yet questions and berates herself about whether she is working hard enough. Looking at consumerism and the modernisation of health care, Newman & Vidler (2006) state that health consumerism sees the empowered user as constituted as a knowledgeable individual able to participate successfully in treatment processes. Yet the burden of treatment is underreported within ideas of the health consumer – a burden that is indexed by Jacqui ‘fighting’ within herself and ‘giv[ing] [her]self a really …hard time’ about whether she is trying hard enough (‘should I push more’) or not (‘I should just chill’) in the pursuit of successful treatment and health. Jacqui does not see herself as well but does not label herself as sick or as a patient or as ‘anything at the moment’. Jacqui uses the term “recovery” or a type thereof, to articulate the liminal position of being in-between the two opposing categories of being well and being ill.

The utterance ‘feeling quite frozen’ by Jacqui also speaks to being caught in-between and the absence of meaning attached to liminality.

In extract 16 Bree describes experiences of panic attacks, depression and distortions in time in relation to her treatment and, similarly to Jacqui spoke of being ‘frozen’ and the hard work attached to self-management/health consumer practices. Bree’s question surrounding her identity, which treatment seems to have amplified, also causes distress – something to which ideas of a health consumer cannot be responsive.

<u>Extract 16. HNSW member interview: Treatment amplifying liminality: ‘what's me in a new life with a new identity’.</u>

> I had a really scary 6 weeks of depression that I’d never known before and I’m quite prone to depression like lot of people are but that was really full on scary. I was at the stage where I felt that it was forever and when you are in that state you’re kinda a little bit frozen. I’ve been getting really severe panic attacks as well and that's not unusual. It's just hard to differentiate what the treatment in it is, what's me in a new life with a new identity not using drugs any more, and trying very hard not to drink kinda thing, and what's interferon and what the effects of that is? It’s really hard to kinda work out which one’s what and trying to be really conscious and not saying “oh it's all interferon” like I said I’m about to stop and that's scary in itself because, fuck what if I’m still this head case after the interferon and you know remove the cause of the symptom and it's still there.
>
> (Bree, HNSW member interview)

In extract 16, Bree’s categorical questions concerning past, present and future identities and feeling ‘frozen’ and a ‘headcase’ are linked to questions of what role interferon does or does not play in her present and future “new” identity. These questions index a suspended life and liminal identity. It may be stated that as modern societies lack the rituals or rites of passages studied by Turner (1969), other contemporary symbols, agents and discursive systems can be seen to address the liminal individual. Hepatitis C-affected individuals are likely to be initiated within public sector contexts, informed by biomedically derived discursive relations and agents. In this sense, biomedicine and its derivatives, such as health promotion provide ritual and symbolic guidance while doctors and allied health professionals supplant Turner's shamans or priests to instruct the initiate in order to guide or mediate the "polluted" or "sick" towards some hope of renewal and incorporation. This is especially so for individuals undergoing anti-viral treatment – where biomedical hegemony reclaims the subject.

A limited aspect of the reinstated biomedical hegemony within anti-viral treatment relates to its focus on physical symptoms at the expense of socio-political considerations and experiential knowledge attached to HCV treatment. The social and experiential mind become "bracketed off" – dissociated from the body and the clinical gaze (Jackson, 2005). This dissociation problematises the meanings attached to HCV and the experiences attached to its anti-viral treatment, intensifying a sense of liminality. Terms reported in the HCV literature such as "gulf" (Harris, 2005), "dividing life", "splitting the self", "epistemic chasms" (Krug, 1995) and "oscillate between" (Treloar & Rhodes, 2009) conceptually speak to liminality and relate to how, under biomedical hegemonic forces, the self becomes simplified, dichotomised. For Jacqui and Bree, treatment-related experiences emphasise the relevance of these terms. Although not exclusively talking about HCV treatment, in extract 17 Krug expands on this point:

<u>Extract 17. Social research/literature: 'most damaging to the individual when one of the domains lays claim over all of the others'.</u>

> The temporality of people's lives is disrupted. This dividing of life, this splitting of the self in relationship to different domains that have different meanings and make incommensurable demands, is most damaging to the individual when one of the domains lays claim over all of the others, as the medical formation lays claim over the personal

> domain. This is perceived in people's lived experience as the absence of meaning, and the indeterminacy of which almost all HCV-positive persons speak is not a vacuum to be filled with meaning but an effect of the circulation of the discourses of disease and medicalisation that displace the care of self with an illusion of meaning, a simulation. The absent meaning is not a space but the creating of gaps, epistemic chasms, divides of knowledge and of the possibilities of knowing that cannot be bridged.
>
> (Krug, 1995, p.317)

This biomedical approach sits against scholarly contributions illustrating that the boundary between self-consciousness and the body is not oppositional but mutually dependent, and in this mutual dependence, neither can be privileged over the other (see Chalmers, 1995). Without alternative cultural scripts or public narratives to interpret this mutual dependence, HCV meaning and lived experience, particularly during treatment, becomes difficult to express, appearing contradictory, absent, frozen, liminal. In its failure to capture the complexities of individuals and HCV, social settings and practices that encourage health consumer identities reveal themselves as inflexible, 'incapable of engendering the kind of adaptability which seems to be required' in confronting pressing concerns surrounding HCV illness and treatment experience and identity (Arnott, 2001, para.17).

Such inflexibility puts health consumerism and biomedicine's premise of rationality under suspicion. Fraser and Seear, in response to the medical uncertainties of HCV and health consumer assumptions of HCV subjects, argues that 'medicine, public health and their exponents operate beyond the realms of the rational no less than do those they wish to re-make as rational biological citizens' (2011, p. 146). Without considerations to individual and social particularities, such dichotomies provide a fertile ground for the inherently paradoxical HCV health consumer, as Fraser and Seear highlight in extract 18 when asking:

Extract 18. Social research/literature: the HCV health consumer as inherently paradoxical

> What happens … when hepatitis C-positive people who inject drugs are seen both as flawed, addicted subjects for whom rationality and self-management are but fantasies, and as reasoning health consumers in possession of the resources and ambition to choose onerous health measures as an expression of their agency and efficacy?
>
> (Fraser and Seear, 2011, p. 146)

In the context of treatment, perhaps what happens is we see very low rates of treatment uptake, and among those who do manage to enter treatment, we might see hardship attached to striving to be a successful health consumer alongside liminal experiences, as described by Jacqui and Bree.

CONCLUSION

This chapter reported on the medicalisation of the self in relation to HCV before articulating the emergence and predominance of the HCV health consumer. I illustrated that although derived and produced within the public (health) sector, such dominant HCV narrative identities corresponded to those produced in the HNSW texts as well as HNSW member interviews. I presented how such identities, although providing productive benefit for some by way of a sense of empowered consumer agency, instantiate a responsibilised, autonomous, (neo)liberal self that overlooks the social and cultural aspects of the individual and HCV. Consequently, I reported that dominant

HCV identities invite blame to be placed on those who are unable to “successfully” participate or enact such identities. The chapter closed by presenting how HCV health consumer identities represent and facilitate “representational silences” among those affected by HCV that along with paradoxical elements inherent within the health consumer facilitate HCV lived experience, and particularly treatment experience, as a liminal illness identity filled with hardship.

In Chapter Seven I report on alternative HCV identities located outside the public sector. Specifically, I articulate how HNSW text and HNSW members present understandings of HCV that mark incipient alternative HCV identities which are more responsive and relevant to individuals than dominant HCV identities.

CHAPTER SEVEN

ALTERNATIVE HEPATITIS C IDENTITIES

CHAPTER INTRODUCTION

This chapter reports on alternative HCV identities. Alternative identities are conceived of as identities that diverge from the dominant medicalised and health consumer identities presented in the previous chapter. Such identities, as will be illustrated, are socially orientated meaning they are built from understandings of HCV and the self that extend beyond medical models and consumer agency ideas towards understanding HCV and the self as socially constituted. I begin by presenting how ideas to address traditional HCV medicalization concerns point to the idea of "biosociality" referring to when both individual identity and new social formations become informed by shared experience in relation to a biomedical "truth" or diagnosis (Whyte, 2009). I then present how HNSW text and members construct socially orientated identities around the ideas of advocacy, negotiating liminality, and volunteerism.

Addressing medicalisation concerns

In response to medicalisation concerns reported in the previous chapter, Krug (1995) calls for people to become less reliant on medical discourse to produce meaning for those affected by HCV. Krug (1995) proposes that people reposition themselves in relation to the dominant HCV discourses. Factors reported to facilitate repositioning include creating new knowledge, narratives and social formations (Krug, 1995; Hopwood & Southgate, 2006.

Krug (1995) states that this repositioning can more readily occur as people share their HCV lived experiences with others. Hopwood and Southgate state that ‘stories which give back a sense of meaning to life are needed most, more so than medical and scientific information’ (2003, p. 260). Narratives of this sort are widely recognised for those living with chronic illness (Kleinman, 1988; Frank, 1995) and for those in marginalised positions (Somers, 1994; Violi, 1992). Furthermore, narratives informed by others’ experiences, or HCV experiential knowledge, are reported to be of particular benefit by those HCV-affected (Richmond et al., 2010).

Thus new public narratives and new social formations deriving from one’s experience of HCV seem warranted. This corresponds to redressing the narrative or “representational silences” within public sectors of those HCV-affected, as referred to in Chapter Six. Violi (1992) reminds us that the presence or absence of particular public narratives is important in constructing subjectivities and social identities. Pointing out how representational silences keep invisible the very subjectivities of women, Violi calls for representations of women to ‘be socially visible in narratives, in stories or in myths, as they are present for men’ (1992, p. 162). Further, Somers reports that public narratives which express multiple subjectivities can work in deliberate ways to reject ‘the neutrality and appearance of objectivity typically embedded in master’ or dominant narratives (1994, p. 630). The coupling of a medical diagnosis with the call for new experientially based narratives and social formations speaks to the concept of “biosociality”.

Biosociality

Biosociality refers to a collective manifestation of ‘biological citizenship’ described as: ‘citizenship projects that have linked their conception of citizens to beliefs about the biological existence of human beings’ (Rose & Novas, 2005, p. 40). Citizen projects here refer to ‘the way that individuals are categorised by authorities as a certain type of citizen which then affects how they are viewed and treated’ (Rose & Novas, 2005, p. 442). Biosociality sees new “truths” presented by biomedicine helping to construct both individual identity and new social formations based on shared experience. Biological commonality thus is said to produce “community”/collective illness identities. These new social formations and identities may appropriate or challenge dominant health consumer identities with a focus on consumer agency and individual responsibility and can inform collective strategies for financial, pharmacological, and social support, as well as political action towards recognition, rights and social justice for all who experience the impact of particular illnesses (Whyte, 2009).

Biosociality was originally ‘developed to enhance our understanding of the manner in which new genetic truths shape knowledge and identity and form group activism’ but has since ‘fruitfully been drawn upon in attempts to grasp how people relate to and identify themselves with a particular illness, and how they relate to others suffering from the same illness’ (Blystad & Moland, 2009, p. 1-2; see also Gibbon & Novas 2008). For example, biosociality has been applied to the analysis of AIDS activism, Contextualising this, Epstein notes that since the late 1980s, the United States has ‘seen an upsurge of health-activism of a distinctive type: the formation of groups that construct identities around particular disease categories and assert political claims on the basis of those new identities' (1995, p. 428). In more recent years Orsini (2008) and Harris (2010) have looked at biosociality/biological citizenship within a HCV context.

Health-orientated CBOs are centrally implicated in mediating biosociality (Rabinow, 1996). One marker within the *Hep C Review* of HCV biosociality can be seen through advocacy-based narratives that evoke social and political understandings within individual and collective contexts of HCV. Hepatitis NSW texts presented that express social advocacy themes and identities come from different authors: the Hepatitis NSW editorial team ("“editor's intro”") and HNSW members/readers through published "reader stories".

HEPATITIS C SOCIAL ADVOCACY IDENTITIES

Social advocacy identities produced in Hepatitis NSW text

Treatment and drug use were the two advocacy-related topics that reoccurred most often in the "editor's intro" and "reader story" sections of the *Hep C Review*. Hepatitis NSW narratives that address these topics draw from various types of knowledge, discourses and textual devices that work at constructing social advocacy identities. Text containing a description of a concern or problem linked to a call to action corresponds to a social justice discourse of health (Körner & Treloar, 2006) wherein social "advocacy" positions or identities are constituted. Extracts presented below describe a particular concern in relation to treatment and drug use topics and present a call to action to begin addressing such concerns. Concerns raised relate to understandings of health and the individual that reference ideas of social exclusion and stigma thus informing a social orientation to HCV.

Editorial text

Extract 1. HNSW editorial text: Increasing access to the medical treatment

> The news item "Changed biopsy rule will lead to increased treatment availability" highlights our increasing access to gold standard hepatitis C treatment. Perhaps the next step will be offering PBS funded pegylated combination therapy to those people who responded to monotherapy or standard combination therapy but then relapsed.
>
> (HNSW, 2006b, *Hep C Review*, Edition 52, p. 2)

Extract 1 comes from an "editor's intro" article and presents the topic of increasing access to anti-viral treatment with reference to an (abridged) news article. The text reproduces the central proposition of this news article, that a 'changed biopsy rule will lead to increased treatment availability'. A positive evaluation statement ('highlights our…gold standard') implies collective benefit for both readers and author helping to reinforce this statement. Following this, the text; 'Perhaps the next step will be' suggests that more needs to be done in order to increase treatment availability; consequently a call to action is presented, albeit tentatively ("perhaps"). Extract 1 thus indirectly flags access to biomedical treatment as a concern and describes an action that has occurred (i.e. public health policy change) which addresses this problem to a certain extent, noting, however, more action is required.

The discourse modes that inform extract 1 appear to be more complicated than those which inform health consumer identities, as discussed in Chapter Six. Firstly, biomedical and public health discourse modes inform the problem of treatment access exclusion. Terms such as ‘biopsy’, ‘monotherapy’, ‘standard combination therapy’ and ‘relapsed’ index biomedical discourse. ‘Changed biopsy rule’ and ‘PBS [Pharmaceutical Benefits Scheme] funded…’ mark a combination of biomedical and public health discourses. As such, in describing “the problem” these terms help construct and locate those affected by HCV according to their relationship to biomedical and public health practices.

However, elements representative of a social justice discourse of health are also present. Firstly, the proposition in extract 1 represents people affected by HCV in terms of a mode of exclusion (concerning treatment access). Secondly, a social justice discourse of health is present in the argument that more needs to be done in relation to policy changes which ‘will lead to increased treatment availability’; furthermore a call for further action is tentatively presented (‘Perhaps the next step will be offering…’). The mixture of discourse modes (biomedical, public policy and social justice) helps set up the author’s social advocacy identity in relation to treatment access.

Extract 2. HNSW editorial text: Drug law reform and NSW goals.

> We continue to carry articles on drug law reform and NSW gaols. Anyone who saw the recent ‘Four Corners’ episode on NSW Corrections Services would probably agree that things are pretty tough in NSW gaols. Some of us probably think about things that have happened in our past and think “there but the grace of God…” I guess any improvements that we can help promote can’t be a bad thing.
>
> (HNSW, 2005b, *Hep C Review*, Edition 51, p. 2)

Text in extract 2 similarly works at presenting a social advocacy identity. Extract 2 comes from an “editor’s intro” article and presents ‘drug law reform and NSW gaols' as regular themes featured in the *Hep C Review*. The text sets up existing drug laws and gaol conditions as a problem. The term 'reform' suggests action or change is warranted. The presentation of drug law reform introduces legal and political discourse into HCV narratives helping construct a social advocacy identity attached to HCV.

Interestingly, the text building a social advocacy identity works at excluding particular individuals. The utterance: '[*s*]*ome* of us probably think about things that have happened in our past and think there but for the grace of God… I guess any improvements that we can help promote can't be a bad thing' (italics my own) highlights erosion in "proposition affinity". Fairclough (1992) asserts that proposition affinity or presupposition carries importance as it contributes to the ideological constitution of identity. So does negation (i.e. negative sentence) which is employed by the words 'can't be a bad thing' suggesting a premise that past texts have presented that prison reform is a bad thing. Taken together we may ask: what does this narrative identity point to in terms of affinity assumptions with readership/membership – who is included and who is excluded?

This editorial section looks to be speaking to readers/members who have *had* a history of behaviour that is deemed illegal by the state (e.g. injecting drug use and other crime). The prospect or acknowledgement that some or many readers/members are currently engaged in these activities, or are currently in prison, is absent. This suggests such text is directed at those who see these issues as irrelevant, problematic and/or passé to their current circumstances. Modality, constituted through a lack of proposition affinity, along with informal style and politeness are employed reflecting the social and political contentiousness surrounding many or a particular group who are affected by HCV. This creates a social advocacy identity that excludes current IDUs and prisoners.

This corresponds with HNSW key informant Carl's speculation on their readership/membership who states that 'my gut feeling is that the readership is skewed towards people who no longer inject drugs, aren't in prison' (Carl, key informant interview).

This highlights a challenge for HNSW in terms of communicating to its heterogeneous readership/membership. A consequence of this challenge being unmet can be found in extract 3. Extract 3 is from a "reader story" by John, who is currently in prison, question public health policy surrounding the changed biopsy rule for state-subsidised HCV treatment. However, this question is also indirectly posed to the HNSW: 'You didn't actually mention inmates in the article, but I just assumed that it would apply to us in here', thus highlighting exclusionary effects of *Hep C Review* texts. The answer John gives to his own question indicates despair, accompanied by the claim that prisoners are treated as second-class citizens ('Are we classed as Australians too?').

Extract 3. HNSW reader story text: Excluding prisoners:'This is for inmates isn't it?"

> Then I read A*ustralians with hep c gain easier access to treatment* [HNSW, 2006b, *Hep C Review*, Edition 52, p. 7]. Wow, we don't need to get the mythical liver biopsy anymore, so there is a real chance of inmates in Junee Correctional Centre getting some treatment for the insidious hepatitis C. Thank you, thank you, thank you! I just cannot believe the government actually did something to make life easier (and ... possible) for so many Australians. What happened? No don't tell me, it might spoil the magic. Wait a minute! Are we classed as Australians too? I mean we will get access to this treatment too, won't we? You didn't actually mention inmates in the article, but I just assumed that it would apply to us in here.
>
> (HNSW, 2006d, *Hep C Review*, Edition 54; p. 22)

Reader stories

Reader stories in the Hep C Review represent an experiential and potentially counter-narrative space (Carey, 2007), wherein those affected by HCV can tell their stories and have a voice, thereby addressing representational silence. Dominant narratives of HCV are more overtly challenged by the social advocacy identities produced in the reader stories than they are in the editorial section. In this sense, reader stories more explicitly represent HNSW alternative or counter-narratives. Multiple discourses of HCV are more actively advocated and stories include more categorical action-orientated utterances, helping build more determined and inclusive social advocacy identities than in the extracts 1 and 2 presented above.

Thirteen reader stories were published in editions 51 to 54. A table was constructed detailing the categories, writer demographics, story title, topics and message to readers (see Appendix D). The aim of this was to firstly identify common topics in reader stories. Discourse modes and linguistic devices employed to present these topics and themes were then examined and illustrate how social advocacy identities are produced. Reader stories commonly featured a combination of personal memoir and advocacy propositions. Treatment and drug use were the most recurrent topics within reader stories. These topics were selected by the editorial team. In each edition a text box is present asking readers to submit stories. In editions 50, 51, and 52 the editor/editorial team set the topics readers that were invited to write about. These topics included: 'injecting drug use and hepatitis C' (HNSW, 2005a); 'access to, and quality of treatment services' (HNSW, 2005b); and 'strategies for self-management' (2006b), respectively. In editions 53 and 54 set topics were dropped and replaced with a general request for personal stories. In editions 53 and 54 different kinds of authors were sought including family and friends of individuals living with HCV as well as healthcare workers. Incidentally, there were no reader stories authored by family members, friends or health care workers in editions 51 to 54.

Extract 4. HNSW reader story text: "People are not just a vector of disease".

> From my own experience and in talking to others I believe that there is a need for increased dialogue in the medical encounter and for recognition of the patient in their entirety, not just as a vector of disease. The efficacy and adherence to interferon treatment could be greatly improved if individuals' concerns were attended to and the social, contextual and emotional locality of the patient taken into account.
>
> (HNSW, 2006b, *Hep C Review*, Edition 52, p. 34)

Extract 4 is from a "reader story" by Magdalena who challenges biomedical practices by questioning (insufficient) dialogue between patient and physician and how biomedical discourse positions the patient, in a reductionist sense, 'as a vector of disease'. Experiential knowledge of the author ('from my own experience'), combined with an indication of shared experience ('and in talking to others') provides the premise for Magdalena's claim. This works at positing a commonality between Magdalena and others affected by HCV helps to strengthen the premise of her advocacy claim. The use of terms as 'social, contextual and emotional locality…' and 'efficacy and adherence' reflects a vocabulary informed by expert knowledge elements. As such, a combination of experiential and expert knowledge helps build a social advocacy identity.

Through a subjective modality ('I believe'), Magdalena proposes that 'treatment could be greatly improved' if patients were recognised in their 'entirety' as people, and as such reflects, in an advocacy sense, a need for more discourse diversity: different systems of knowledge to inform the treatment domain. Magdalena posits that by denying a person's "social, contextual and emotional locality" the "efficacy and adherence to interferon treatment" is called into question. Biomedical dominance within a treatment context is thus challenged.

Extract 5. HNSW reader story: "You can't just treat one piece of the person's problem, it is all interwoven".

> I'm writing this story from where I see it, grass roots view. I myself have hep C for some time as you probably already know (I've written a couple of other stories). I reckon whatever you would think that will help the "cause" out, don't wait, write in and let everyone know what you think…You can't just treat one piece of the person's problem, it is all interwoven, drug use, lifestyle, social issues, etc. All government and non-government departments should be inter-linked so referrals aren't a problem.
>
> (HNSW, 2005b, *Hep C Review*, Edition 51, p.36)

Consistent to Magdalena, the "reader story" by Snake's in extract 5 presents a claim to truth informed by experiential knowledge indicated by a positioning of his story as coming from a 'grass roots view'. In one sense Snake presents a social advocacy voice through a collective call for action from others affected by HCV to help the 'cause'. The term "cause" is a colloquial abbreviation for: making common cause with, joining collective efforts, siding with; helping and supporting. This call to action is a call for HCV experiential narratives. Snake also employs categorical modal expressions. The utterances 'don't wait, write in and let everyone know what you think', 'You can't just treat…', and 'All government and non-government departments should be inter-linked' demonstrate this reflecting a strong commitment to his statements regarding problem description and calls to action.

Both Snake and Magdalena critique biomedical discursive practices (and potentially public health policy) in relation to the proposed practice of treating only 'one piece of the person's problem'. Through the use of categorical modality and negation Snake suggests that if treatment is not informed by a range of considerations or discursive approaches, which include social understandings ('You can't just treat one piece'), HCV and drug use will remain a problem. As such discourse diversity is proposed to more effectively help those using drugs and HCV-affected. Both Magdalena and Snake present a call for action based on the idea of biomedical discourse denying a person's wider social reality. These descriptions and calls to action relate to social structure elements of receiving help: discursive practices of medical consultations (extract 3) and government and non-government agencies not being "inter-linked" (extract 4). Magdalena's and Snake's stories represent two examples of HNSW member-derived narratives that advocate for expanding ideas of health and the individual beyond biomedical and consumer-derived models attached to the health consumer, and present calls to action that address this expansion. Textual devices in these stories point towards a conviction of truth and call to action within utterances. Cumulatively, these work at building social advocacy identities.

A minority of reader stories (three out of 13) featured the topic of drug use in terms of challenging dominant conceptions of drug use. For example, a "reader's story" by Grenville (in extract 6) asks: is drug use a disease or a voluntary act? The answer to this question is framed in terms of whether to intervene in drug users' lives medically or legally. Grenville posits the medicalisation of drug use as a way to challenge criminal narratives and legal discourse. The effects of achieving this goal are presented in categorical modal expressions ('would make society…', 'would help family…:', 'would help users' (HNSW, 2005b, p. 38), suggesting a strong claim to truth – helping build a resolute position. While advocating for medicalisation corresponds to a medical model in understanding drug use, it is unclear whether Grenville's position also derives from personal experience, in terms of using drugs or working within the drug field as Magdalena and Snake's identity enactment does.

Extract 6. HNSW reader story: Medicalising drug use

> Treating problem injecting drug use as a disease rather than a crime would make society at large more productive and happy, would help family and friends of users, and would help the users themselves, most of whom are society's young and deserving of its protection not its punishment.
>
> (HNSW, 2005b, *Hep C Review*, Edition 51, p.38)

Snake puts forward a similar yet stronger claim as Grenville. Like Grenville a strong affinity to Snake's proposal is suggested through use of categorical modality:

Extract 7. HNSW reader story: Medicalising drug use

> Illicit drug use is a DISEASE just like alcohol and tobacco, the first is illegal, the other two are legal. They can all kill you if you over indulge.
>
> (HNSW, 2005b, *Hep C Review*, Edition 51, p.36)

Medicalisation initially informs Snake's advocacy position. Advocates of the medicalisation of drug use consider it a more 'rational and humane alternative to the present militaristic approach of law enforcement' (Singer, 2001, p. 2). While medicalisation was presented in Chapter Six in terms of concerns attached to HCV, here medicalisation is considered to carry productive potential within a drug user advocacy position. As reported in Chapter Six medicalisation can carry various processes and effects to different people in different contexts - an idea supported by medical sociologists who examine the 'different forms that medicalisation might take, rather than assuming it to be the inexorable outcome of medical dominance' (Ballard & Elston, 2005, p. 234). While the shifting drug user identities from "the criminal" to "the patient" can be seen as a step forward in terms of supporting and de-stigmatising users, the medicalisation of drug use potentially overlooks its social and cultural determinants (Spooner & Heatherington, 2004). However, Snake's story goes on to imply such determinants.

While both Snake and Grenville are critical of legal interventions, Snake (elsewhere in his story) also moves beyond dichotomising drug use interventions through either medical or legal discourses, and proposes that the problems associated with drug use are informed by a more complex set of "interwoven" issues. Issues raised include:, social location, social issues, family environment, "drug culture", "psych issues", public perceptions of drug users, state agency responses to drug users and political attitudes and strategies towards drugs (e.g. Snake states elsewhere in his story that 'the war on drugs has failed', HNSW, 2005b, p. 36). This interpretation expands on the medicalisation model from which Snake draws earlier and introduces discourse diversity into advocating alternative ways to understand and intervene upon drug users.

Extracts 1 to 7 (with the exception of extract 3) point to the production and expression of HCV biosociality in terms of thinking about HCV as a social and political arrangement through which HNSW and its members work at framing their social and political demands and in doing so construct and enact social advocacy identities. Whyte suggests that considerations of biosociality tend to be 'programmatic and decontextualised' - people are viewed as passive subjects of categorisation and "behave (or not)" in conformity with biomedical discourse. Acknowledgement of the different ways people attempt to make claims and relate to agency and institutions through health identities' can be absent (2009, p. 11). Contexts relating to social, political and economic conditions that help determine these attempts and ways of biosocial identity uptake can be overlooked (e.g. Blystad & Moland, 2009; Anderson, 2002).

Although Harris (2010) in her examination of HCV biosociality tends to overlook these factors, Orsini (2008), looking at HCV suggests that such biosociality is limited if it does not take up the issues that produced the problem/s of HCV in the first place. My analysis above illustrates how biosociality among HNSW and members is variously expressed. Some expressions exclude particular people and overlook social cultural and economic contexts, while others, namely member reader stories (and to a lesser extent the HNSW editorial text) bring social justice, legal and political considerations to HCV – representing discourses that extend beyond a biomedical passive subjectivity or health consumer agency. The linguistic devices deployed to present these HCV-associated understandings and identities suggest an empowered voice enacted with social and collective understandings of HCV.

It should also be noted that the effects of biosociality can play out differently for different people. For example, Blystad and Moland (2009) found little evidence of positive identity-making or "empowering" transformative processes among women enrolled in prevention of mother-to-child HIV transmission programmes. Rather, they 'found processes producing utterly negative identification with the HIV positive status and related problematic perceptions of body and self' (Blystad & Moland, 2009, p. 9). Biosociality 'worked 'to dissolve or "unmake" rather than to "make" the person' (Blystad & Moland, 2009, p. 9). Harris (2010) found ambivalence among HCV-positive people towards participating in biosocial settings (e.g. the Hep C Australiasia web forum) due to a felt morality that some expressed in the course of enacting "correct" health consumer behaviours. Therefore, despite the productive connotations, biosociality appears distressful for some, even comparable to the "absences of meaning" and "representational silences" reported earlier. Indeed, Rapp (1999) in extract 8 notes that the relationship between dominant biomedical discourses and the production of biosociality is not a simple one.

Extract 8. Social research/literature: Biosociality and difference.

> Biomedicine provides discourses with hegemonic claims over this social territory, encouraging enrolment in the categories of biosociality. Yet these claims do not go uncontested, nor are these new categories of identity used untransformed … At stake in the analysis of the traffic between biomedical and familial discourses is an understanding of the inherently uneven seepage of science and its multiple uses and transformations into contemporary social life.
>
> (Rapp, 1999, p. 302)

Terms such as "uneven seepage" and "multiple uses" suggest difference. Social, political, economic and biological factors are likely to inform difference. In the next section I examine how biosociality among some member participants plays out in a different direction to the more socio-political focus reported above. In this different direction, "seepage" or transformation relates to a more ontological or identity context whereby pharmaceutical-based HCV treatment, liminality and drug user-related stigma are implicated. I term this expression of biosociality "social liminal identities" referring to the way HCV liminality is mediated by others affected by HCV – others who share their experiences through HNSW reader stories.

HEPATITIS C SOCIAL LIMINAL IDENTITIES

Social liminal identities produced by Hepatitis NSW members

Most participants who were interviewed spoke of the value of accessing experiential narratives through reader stories in the *Hep C Review*. For some this was not initially a primary or conscious reason for engaging with the HNSW but emerged as an important reason to remain engaged with HNSW. One participant, Chris, spoke of the value of reader stories in addressing HCV as a ‘silent epidemic’ (Chris, HNSW member interview). Others (Nick, Josie, Jen and Pete, HNSW member interviews) cursorily spoke of how they can personally relate to reader stories.

For Jacqui and Bree, reader stories with a social orientation to HCV appeared very important in negotiating identity formations in relation to HCV treatment. For this reason, I return to Jacqui and Bree’s stories, about which I first reported on in Chapter Six (extracts 15 and 16). I focus and examine Bree and Jacqui’s liminal identities in the context of their engagement with HNSW alternative narratives. Jacqui and Bree’s stories are about issues and experiences of treatment and being former drug users. Their talk indexes an intense mediation of their identities in terms of questioning who one is or will become. Texts presented suggests that at this time the socially-orientated experiential narratives of others affected by HCV who have experienced treatment become an important kind of biosociality in facilitating identity (re)formation work, assisting or guiding Jacqui and Bree through this treatment period and liminality.

Extract 9. HNSW member interview: HNSW test helping with HCV liminality

> It's just hard to differentiate what the treatment in it is, what's me in a new life with a new identity not using drugs any more, and trying very hard not to drink kinda thing, and what's interferon and what the effects of that is? It’s really hard to kinda work out which one’s what and trying to be really conscious and not saying “oh it's all interferon” like I said I’m about to stop and that's scary in itself because, fuck what if I’m still this head case after the interferon and you know remove the cause of the symptom and it's still there. So it's a tricky one but what the *Hep C Review* did help me to do was realise hey it is true that it's you but the interferon is amplifying everything and it is, it's amplifying everything.
>
> (Bree, HNSW member interview)

Extract 9 is an extension of extract 16 in Chapter Six by way of presenting Bree’s claim that the *Hep C Review* helped her negotiate experiences and identities while undergoing treatment. Experiences included panic attacks, depression and distortions in time (‘I felt like was it forever’) described further as being ‘frozen’ and a ‘head case’. Bree’s interpretation of these experiences include questions of causality: ‘what’s interferon and what’s the effects of that’, and ‘what’s me in a new life and a new identity not using drugs anymore’. To a certain degree, these questions appear to be addressed with the help of the *Hep C Review*. Bree discovers a “truth” in a sense (‘did help me to do was realise, hey it is true’) through reading other’s peoples stories about treatment experience (which Bree articulates later in the interview). The utterance ‘it is true that it's you but the interferon is amplifying everything and it is, it's amplifying everything’, indicates that HNSW experiential narratives helped Bree realise a relationship between medical intervention and the historical and social location and identities of the person.

Extract 10. HNSW member interview: Liminality and HNSW experiential narratives – ‘It’s about people more than disease’.

> It’s like, I’m not the only people to struggle because its treatment based but it’s also life based. It’s person based and it’s really important the *Hep C Review* and Council and the things to be really aware is, it’s about people more than disease you know and the variation.
>
> (Jacqui, HNSW member interview)

Jacqui also spoke of the importance of HNSW experiential narratives found in reader stories - narratives informed by types of knowledge that consider the social constitution of people and illness experience. The final two lines of extract 10 form an epistemic statement containing a cautionary and evaluation tag to conclude that, ‘the things to be really aware is, *it’s about people more than disease*’ (italics my own). Elsewhere in Jacqui’s interview, the use of the term “people” indicates that the issues involved surrounding HCV extend beyond simply biomedical properties and insights and towards other discourses that consider the “social” – the total biography of a person and their relational contexts. This view of the person and their relationship to HCV overlaps with social advocacy identity elements as derived from reader stories discussed earlier (e.g. Snake & Magdalena). For example, Magdalena’s story encouraged the view that people are more than a vector of disease. In this sense, similar elements thread through social advocacy identities (as constructed in reader stories) and within the mediation of liminal identity formations by HNSW members. The difference being that the former represents a type of biosociality directed externally, towards challenging social structures and practices, while the latter is directed internally towards the individual and their sense of who they are or will be.

Liminality and volunteering

Extending understandings of HCV and related help beyond the biomedical to more social understandings helps address what Little et al. refer to as a sense of 'boundedness' that accompanies illness-related liminality (Little, et al., 1998, p. 1488). Boundedness here refers to constraints in time, space, practices and power as effects of the deployment of certain biomedical practices (among other things). In examining this aspect of liminality, Little et al. (1998) found that research participants spoke of volunteering roles to counter this sense of liminally related boundedness.

The desire to participate in HNSW volunteering emerged as a common theme in participant interviews (e.g. Bree, Chris, Josie, Nick and Andrew). In approaching the end of treatment Bree spoke of the wish to volunteer and participate in activities with 'substance' (see extracts 11 and 12). The repeated use or 'overwording' (Fairclough, 1989, p.115) of the term "substance" in these extracts presents an interesting preoccupation given Bree and Jacqui's reported detachment and feelings of being frozen. Doing something with "substance" in a sense, sits as a counter position to feeling "frozen", "detached", which contribute to the idea of boundedness. Substance implies something with an essence which counters emptiness or meaninglessness. Volunteering, the (bio)social act of giving or helping others is a suggested activity with substance for Bree. Bree gives an example of creating HCV-related discourse within public spaces through art projects, whereby the street walls are her canvas (see extract 12). The idea of mutual-aid is also present in extract 11 ('…the amount of support I have received …'). However, Bree's economic position is also presented as an obstacle to volunteering.

Extract 11. HNSW member interview: Post-treatment incorporation and volunteering – ‘things with substance’.

Paul:	Looking at your thinking about maybe volunteering and helping out with the hep C, maybe looking at your thinking around that.
Bree:	Things with substance, things with substance, something with substance. I mean it's a whole lot of things. The amount of support I have received and it’s just been such an enormous profound help and I really support it. I really, really support all the support that the Hep C Council gives and then I look at things like I really need some money cause yea, I haven’t really worked throughout this treatment.

(Bree, HNSW member interview)

Extract 12. HNSW member interview: Post-treatment incorporation and volunteering – ‘I wanta do something with substance’.

> I want to get back into the work force. I mean hospitality is my forte but I don’t wanta do hospitality anymore. I wanta do something with substance. So yea, I want to definitely volunteer and get into. I'm doing a lot of personal art projects and liquid nailing canvasses onto street walls and stuff - just raising awareness about hep C and loving yourself kinda messages. This sounds kinda wankie but yea in kinda graffiti style…
>
> (Bree, HNSW member interview)

The difficulties of “re-entering life” again and identity (re)formation post-treatment have been documented by Hopwood (2009) who proposes support and counselling services for such individuals. This issue of post-HCV identity is also illustrated by Jacqui in extract 13 and highlights the role of the social, in this case expressed through stigma, as part of such identity work.

Extract 13. HNSW member interview: HCV residual identity work – ‘you don’t just wash that away overnight’.

> …because there are no antibodies there anymore doesn't mean you just go aaw [utterance suggests relaxed contentment]. Absolutely it’s weird because it has, it does become a little part of your subconscious identity I think and you don't just wash that away overnight because there is unfortunately a definite amount of dirtiness to it. Not that I've put it on myself so much that I think maybe, but um yea stigma and so on.....
>
> (Jacqui, HNSW member interview)

Similar to Hopwood (2009), in extract 14 Jacqui proposes counselling support after HCV treatment. The idea of post-HCV residual identity work is also supported by Jacqui’s claim that the ‘end (of treatment) is just the beginning’.

Extract 14. HNSW member interview: Post-treatment and ‘residual identity work – ‘you've reached the end but in actual fact you've just got to the beginning’.

> …it’s very much a lifestyle helping out process. I think a lot of people find themselves, even if there really good and have a lot of energy, it’s like how do you reengage, how do you let go? I don’t know. Some sort of really good counselling service, cause you do all this work and you think you've reached the end but in actual fact you've just got to the beginning. You can feel it drifting away and you think aww shit. So to have a support team when you've reached the end of it, actually you need support more so.
>
> (Jacqui, HNSW member interview)

Alongside Hopwood (2009) and Jacqui’s proposals for counselling services, Bree’s talk of participating in volunteering as a form of biosociality, entailing the idea of mutual help, may also represent an attempt to (re)incorporate oneself meaningfully (back) into society, and address a post-HCV or residual identity. Thus, for some, counselling or biosocial-based volunteering may be a more responsive practice post-

HCV. In the next section I examine the talk of those who engage with the HNSW in a volunteering capacity. Interestingly, consistent with Bree's wish to volunteer post-HCV treatment, the only members interviewed who volunteered at HNSW had completed treatment and had "cleared" the virus.

Wanting to help others by volunteering was usually not the initial or primary reason participants joined or engaged with HNSW. Six participants (Bree, Chris, Josie, Aaron, Nick and Andrew) spoke about helping, or the desire to help others by way of volunteering at HNSW. However, only two of these participants had been or are currently HNSW volunteers (Aaron, Chris and Josie spoke of the desire to volunteer but spoke of certain barriers such as fear of stigma and health concerns in preventing them from pursuing this). Consequently, I focus on these participants who I argue participate in *HCV community-mutualist identities*.

HEPATITIS C COMMUNITY-MUTUALIST IDENTITIES

Community-mutualist identities produced by Hepatitis NSW members

This section looks at how two participants (Nick and Andrew) talk about the kinds of help they value from their HNSW engagement, point to biosocial identities that I term HCV "community-mutualist". This is because participants work at representing themselves as volunteers informed by the shared themes of "giving something back" (i.e. indexing mutual help) and "community" - ideas that implicate participants' identifications and temporal relations with drug use and HCV.

Nick is an Anglo-Australian in his thirties and lives in an inner-city suburb of Sydney. Nick receives a disability pension and is the father of two children who live with their mother. After clearing HCV through treatment Nick became a HNSW volunteer where he says he began doing ‘general duties’. After a break from this volunteering due to health reasons, Nick now volunteers one day a week. Andrew is an Anglo-Australian in his forties living in Sydney. Andrew lives with his partner and currently works as a drug and alcohol counsellor. Andrew has been a HNSW volunteer in the *C-een and Heard* speaker program. The *C-een and Heard* program provides training and opportunities for those HCV-affected to ‘tell their story to health professionals and community groups about their experience of living with hepatitis C. The aims of the program are to reduce discrimination and to increase and broaden people’s understanding of the experience’ of HCV (Rose & Treloar, 2007, p. 2).

Mutual help

<u>Extract 15. HNSW member interview: Mutual-help – ‘I wanta give something back’.</u>

Paul: Some people might say usually its people that are in or considering treatment or are still positive that may get involved with hep C um, what's the thinking maybe behind wanting to get involved in the hep C even though you’re…

Nick: Aw that's interesting. I’ve never thought about it in that way. I’m over it but well because I think at some [pause]. I’m more open in general why I go there [HNSW]. Ok it's because I feel society has contributed, have given me some, some good things and although I have some other ongoing health problems, I wanta give something back. Pretty daggie buts that's about what happens inside me because what directly motivates me is that those stories that I did read in the hep C journal, and then the stuff I learn was able to directly apply that to my treatment and I just, I just am idealistic enough to think that maybe I can work with other people or myself or help other people who are in that position. Just educate them. It's not just that I wanta go out and

> help people it's not that,… it's a mixture of personal and professional and myself you know. It's really good for me to work in an environment with other people cause I do a lot of stuff by myself and I just need groups occasionally and I want to contribute, yea. It's hard to say why you're doing something…
>
> (Nick, HNSW member interview)

In extract 15 Nick presents a combination of reasons for volunteering. Society, how "reader stories" affected him personally and idealism are all cited as reasons. The former two reasons indicate Nick has previously received help regarding his health concerns and HCV treatment and thus align with self-interest ideas of volunteering albeit located in the past. Reference to idealism suggests a more traditional altruistic motive (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985). However, an evaluation statement is presented ('Pretty daggie', Nick, HNSW member interview) implying that to help others may not be seen as socially desirable to Nick and/or me the interviewer. Nick employs hedging ('I just, I just') to minimise his commitment to idealism and thus positions himself as not idealistic but "idealistic enough" thus suggesting he sees himself as retaining a footing in "the real world".

Altruistic reasons are further toned down towards the end of the extract where Nick in a summary manner states, 'It's not just that I wanta go out and help people it's not that… it's a mixture of personal and professional and myself'. The utterances 'happens inside me" and "myself' within Nick's statement that "it's a mixture of personal and professional and myself" suggest that both these self-interested and altruistic ideas of volunteering convene "in" Nick somehow. This combination of reasons thus appears mutually reinforcing, or fused together.

Extract 16. HNSW member interview: Mutual-help – ‘it’s been turned around with help from them people and I’m able to put back’.

> …just knowing that I’m linked in with something good that’s happening in the community, that I have a history of you know in relation to that stuff, plus now it’s been turned around with help from them people and I’m able to put back and that’s something else I’m able to do within the community and just knowing that in the back of my mind is a good thing. But also it helps to no end with my work you know.
>
> (Andrew, HNSW member interview)

Similarly, Andrew’s talk in extract 16 features a mixture of self-interest and altruistic ideas indicative of mutual help. This is best captured by the statement, ‘now it’s been turned around with help from them people [self-interest - receiving help in the past] and I’m able to put back [altruism - giving help now]’. This combination of self-interest and altruism is more noticeably fused in Andrew’s present life when looking at how HNSW membership helps him personally in his occupational role (‘it helps to no end with my work – see also extract 17). This simultaneously helps Andrew be “better” at his job (self-interest) *and* helps others affected by HCV (i.e. those affected by HCV and drug use whom Andrew counsels).

Interpreting Nick and Andrew’s talk about their reasons for helping others by way of separating ideas of self-interest and altruism appear inadequate as both these ideas appear more interwoven in participants’ talk about volunteering. As such the term mutual help or mutualism better captures Nick and Andrew’s enacted identitities. The idea of mutualism can be seen to be linked to the idea of “community”.

Community

Andrew's talk in extract 16 informing the idea of mutualism is also accompanied by the term "community". The term community is also referenced by Andrew in extract 17 in talking about his involvement in the *C-een and Heard* program ('speaking with services sharing my story', Andrew, HNSW member interview). This program indirectly aims to help others affected by HCV and allows Andrew to see himself as part of a community ('So you know, I'm part of the community as well') through engaging in a HNSW narrative space. Hepatitis NSW experiential narrative spaces appear in both Nick and Andrew's talk about volunteering and for Andrew ideas of being part of a "community".

Extract 17. HNSW member interview: Mutualism and community – 'I'm part of the community'.

Paul:	… what do you value or what are the benefits of being a member of the council…any type of service or...
Andrew:	Aw look I work in the field of drug and alcohol. I work with youth at risk at [unclear]. I also work in one of the rehabs in the inner city area and I work with ex-prisoners who have a high rate of hepatitis C. So probably 70% of my clientele I deal with in that situation have hep C. So me having a good strong link with the hep C Council enables me to pass on good pre and post-test counseling in my job. I have information at hand I'm a member. They send me all the local stuff every couple months or whatever. I do some work for the Hep C Council you know like I do a bit of speaking with services sharing my story, stuff like that. So you know, I'm part of the community as well, a bit more of a community and some the guys who work there are, yea pretty cool to communicate with yea.
	(Andrew, HNSW member interview)

The concept of “community” becomes a running theme when Andrew talks about the HNSW and his past and present life. Specifically, community appears when Andrew talks about a previous history of drug use (‘as a result of cleaning up my act I got involved with some other support networks in the community and there were other people similar to me…it was only because I was in a specifically related community…’). It also appears when talking about his HCV-related history in terms of: receiving support and information through HNSW membership; helping him with his current employment and; finally “giving back” to the HNSW and those living with HCV as seen in extract 17. The term “community” thus appears “emplotted” throughout Andrew’s story, connecting his past as a drug user and living with HCV with his present as a drug and alcohol counsellor, as well as HNSW member and volunteer who shares his experiential knowledge with others.

For Nick the use of the term community is also connected to his identification with a past drug using community as well as, volunteering for community associations. When Nick was asked when he was first diagnosed as HCV-positive he states; ‘I actually, um part of the drug using community for a few years…’ and immediately follows this declaration by saying how he got involved in a community association participating in harm reduction projects for people who use drugs. As such Nick’s identification with a particular community is connected to volunteering in a community association. In talking about themselves as volunteers in connection with “community”, Nick and Andrew can be seen to draw from conceptions of community in different ways – ways that implicate ideas of mutual-help behind their volunteering. To discuss this further I draw from Omoto and Sydner’s (2002) model of volunteerism.

Based on their research on HIV/AIDS volunteerism, Omoto and Synder (2002) developed a theoretical model of volunteerism that considers community as both *context* and *process*. Context refers to the standards, norms, resources, institutions and organisations of a community and provides a "backdrop" for volunteer efforts. In a HIV context, individuals located within this backdrop may include 'not only those individuals with HIV and at risk of it but also the members of their social networks, as well as the volunteers and staff of organizations that provide services relevant to HIV' (Omoto & Synder, 2002, p. 856). Process refers to a psychological sense of community and is conceived by factors such as, membership, influence, integration and need fulfilment, and shared emotional connection (McMillan & Chavis, 1986). "Membership" refers to a sense of acceptance and belonging; "influence" refers to mutual influence among community members and relates to community norms and recognized authority figures and structures'; "integration and "need fulfilment" 'focuses on the reinforcement that community members receive from having their needs, including psychological needs for status, success, and protection from shame, met'; and "shared emotional connection" emphasises 'the value and importance of shared experiences and history' (Omoto & Synder, 2002, p. 856). In this model the propensity to volunteer is informed by a non-linear relationship between community as context and process.

Nick and Andrew's talk indexes community as context by way of their positions within HCV and drug user CBOs as well as Andrew's employment as a counsellor within various organisations that work with individuals affected by HCV. As such these contexts provide a backdrop to current HNSW volunteering. Utterances within Nick and Andrew's stories that point to factors constituting a psychological sense of community include:

- Shared emotional connection (i.e. shared experiences and history)

  Pretty daggie buts that's about what *happens inside me* because what directly motivates me is … *those stories* (Nick, HNSW member interview, italics my own).

- Shared emotional connection (i.e. shared experiences and history) & influence

  I do a bit of *speaking with services sharing my story*, stuff like that. So you know*, I'm part of the community* as well, a bit more of a community and some the guys who work there are, yea pretty cool to communicate with yea (Andrew, HNSW member interview, italics my own).

- Need fulfilment

  It's really good for me to work in an environment with other people cause I do a lot of stuff by myself and *I just need groups* occasionally and I want to contribute, yea (Nick, HNSW member interview, italics my own).

  I'm able to put back and that's something else *I'm able to do within the community* and *just knowing that in the back of my mind is a good thing* (Andrew, HNSW member interview, italics my own).

Furthermore, membership is a likely factor in Andrew and Nick's sense of community due to being affected by HCV and through their formal membership with HNSW. Consequently, a relationship between community as context and community as process can be seen in Nick and Andrew's talk about ideas of "giving something back" (mutual-help) behind their HNSW volunteering. As such their volunteer-related identities may be viewed in terms of "community-mutualist" identities.

Other participants saw social stigma (Josie, see extract 18) and health concerns (Chris) as barriers to helping others and engaging in ideas of community. When Josie was asked why she decided to become a member of HNSW, she states: 'I got an interest in you know in community and all that sort of stuff'.

Extract 18. HNSW member interview: Community, volunteer identification and the barrier of stigma

> Yea I, I feel very passionate about um you know community and people and health um you know I hope one day I can be in a position where I can disclose publicly and I can perhaps help other people. I don't feel I can do that now yea so it's all that sorta stuff like a desire for um a proper communication to cut through the community for the stigma to dissolve. Yea I've done a lot of different things like volunteer work and all that that sorta stuff.
>
> (Josie, HNSW member)

Like Andrew, Josie, who is not a current IDU, connects the idea of helping others to the notion of community and despite a desire to help others, feels that there are stronger (social stigma) forces at play that prevent her fulfilling this desire. In contrast Andrew and Nick, who are the only participants who do volunteer with the HNSW, have cleared HCV thus negotiating HCV-related stigma maybe less of a concern for them. In extract 15 Nick's statement 'I'm more open in general why I go there [HNSW] tacitly points to this. This issue of stigma speaks to Snyder, Omoto and Crain's study on HIV/AIDS volunteerism where they found that 'people who believe that they will be stigmatized for AIDS volunteerism are less likely to follow through on their initial intentions to volunteer, and that those who expect the most negative reactions from others are least likely to complete volunteer training programs' (1999, p. 853). HCV biosociality in terms of HNSW volunteering may for some be a threat to the self, whereby biosociality may work 'to dissolve or "unmake" rather than to "make" the person' (Blystad & Moland, 2009, p. 9).

In talking about the challenges of developing HCV biosocial identities, Rhodes and Treloar state:

Extract 19. Social research/literature: challenges to HCV biosocial identities.

> Unlike HIV, a shared bio-identity or normative HCV discourse has not generated an activist movement or community impetus for behaviour change. This highlights a specific need for interventions to foster collective responsibility for change, including via social network, peer driven and self-help interventions. The physiological and material demands of addiction in the context of socially, legally and politically hostile risk environments make galvanizing for community identity and change extremely challenging.
>
> (Rhodes & Treloar, 2009, p. 1600)

These challenges, as Josie's story indicates, include social stigma and extend to individuals regardless of whether they are currently IDUs or not.

Despite questions regarding the ability of biosociality to address biomedical dominance, the structural determinants of health and, to materialise and be productive in the face of social stigma, the stories of Snake, Magdalena, Nick and Andrew indicate that for some the expression of a biosociality and alternative identities (be they social advocacy or community-mutualist identities) can consider and/or challenge biomedical hegemony and wider structural elements. However, the enactment of biosocial alternative identities in the face of social stigma may be more of a potential among those who express such an identity through more anonymous textual narrative spaces (e.g. reader stories). For the more visible face-to-face expressions, in terms of HNSW volunteering, this possibility is perhaps stronger among those for whom "clearing" HCV is becoming a real possibility (Jacqui and Bree) or is a medical "fact" (Andrew and Nick).

CONCLUSION

This chapter reported on alternative HCV identities in terms of those that diverge from the dominant medicalised and health consumer identities presented in Chapter Six. Alternative identities termed social advocacy, social liminal and community-mutualist were presented as constructed through HNSW newsletter text and by HNSW members. Each of these identities drew from socially orientated understandings of HCV and the self that extended beyond medical models and consumer agency ideas. I illustrated how such identities point to HNSW narratives and spaces that encourages a HCV biosociality which carries potential in terms of: advocating for a more social view of HCV through a variety of discourses; negotiating treatment-related liminality; and, for some, mobilising a desire to help others and become community-minded. However, HCV-related stigma and one's economic position is likely to impact on such desires.

In Chapter Eight I draw from Chapters Six and Seven, as well as key informant interviews and the wider literature, to assess and articulate HNSW distinct expertise in terms of the narrative communitas model.

CHAPTER EIGHT

BETWIXT AND IN-BETWEEN STATE AND COMMUNITY: EXPRESSION AND CONTAINMENT OF PROSPECTIVE NARRATIVE COMMUNITAS SPACES IN A HEPATITIS C COMMUNITY-BASED ORGANISATION

> So we kind of have a funny, we kind of straddle a particular divide between the professional sectors that relate to hep C and the people who experience hepatitis…
>
> (Alice, HNSW key informant interview)

CHAPTER INTRODUCTION

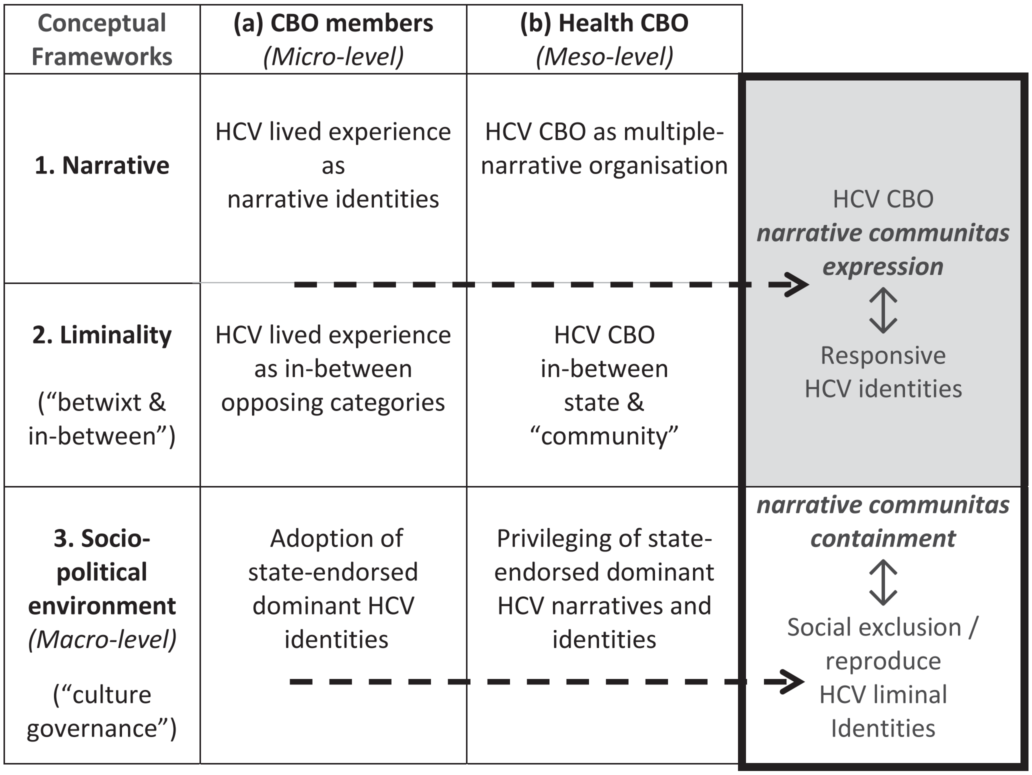
In this chapter I draw from dominant and alternative HCV narrative identities presented in Chapters Six and Seven to assess and articulate HNSW distinct expertise against the narrative communitas model developed in Chapters Three and Four. Drawing from HNSW key informant interviews I discuss HNSWs' relational and liminal position between state and "community" by way of it negotiating or "balancing" different types of HCV knowledge and narratives within the *Hep C Review*. This leads me to discuss expressions and containment of HNSW narrative communitas elements. I return to participants Bree and particularly, Jacqui's stories to illustrate how their enacted identities point to prospective narrative communitas elements within the *Hep C*

Review. I then draw from HCV narratives and identities produced within the *Hep C Review*, HNSW key informants and the literature to discuss narrative communitas containment and interpret this in light of the contemporary social-political environment to which CBOs are subject.

HEPATITIS NSW DISTINCT EXPERTISE AS PROSPECTIVE NARRATIVE COMMUNITAS SPACES

In Chapter Four a model of distinct expertise of HCV CBOs was presented that postulated a critical potential within CBOs to facilitate a type of "narrative community" that has productive implications for member identity formations. Drawing from Somers (1992, 1994) framework of narrative identity, Boje's (1994, 1995, 2001, 2008) idea of the multiple-story telling organisation and Turner's (1969, 1974) concepts of liminality and communitas, I articulated CBO distinct expertise as 'narrative communitas' that implicated the key roles public and ontological narratives and liminality play in mediating illness/HCV identities (see figure 5).

Figure 5. "Narrative communitas" model of HCV CBO distinct expertise



Conceptual Frameworks	**(a) CBO members** *(Micro-level)*	**(b) Health CBO** *(Meso-level)*	
1. Narrative	HCV lived experience as narrative identities	HCV CBO as multiple-narrative organisation	HCV CBO ***narrative communitas expression*** ↕ Responsive HCV identities
2. Liminality (“betwixt & in-between”)	HCV lived experience as in-between opposing categories	HCV CBO in-between state & “community”	
3. Socio-political environment *(Macro-level)* (“culture governance”)	Adoption of state-endorsed dominant HCV identities	Privileging of state-endorsed dominant HCV narratives and identities	***narrative communitas containment*** ↕ Social exclusion / reproduce HCV liminal Identities

Interpreting HNSW distinct expertise in terms of a narrative communitas model rests on conceiving organisations as liminally positioned multiple-story telling social arenas. One expression of HNSWs' liminal position between the state and community presented concerned the production and circulation of multiple and opposing HCV narratives. Some of these stories or narratives correspond to dominant HCV narratives aligning with social structure (expert knowledge mediated by the state) while other stories represent alternative or counter-narratives thus corresponding to anti-structure (typically experientially derived), in Turnerian terms (Turner, 1969). While Boje (1994) interprets multiple organisational narratives as carrying unproductive elements for business sector organisation, this thesis claims that multiple and dialectical narrative expression provides a productive potential for CBOs and their members, instantiating

HNSW as a distinct cultural agency. It is this broadly conceived dialectical narrative expression (containing within it a multiplicity of nuanced narratives) that underpins prospective ‘narrative communitas’ spaces.

Looking at findings concerning HNSW-constructed medicalised and health consumer identities alone suggests that HNSW distinct expertise via narrative communitas is unlikely to be realised. Rather, the (re)production of medicalised and health consumer identities point to a HCV narrative-based isomorphism between the public sector and HNSW, wherein HNSW appears to mimic the dominant HCV narratives and identities of the public sector. As such understanding HCV is heavily confined to the prevailing and dominant social structure. The biological status of HCV should of course be considered here. As one HNSW key informant interviewed states: ‘it’s a medical condition – it’s managed and treated by clinicians, it’s diagnosed by doctors; by our nature we can’t escape that’ (Carl, HNSW key informant interview). While such dominant medical understandings carry benefit at different periods during one’s life with HCV (e.g. contemplating or waiting for treatment as illustrated by Kate and Josie), they may also instantiate representational silences (e.g. overlooking Josie’s position as a parent) and liminality (as expressed in part by Bree and Jacqui). This corresponds with Krug’s (1995) insight that most damaging to the individual affected by HCV is when one dmain (i.e. the medical) lays claim over all others.

However, medicalised and health consumer identities derive from one, albeit well-rehearsed, set of HNSW narratives that sit alongside many others – others that extend beyond or counter dominant HCV narratives and identities. These other narratives point to alternative HCV understandings and are suggestive of Turner’s (1969) anti-structure whereby individuals and biosocial processes express alternative structures of social relationships, symbols and text which are derived from and, to some extent, dependant on the dominant social structure for legitimacy. The socially orientated narrative identities presented in Chapter Seven such as, social advocacy identities (particularly those constructed within *Hep C Review* reader stories), represent to various degrees anti-structure HNSW narratives. Thus alongside dominant expert narratives (social structure) exist alternative and experiential narratives that typically derive from HCV "community" members (anti-structure). A key process proposed in realising CBO distinct expertise involves HNSW mediating between state-endorsed expert structure and "community" led, or experientially derived anti-structure. HNSW key informant Alice refers to this mediating role in terms of a connection expressed through the term "straddle" in the opening extract of this chapter.

This dialectical narrative expression provides HNSW with a 'narrative communitas' substructure which in turn provides the conditions in which liminal individuals can scrutinise and negotiate multiple and opposing HNSW narratives against their own particular stories and social circumstances, resulting in more responsive mediation of HCV and how it relates to one's life story or identity, given the immediate relational setting. Similarly, but in a rather different organisational context, Dressman (1997) discusses the distinct cultural agency of school libraries to potentially provide liminal students a space where structure and anti-structure are negotiated. In examining student mediations of texts that reflect enculturation attempts towards dominant narratives and ideologies, Dressman states: 'people in more liminal social circumstances, who sense their interests to lie apart from, but not against, alignment with authority, may construe the act of reading-as-consumption as an act of de/reconstruction of textual meaning' (1997, p. 268). This according to the author allows individuals to

> take advantage of the multiplicity of texts available to them at large; they may read intertextually, appropriating signs from different texts for their own use, ignoring or subverting the terms of address in some or in all, and finding, in the inconsistencies of each text's webbed construction, …. the means to reconstruct a reality more in line with their own social position and subjective view of the world' (1997, p. 268).

The (re)production and circulation of both dominant and alternative HCV narratives and identities within HNSW textual spaces presents a dialectical cultural agency that is subject to the deployment of power. That is, there arguably can be circumstances, social forces and deployments of power that impact on the ratio and discursive weight afforded to dominant narratives and alternative narratives. For HNSW distinct expertise to be realised through narrative communitas spaces, opportunities to generate and engage in anti-structure/alternative narratives should be readily available. Such availability could be compromised by the over-production of, or "crowding out" by, dominant narratives representative of, or reflective of the power inherent within structure. Considerable opportunities for anti-structure creation are important in helping ensure that structure does not maintain an unbreakable grip on those subject to it (Arnott, 2001). Consequently, this places the act of negotiation between structure and anti-structure as an important factor to the creation of narrative communitas spaces. In a HNSW context this manifests in terms of keeping in balance types of knowledge, stories and narratives that are produced by HNSW.

Extract 1. HNSW key informant: Balancing dominant and alternative narratives within the *Hep C Review*

> ...it seems to me there is kind of [*Hep C Review* content], an ok balance.
>
> (Alice, HNSW key informant interview)

Extract 2. HNSW key informant: balancing dominant and alternative narratives within the *Hep C Review*

> I guess the balance is to try and have a magazine where the articles are amended down so that people aren't put off too much by dry, over clinical articles.
>
> (Carl, HNSW key informant)

Extract 3. HNSW key informant: Balancing dominant and alternative narratives within the *Hep C Review*

> We will go with scientifically or collectively from the community on what we know that works. We don't tell people, we give people information so that they can make their own choice at the end of the day.
>
> (Michael, HNSW key informant)

The theme of the balance between, and coexistence of, structure and anti-structure, dominant narratives and alternative narratives, expert-state knowledge and experiential "community" knowledge, emerged within all HNSW key informant interviews as indexed when talking about the prevalence of dominant HCV narratives (see extracts 1 to 3). In extract 3 Michael broadly points to the idea behind narrative communitas spaces by way of suggesting that people generate their own relevance from the coexistence of scientific and community knowledge within the HNSW newsletter. However, the utterance "they can make their own choice" by Michael negates considerations of the circumstances, social forces and deployments of power that impact on the ratio and discursive weight afforded to dominant narratives and alternative narratives within the *Hep C Review* (and also indexes a health consumer logic of 'choice') (Hopwood, 2007; Greener, 2008).

In the following section I extrapolate this idea of "balance" towards findings indicative of the expressions and containment of HNSW narrative communitas. Firstly, I present how participant social-liminal and community-mutualist identities tentatively point to the expression and productive potential of HNSW narrative communitas elements. I then report how findings also suggest a marginalisation and management of alternative HCV narratives and identities, suggestive of a containment of narrative communitas spaces.

NARRATIVE COMMUNITAS EXPRESSIONS THROUGH MEMBER IDENTITY WORK

Social-liminal identities indicative of Hepatitis NSW narrative communitas elements

Bree and Jacqui's expressions of social-liminal identities characterise responsive HCV-informed identities that help guide them through HCV-related liminality. These identities can be interpreted to derive from, and point to, narrative communitas elements within HNSW textual spaces. As discussed in Chapter Four, symbolic guidance associated with illness-related liminality can assist in a return to a revitalised or renewed position in relation to self and social structure (or "incorporation" to use Turner's term). Bree spoke generally about the *Hep C Review* helping negotiate experiences indicative of liminality (see extract 9, Chapter Seven). When asked what she values most from the *Hep C Review*, Jacqui in extract 4 below, echoes Bree's sentiment but in more detail indicating the importance of scrutinising opposing HNSW narratives (in this case found in *Hep C Review* reader stories).

Extract 4. HNSW member interview: Scrutinising multiple, opposing HNSW narratives – ‘It’s about people more than disease’.

1 The variety I think it important, to have variety of experience. Like
2 sometimes remember reading someone who had been on the year one and
3 they just went, “oh my god I’ve got so much energy. I feel so alive and just
4 good” and to be able to feel good and look back, and just as helpful but in
5 a different way is reading someone's struggles. I remember one making
6 you realise how hard it is and everything you go through in life is just
7 kinda like a symptom of it, and my hep and my treatment of it and the Hep
8 C Council is only a part of the picture. You get rid of the hep C, especially
9 if you've had it for years; it turns into a small secret part of your identity I
10 suppose. The way you deal with life, it does it becomes a little part of
11 yourself the longer that you have it. So when that thing is taken, when you
12 know when you've finally got rid of it, then you’re left with all the shit
13 underneath that you have not been dealing with or whatever. The more you
14 take off layers the more stuff you reveal. So reading a woman's story
15 about, because there's that whole thing - I think you need to buy into it.
16 Kinda like my life is gonna change, it's gonna get better because I’m going
17 through this process of putting in a lot of hard work for this treatment for
18 myself and I will gain afterwards and life will be great, but the thing is,
19 that is all true but at the same time there is that life thing after with you. So
20 reading that realistic side with this one story like, “It’s great, I feel
21 amazing. I’ve got lots of energy and yay”. I want that but also reading that
22 on the other side and everything in between, I think I’m having a really
23 hard time in letting go of being on treatment because I haven't got an
24 excuse anymore and I’m actually feeling that myself and I thought I’ve
25 been giving myself a bit of a hard time. It’s like, I’m not the only people to
26 struggle because its treatment based but it’s also life based. It’s person
27 based and it’s really important the *Hep C Review* and Council and the
28 things to be really aware is, it’s about people more than disease you know
29 and the variation (Jacqui, HNSW member interview).

(Jacqui, HNSW member interview)

In extract 4, Jacqui scrutinises and negotiates various positions as mediated from “a variety or experiences” or at least two HNSW reader stories. One story is indexed twice though direct reporting of a reader story Jacqui had previously read (‘*they* just went, oh my god *I’ve* got so much energy *I* feel so alive and just good’ [lines 2-4] and ‘It’s great, *I* feel amazing. *I’ve* got lots of energy and yay’ [lines 20-21], italics my own). The story Jacqui cites here is in a sense the “poster story” of biomedicine, a dominant narrative: a straightforward and simple success story of HCV anti-viral treatment without any social complexities interceding. The other reader story cited contains themes of struggle, the emergence of personal history ('everything you go through in life is just kinda a symptom of it' [lines 5-9]) and how HCV, treatment and the HNSW is 'only one part of the picture' [lines 7-8]. This in a sense is a "biographical work" story; representing an alternative narrative to the dominant "biomedical poster story", indexing the complexities of how social history, social position and relational settings convene to mediate the lived experience of HCV and its treatment.

Jacqui presents herself as someone who is aware of the need to believe or "buy into" the position that her future self will reflect the "biomedical poster story" (I think you need to buy into' [lines 15-16]). In this sense Jacqui's story marks a belief that biomedicine can help facilitate a kind of restitution as similarly reported by Hopwood (2009) in looking at post-HCV treatment outcomes. However, textual devices suggest that Jacqui aligns herself more with the "biographical work" story. This interpretation comes from the lack of distinction set up in the text between the position of Jacqui and the original author of this "biographical work" story. The author of this latter story is absent and replaced by the voice of Jacqui ("my") and the universal subject ("you", "your" and "you've). This suggests that the original author's position has in a sense become Jacqui's position. Jacqui's statement, 'I mean so reading that realistic side with this one story how hard it is…' [lines 19-20], presents this narrative as "more true" or at least more connected to Jacqui's experiences than the biomedical poster story.

Jacqui's story points towards narrative communitas elements within HNSW. Her personal narrative or negotiation of enacted identity can be seen to reflect a scrutiny of opposing HNSW narratives. The HNSW 'biomedical poster story' reflects a dominant

HCV narrative and thus aligns to social structure. The “biographical work story” suggests an alternative narrative to the “biomedical poster story” and points towards the mediation of a socially orientated alternative narrative or anti-structure. As such, Jacqui’s story appears to mediate both structure and anti-structure story elements, oscillating between both yet gravitating towards the more personally relevant “biographical work story”.

The final four lines (26-29) in extract 4 seem to subsume the various voices or positions within the text under an epistemic statement to conclude that, ‘… the things to be really aware is, it’s about people more than disease you know and the variation’. When we look at extract 4 and elsewhere in Jacqui’s interview, the use of the term “people” suggests how the issues involved surrounding HCV include, yet extend beyond, simply biomedical properties and insights towards other discourses that consider the “social” – the total biography of a person and their relational contexts. This can be seen for example, in Jacqui’s talk indexing an adoption of the “biographical work” story, as well as talk about previous, present and future identities.

Jacqui’s (and possibly Bree’s) stories thus can be seen to mark narrative communitas elements through the mediation of both structure and anti-structure story elements, oscillating between both yet gravitating towards the “biographical work story” presented in the newsletter. Text and talk are important to such liminal and communitas processes. By ‘composing thoughts in the mind and either simultaneously or subsequently composing them in writing’ or verbally, textual spaces and practices within the context of liminality ‘can foster particularly rich, individual reflection and analysis and particularly rich processes of identity formation’ (Cook-Sather, 2006, p. 122). This inter-textual like process of negotiating and transforming various narratives to use for one's own purpose has been viewed as affording the speaker/writer with power (Glenister-Roberts, 2004). This coexistence of structure and anti-structure-imbued HNSW narratives within the *Hep C Review* speaks to the notion of balance, as HNSW key informant Carl explains regarding the selection of reader stories in extract 5 below.

Extract 5. HNSW key informant interview: Balancing opposing narratives

> But if someone can somehow achieve some sort of growth through their experience I think there good stories [to publish]. Ultimately we want the resource to support people and if a story is enlightening and encouraging and positive does that then I look for those sorts of stories. On the other side of the coin we want to give readers opportunities to share their stories and some stories are literally about hardship and we don't shy away from those stories as well. I certainly try to look for a balance.
>
> (Carl, HNSW key informant interview)

However, it should be noted that although Bree and Jacqui's social-liminal identities can be viewed as responsive and HCV-informed (and, for Jacqui, mediated via narrative communita elements), this does not remove Jacqui and Bree completely from a sense of treatment-related hardship and particular anxieties about who they will become after treatment (as reported in Chapter Seven).

Community-mutualist identities as an effect of Hepatitis NSW narrative communitas spaces?

Oppositional narratives that correspond to structure and anti-structure may also be implicated in a tentative connection I would like to make between participant social-liminal and HCV community-mutualist identities, to which the idea of post-HCV residual identity draws attention.

In Chapter Seven, a mixture of post-HCV residual identity work and HCV-related stigma were interpreted to be potentially at play when considering the relationship between "clearing" HCV and Nick and Andrew's community-mutualist identities. Post-HCV residual identity work was also suggested in Chapter Seven in interpreting Jacqui and Bree's stories. Jacqui spoke of how HCV is likely to stay as a part of one's (her) identity, even if treatment "clears" HCV. Further, Jacqui and Bree spoke of concerns about their futures and identities after treatment, and of the desire for counselling support (for Jacqui) and volunteering at the HNSW (for Bree) after treatment. Such desires speak to Hopwood's (2009) study, which looked at recovery from HCV treatments, wherein participants' demands for information at the end of treatment were high, in order to deal with the difficulties of re-adjusting to life after treatment. Similarly, I interpreted Jacqui and Bree's suggestions for counselling and volunteering as a way to negotiate a residual HCV (and drug user) identity in seeking, to use Turner's (1969) terms, a revitalised incorporation back into life and its social structures. Volunteering might be one way to receive help after treatment in terms of helping address any post-HCV (and drug user) residual identity work. Support for this can be gleaned from the mutual-help literature.

Silverman, looking at mutual-help groups, has argued that using experiential knowledge in the process of helping others allows the helper to work 'through some of his [or their] own residual difficulties, and therefore receives some help from the process of helping another' (1976, p. 233). Roberts et al. (1999) also found that support provided by someone viewed as having experiential knowledge was beneficial to the provider of help in terms of personal learning. Further, Omoto and Synder (2002) and Gartner and Reismann (1977) report that helping others increases self-confidence and a sense of social usefulness helping with need fulfilment, social integration and with adopting "strength-based roles" that are lacking in other areas of life – an interpretation that resonates with Nick's position, wherein reasons for volunteering were a "mixture" of both personal and professional ones. Such studies support the well-known theories of "helper therapy principle" (Reissman, 1965) and "bidirectional support" (Maton, 1988).

Nick and Andrew were the only participants who had volunteered with the HNSW and the only participants to have "cleared" HCV from treatment. Therefore, Andrew and Nick's HNSW volunteering and enactment of community-mutualist identities may have, in part, a relationship to residual or unfinished identity work in relation to HCV and its association with previous drug use. Post-HCV residual identity work speaks to elements of Olson et al. (2005) application of the "transtheoretical model" to mutual-help organisations. Aimed at bridging professional and mutual-help understandings of change, Olson et al.'s model outlines ten processes of change attached to 'the activities and events experienced by the person in recovery' (2005, p. 168). While most of these processes are confined to individual cognitive and behavioural tenets, the final process, "social liberation", is interesting as it speaks to the tentative connection between social liminal identities and HCV community-mutualist identities by way of the idea of volunteering to address incorporation and post-HCV residual identity work. The process of social liberation according to the authors, involves the person in recovery 'focusing attention away from oneself and developing a broader recognition of social issues that contributed to the targeted problem' seeing a social consciousness emerge 'encouraging recovering individuals to take more helping-related attitudes toward others who face similar problems; problems socially liberated people have worked hard to overcome' (Olson et al., 2005, p. 174). This also speaks to Frank's (1995) illness "quest" narrative classification which entails a belief that finding alternative meanings of illness experience can lead to an attention and work towards social and political awareness, joining support and patient rights groups as well as helping others in a similar position.

Participant social-liminal identities which point to HNSW expression and the potential of narrative communitas elements may also facilitate this idea of 'social consciousness/liberation' (Olsen et al., 2005, p. 168) or quest narrative (Frank, 1995), bringing about the desire to help others ,which at the same time assists the individual in working through any residual issues attached to HCV. For community-mutualist identity participants, experiential knowledge, along with other factors, was important in opening up a desire to volunteer to help others.

In sum, participant social-liminal and community-mutualist identities tentatively mark HNSW narrative community elements through their construction and enactment of stories of HCV treatment experiences and life after HCV. Narrative communitas elements point to the importance of opposing HNSW narratives, some aligning to dominant public sector or state-endorsed narratives (structure) and others that are more socially orientated deriving from many types of knowledge but noticeably from the experiential knowledge of people HCV-affected (anti-structure). Although social-liminal and community-mutualist identities suggest the importance of alternative HCV narratives and anti-structure, findings also suggest an asymmetrical relationship between dominant expert narratives and alternative experiential narratives within the *Hep C Review*. Such asymmetry is likely to work at containing the production of narrative communitas spaces.

HEPATITIS NSW NARRATIVE COMMUNITAS CONTAINMENT

This section begins by presenting findings that point to the containment of narrative communitas spaces. Specifically, I report on how the privileging of the state-endorsed dominant HCV identities as well as the marginalisation and management of alternative and volunteer HCV identities within the *Hep C Review* jeopardises HNSW distinct expertise in terms of facilitating narrative communitas spaces. I then interpret such privileging and marginalisation according to the "socio-political environment" component of the narrative communitas model.

A self-defined HNSW core value concerns: 'Working from a strong evidence base that draws from both research based evidence and community and stakeholder input' (HNSW, 2006a, p. 5; see also HNSW, 2011a). This indicates that HNSW work is informed by three "inputs" or social domains. Firstly, "research based evidence" indicates expert knowledge stemming from research centres or other organisations (that undertake or commission research), deriving from both public and civil society sectors. "Community" input we can assume is constituted by the experiential knowledge of those affected by HCV and helps locate the HNSW within ideas of "community" and civil society (Omoto & Sydner, 2002; Carey, 2007). Lastly, "stakeholder" input, despite being unspecified, likely refers to state funders and possibly other organisational affiliates (e.g. Hepatitis Australia, which in turn has its own relationship with the state).

These three input areas, expert/research evidence, "community" and state funders manifest within the *Hep C Review* asymmetrically, suggesting a partiality towards topics couched within expert-based dominant narratives. Examining the content of the *Hep C Review*, both cursorily and analytically, reveals that dominant HCV narrative identities are readily reproduced and privileged within the publication. The frequency of biomedically derived (including health consumer) topics and identities in the texts presented, and generally in the *Hep C Review*, along with the textual devices illustrated in Chapter Six, point to dominant, expert HCV narratives as being those privileged within HNSW. Consequently this may steer particular members towards medicalised and expert health consumer identity formations.

Narratives within the *Hep C Review* which drew from socially orientated knowledge appeared important to HNSW social advocacy identities and to participant social-liminal identity formations (and probably community-mutualist identities). However, at time such narratives at times appear marginalised and "managed". References to "community" and 'participation of people with hepatitis C' in the HNSW core values (HNSW, 2006a, p. 5) illustrate how the experiential knowledge of those affected by HCV is considered an important component in achieving not only the HNSW mission and goals but also meeting definition claims in relation to being a CBO. Reader/member surveys, the *C-een and Heard* speaker program, the *Hep Connect* phone service (introduced in 2007), governance participation (i.e. becoming a board member) and submitting reader stories for the *Hep C Review* are ways in which experiential narratives can contribute to the HNSW meeting these goals. However, with the exception of reader stories, promotion and talk of member or community participation was relatively scant compared to the space given over to dominant expert narratives. Further, linguistic devices that attempt to "manage" alternative narratives and identities in relation to advocacy and volunteer positions constructed can be seen to be present within the Hep C Review.

Hep C Review experiential and alternative narratives identified and selected for analysis in Chapter Seven worked towards producing two styles of social advocacy identities. Reader story social advocacy identities often resolutely countered dominant HCV narratives. In contrast, editorial social advocacy identities were more cautious and temperate and, to different degrees, represented HCV-affected persons within dominant biomedical and public health policy understandings of HCV. In this sense, particular social advocacy identities appeared "managed", working (consciously or not) at mitigating any prospective tensions that might arise from diverging too far, style and content wise, from state priorities. Further, volunteer opportunities that can lead to the production of experiential alternative narratives and community-mutualist identities also appeared to be managed.

Participant community-mutualist identities were enacted through talking about ideas of mutual-help and "community" (as context and process) behind their HNSW volunteering. Ideas of mutual help and community were connected to participants experiential knowledge of living with HCV and drug use; a history of volunteering at, or participating in, drug user CBOs/support groups, and importantly, HNSW experiential narrative opportunities (be that relating to reader stories or participating in the *C-een and Heard* program). The place and construction of volunteering and "community" within CBOs like HNSW present a complex and important component that speaks to the defining and distinct character and expertise of CBOs.

As reported earlier, core HNSW values implicate individuals affected by HCV in contributing or volunteering their time to share their experiences, skills and views. As Carey (2007) states, in defining an organisation as a "community association", HCV-affected volunteers, representative of one idea that constitutes "community", are implicated as an integral part of the organisation. The *Hep C Review* editions reviewed in this thesis contained little text about volunteering and opportunities for people to volunteer. Text and narratives about volunteering that were present, which I will now examine, worked at constructing two types of volunteer identities, which I respectively call the "universal" and "HCV-affected" volunteer. Such volunteer identities can be seen to correspond to negotiating HNSWs' liminal position between state and community.

The idea of the universal volunteer characterises a type of volunteer informed by a set of universal notions concerning the relationship between the self and helping others. This idea of universalism derives from a motivation-based understanding of volunteering, whereby a personal experience, relationship or identification to HCV is absent. Instead, a more generic or universal volunteer reflects someone who may identify HCV as a humanitarian problem and not a personal one.

Extract 6. HNSW text: Volunteering at HNSW – 'all motives are valid'.

> Volunteering at HNSW - The Council relies heavily on the involvement of volunteers, mostly here at our office in Surry Hills, Sydney. If you are interested in dropping in on an occasional or regular basis, please give us a call. Many of our volunteers have different desires: some tie volunteering in with workplace training plans; others want to fill spare time; others simply have a desire to help and all enjoy the company and friendly atmosphere. All motives are absolutely valid and we welcome everyone. For more information, contact Paul on HNSW …
>
> (HNSW, 2006c, *Hep C Review*, Edition 53, p. 39; HNSW, 2006d, *Hep C Review*, Edition 54, p. 42)

Extract 6 comes from a short article titled *Volunteering at HNSW* that features in editions 53 and 54. It provides an example of talking about volunteers in terms of proposed antecedents (e.g. motives), experiences (role opportunities - found elsewhere in the *Hep C Review*) and to a minor degree, the consequences of volunteering (rewards). Representations of volunteers based on these elements reflect a functionalist approach to volunteerism (Omoto & Snyder, 2002). The motive, 'simply… a desire to help' in extract 6 above, suggests a basic and traditional understanding of the volunteer - someone who is viewed as simply altruistic and selfless, who helps others for rewards other than money (Kayal, 1993). "Workplace training opportunities" as a volunteer motive is a form of "corporate volunteerism". Corporate volunteerism is said to be about recognising 'the value of business engaging with people in the community' (Holroyd & Silver, 2001, p. 2). Reported benefits for business include improving the corporation's

> reputation, internal culture, productivity and long-term sustainable future in the community. For employees of such corporations, this type of volunteering can improve 'professional development, leadership opportunities and morale (Holroyd & Silver, 2001, p. 2).

The inclusion of various motives and the evaluation statement that 'all motives are valid' helps construct HNSW volunteers positively as a varied and diverse bunch of people who have legitimate motives for volunteering whatever they might be. Inversely, this statement suggests there is a view elsewhere that presents some motives as invalid or questionable. This raises the question, what motives may be viewed as dubious? One interpretation concerns self-interest-based motives, as this runs against the traditional moral view of the volunteer that is pervasive in Australian society (Fahey, 2005). The utterance "all motives are valid" might also be interpreted as speaking to those who are not affected by HCV to counteract assumptions that being HCV-affected is a privileged criterion for volunteering at a HCV CBO. This interpretation ties into questions about how a CBO like the HNSW defines itself – in terms of ideas of a "community" or a "HCV-affected community".

Carey, looking at understanding ideas of community in a HCV CBO, states: 'Community, and how it is conceptualised by workers, alternates between being something which is "in here", inside the organisation, and "out there" beyond Council walls' (2007, p. 104). The author reports that workers spoke of the presence of volunteers in the organisation as representative of community being "in here". This suggests that HCV CBO volunteers who are affected by HCV are important to ideas of the CBO being "community-based". Thus, when presenting representations of volunteers, acknowledging the importance of specifically HCV identified or affected volunteers, and the experiential knowledge this can bring to the organisation, appears to be important. These kinds of representations are absent in extract 6 above.

In the absence of ideas of identification and associated experiential knowledge, a more universal volunteer is constructed. Ideas of community, identification and experiential knowledge are supplanted with a more generically orientated motivational approach to volunteering. This interpretation relates to viewing such volunteers as people who identify HCV not as a personal or HCV-positive community problem but as a humanitarian problem. This has implications concerning reported benefits stemming from biosocial collective identities (Rhodes & Treloar, 2009; Orsini, 2006a). Alternatively, the absence of HCV identification in certain text could indicate that identification with HCV is assumed.

Although extract 6 points to the idea of HNSW volunteers in a universal sense, other HNSW texts present people affected by HCV as the central idea behind volunteering. The idea of experiential knowledge is important here as it is constitutive of the volunteer task presented. For example, it is mostly assumed that volunteers who submit reader stories or become *C-een and Heard* speakers are, or have been, affected by HCV in some way. These volunteer opportunities mark a prospective narrative communitas element that potentially builds alternative counter-narratives, within which HCV identification and negotiations through experiential narratives are present. However, HNSW texts that present volunteering opportunities concerning reader stories set particular parameters for this potential counter-narrative space suggesting such spaces are "managed" by HNSW.

Extracts 7 and 8 present ways readers are asked to contribute to the *Hep C Review*. Extract 7 comes from an "editor's intro" article, wherein readers are asked to write stories to express their experiences and opinions about a particular topic selected by the HNSW. The text from extract 8 featured in all *Hep C Review* editions reviewed, the only text that changed being the topic which readers were asked to write about.

<u>Extract 7. HNSW text: Alternative and counter-narrative "management"</u>

> 'Get Hep C Free' was the slogan for the 2005 treatment focused awareness campaign…. In line with this theme, we have made 'access to, and quality of treatment services' the topic for the next *Hep C Review* article writing competition - so if you have any opinions, please put pen to paper (also see p13).
>
> (HNSW, 2005b, *Hep C Review*, Edition 51, p. 2)

<u>Extract 8. HNSW text: Alternative and counter-narrative "management"</u>

> *Hep C Review* article writing competition:
>
> The focus for our upcoming edition will be "Strategies for self-management," and we invite people to write and submit articles exploring these issues.
>
> - Published articles attract a $50 prize

- The competition is open to anyone within Australia
- Author's name and contact details must be supplied (for editorial purposes but need not be included in the printed article)
- Articles must be between 400-500 words
- Whether a submitted article is published or not is at the discretion of the Editorial Committee.
- We seek different viewpoints, although articles considered unnecessarily inflammatory or vilifying will not be published
- The deadline for contributions to the ED53 article writing competition is 5 May 2006.

We're really looking forward to receiving your articles.

Editor

(HNSW, 2006b, *Hep C Review*, Edition 52, p. 2)

By setting the parameters for what readers can write about and whose story gets selected for publication, extracts 7 and 8 illustrate attempts to "manage" the experiential knowledge of readers who volunteer their time and stories. This is achieved in two ways. Firstly, the idea of a writing competition suggests articles submitted undergo some form of assessment and selection process which implies some readers stories are more appropriate, worthy or "better" than others, in terms of publication, or the voice the HNSW is indirectly promoting. How this assessment takes place is not disclosed to readers except in stating: 'Whether a submitted article is published or not is at the discretion of the Editorial Committee' (see extract 8). The editorial committee is 'made up of a mix of professionals from a clinical, social care background as well as members of [HNSW] staff' (Michael, HNSW key informant interview). Thus reader story selections are likely to be mediated largely by "experts" as well as HNSW staff who may or may not have HCV experiential knowledge. Extract 5 from key informant Carl also indicates that a "balance" of stories is considered.

Secondly, HNSW selects the topic upon which readers are encouraged to write. This encourages readers to locate and organise their thoughts and experiences in relation to a topic selected for them. For example, the topic presented in extract 7 above, 'access to, and quality of treatment services,' (HNSW, 2005b, p. 2), frames HCV issues in terms of relations to treatment. Those like Kate, Aaron, and Josie, who are unable to, or do not currently want to, undergo treatment, become excluded. The focus on treatment is a public health priority and as such this topic selection sets up an "intertextual chain" (Fairclough, 1992) connecting state-prioritised understandings of HCV in terms of a treatment imperative (Harris, 2009; Pugh, 2006) to those affected by HCV who submit their stories. As such, aspects of the *Hep C Review* can be seen to represent a medium or nexus wherein state-informed and reader's story texts convene in such a way as to encourage and frame ways those affected by HCV should think about HCV and related help.

Other volunteer opportunities (during the period of study) that position volunteers as HCV-informed or identified are those as speakers for the *C-een and Heard* service. Yet a keyword search of the *Hep C Review* editions reviewed (keyword search function available on the HNSW website) indicated that the terms *C-een and Heard* featured only twice; once under a "council keyhole" article titled *Worker education sessions* (HNSW, 2006d p. 27); and on another occasion in an article titled *Community and stakeholder consultations – strategic directions for your Council* (HNSW, 2006c, p.12). These articles respectively report on the *C-een and Heard* program as a way to inform readers of what activities the HNSW education and development team undertake, and to thank the speakers of this program. Consequently, *Hep C Review* text was not found to work at encouraging or constructing a volunteer position in relation to this program. The scarcity of volunteer-related text, differences between the universal and HCV-affected volunteer identities and, by extension, the marginalisation and management of alternative narratives, can be interpreted by considering the idea of “identity politics” within volunteering.

Lacey and Ilan argue the international NGO ‘sector is increasingly implicated in assembling volunteers as “responsible citizens” in the delivery of public services’ (2006, p. 34). Consequently, this ‘produces new effects and plans of actions that are different from the way traditional liberal approaches view volunteers and volunteerism’ (Lacey & Ilan, 2006, p. 34). While the international NGO sector contains different dynamics from the Australian CBO sector, the context of CBOs being increasingly positioned to mediate relations between the state and citizen subjects (McDonald & Marston, 2002; Rose, 2000) is likely to see some parallels between these contexts as they relate to volunteer identities.

The “responsible citizen” approach appropriates ideas from the traditional altruistic discourse of volunteers, wherein volunteers are seen as “special” people; people who are caring and altruistic and ‘doers who get things done’ (Fahey, 2005, p. 206). This discourse works to overlook people who participate in the more experientially informed socio-political projects, and thus works to depoliticise volunteers. This approach favours the state, enabling it by providing unpaid labour as the provider of services that were previously state-provided. Depoliticisation also favours the state in terms of “managing” resistance to state power and policy. In extract 9, Lacey and Ilan underscore this situation.

Extract 9. Social research/literature: Depolitising CBO volunteers

> Despite the deliberative use of voluntary labor by advanced liberal states as part of this responsibilization process … volunteerism is often constructed passively … such social constructions of political action are central to our understanding of the role of voluntary labor in enabling

> states and, more specifically, in international development NGOs. If voluntary labor is depoliticized, the agency of the volunteer is effectively negated. Volunteerism thus easily becomes a neutralized act
>
> (Lacey & Ilan, 2006, p. 38).

Differences between the universal and HCV-affected volunteer identities can reflect a division between a potentially depoliticised and a politicised volunteer base. Such a dichotomy is informed by the types of knowledge volunteers can bring to the organisation. Distinctions between expert and experiential knowledge, and their connection to the idea of "identity politics", are important here. In discussing "identity politics and expertise" in a HCV CBO, Carey (2007) unwraps some of these issues. In reporting the different uses of the term 'identity politics' among neo-Marxist, New Social Movement and postmodern approaches, Carey notes that what these approaches have in common is the 'belief that identity is important to social movements' (2007, p. 112). Consistent with Brown (1997) and Chambre (1991), Carey refers to identity politics within a CBO context as 'the practice of imparting knowledge, services and support along the lines of identity' and, furthermore, that shifting notions of expertise (from experiential to expert) within a CBO can impact on the benefits that identity politics within an organisation may bring (2007, p. 112).

Carey also reports on a shift in service delivery and volunteer policy at a HCV CBO, which was explained by workers at the HCV CBO as 'working with workers instead of working with the community' (2007, p. 119). While it was noted that this shift accompanied a reduction of volunteer duties within the HCV CBO, the shift also allowed people who were not affected by HCV to volunteer. Those not affected by HCV are seen here to be valued as they bring a "ready-made" set of skills and expertise into the CBO, overcoming "resource drainage" that would result if the HCV CBO were to develop such skills among HCV-affected persons (originally without such skills) (Carey, 2007). Yet this perspective overlooks strategies practiced by other CBOs to develop the skills of members with direct and relevant experiential knowledge, while minimising "resource drainage". For example, an Australian sex worker CBO, Scarlet Alliance, develops leader skills within their sex worker-identified membership through 'double positions', seeing, for example, a newer or less experienced member elected as a 'double' to each elected Executive Committee member, with the more experienced member training the less experienced one in the roles and responsibilities of CBO governance, among other things (E. Jeffreys, personal communication, June 28, 2012; see also Scarlet Alliance Strategic Plan 2010-2013, p. 7-8).

The issue of identity politics within CBO membership/volunteers raises broader concerns about 'the community-based nature of the organisation, and the values and work which should be associated with' CBOs – values that see social justice ideas and identity politics at times convene (Carey, 2007, p. 122). In discussing the combination of identity politics and service provision in an HIV/AIDS community organisation, Brown (1997) claims that such a combination can increase accessibility and is critical to service delivery. Findings from Chambre's (1991) study on HIV/AIDS volunteers speaks to the role identity politics can also have in contributing to volunteers being poised for mobilisation if needed. That is, when a problem emerges (such as new state policies seen as negative), service delivery volunteers can "double up" as activists to mobilise resources and people to address the problem at hand.

As reported earlier, experiential knowledge of those HCV-affected is important for the production of narrative communitas in terms of the development of alternative socio-politically informed HCV narratives which can critique and counter dominant narratives about HCV. This experiential knowledge contribution ties in with issues of representation (helping address representational silence concerns). In claiming to represent those affected by HCV, then besides quantitative measures such as HNSW membership numbers, HNSW use and circulation of experiential knowledge, whether they critique dominant HCV narratives or not, is important. If experiential knowledge is increasingly replaced by expert knowledge and 'professional expertise' then, as Carey highlights, this raises broader questions about 'what kind of organisation the [CBO] will be in the future' (2007, p. 112).

Furthermore, Considine (2003) notes the conflicting philosophies that could arise when state funding is used to replace CBOs volunteers with paid workers. Concerns about the ability of CBOs 'to work with people marginalised from the government and market sectors' may also emerge as a result of these changes (Carey, 2007, p. 139). Nonetheless, there remain roles and experiential (counter)narrative spaces within HNSW that allow those affected by HCV to volunteer their skills and their voice to help others. Nick and Andrew's community-mutualist identities attest to this, as both spoke of HNSW experiential narrative spaces informing their volunteer identities, and for Andrew, providing a sense of community. This adds weight to the importance of developing these roles and spaces for those HCV-affected and (re)instantiating HNSWs' relations to the idea of the "HCV community". Accordingly, there is recognition within HNSW concerning the value of mobilising HCV-affected volunteers for advocacy-related work, as key informant Michael makes clear in extract 10 below. Michael's utterances: "what I'd like to see more of" and; "I think we can do better" indicates that current levels of active membership by those affected by HCV are viewed as inadequate.

Extract 10. HNSW key informant: Recognised value of mobilising identity politics within HNSW membership.

> In fact if anything what I'd like to see more of is a more grassroots approach to advocacy involving members at a local level but coordinated so memberships involving members coming together as well, I'd like to see more of it. I think we can get better across NSW in terms of a more membership, individual-peer however you want to describe it, approach.
>
> (Michael, HNSW key informant interview)

Since data was collected for this thesis, there have been moves by HNSW towards the notion of community-mutualist and volunteer-based politicised identities. Once example of this is the introduction of a peer-based telephone service called *Hep Connect*, through which volunteers' experiential knowledge is directed towards helping callers deal with a sense of isolation and various treatment-related difficulties. More recently, the *C me* advocacy project was created, which aims to empower and develop the skills of local community advocates. Such strategies are likely to bolster narrative communita elements within HNSW and assist in creating more community- or collectively orientated HCV identities and volunteer behaviour, perhaps similar to those enacted by Nick and Andrew.

The issues of marginalising alternative HCV and volunteer narratives, depoliticising volunteers, and related narrative communitas containment, correspond to an important tension, as expressed by HNSW key informant Alice in extract 11. For the purposes of this thesis, this tension expresses itself through the asymmetry of structure and anti-structure, dominant and alternative narratives constructed and circulated by HNSW through the *Hep C Review.*

Extract 11. Social research/literature: Depolitising CBO volunteers

> You know where the tensions do lie in that for us…..the story goes that because we're not a peer-based service, although we have and have had people with hep C working here and clearly all the 'Ceen and Heard' and all the 'Hep Connect' stuff are people living with hep C but we're not specifically a peer-based service. So the story goes there is a tension between us and peer-based NGOs because they say you don't really know what it's like so how can you represent people living with Hep c because you don't know.
>
> (Alice, HNSW key informant interview)

In the following section I conclude by examining how the contemporary climate in which CBOs find themselves contributes to the above reported elements, which work to constrain prospective narrative communitas elements. I also discuss what this might mean to individuals affected by HCV.

CONTEMPORARY SOCIAL-POLITICAL ENVIRONMENT AND NARRATIVE COMMUNITAS CONTAINMENT

Extract 12. Social research/literature: 'the issues of power and politics is ever present'

> But theatrics are tenuous, and liberation and change is far from guaranteed. While organizations themselves are becoming more fragmented, polyphonic (many voiced) and collectively produced, and we would like to think that as modernist organizations make way for postmodern organizations, dominant narratives must make way for multiple stories. The issues of power and politics, along with the marginalization and silence of alternative discourses and antenarrative are ever present.
>
> (Boje et al., 2007, p. 70)

As discussed in Chapter Four, civil society organisations have been subject to growing scholarly debate in relation to the challenges they face as a result of being increasingly positioned to mediate their liminal position between the state and communities, and how this may affect their practices and members (Onyx, 2008; Carey, 2007; Lyons, 2001; McDonald & Marston, 2002; Rose, 2000). While this thesis contends that such positioning can be understood as a productive liminality, giving rise to CBO distinct expertise, this section considers that this same liminal positioning might also jeopardise this distinct expertise.

As reported in Chapter Four, the conditions that implicate HNSW in state-CBO relations include the fact that HNSWs' current primary funder is the NSW government; the other, less tangible, condition stems from HNSWs' health-orientated nature, meaning that 'it is also subject to the influences of medical institutions that in turn have their own complex relationships with the state' (Carey, 2007, p. 134). Such conditions are to a degree formalised within the National Hepatitis C Strategies, heavily imbued with "partnership" rhetoric (Pugh, 2006). A self-defined HNSW "core value", which points to the idea of negotiating HNSW-state relations, is: 'Working from a strong evidence base that draws from both research based evidence and community and stakeholder input' (HNSW, 2006a, p. 5; see also HNSW, 2011a). This indicates that HNSW work is informed by a negotiation of three "inputs", or social domains.

In examining organisations like CBOs which are positioned between the state and civil society, Sending and Neumann (2006) argue that such organisations may both resist and perpetuate state agendas. Carey states that 'the power of the state also acts upon organisations themselves causing them to self-regulate in accordance with government perceptions and objectives' (2007; 133), while Pugh calls for further research regarding any 'controlling effect that contracting HCV CBOs to deliver public health services has on the free expression of CBOs' (2006, p. 130). Looking at such influences at a HCV CBO, Carey (2007) suggests the CBO self-regulates in order to maintain its relationship with the state. This manifests through ‘adapting projects, appearance and information for distribution to suit government objectives and policy’ for as if the ‘Council does not self-regulate, it faces the possibility of losing funding’ (Carey, 2007, p. 139). I contend that these adaptations extend to buttressing expert knowledge and narratives that align with dominant public sector HCV narratives and identities.

Interviews with HNSW key informants point to a requirement for HNSW to discursively mediate state funder policy objectives. This is most explicitly represented through a “signing off” process by NSW Health of resources produced by HNSW. In a sense, this requires HNSW narratives (and by extension HCV identities) to be ratified by the state. Extract 13 below suggests that HNSWs’ autonomy appears undermined, challenging the “point” of the existence of non-government organisations.

Extract 13. HNSW key informant interview: “the whole point of an NGO”

> Any resource as well as being peer-reviewed and quality assurances internally, has to be reviewed through NSW Health. There was a process of sign off. If we produced a poster or a leaflet which I find it quite interesting as the whole point I thought in funding of an NGO is so that they potentially can do things you can’t and the fact you have to have sign off cause of some political decision somewhere is very interesting.
>
> (Michael, HNSW key informant interview)

This process of state ratification is likely to help privilege state-endorsed dominant HCV narratives and identities and impact on the kinds of social advocacy narratives and identities produced by the *Hep C Review* produces. Pugh notes that advocacy by HCV CBOs may be limited by the Federal Government’s ‘strategicallyoriented approach, which links funding to performance' (2006, p. 110). Michael further touches on this issue in in extract 14 below, in terms of citing a risk management understanding of "good" CBOs.

<u>Extract 14. HNSW key informant interview: advocacy risk management.</u>

> I think any sensible organisation needs to assess risk on an ongoing basis and there are potential risks around advocacy cause you're getting into the realm of politics, you're getting into the realm of potential conflict and dialogue and so I think a good organisation will assess that in an ongoing basis.
>
> (Michael, HNSW key informant interview)

An outcome of such risk management arguably manifests in self-regulation by 'adapting projects, appearance and information for distribution to suit government objectives and policy', for as if the HCV CBO 'does not self-regulate, it faces the possibility of losing funding' (Carey, 2007, p. 139). Yet in extract 15, Carl states that the threat of losing funding has not seen HNSW shy away from a chosen advocacy position.

<u>Extract 15. HNSW key informant interview: State funding not affecting HNSW advocacy</u>

> I don't think anyone can say that's totally irrelevant of them, it's a case of balancing the risks involved. I don't think we've every purposefully chosen a position solely on the basis that it would threaten our funding. It's a case of balancing the risks involved.
>
> (Carl, HNSW key informant interview)

However, the interpretation of what constitutes advocacy should be considered. Pugh, in discussing the meaning of HCV CBO advocacy from the states perspective, notes that ‘it is not clear if the advocacy role that the Department envisages for community groups is a consultative role, or whether the term refers to “robust” debate of public policy in a bid to influence outcomes of public health decision-making and policy formulation’ (2006, p.126). Thus there may be a degree of freedom in choosing a HNSW advocacy position; however, whether this is taken up by and influences the state or acts as mere consultation requires further investigation.

In extract 16, key informant Michael also talks of a strong relationship with state funders, while minimising the claim of any state intrusion into HSW affairs.

Extract 16. HNSW key informant interview: State funding not affecting HNSW advocacy

> So by the fact the majority of your funding [is from the state government] I think demonstrates its [HNSW] strength - demonstrates the partnership and collaboration between the two bodies. I think there is always the potential risk on how much role the funder has in service delivery and strategic direction I think the balance is a good balance in terms of my experience with NSW Health um, I wouldn’t say hands off but they aren’t as, what’s the word I’m looking for, it’s not an intrusive relationship I guess.
>
> (Michael, HNSW key informant interview)

While losing funding may not be a salient issue for HNSW, its relationship with NSW Health (combining state and expert medical authorities) is likely to have more nuanced discursive effects in terms of the kinds of HCV narratives and identities it produces. The connection made between state-CBOs relations and CBO discursive regulatory effects is examined further by returning to the concept of culture governance.

Culture governance provides a lens through which to consider some of the processes underlying this connection.

Culture governance and reinstantiating utilitarianism

As outlined in Chapter Four, the social approaches of the state have been increasingly challenged from all sides of the political spectrum. Ideas of the enabling state have emerged from this political landscape, whereby the ‘community orientated aspects’ of the so-called Third Way attempt to create some ‘novel links between the personal and the political’ (Rose, 2000, p. 1398). Bang (2003) and Dean’s (2003) work speaks to these novel links within a Third Way context, providing an interpretative lens for understanding the containment of HNSW narrative communitas and what this might mean to people affected by HCV.

As reported in Chapter Four, Bang (2003c, p. 241) and Dean (2003, p. 117) both present the term ‘culture governance’ to refer to how network and partnership relations between the state and CSOs are helping to rearticulate the relationship between political authorities and lay people through governance. Culture governance involves key staff and authority figures within public sector and CSO partners/networks/systems, or culture governors, promoting practices ‘to socialize and regulate people’s conduct in an indirect manner by working on their identities and thereby their values, feelings, attitudes and beliefs via a variety of new interactive modes of dialogue and co-operation’ (Bang, 2003c, p. 247). The goal of culture governance is to achieve ‘effective outcomes’ by way of getting ‘people freely and willingly to employ their self-governing powers for the strategic purposes of success and influence within the configurations of the system, political regime and its governance imperatives (Bang, 2003c, p.247).

The concept of “effective outcomes” within HNSW-state relations or partnerships derives from the National Strategies, which work at linking state ‘goals and priorities for safeguarding the Australian community from the hepatitis C epidemic to the performance of the public sector’ and agents within partnership arrangements (Pugh, 2006, p.145). Thus, ‘the professional practices of public health - particularly evidence-based practice and performance measurement’ are heavily implicated (Pugh, 2006, p. 267). The privileging of these kinds of knowledge is likely to constrain the types of practices promoted by the state and HCV-related CBOs. In extract 17, Pugh (2006) contextualises this by referring to constraints on funding arrangements with NGOs.

Extract 17. Social research/literature: Culture governance and restricting CBO practices.

> Knowledge from this point of view derives from measurable data. In the Strategy the terms “outcomes” and “health outcomes” collocate with “measuring”, “monitoring”, “evaluation” and “the best available evidence”. The ideological and dominant assumptions embedded in such language are commonly found in professional sites such as biomedical institutions (including public health) and those of business or commerce. What can be seen and measured is considered legitimate and is privileged over what is spoken, heard and felt or intuitive. The written word is also privileged over the spoken. This, in turn, constrains the types of activities or practices and types of data that are monitored and evaluated and, hence, promoted and funded within Commonwealth – state/territory funding arrangements (and subsequent Commonwealth funding arrangements with non-government organisations (NGOs) and state/territory–NGO funding arrangements).
>
> (Pugh, 2006, p. 147-148)

Drawing from Pugh (2006) in extract 17, the ideological and dominant assumptions embedded within the culture governance goal of effective outcomes, find expression within dominant HCV medicalised and health consumer identities. Hepatitis C CBOs represent culture governance sites where the more measureable and tangible ideas of treatment and self-management, priorities of the public sector, convene with individual morality and organisational responsibility towards an incitement of the ethical community (McDonald & Marston, 2002; Boyle & Rodgerson, 2006). Such an "ethopolitical community", to draw from Rose (2000), relies on public sector narrative identities as informed by health consumerism and biomedical expertise, as such identities champion the presumption of the double ethical movement of autonomization and responsibilization – presumptions that are seen to help materialise effective outcomes via an individualist ethos. However, there are even likely to be further morality-related restrictions attached to narratives encouraging health consumer identities, as reported by Winters et al. who, in a technical review of HCV health promotional resources, indicate that CBOs 'may be restricted by the perceived moral implications of providing considerable detail in directing the (safest) preparation and consumption of illicit drugs' (2011, p. 7). Nonetheless, such culture governance processes can be seen to work at reinstantiating a utilitarian logic towards achieving effective outcomes within the expressive domain of CBO member identity formations.

Concerns attached to this reinstantiation of utilitarianism, through ethopolitical community building, include social exclusionary effects. In extract 18, Bang (2003, p. 251) highlights this using a culture governance focus.

<u>Extract 18. Social research/literature: Culture governance and restricting alternative identities.</u>

> It is the culture governor, who does pay respect to lay people as subjects of knowledge, but who simply cannot see that there can be other logics than the strategic one of success and influence. When, say, leaders and managers of voluntary organizations drop their old oppositional identity and enter into partnership with political systems on culture governance conditions, that is, for effectively producing outcomes, they become one

> more sub-elite in such systems. This need not be a problem for democracy, since it can help to expand pluralism further and establish new access points for ordinary people to the going regime. The problem only emerges if one forgets that voluntary associations are not only, and not even primarily, the terrain of elite activities joining the organized programming of decisions and action on the terrain of the political regime and political authorities. It also comprises all those individuals and collectivities in the political community who choose to try to exercise their political influence more indirectly, whether as oppositional movements fighting 'the system' or as everyday makers who rather want to create and enjoy their own small tactics, when they feel like it and when they can afford the time to do it.
>
> (Bang, 2003, p. 251)

The most concerning scenario here it that those who cannot, or 'refuse to become responsible and govern themselves ethically', those who challenge the logic of culture governance and its promotion of dominant HCV identities, 'have also refused the offer to become members of our moral community' (Rose, 2000, p. 1402). Thus, membership of this moral community may be granted to some over others. As McDonald and Marston state, 'participation is presented as an unmitigated and unproblematized good, which conveniently ignores the wealth of community development knowledge that alerts us to the potential exclusivity of social participation' (2002, p. 385).

In the context of HNSW, 'exclusivity of social participation' (McDonald & Marston, 2002, p. 385) may speak to those who are better equipped, resources-wise, to be able to adopt self-administrative regimes behind health consumer identities. Elements reported earlier indicative of the marginalisation and management of HCV alternative narratives and identities within the *Hep C Review* (e.g. the prevalence of health consumer narrative identities in contrast to counter-narratives and identities, reader story topic selection, differences between editorial- and reader story-produced social advocacy identities and the promotion of the universal volunteer) may then work to characterise HNSW membership as socio-economically advantaged and depoliticised expert health consumers and universal volunteers. Particular people, practices and identities may therefore come to dominate, which in turn may guide social and moral norms within, the HNSW. Similar to Pugh's (2006) critique of the rhetoric of government-incited "partnership" within national HCV Strategies, which obscures the way expert and formal discourses and social networks constrain participation of those affected by HCV, rhetorical conceptions of the health consumer and also the (HCV) "community" can work to obscure the processes which work towards social exclusion and "polarisations" (McDonald & Marston, 2002). Claims on being "based" in the community" become tenuous, the "voice" of the community becomes diluted, delegitimised (Orsini,

The power and politics that Boje et al. (2007) talks of in extract 12 plays out through culture governance processes and through their incitement of ethopolitical communities. Such processes ultimately may jeopardise HNSW narrative communitas elements and promote social exclusionary effects, thus threatening what bestows HNSW with its distinct expertise. The contemporary socio-political climate that has seen many CBOs increasingly positioned to mediate their liminal position between the state and communities (Onyx, 2008; Carey, 2007; Lyons, 2001; McDonald & Marston, 2002; Rose, 2000) thus presents a tension. While this thesis has argued that such positioning can be understood as a productive liminality giving rise to CBO distinct expertise, this same liminal positioning may also jeopardise this distinct expertise.

CONCLUSION

In this chapter I drew from the dominant and alternative HCV narrative identities presented in Chapters Six and Seven to assess and articulate HNSW distinct expertise in terms of the narrative communitas model developed in Chapters Three and Four. Drawing from HNSW key informant interviews, I discussed HNSWs' position between state and community by way of negotiating or "balancing" types of HCV knowledge and narratives within the *Hep C Review*. I extrapolated this idea of "balance" in terms of discussing the expression and containment of HNSW narrative communitas elements.

The expression of HNSW narrative communitas elements was discussed by way of members' social-liminal and community-mutualist identities and the tentative post-HCV/residual identity link between them. I then reported on containment of narrative communitas elements through the management and marginalisation of alternative HCV narratives and identities by HNSW and discussed this containment in light of the contemporary social-political environment to which CBOs are subject. The notion of culture governance was revisited to put forward the idea that the contemporary socio-political environment may see CBO-state relations result in HNSW privileging dominant state ratified HCV identities at the expense of marginalising and managing alternative identities, in service of the strategic purposes of success and influence within the configurations of the system, political regime and its governance imperatives.

Consequently, the culture governance process, through its incitement of dominant HCV medicalised and health consumer identities within HCV (ethopolitical) communities, is likely to jeopardise HNSW narrative communitas elements, thus threatening what bestows HNSW with its distinct expertise. Thus in interpreting findings against the narrative communitas model, a tension is highlighted - a tension that sees a CBO’s liminal position between state and “community” both work at facilitating and work at containing its distinct expertise.

CHAPTER NINE

CONCLUSION

This thesis investigated the notion of the distinct expertise of a HCV CBO in relation to facilitating responsive HCV identities among its members, and responded to the paucity of research concerning HCV CBOs and the mediation of HCV identities, as well as understanding CBOs beyond traditional utilitarian approaches. This was achieved through developing a “narrative communitas” model of CBO distinct expertise, which provided a framework for investigating how a HCV CBO could realise, or could be realising, the specific elements and processes that underpin its distinct expertise. Findings revealed prospective narrative communitas within HNSW textual spaces that in turn facilitated responsive HCV identitities (i.e. “social-liminal” identities and tentatively, community-mutualist” identities) among some participants, namely those undergoing treatment, or those who had “cleared” HCV. However, it was also found that such narrative communitas spaces appeared to be compromised by the marginalisation and management of alternative HCV narratives and identities by the HNSW. This compromise was seen to be a negative effect stemming from state-CBO governance relations. As such, this thesis demonstrated a challenging dialectic for the HNSW: that the liminal positioning of the HNSW between the state and “community” may *both* facilitate and threaten its distinct expertise.

Before articulating further on the conclusions of this study in relation to the research aim and question, as well as implications for and directions of future research, the limitations of this study are firstly acknowledged in order to qualify findings and interpretations. As reported in Chapter Five, the research is qualitative and inter- or transdisciplinarily informed. This allows for a number of different theoretical approaches or lenses to be applied to the research aim. Due to the confines of a thesis, I narrowed my approach to the theoretical area relating to narrative ideas of identity and organisations, keeping in mind that no single approach can capture all elements that are likely to be at play. This choice was informed by a number of factors: reviewing literature on identity and CSOs; my undergraduate background in psychology and working with marginalised people identified as part of a "community", as well as for a civil society research centre wherein an appreciation of identity in a CSO context emerged.

One limitation in choosing a narrative approach is that it forsakes the consideration of non-textual/discursive elements which can arrive at the site of identity formations and organisational practice (e.g. non-verbal communication among individuals and HNSW programs and services constituted through non-textual and discursive elements outside the *Hep C Review*). Another possible limitation of using a narrative lens to look at identity stems from its social constructionist premise. This becomes a question of how such an approach to research design and method of analysis constructs the data and the findings. Essentially this is about my constructions of others' constructions and the factors that might influence my preferential selection of particular constructs over others. It is therefore acknowledged that my own experiences and relations with CBOs, infectious disease and drug use, as well as my beliefs, left-wing political commitments and the management of my research "stakeholders" perceptions, among other things, have likely shaped my constructions and interpretations within this study. However, this acknowledgement should be read within the context of what Lincoln and Guba refer to as a ‘new-paradigm (of qualitative) inquirers’ where the issue of study control and claims to objectivity are less problematic than they are for conventional positivist inquirers (2000, p.175).

Limitations within the data corpus should also be acknowledged. While in Chapter Five I acknowledged the issue of abandoning an ethnographic component to the methodology (in terms of observing HNSW board meetings) and the accessibility and diversity of practice of the data corpus, I should add here that the relative small number of, and potential bias in, research participants also invites caution when interpreting findings. More participants could potentially add to or strengthen the identified themes and components that informed the identity templates (or not) presented in Chapters Six and Seven. Additionally, those who consented to be interviewed may reflect an agency bias, in that those who are more actively negotiating HCV in their lives may be more likely to participate in this research.

The selected HNSW text may also carry limitations in regards to representations of HNSW public narratives and their constitutive elements. All texts in the *Hep C Review*s that potentially represented alternative or counter-narratives to dominant ones as constructed by those affected by HCV were selected. However, expert health identities and one style of social advocacy identity were identified within editorial texts and some-news related articles. This means that the remaining *Hep C Review* (which mostly include feature articles and numerous ‘abridged’ news articles usually derived from expert knowledge) were excluded from analysis. Thus other kinds of narratives and identities that are likely to be constructed and interpreted were not represented in this study. With these limitations in mind, I now summarise some of the conclusions of this study in relation to the research aim and question, against which the narrative communitas model has been developed.

Investigating the notion of the distinct expertise of a hepatitis C community-based organisation

In presenting a background to HCV in Chapter Two, attention was drawn to how HCV lived experiences can be understood through the lens of identity (re)formations, as mediated by interweaving individual and collective interpretations of HCV and illness. Relational settings such as the public (health) sector and CSOs like CBOs were highlighted as important sites in mediating such individual and collective interpretations of HCV and thus HCV identities. It was argued that this compels an examination of the kinds of public narratives HCV CBOs produce, and that such narratives must be considered in light of state- and public health-led conformity pressures, as highlighted by Carey (2007), Pugh (2006) and Krug (1995).

The issues raised in Chapter Two were centrally considered in Chapters three and four in developing a narrative communitas model to investigate CBO distinct expertise. This model linked questions of HCV identity formations and HCV CBOs' relational position between the state and the "community". This was achieved by combining the conceptual and methodological approach of "narrative" together with the idea of "liminality" to present the notion that the distinct expertise of CBOs lies in their capacity to facilitate what I have termed "narrative communitas" spaces, which in turn provide productive potential for mediating responsive HCV identities among CBO members. Although CBOs' liminal position between state and community was conceived as a productive potentiality in terms of the multiple and opposing narratives

CBO produce, allowing individuals to scrutinise and experiment with factors that may lead to new and responsive identities, Chapter Four considered the potentially negative aspects of this liminal positioning in terms of how contemporary socio-political forces and (culture) governance relations may see the privileging of dominant HCV narrative identities and the suppression of alternative ones, thus threatening CBOs' distinct expertise as narrative communitas spaces.

The narrative communitas model informed the kinds of data that were collected in order to meet the aim and research question. Hepatitis NSW texts (*Hep C Review* publication), HNSW member interviews, HNSW key informant interviews, and social research/literature were analysed and/or drawn upon to articulate upon the dominant and alternative HCV narrative identities and the realisation and negotiation of these narratives identities by HNSW and its members, while also considering the possibility of state and HNSW governance effects.

Chapters Six and Seven presented dominant and alternative HCV identity templates. Chapter Six presented extracts from the *Hep C Review* and HNSW member and HNSW key informant interviews, exhibiting utterances and narratives that drew from discourses and linguistic devices which taken together, pointed to dominant HCV identities, termed "medicalised" and "health consumer" identities. Social research and literature was also drawn upon to support the presentation of, and claims made about, HCV dominant identities. Chapter Seven achieved the same thing, but for alternative HCV identities. Alternative HCV identities presented were illustrated to be socially and experientially orientated in relation to: *Hep C Review* editor/s' and readers' enactment of HCV advocacy positions (social advocacy identities); HNSW member-participants mediating treatment related liminality (social-liminal identities); and HNSW member-participant reasons behind HNSW volunteering, which evoked ideas of mutual-help and a sense of “community” (community-mutualist identities).

Chapter Eight drew from the dominant and alternative identities discussed in Chapters Six and Seven to illustrate prospective HNSW narrative communitas elements according to the model developed. Such illustrations rested on a conception of CBOs as multiple-story telling and institutionally liminal social arenas. One expression of this liminality concerns the production and circulation of multiple and opposing HCV narratives. It was then illustrated how some HNSW stories or narratives corresponded to dominant HCV narratives, aligning with social structure, while other stories represented alternative counter-narratives, thus corresponding to anti-structure, in Turnerian terms (Turner, 1969). As such, the *Hep C Review* was shown to represent a prospective narrative communitas substructure or foundation speaking to cells 1(b) and 2 (b) in the model (see page 214). While Boje (1994) conceives of, or at least infers that, multiple organisation narratives as carrying unproductive elements for business sector organisation, this prospective narrative communitas substructure was considered in terms of its productive potential, instantiating HNSW as a distinct cultural agency.

In what ways does a hepatitis C community-based organisation facilitate the construction of responsive hepatitis C identities among those who engage with it?

Responsive identities among participants were presented as “social-liminal” and “community-mutualist” identities. Looking at social-liminal identities, the substructure of narrative communitas spaces, as located within the *Hep C Review*, was shown to provide productive potential for participants experiencing intense liminality as a result of treatment. This saw participants Bree and, particularly, Jacqui draw from and scrutinise *Hep C Review* reader stories. For Jacqui, stories representing both dominant ("biomedical poster" story) and alternative ("biographical work" story) HCV narratives were scrutinised in order to examine factors that seemed relevant to her past and present personal and social circumstances. Jacqui's story was thus seen to mark the productive potentiality of HNSW narrative communitas elements through the mediation of both structure and anti-structure story elements, oscillating between both, yet gravitating towards a story that indicated the historical and social constitution of a person and HCV lived experience. As a more socially orientated understanding of HCV and treatment experience was indexed in Bree and Jacqui's stories, which helped mitigate or guide them through an intensive liminality, the identity label of "social-liminal identity" was used. As such, social-liminal identities represent a responsive HCV identity and were shown to be facilitated by HNSW via the idea of narrative commuita spaces within the *Hep C Review* – thus lending support to the model. However, it is worth noting that from all member interviews conducted only the stories told by Jacqui and (tentatively) Bree were seen to correspond to the central premise of the narrative communitas model here presented. This is possibly due to the more noticeable HCV treatment-informed limnality they presented, which likely saw a more unconcealed need or effort to engage in HNSW narrative communitas spaces. Thus, while the narrative communitas model may (or may not) find support from other members who experience liminality more subtly and outside of the treatment episode, the methodology employed may be limited in terms of finding support for the model only through members with more salient expressions of liminality.

Participant "community-mutualist" identities were viewed as responsive for those who had "cleared" HCV. A tentative connection was made between such identities and the narrative communitas model based on the importance of alternative experiential narratives spaces (be they found within reader stories or the *Ceen and Heard* speaker program), as well as to Bree's social-liminal identity enactment in terms of addressing a post-HCV residual identity through volunteering. Community-mutualist identities highlighted the role that may be played by previous help received from HNSW, as well as previous identities (in relation to drug use) and "community" engagement (i.e. involvement with non-profit associations) in the formation of responsive identities – identities that illustrate a sense of HCV community. Accordingly, this supports the importance of considering an individual's social history within deliberations of whether and how narrative communitas elements may facilitate responsive HCV identities.

Investigating the factors that help express and constrain the distinct expertise of a hepatitis C community-based organisation

Although participants' social-liminal identities (and tentatively community-mutualist identities) were seen to express or mark a productive potentiality of HNSW narrative communitas elements, Chapter Eight also considered how narrative communitas elements were somewhat contained within the *Hep C Review*. Such containment was illustrated through an asymmetrical expression of structure and anti-structure, in particular, the prevalence of medicalised and health consumer identities and the management and marginalisation of alternative and volunteer identities which are socially and experientially constituted.

This expression and containment was linked to the theme of "balance" that was identified within HNSW key informant interviews. Although key informants saw a reasonable balance of narrative types within the *Hep C Review*, there was also acknowledgement that there was room for improvement in terms of more "community" input – input of a social and political nature. Further, one key informant also spoke of a 'tension' around HNSW being viewed by those external to the organisation as more of an expert's CBO rather than a peer-based CBO. This acknowledgement likely relates to recent moves within HNSW (albeit outside of the *Hep C Review*) to introduce further services and programs centrally dependent on the experiential knowledge and stories of individuals affected by HCV.

The idea of CBO culture governance was presented in order to interpret why the HNSW appears to privilege dominant state HCV narratives and identities over alternative ones. Culture governance in this context was articulated in terms of CBO relations with the state, whereby strategic practices directed at success and influence within the configurations of the system, political regime and its governance imperatives materialise. Consequently, culture governance processes through their incitement of dominant HCV medicalised and health consumer identities within HCV (ethopolitical) communities, were seen likely to threaten HNSW narrative communitas elements and thus what bestows HNSW with its distinct expertise. Such culture governance processes were also seen as reinstantiating a utilitarian logic towards achieving effective outcomes within the expressive domain of CBO member identity formations. Such discussion led me to conclude that within the narrative communitas model lies a tension - a tension that sees a CBO's liminal position between state and "community" both work at facilitating and containing its distinct expertise.

Implications and directions for future research

The implications of this study highlight the challenges HCV CBOs face and are tied to proposed future directions for research. These are presented under the categories:

1) HCV identities; and 2) conceiving distinct expertise of health CBOs, as informed by the research question and aim respectively.

Hepatitis C identities

Multiple HCV narrative identities were constructed within HNSW texts and by the members interviewed. Most of these identities were dominant medicalised and health consumer identities, yet others diverged from dominant models, expressing identities that were socially and experientially orientated, constituted by a diversity of discourses (that in some instances also incorporated biomedical understandings, such as the medicalisation of drug use). This not only illustrates the hegemonic forces attached to biomedicine and the state via public health institutions, but also how HCV CBOs like HNSW and their members appropriate, transform and/or challenge such forces to generate alternative HCV narratives and identities which reflect a diversity of biosocial expressions. However, some HNSW biosocial expressions trod carefully around particular advocacy topics (e.g. prison reform within the *Hep C Review* "editor's intro") and worked at excluding current IDUs and prisoners. Further, there were attempts to "manage" biosocial expressions within reader stories through topic selection, and the promotion of "universal" volunteer identities by HNSW – topics and identities conducive to state priorities or mitigating member resistance to such priorities. Other HNSW biosocial expressions (seen through the *Hep C Review* reader stories) informed by a diversity of socially and politically informed discourses, more overtly challenged dominant understandings of HCV. Nonetheless, this highlights a challenge faced by HNSW in terms of speaking to, and being inclusive of, a heterogeneous membership, coinciding with being subject to potential culture governance effects.

A key implication in relation to the prevalence and promotion of dominant health consumer identities within HNSW textual spaces, with its presumptions of autonomy and self-responsibility, involves the inherent contradiction between health promotion/self-management narratives attached to the health consumer and the structural inequalities of many affected by HCV – thus assuming many resource-poor individuals to be resource-rich in order to excel at becoming successful health consumers. This contradiction requires further investigation as if overlooked, it is likely to result in the encouragement of the HCV community as an ethopolitical community (Rose, 2000, 2007), that in turn may facilitate another type of social exclusion among those who do not have the resources or "ambition" to successfully adopt the health consumer identity. This is likely to present a sizeable and important challenge for CBOs like the HNSW. Meeting such a challenge may be aided by allowing more production of, and attention towards, alternative and experiential HCV narratives that sit beside these dominant HCV narratives and identities, thus creating fertile ground for further narrative communitas spaces to materialise and the productive potential that can result from such spaces.

Another implication of this research that demands further investigation relates to the intensive liminal experience that can accompany treatment and the tentative relationship life after treatment may have with residual HCV identity work and HCV volunteering and community development. Specifically, relations between illness liminality, treatment, mutual-help and building a sense of community that may result in socio-political awareness and influence warrants further investigation. Olson et al.'s (2005) application of the transtheoretical model of recovery and change to a CBO context was drawn upon to suggest a relationship between narrative communitas elements and "social liberation", and possibly provides a productive starting point here.

Research under this approach should also investigate how change and socio-political awareness differs among members within different experiences of treatment and at different stages of recovery during and after treatment.

Conceiving distinct expertise of a health-orientated community-based organisations

In developing and "testing" a model of CBO distinct expertise that centrally links members' illness experience to CBOs' relational position between state and "community", this study responded to calls to move beyond traditional understandings of CBOs that are located within economic and utilitarian approaches which, according to Lehman, reflect a 'commodity fetishism' (2007, p. 652). This study helps illustrate that health-orientated CBOs complicate traditional understandings, as people who engage with health and HCV CBOs do so not only for service access, but also for biosocial and identity reasons to help, and learn from, others in order to answer questions such as 'who am I?' and 'who can I and we hope to become?' as a result of illness/HCV. This is especially important given Rose's (2007) concerns about the rise of biological citizenship in recent decades and what some expressions of biological citizenship may presume about the worth of different people and lives. Within this context, biomedical discourses and their reproduction within relational settings like CBOS have 'extended choice to the very fabric of vital existence' (Rose, 2007, p. 254), In doing so, 'we are faced with the inescapable task of deliberating about the worth of different human lives - with controversies over such decisions, with conflicts over who should make such decisions and who should not, and hence with a novel kind of politics of life itself' (Rose, 2007, p. 254). Such ethical and political questions require attention and scrutiny within CBO spaces, particularly in the context of HCV whereby some of those at risk of HCV, those who use illicit drugs and those who are incarcerated, are likely to be misconstrued and/or devalued within judgements attached to particular expression of identities attached to illness. Narrative communitas spaces provide a potential to unwrap and critically engage with these important issues.

A narrative communitas model also provides new insight into particular anxieties surrounding the idea of sector "blurring" or a hybridity between public and civil society sectors, which commonly relates to viewing CSOs with "rose-tinted glasses" as social arenas that have monopoly on virtue. Instead, a narrative communitas model can provide a framework that allows us to examine in more nuanced ways the potential impact state governance relations, or culture governance, has on CBO practices and what this means to CBO members.

It also suggests a challenging dialectic: that the liminal positioning of CBOs between the state and "community" may *both* facilitate and threaten their distinct expertise: facilitate in terms of producing and circulating both dominant state-endorsed and alternative socially orientated organisational narratives within spaces that encourage scrutiny and experimentation by members; threaten by way of state and expert power deploying culture governance processes that see the marginalisation and management of alternative narratives in order to achieve effective system-orientated outcomes. The narrative communitas model thus supports and articulates Sending and Neumann's (2006) argument that CBOs have the capacity to both resist and perpetuate state agendas, yet it does so by providing a new lens for understanding this challenging dialectic.

A potential research avenue for exploring how culture governance processes contribute to this challenging dynamic, concerns investigating other ways to conceptualise a CBOs "effectiveness" and to advocate for other measures of effectiveness within state-CBO partnerships and networks. Evaluating and measuring the ‘effectiveness’ of CBOs in this sense would require a reconfiguration of the idea of “effective outcomes” away from public sector and culture governance logics towards new civil society sector logics. Such a position is supported by Carey who states that ‘in understanding their distinct political and social position, and what they have to offer the state, [HCV CBOs] may begin to determine how it answers to the state in terms of its effectiveness and accounting for its outcomes and achievements’ (2007, p. 184-185). Answers to the state by CBOs here would be strengthened by a more conscious and assured awareness by CBOs of the merits attached to their distinct expertise in terms of their ability to provide narrative communitas spaces that can create new ways to address HCV. In this sense CBOs have the potential to (re)instantiate a genuine leadership role within the public policy arena rather than ‘sensibly’ following state-based policy priorities under a degree of reassurance that such priorities are premised on an understanding that they have been consulted in developing such policies.

In recent years the concept and measurement of “social impact” has become a new domain for the evaluation of CBOs. The Australian government’s recent development of the “national compact” signifies state recognition and promotion of the social contribution of CSOs (CoA, 2011). However, these ‘initiatives whilst significant are inconclusive in determining a methodology for attributing the social contribution of organisations like CBOs (Edwards et al., 2012, p. 19). Further, existing social impact approaches have the specific aim of measuring the social impact of CBO programs and derive from business approaches to CBOs which seek to determine a social return on investment (Zappala & Lyons 2009) – reflecting again an expression of commodity fetishism as applied to CBOs. Edwards et al. (2012) propose that CBOs should develop and determine their own kinds of logics which can demonstrate their effectiveness in terms of social impact. Carey suggests these new logics 'may be modelled on third sector values which may, for example, incorporate elements of community and/or counter-discourse' (2007, p.184). This also resonates with other scholars who have studied HCV and community-based organisations. For example, Krug's (1996) recommendation concerning repositioning oneself in relation to dominant HCV discourses, Orsini's (2006) call for community members to critique dominant ways of knowing, and Pugh's (2006) proposal for HCV CBOs to consider critical discourse analysis within texts that represent people living with HCV.

Consistent with elements put forward by Edwards et al. (2012), Carey (2007) and Pugh (2006), the distinct expertise conceived and examined within this study speaks to a new logic of social impact worth further investigation – a logic that considers the elements and effects bound up within CBO narrative communitas spaces. This may present a difficult task, as "social impact" by its nature can be an elusive thing to measure, as it is qualitative rather than quantitative, long-term rather than short-term, diffuse and multi-layered rather than specific and focussed, and probably means different things in different contexts (Edwards et al., 2012). Further, 'some critique that in principle, social impact can never be reduced to a simple metric, and to do so is dangerous, and can lead to serious abuse of the measure' (Edwards et al., 2012, p. 22). Nevertheless, this should not prevent research efforts directed, for example, at finding ways to translate the impacts of CBO narrative communitas spaces in terms of demonstrating a CBOs social impact. Within this research direction, attention needs to focus on CBO member engagement with dominant narratives and discourses and 'how they articulate critical responses, and challenge dominant ways of knowing' (Orsini, 2006b, p. 25). Another important implication of this study concerns the role CBO culture governors play in negotiating relations between the state and the HCV "community". This study has highlighted concerns in relation to a tendency (conscious or not) among CBO culture governors to privilege state-endorsed dominant narratives at the expense of alternative ones. Consistent with Brandsen (2005), who proposes that CSOs as hybrid organisations could be examined in terms of their strategies and methods of adaptation to conflicting demands, further research examining a variety of CBOs and how their boards and senior staff members negotiate and interpret contractual relations with government against social and community membership needs may provide more nuanced understandings and further insight into how culture governance processes can threaten or promote CBO distinct expertise. Identifying and examining CBOs that circumvent or challenge the negative aspects and effects of governance structures and processes would also be a fruitful direction for future research.

Such future research endeavours tied to culture governance and narrative communitas ideas are important as they are, to restate, likely to have implications about the worth of different human lives. In this sense, future CBO and CBO social impact research requires a consideration of the kind of CBO practices that allow narrative communtas spaces to flourish in order to allow for the critical engagement of the underpinnings and presumptions attached to, and interact between, an expanding age of biological citizenship and state-utilitarian logics. This research has illustrated that a narrative communitas understanding of CBOs can see CBOs and their members furnished with a potential to intervene in the present policy landscape as well as the lives of HCV-affected or "at risk" individuals in order to open up possibilities towards shaping new futures.

◊ ◊ ◊

Health-orientated CBOs like HNSW are vital and relevant organisations for many affected by concerns of illness and wellness. To remain relevant to, and representative of, their constituents, and to prevent a loss of distinct expertise, the issues raised in this thesis require deliberative attention. As reported, recently HNSW have initiated strategies and programs that suggest productive direction here, as such programs focus on providing new experiential narrative spaces that can facilitate narrative communitas potentialities which may challenge the grip of state utilitarian logics - logics that ultimately presents a paradox of sorts, reminding me of a contradictory element within urban gentrification projects. By "gentrification", I refer to the "in-migration" of affluent and professional individuals 'to poorer and lower value areas of the city' (Atkinson & Wulff, 2009, p. 4), due to the attraction to culturally heterogeneous communities and economic gain through property investment, resulting in 'the displacement of lower-income and vulnerable residents' due to increased property values and a more affluent consumerism, threatening the very heterogeneity of the community that attracted affluent groups to the area in the first place (Atkinson & Wulff, 2009, p. 4; see also Smith, 1996). Similarly, the state is attracted to CBOs due to the values, identities and communities to which they provide access, yet through state-CBO relations whereby values, identities and communities are reconfigured in terms of utilitarian and effective outcomes, the state may jeopardize the very relations CBOs have with their communities, relations that attracted the state to them in the first place. For HNSW, the ideas underpinning this analogy principally connect questions of supporting and representing the voices of those affected by HCV to questions concerning what kind of organisation the HNSW is or will be, as well as questions about the worth of the different lives of those affected by HCV. These ideas and questions (however answered) ultimately are about CBOs providing productive opportunities for people to understand the place HCV has in one's life – opportunities that may also give rise to socio-political awareness and influence.

REFERENCES

Abrahamsen, R. (2004). The power of partnership in global governance. *Third World Quarterly, 25*(8), 1453-1467.

ADBNSW. (2001). *C-Change: Report of the enquiry into hepatitis C-related discrimination*. Sydney: Anti-Discrimination Board of New South Wales.

AIDB. (2008). *Review of Hepatitis C Treatment and Care Services.* Sydney: New South Wales Health.

Alexander, J., Nank, R., & Stivers, C. (1999). Implications of welfare reform: do nonprofit survival strategies threaten civil society? *Nonprofit and Voluntary Sector Quarterly, 28*, 452-475.

Allsop, J., Jones, K., & Baggott, R. (2004). Health consumer groups in the UK: A new social movement? *Sociology of Health & Illness, 26*(6), 737–756.

Altman, P. (1994). *Power & Community: Organisational & Cultural Reponses to AIDS*. UK: Taylor & Francis.

ANCHARD. (2002). *Hepatitis C virus projections working group: estimates and projections of the hepatitis C virus epidemic in Australia 2002*. Canberra: Australian National Council on AIDS, Hepatitis C and Related Diseases, Hepatitis C Sub-Committee. Commonwealth Government of Australia.

Anheier, H. K. (2009). *Global Civil Society: Poverty and Activism*. London: Sage.

Arminen, I. (1996). On the moral and interactional relevancy of self-repairs for life-stories of Alcoholics Anonymous. *Text, 16*(4), 449-480.

Arminen, I. (2004). Second stories: the salience of interpersonal communication for mutual help in Alcoholics Anonymous. *Journal of Pragmatics, 36*, 319-347.

Arnott, S. J. (2001). Liminal subjectivity and the ethico-aesthetic paradigm of Félix Guattari. *Limen: Journal of Theory and Practice of Liminal Phenomena, 2*. Retreived from http://limen.mi2.hr/limen1-2001/stephen_arnott.html

Atkinson, R., & Wulff, M. G. (2009). Gentrification and displacement: a review of approaches and findings in the literature *AHURI Positioning Paper*. Melbourne: Australian Housing and Urban Research Institute Southern and Monash Research Centres.

Ballard, K., & Elston, M. (2005). Medicalisation: A multi-dimensional concept. *Social Theory and Health, 3*, 228-241.

Bamberg, M. (1997). Positioning between structure and performance. *Journal of Narrative and Life History, 7*, 335-342.

Bamberg, M. (2004). Narrative discourse and identities. In J. C. Meister, T. Kindt, W. Schernus & M. Stein (Eds.), *Narratology beyond literary criticism* (pp. 213-237). New York: Walter de Gruyter.

Bamberg, M., & Andrews, M. (Eds.). (2004). *Considering counter-narratives: Narrating, resisting, making sense*. Amsterdam: John Benjamins.

Bamberg, M., & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk, 28*(3), 377-396.

Bandura, A. (2005). The growing centrality of self-regulation in health promotion and disease prevention. *The european health psychologist, 1*, 11-12.

Bang, H. P. (2003a). Governance as political communication. In H. P. Bang (Ed.), *Governance as Social and Political Communication* (pp. 7-26). Manchester: Manchester University Press.

Bang, H. P. (2003b). A new ruler meeting a new citizen: culture governance and everyday making. In H. P. Bang (Ed.), *Governance as Social and Political Communication* (pp. 241-266). Manchester: Manchester University Press.

Bang, H. P. (2004). Culture governance: governing self-reflexive modernity. *Public Administration, 82*(1), 157-190.

Bang, H. P. (Ed.). (2003c). *Governance as Social and Political Communication*. Manchester: Manchester University Press.

Barraket, J., & Crozier, M. (2008). *The social economy in Australia: A research agenda*. Paper presented at the Annual Conference of the Australian Sociological Association : Re-imaging Sociology, The University of Melbourne, Melbourne.

Barrett, R. J. (1998). The 'schizophrenic' and the liminal persona in modern society. *Culture, Medicine and Psychiatry, 22*(4), 465-494.

Bellah, R. N., Madsen, R., Sullivan, W. M., Swidler, A., & Tipton, S. M. (1985). *Habits of the heart: Individualism and commitment in American life*. Berkeley: University of California Press.

Billig, M. (2008). The language of critical discourse analysis: the case of nominalization. *Discourse & Society, 19*(6), 783-800. doi: 10.1177/0957926508095894

Billis, D. (2010). *Hybrid Organizations and the Third Sector: Challenges for Practice, Theory and Policy*: Palgrave Macmillan.

Billis, D., & Glennerster, H. (1998). Human Services and the Voluntary Sector: Towards a Theory of Comparative Advantage. *Journal of Social Policy, 27*, 79-98.

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science and Medicine, 44*(6), 747-756.

Bloom, F. R. (1997). Searching for Meaning in Everyday Life: Gay Men Negotiating Selves in the HIV Spectrum. *Ethos, 25*, 454-479.

Bloomfield, K. (1994). Beyond sobriety: the cultural significance of Alcoholic Anonymous. *Non-profit and Voluntary Sector Quarterly, 23*, 21-40.

Blystad, A., & Moland, K. M. (2009). Technologies of hope? motherhood, HIV and infant feeding in Eastern Africa. *Anthropology & Medicine, 16*(2), 105-118.

Boje, D. M. (1994). Organizational storytelling: The struggles of pre-modern, modern and postmodern organizational learning discourses. *Management Learning, 25*(3), 433-461.

Boje, D. M. (1995). Stories of the storytelling organization: A postmodern analysis of Disney as 'Tamara Land'. *Academy of Management Review, 38*(4), 997-1035.

Boje, D. M. (2001). *Narrative methods for organizational and communication research*. London: Sage.

Boje, D. M. (2008). *Storytelling Organizations*. London: Sage.

Boje, D. M., Hansen, H., & Rosile, G. A. (2007). From theatrics to metatheatre: The Enron Drama. *Revue Sciences do Gestion, Management Sciences, 58*, 63-83.

Bologh, R. W. (1981). Grounding the alientation of self and body: a critical, phenomenological analysis of the patient in western medicine. *Sociology of Health and Illness, 3*(2), 189-206.

Bonkovsky, H. L., & Mehta, S. (2001). Hepatitis C: A review and update. *Journal of the American Academy of Dermatology, 44*(2), 159-182.

Borgia, G., Reynaud, L., Gentile, I., & Piazza, M. (2003). HIV and Hepatitis C Virus: Facts and Controversies. *Infection, 31*(4), 232-240.

Borkman, T., & Munn-Giddings, C. (2008). Self help organisations and changing relations between patients/consumers and health care systems in the U.S. and the U.K. In S. Chambre & M. Goldner (Eds.), *Advances in Medical Sociology* (Vol. 10: Patients, Consumers and Civil Society, pp. 127-150). Bingley, UK: Emerald Group Publishing Limited.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic Analysis and code development*. Thousand Oaks: Sage.

Boyle, M., & Rogerson, R. (2006). Third way urban policy and the new moral politics of community : a comparative analysis of Ballymun in Dublin and the Gorbals in Glasgow. *Urban Geography, 27*(3), 201-227.

Brainard, L. A., & Siplon, P. D. (2002). The Internet and NGO–government relations: injecting chaos into order. *Public Administration and Development, 22*(1), 63-72.

Brandsen, T., van de Donk, W., & Putters, K. (2005). Griffins or chameleons? hybridity as a permanent and inevitable characteristic of the third sector. *International Journal of Public Administration, 28*, 749-765.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Brinkerhoff, D. W. (1999). Exploring state–civil society collaboration: policy partnerships in developing countries. *Nonprofit and Voluntary Sector Quarterly, 28*(4), 59-86.

Brinkerhoff, J. M., & Brinkerhoff, D. W. (2002). Government-nonprofit relations in comparative perspective: Evolution, themes, and new directions. *Public Administration and Development, 22*(1), 3-19.

Brockmeier, J., & Harré, R. (2001). Narrative: Problems and Promises of an Alternative Paradigm. In J. Brockmeier & D. Carbaugh (Eds.), *Narrative Identity: Studies in Autobiography, Self and Culture* (pp. 9-58). Philadelphia: John Benjamins.

Brown, A. D., Gabriel, Y., & Gherardi, S. (2009). Storytelling and change: an unfolding story. *Organization, 16*(3), 323-333.

Brown, A. D., & Humphreys, M. (2006). Organizational identity and place: A discursive exploration of hegemony and resistance. *Journal of Management Studies, 43*(2), 231-257.

Brown, A. D., Humphreys, M., & Gurney, P. M. (2005). Narrative, identity and change: a case study of Laskarina Holidays. *Journal of Organizational Change Management, 18*(4), 312-326.

Brown, M. P. (1997). *Replacing citizenship: aids activism and radical democracy*. USA: Guildford Press.

Bruner, E. M., & Gofrain, P. (1984). Dialogic narration and the paradoxes of Masad. In E. M. Bruner (Ed.), *Text, play, and story: the construction and reconstruction of self and society*. Washington, DC: American Ethnological Society.

Bruner, J. (1986). *Actual Minds, Possible Worlds*. Cambridge: Harvard University Press.

Bruner, J. S. (1991). The narrative construction of reality. *Critical Inquiry, 18*(1), 1-21.

Buber, M. (1958). *For the Sake of Heaven*. New York: Meridian Books.

Burrows, D., & Bassett, B. (1996). *Meeting the needs of people in Australia living with hepatitis C*. Canberra: Commonwealth Department of Health and Family Services.

Bury, M. R. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-169.

Butler, T., Boonwaat, L., & Hailstone, S. (2005). *National Prison Entrants' Bloodborne Virus Survey, 2004*. Sydney: Centre for Health Research in Criminal Justice & National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.

Butler, T., D, L., & D, C. (2011). *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, and 2010*. Sydney: Kirby Institute (University of New South Wales) and National Drug Research Institute (Curtin University).

Carey, G. (2007). *The place of community in a community organisation: Negotiating relationships in the third sector*. Third Sector Review. Unpublished Master's thesis. University of Adelaide. Adelaide, Australia.

Carey, G. (2008). *Conceptualising the third sector: Foucauldian insights into the relations between the third sector, civil society and the state*.

Carricaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: The case of HIV-positive men. *Sociology of Health and Illness, 17*(1), 65-88.

Carrier, N., Laplante, J., & Bruneau, J. (2005). Exploring the contingent reality of biomedicine: Injecting drug users, hepatitis C virus and risk. *Health, Risk & Society, 7*(2), 123-140.

Chalmers, D. (1995). Facing up to the problem of consciousness. *Journal of Consciousness Studies, 2*(3), 200-219.

Chambre, S. M. (1991). The volunteer response to the aids epidemic in new york city: implications for research on voluntarism. *Nonprofit and Voluntary Sector Quarterly, 20*(3), 267-287.

Charmaz, K. (1987). Struggling for a self: identity levels of the chronically ill. *Research in the Sociology of Health Care, 6*, 283-321.

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick & New Jersey: Rutgers University Press.

Charmaz, K. (1995). The body, identity, and self: adapting to impairment. *Sociological Quarterly, 36*(4), 657-680.

Chaves, M., Galaskiewicz, J., & Stephens, L. (2004). Does government funding suppress nonprofits' political activity? *American Sociological Review, 69*, 292-316.

Choi, B. C. K., & Pak, A. W. P. (2006). Multidisciplinarity, interdisciplinarity, and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. *Clinical and Investigative Medicine, 29*(6), 351-364.

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R., & Fishman, J. R. (2003). Biomedicalisation: technoscientific transformations of health, illness, and U.S. biomedicine. *American Sociological Review, 68*, 161-194.

Clegg, S. M. (1989). *Frameworks of Power*. London: Sage.

CoA. (2000). *National hepatitis C strategy 1999–2000 to 2003–2004*. (2733). Canberra: Commonwealth of Australia.

CoA. (2005). *National hepatitis C strategy 2005–2008*. (3642 (JN9005)). Canberra: Commonwealth of Australia.

CoA. (2010). *National hepatitis C strategy 2010–2013*. (6637). Canberra: Commonwealth of Australia.

CoA. (2011). *National Compact 2010*. Canberra: Department of the Prime Minister and Cabinet, Commonwealth of Australia.

Cockerham, W. C., Kunz, G., Leuscher, G., & Spaeth, J. L. (1986). Symptoms, social stratifications and self-responsibility for health in the United States and West Germany. *Social Science & Medicine, 22*(11), 1263-1271.

Cockerham, W. C., Rutten, A., & Abel, T. (1997). Conceptualizing contemporary health lifestyles: moving beyond Weber. *The Sociological Quarterly, 38*, 321-342.

Connolly, W. E. (2002). *Neuropolitics: Thinking, Culture, Speed*. Mineapolis: University of Minnesota Press.

Conrad, P. (1992). Medicalization and social control. *Annual Review of Sociology, 18*, 209-232.

Conrad, P. (2005). The shifting engines of medicalization. *Journal of Health and Social Behavior, 46*(1), 3-14.

Considine, M. (2003). Governance and competition: the role of non-profit organisations in the delivery of public services. *Australian Journal of Political Science, 38*(1), 63-77.

Cook-Sather, A. (2006). Newly betwixt and between: revising liminality in the context of a teacher preparation program. *Anthropology and Education Quarterly, 37*, 110-127.

Copeland, L. (2004). The drug user's identity and how it relates to being hepatitis C antibody positive: A qualitative study. *Drugs: Education, Prevention and Policy, 11*(2), 129-147.

Crampton, P., Woodward, A., & Dowell, A. (2001). The role of the third sector in providing primary care services: theoretical and policy issues. *Social Policy Journal of New Zealand, 17*, 1-21.

Crawford, R. (1980). Healthism and the medicalization of everyday life. *International Journal of Health Sciences, 10*(3), 365-388.

Crawford, R. (1994). The boundaries of the self and the unhealthy other: reflections on health, culture and aids. *Social Science and Medicine, 38*(10), 1347-1365.

Crawford, R. (2006). Health as a meaningful social practice. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 10*(4), 401-420.

Crockett, B., & Gifford, S. (2004). "Eyes wide shut": Narratives of women living with hepatitis C in Australia. *Women & Health, 39*(4), 117-137.

Crofts, N., Louie, R., & Loff, B. (1997). The next plague: Stigmatization and discrimination related to hepatitis C virus infection in Australia. *Health and Human Rights, 2*(2), 86-97.

Dean, M. (2003). Culture governance and individuation. In H. P. Bang (Ed.), *Governance as Social and Political Communication* (pp. 117-139). Manchester: Manchester University Press.

De fina, A., Schiffrin, D., & Bamberg, M. (2006). Introduction. In A. De fina, D. Schiffrin & M. Bamberg (Eds.), *Discourse and identity* (pp. 1-23). Washington DC: Cambridge University Press.

Defourny, J., Develtere, P., & Fonteneau, B. (Eds.) (1999). *The social economy*. Brussels: North and South.

Denzin, N.K., & Lincoln, Y.S. (2000). *Handbook of Qualitative Research* (2nd ed.). Thousand Oaks California: Sage Publications.

Deumert, A. (2003). Standard languages as civic rituals: Theory and examples. In U. Ammon & K. J. Mattheier (Eds.), *Sprachstandards/ Language Standards*. (= Sociolinguistica 17) (pp. 31-51). Tübingen: Niemeyer.

Dobkin-Hall, P. (1992). *Inventing the Nonprofit Sector: Essays on Philanthropy, Voluntarism, and Nonprofit Organizations*. Baltimore: Johns Hopkins University Press.

Dollery, B., Wallis., & Crase, L. (2002). Public Policy Approaches to the Voluntary Sector

Working Paper Series in Economics. Armidale: University of New England School of Economics.

Dore, G. J., Law, M., MacDonald, M., & Kaldor, J. K. (2003). Epidemiology of hepatitis C virus infection in Australia. *Journal of Clinical Virology, 26*(2), 171–184.

Dressman, M. (1997). Congruence, resistance, liminality: Reading and ideology in three school libraries. *Curriculum Inquiry, 27*, 267-315.

Driver, S. (2004). North Atlantic drift: welfare reform and the ‘Third Way’ politics of New Labour and the New Demoncratics. In S. Hale, W. Leggett, & L. Martell (Eds.), *The Third way and beyond: Criticisms, futures and alternatives* (pp. 31-47). Manchester: Manchester University Press.

Dungan, K. B. (2008). Just like you: the dimensions of identity presentations in an antigay contested context. In J. Reger, D. J. Myers & R. L. Einwohner (Eds.), *Identity Work in Social Movements* (pp. 21-46). Minneapolis: University of Minnesota Press.

Dutton, J. E., & Dukericj, J. M. (1991). Keeping an eye on the mirror: the role of image and identity in organizational adaptation. *Academy of Management Journal, 34*, 517-554.

Edwards, M., Onyx, J., Maxwell, H., & Darcy, S. (2012). Meso level social impact: meaningful indicators of community contribution. *Cosmopolitan Civil Societies Journal, 4*(3), 18-37.

Enosh, G., & Buchbinder, E. (2005). The interactive construction of narrative styles in sensitive interviews: the case of domestic violence research. *Qualitative Inquiry, 11*(4), 588-617.

Epstein, S. (1995). The construction of lay expertise: aids activism and the forging of credibility in the reform of clinical trials. *Science, Technology, & Human Values, 20*(4), 408-437.

Etzioni, A. (1995). *Rights and the Common Good: The Communitarian Perspective*. New York: St. Martin's Press.

Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science and Medicine, 50*, 605-617.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness, 26*(2), 242–61.

Fairclough, N. (1992). *Discourse and Social Change*. Cambridge: Polity Press & Blackwell Publishers.

Fairclough, N. (2007). The contribution of Discourse Analysis to research on social change. In N. Fairclough, G. Cortese & P. Ardizzone (Eds.), *Discourse and Contemporary Social Change* (pp. 25-48). Bern: Peter Lang AG, International Academic Publishers.

Faye, B., & Irurita, V. (2003). Balancing perspective: The response to feelings of being condemned with the hepatitis C virus. *Journal of Substance Use, 8*(2), 92-103.

Ford, J. D. (1999). Organizational change as shifting conversations. *Journal of Organizational Change Management, 12*, 480-500.

Fowler, A. (2000). *NDGO values and the fourth position*. In A. Fowler (Ed.), *NGO Futures: Beyond Aid, Third World Quarterly Special Issues, 21*(4) (pp. 589-603).

Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.

Fraser, S. (2004). “It’s your life!”: Injecting drug users, individual responsibility and hepatitis C prevention. *Health, 8*(2), 199-221.

Fraser, S., & Seear, K. (2011). *Making disease, making citizens: The politics of hepatitis C*. Surrey: Ashgate Publishing.

Fraser, S., & Treloar, C. (2006). “Spoiled identity” in hepatitis C infection: The binary logic of despair. *Critical Public Health, 16*(2), 99-110.

Freeman, A. J., Dore, G. J., Law, M. G., Thorpe, M., Von Overbeck, J., Lloyd, A. R., Marinos, G., & Kaldor, J. M. (2001). Estimating progression to cirrhosis in chronic hepatitis C virus infection. *Hepatology, 34*(4), 809-816.

Galvin, R. (2002). Disturbing notions of chronic illness and individual responsibility. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 6*(2), 107-137.

Gartner, A., & Riessman, F. (1977). *Self-help in the human services*. San Francisco: Jossey-Bass.

Gatter, P. N. (1995). Anthropology, HIV and contingent identities. *Social Science Medicine, 41*(11), 1523-1533.

Gergen, K. J., & Gergen, M. M. (1988). Narrative and the self as relationship. *Advances in Experimental Social Psychology, 21*, 17-56.

Gibbon, S., & Novas, C. (Eds.) (2008). *Biosocialities, genetics and the social sciences: making biologies and identities*. London: Routledge.

Gifford, S., O’Brien, M., Bammer, G., Banwell, C., & Stoove, M. (2003). Australian women’s experiences of living with hepatitis C virus: Results from a cross-sectional survey. *Journal of Gastroenterology and Hepatology, 18*, 841-850.

Gilbert, N., & Gilbert, B. (1989). *The enabling state: modern welfare capitalism in America.* New York: Oxford University Press.

Gillard, J. (2008). *The federal government's social inclusion agenda*. Paper presented at the Australian Council of Social Service conference, Melbourne.

Giroux, H. A., Lankshear, C., McLaren, P., & Peters, M. (1996). *Counternarratives: Cultural Studies and Critical Pedagogies in Postmodern Spaces*. New York: Routledge.

Glacken, M., Kernohan, G., & Coates, V. (2001). Diagnosed with hepatitis C: A descriptive exploratory study. *International Journal of Nursing Studies, 38*, 107-116.

Glenister-Roberts, K. (2004). Liminality, authority, and value: reported speech in epideictic rhetoric. *Communication Theory, 14*(3), 264-284.

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Middlesex, New York, Victoria, Ontario & Auckland: Penguin.

Goldberg, M. (1987). *Jews and Christians: getting our stories straight*. Nashville: Abbington Press.

Golden J., O'Dwyer A. M., & Conroy R. M. (2005). Depression and anxiety in patients with hepatitis C: prevalence, detection rates and risk factors. *General Hospital Psychiatry, 27*(6), 431–438.

Golden J., Conroy R. M., O'Dwyer M. A., Golden D., & Hardouin J. B. (2006). Illness-related stigma, mood and adjustment to illness in persons with hepatitis C. *Social Science & Medicine, 63*(12), 3188.

Gough, J., Eisenschitz, A., & McCulloch, A. (2006). *Spaces of Social Inclusion*. New York: Routledge.

Grant, D., & Iedema, R. (2005). Discourse Analysis and the study of organizations. *Text, 25*(1), 37-66.

Greener, I. (2008). Markets in the public sector: when do they work, and what do we do when they don't? *Policy and Politics, 36*(1), 93-108.

Griffiths, C., Motlib, J., Azad, A., Ramsay, J., Eldridge, S., Feder, G., Khanam, R., Munni, F., & Garrett, M. (2005). Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. *British Journal of General Practice, 55*(520), 831-837.

Guattari, F. (1989). The three ecologies. *New Formations, 8*, 131-148.

Guattari, F. (1995). *Chaosmosis: an ethico-aesthetic paradigm* (P. Bains & J. Pefanis, Trans.). Sydney: Power Publications.

Gunn, C. E. (2004). *Third Sector Development: Making Up for the Market*. New York: Cornell University Press.

Halfpenny P., & Reid, M. (2002). Research on the voluntary sector: an overview. *Policy & Politics, 30*(4), 533-550.

Hallstein, A. L., (1992). Spiritual opportunities in the liminal rites of hospitalization. *Journal of Religion and Health, 31*(3), 247-254.

Hancock, P., Hughes, B., Jagger, E., Paterson, K., Russell, R., Tulle-Winton, E., & Tyler, M. (2000). *The body, culture and society: An introduction*. Philadelphia: Open University Press.

Haque, M. (2004). Governance based on partnership with NGOs: Implications for development and empowerment in rural Bangladesh. *International Review of Administrative Sciences, 70*(2), 271-290.

Hardwick, D. F. (2008). Medical Science is a Self Organizing Social Environment. *Studies in Emergent Order, 1*, 119-134.

Hardy, B. (1968). Towards a Poetics of Fiction: An Approach through Narrative. *Novel, 1*, 5–14.

Harris, M. (2005). Living with hepatitis C: The medical encounter. *New Zealand Sociology, 20*(1), 4-19.

Harris, M. (2009). Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis. *Sociology of Health and Illness, 31*(7), 1028-1042.

Harris, M. (2010). *Negotiating the pull of the normal: Embodied narratives of living with hepatitis C in New Zealand and Australia*. Unpublished doctoral thesis. University of New South Wales. Australia.

Harter, L. M., Berquist, C., Titsworth, B. S., Novak, D., & Brokaw, T. (2005). The structuring of invisibility among the hidden homeless: The politics of space, stigma, and identity construction. *Journal of Applied Communication Research, 33*(4), 305-327.

Harter, L. M., Scott, J. A., Novak, D. R., Leeman, M., & Morris, J. F. (2006). Freedom through flight: Performing a counter-narrative of disability. *Journal of Applied Communication Research, 34*(1), 3-29.

Heinen, S., & Sommer, R. (Eds.) (2009). *Narratology in the age of cross-disciplinary narrative research*. Berlin: (= Narratologia, Vol. 20).

Hellard, M., Hocking, J. S., & Crofts, N. (2004). The prevalence and the risk behaviours associated with the transmission of hepatitis C virus in Australian correctional facilities. *Epidemiology and Infection, 132*(3), 409-415.

Hepatitis Australia. (2011). Personal Stories, A tribute to Audrey Lamb. Retrieved 17 June, 2012, from http://www.hepatitisaustralia.com/about-hepatitis/personal-stories2/personal-stories3/a-tribute-to-audrey-lamb

HNSW. (2005a). *The Hep C Review*. (50). Hepatitis NSW. Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index.

HNSW. (2005b). *The Hep C Review*. (51). Hepatitis NSW. Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index.

HNSW. (2006a). *Hepatitis New South Wales Strategic Plan 2006-2010*. Hepatitis NSW. Retrieved from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2006b). *The Hep C Review*. (52). Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index.

HNSW. (2006c). *The Hep C Review*. (53). Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index.

HNSW. (2006d). *The Hep C Review*. (54). Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index.

HNSW. (2007). *Hepatitis New South Wales 2007 Annual Report.* Retrieved from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2008). *Hepatitis New South Wales 2008 Annual Report*. Retrieved from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2009). About Hepatitis NSW. Retrieved 12 May, 2009, from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2010a). Hepatitis New South Wales Organisational Chart. Retrieved August 2, 2011 from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2011a). *Hepatitis New South Wales Strategic Plan 2011-2015*. Retrieved from http://www.hep.org.au/index.php?article=content/about-us/about-hepatitis-nsw

HNSW. (2011b). *Hepatitis C factsheets, Hepatitis NSW - a history*. Sydney: Hepatitis New South Wales.

HNSW. (2011c). *Hep C Review Magazine evaluation Expressions of Interest form, September, 2011*. Sydney: Hepatitis New South Wales.

HCVPWG. (2006). *Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006.* Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.

Hepworth., J., & Krug, G. (1999). Hepatitis C: A socio-cultural perspective on the effects of a new virus on a community's health. *Journal of Health Psychology, 4*(2), 237-246.

Hilhorst, D. (2003). *The real world of NGOs: Discourses, diversity and development*. New York: Zed Books.

Holroyd, C., & Silver, A. (2001). *Corporate volunteering: helping to build business and community sustainability: a handbook for corporations and business*. Bunbury, Western Australia: The Centre for Regional Development and Research.

Hopwood, M. (2009). *Recovery from hepatitis C treatments* (Monograph 6/2009). Sydney: National Centre in HIV Social Research, The University of New South Wales.

Hopwood, M., & Treloar, C. (2003). *The 3D project: Diagnosis, disclosure, discrimination and living with hepatitis C* (Monograph 6/2003). Sydney: National Centre in HIV Social Research, The University of New South Wales.

Hopwood, M., & Southgate, E. (2003). Living with hepatitis C: A sociological review. *Critical Public Health, 13*(3), 251-267.

Hopwood, M., Treloar, C., & Redsull, L. (2006). *Experiences of hepatitis C treatment and its management: What some patients and health professionals say* (Monograph 4/2006). Sydney: National Centre in HIV Social Research, The University of New South Wales.

Hopwood, M. (2007). *Globalisation, healthism and harm reduction: responsibility, blame and cultures of care*. Paper presented at N.C.H.S.R. Consortium Workshop 20, Sydney, Australia.

Horton-Smith, D. (1997). Grassroots Associations Are Important: Some Theory and a Review of the Impact Literature. *Non-profit and Voluntary Sector Quarterly, 26*(3), 269-306.

Humphreys, M., & Brown, A. D. (2002) Narratives of organizational identity and identification: a case study of hegemony and resistance. *Organization Studies, 23*(3), 421-447. doi 10.1177/0170840602233005

Hyden L-C., & Brockmeier, J. (Eds.) (2008). *Health, Illness and Culture: Broken Narratives*. Abington: Routledge.

Hyvärinen, M. (2006). Towards a conceptual history of narrative. In M. Hyvärinen, A. Korhonen, & J. Mykkänen (Eds.), *The travelling concept of narrative*. Retrieved from: http://www.helsinki.fi/collegium/e-series/volumes/volume_1/001_04_hyvarinen.pdf

Hughes, B. (1999). *Health Promotion and Moral Self-Management in Everyday Life*. Paper presented at Critical Management Studies Conference, Manchester School of Management, University of Manchester, England.

Hurwitz, B. Greenhalgh, T., & Skultans, V. (2004). *Narrative Research in Health and Illness*. Massachusetts: Blackwell Publishing.

Jackson, J. E. (2005). Stigma, liminality, and chronic pain: mind-body borderlands. *American Ethnologist, 32*(3), 332-353.

Jenner, A., & Scott, A. (2008). Circulating beliefs, resilient metaphors and faith in biomedicine: Hepatitis C patients and interferon combination therapy. *Sociology of Health and Illness, 30*(2), 197-216.

Jones, E. E. (1984). *Social stigma: the psychology of marked relationships*. New York: W. H. Freeman.

Kaufman, S. R. (2000). In the shadow of 'death with dignity': medicine and cultural quandaries of the vegetative state. *American Anthropologist, 102*(1), 69-83.

Kayal, P. (1993). *Bearing Witness: Gay Men's Health Crisis and the Politics of AIDS*. Boulder: Westview Press.

Keevers, L. (2009). *Practising social justice: community organisations, what matters and what counts.* Unpublished Doctoral thesis. University of Sydney. Australia.

Keevers, L., Treleaven, L., Sykes, C., & Darcy, M. (2012). Made to measure: Taming practices with results-based accountability. *Organiation Studies, 33*(1), 97-120.

Kelly, A. (2008). Living loss: an exploration of the internal space of liminality. *Mortality: Promoting the interdisciplinary study of death and dying, 13*(4), 335-350.

Kendall, J., & Knapp, M. (1995). *Voluntary Means, Social Ends*. Canterbury: PSSRU.

Kennedy, P. (2005). Social policy, social exclusion and commodity fetishism. *Capital & Class, 29*, 91-114.

Kirby Institute. (2012). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012*. Sydney: The Kirby Institute, The University of New South Wales.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. USA: Basic Books.

Koch, T., Jenkin, P., & Kralik, D. (2004). Chronic illness self-management: locating the 'self'. *Journal of Advanced Nursing, 48*(5), 484-92.

Kolariè, Z. (2003). Neprofitno-volonterske organizacije in njihov razvoj – od volontarizmak profesionalizmu [Non-profit Voluntary Organisations and Their Development – From Voluntarism toward Professionalisation], *Teorija in Praksa*, 40(1), 37-56.

Körner, H., & Treloar, C. (2006). Representations of people with HIV and hepatitis C in editorials of medical journals: discourses and interdiscursive relations. *Communication & Medicine, 3*, 15-25.

Korobov, N. (2001). Reconciling theory with method: from Conversation Analysis and Critical Discourse Analysis to Positioning Analysis. *Forum: Qualitative Social Research, 2*(3), Art. 11.

Kramer, R. M. (1981). *Voluntary Agencies in the Welfare State*. Berkeley: University of California Press.

Kristeva, J. (1986). Word, dialogue, and the novel. In T. Moi (Ed.), *The Kristeva reader* (pp. 35-61). New York: Columbia University Press.

Krug, G. J. (1995). Hepatitis C: Discursive domains and epistemic chasms. *Journal of Contemporary Ethnography, 24*, 299-323.

Lacey, A., & Ilcan, S. (2006). Voluntary labor, responsible citizenship, and international NGOs. *International Journal of Comparative Sociology, 47*(1), 34-53.

La Shure, C. (2005). *What is Liminality?* Retrieved 2 November, 2009, from http://www.liminality.org/about/whatisliminality/

Lawn, S. (2008). The person's perspective of chronic condition self-management: Time to shift from rhetoric to reality. *Health Issues, 97*. 22-24.

Lawton, J. (2009). Illness, biography and narrative. *Sociology of Health & Illness* (Virtual Special Issue).

Lehman, G. (2007). The accountability of NGOs in civil society and its public spheres. *Critical Perspectives on Accounting, 18*(6), 645-669.

Levy, M., Baum, F., & Thomas, H. (2002). *Review of National Hepatitis C Strategy 1999–2000 to 2003–04: The road not taken*. In Australian Government Department of Health and Ageing (2003). 2002 Reviews of the National HIV/AIDS and Hepatitis C Strategies and strategic research (pp. 82–146).

Lewis, J. (1993). Feminism, the menopause and hormone replacement therapy. *Feminist Review, 43*, 38-56.

Lewis, D. (1997). NGOs, donors and the state in Bangladesh. *Annals of the American Academy of Political and Social Science, 554*, 33-45.

Lewis, D. (2003). Theorizing the organization and management of non-governmental development organizations. *Public Management Review, 5*(3), 325-344.

Lewis, L. M. (2003). *The people's health: Public health in Australia, 1788 -1950*. London: Praeger Press.

Little, M., Jordens, C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: a major category of the experience of cancer illness. *Social Science & Medicine, 47*(10), 1485-1494.

Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions and emerging confluences. . In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed.) (pp. 189-214). Thousand Oaks, California: Sage.

Ilcan, S., & Basok, T. (2004). Community government: voluntary agencies, social justice, and the responsibilization of citizens. *Citizenship Studies, 8*(2), 129-144.

Loveday, S., & Wallace, J. (2001). Hepatitis C councils in Australia. In N. Crofts, G. Dore & S. Locarnini (Eds.), *Hepatitis C: An Australian perspective*. Melbourne: IP Communications.

Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of Motor Neurone Disease. *Sociology of Health & Illness, 31*(7), 1043-1058.

Loseke, D. R. (2007). The Study of Narrative Identity. *The Sociological Quarterly, 48*, 661-688.

Lohmann, R. (1992). *The Commons: New Perspectives on Nonprofit Organizations and Voluntary Action*. San Francisco: Jossey-Bass.

Lupton, D. (1995). *The Imperative of Health. Public Health and the Regulated Body*. London: Sage.

Lupton, D. (1997). Foucault and the medicalisation critique. In: A. Petersen & R. Bunton (Eds.), *Foucault, Health and Medicine* (pp. 94-110). London: Routledge.

Lyon-Callo, V. (2004). Medicalizing homelessness: The production of self-blame and self-governing within homeless shelters. *Medical Anthropology Quarterly, 14*(3), 328-345.

Lyons, M., & Hocking, S. (2000). *Dimensions of Australia's Third Sector*. Sydney: Occasional Paper, Centre for Australian Community Organisations and Management (CACOM). Sydney: University of Technology, Sydney.

Lyons, M. (2001). *Third Sector: The contribution of nonprofit and cooperative enterprise in Australia*. Crows Nest: Allen and Unwin.

Lyons, M., & Simpson. P. L. (2009). *Reviving Mutuality and Membership: Challenges to Mutual Organisations and Their Responses*. Sydney: Occasional Paper, Centre for Australian Community Organisations and Management, University of Technology, Sydney.

MacIntyre, A. (1984). *After Virtue: A Study in Moral Theory* (2nd ed.). Notre Dame, Indiana: University of Notre Dame Press.

Maguire, S., Phillips, N., & Hardy, C. (2001). When 'silence = death'. Keep talking: trust, control and the discursive construction of identity in the Canadian HIV/AIDS treatment domain. *Organisational Studies, 22*(2), 285-310.

Mak, W., Mo, P., Cheung, R., Woo, J., Cheung, F., & Lee, D. (2006). Comparative stigma of HIV/AIDS, SARS, and tuberculosis in Hong Kong. *Social Science and Medicine, 63*, 1912-1922.

Marelich, W. D., Roberts, K. J., Murphy, D. A., & Callari, T. (2002). HIV/AIDS patient involvement in antiretroviral treatment decisions. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV. 14*(2), 17-26.

Martin-McDonald K., & Biernoff, D. (2002). Initiation into a dialysis dependent life: an examination of rites of passage. *Nephrology Nursing Journal, 29*(4), 347–353.

Maton, K. (1988). Social support, organizational characteristics, psychological well-being, and group appraisal in three self-help populations. *American Journal of Community Psychology, 16*, 53-77.

Matthews, N. A. (1994). *Confronting rape: The feminist anti-rape movement and the state*. New York: Routledge.

Maxwell, J. A. (1996). *Qualitative research design: An interactive approach*. Thousand Oaks, California: Sage.

McAdams, D. P. (1990). Unity and purpose in human lives: the emergence of identity as a life story. In A. I. Rabin, R. A. Zucker, R. A. Emmons & S. Frank (Eds.), *Studying persons and lives* (pp. 148-200). New York: Springer.

McDonald, C., & Marston, G. (2002). Patterns of governance. *Social Policy and Administration, 36*(4), 376-91.

McDonald, C., & Marston, G. (2005). Workfare as Welfare: Governing Unemployment in the Advanced Liberal State. *Critical Social Policy, 25*(3), 374-401.

McMillan, D. W., & Chavis, D. M. (1986). Sense of Community: a definition and theory. *Journal of Community Psychology, 14*, 6-23.

McNally, S., Temple-Smith, M., & Pitts, M. (2004). *Making Decision about Hepatitis C Treatment* (Monograph series no, 49). Melbourne: Australian Research Centre in Sex, Health & Society, La Trobe University.

Melucci, A. (1995). The process of collective identity. In H. Johnston & B. Klandermans (Eds.), *Social Movements and Culture* (pp. 41-63). Minneapolis: University of Minnesota Press.

Mercer, C. (2002). NGOs, civil society and democratization: a critical review of the literature. *Progress in Development Studies, 2*, 5-22.

Mink, L. O. (1987). *Historical Understanding*. London: Cornell University Press.

Molzahn, A., Bruce, A., Shields, L. (2008). Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal, 35*(1), 13-20.

Monsma, S. V. (1996). *When sacred and secular mix: Religious nonprofit organizations and public money*. Lanham: Rowman and Littlefield.

Morrison, K. (2006). *Breaking the cycle: Stigma, discrimination, internal stigma, and HIV*. United States Agency for International Development (USAID) Publication.

Moulaert, F., & Ailenei, O. (2005). Social Economy, Third Sector and Solidarity Relations: A Conceptual Synthesis from History to Present. *Urban Studies, 42*(11), 2037-2053.

Moussa, M., & Scapp, R. (1996). The practical theorizing of Michel Foucault: Politics & counter-discourse. *Cultural Critique, 33*, 87-112.

Murphy, R. F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical disability and social liminality: a study in the rituals of adversity. *Social Science & Medicine, 26*(2), 235-242.

NCHECR. (2010). HIV/AIDS, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2010 National Centre in HIV Epidemiology and Clinical Research. Sydney.

Newman, J., & Vidler, E. (2006). Discriminating customers, responsible patients, empowered users: consumerism and the modernisation of health care. *Journal of Social Policy, 35*(2), pp. 193–209.

Novan, L., & Morag, A. (2004). Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science & Medicine, 58*, 2337-2347.

Olson, B., Jason, L. A., Ferrari, J. R., & Hutcheson, T. D. (2005). Bridging professional and mutural-help: an application of the transtheoretical model to the mutual-help organization. *Applied and Preventive Psychology, 11*, 167-178.

Onyx, J. A., Armitage, L. M., Dalton, B. M., Melville, R., Casey, J. P., & Banks, R. (2010). Advocacy with gloves on: The 'manners' of strategy used by some third sector organizations undertaking advocacy in NSW and Queensland. *Voluntas - International Journal of Voluntary and Nonprofit Organisations*, *21*(1), 41-61.

Onyx, J. A., Dalton, B. M., Melville, R., Casey, J. P., & Banks, R. (2008). Implications of government funding of advocacy for third-sector independence and exploration of alternative advocacy funding models. *Australian Journal of Social Issues*, *43*(4), 631-648.

Onyx, J., & Maclean, M. (1996). Careers in the Third Sector. *Nonprofit Management and Leadership, 6*(4), 331-345.

Orsini, M. (2002). The politics of naming, blaming and claiming: HIV, hepatitis C and the emergence of blood activism in Canada. *Canadian Journal of Political Science, 35*(2). 475-498.

Orsini, M. (2008). Hepatitis C and the Dawn of Biological Citizenship: Unravelling the Policy Implications. In P. Moss & K. Teghtsoonian (Eds.), *Contesting Illness: Processes and Practices* (pp. 107-122). Toronto: University of Toronto Press.

Orsini, M. (2010). From Community Run to Community Based? Exploring the Dynamics of Civil Society-State Transformation in Urban Montreal. *Transdisciplinary Studies in Population Health Series, 2*(2), 172-187.

Omoto, A. M., Snyder, M., & Crain, A. L. (2001). *Hurt because you help: Stigmatization as a barrier to social action*. Manuscript in preparation. University of Kansas and University of Minnesota.

Omoto, A. M., & Sydner, M. (2002). Considerations of community: the context and process of volunteerism. *American Behavioural Scientist, 45*, 846-867.

Oxford English Dictionary. (2009) (2nd ed.). Oxford University Press.

Parsons, T. (1951). *The social system*. London: Routledge & Keagen Paul.

Paterson, B. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33*, 21-26.

Paterson, B. L., & Hopwood, M. (2010).The relevance of self-management programmes for people with chronic disease at risk for disease-related complications. In D. Kralik, B. Paterson & V. Coates (Eds.), *Translating chronic illness research into practice* (pp. 111-142). London: Blackwell Synergy.

Pawar, M. (2004). *Data Collecting Methods and Experiences.* India: New Dawn Press Group.

Persson, A., & Richards, W. (2008). From Closet to Heterotopia: A Conceptual Exploration of Disclosure and Passing among Heterosexuals Living with HIV. *Culture, Health & Sexuality, 10*(1), 73-86.

Petryna, A. (2002). *Life Exposed. Biological Citizens After Chernobyl*. Princeton: Princeton University Press.

Pollner, M., & Stein, J. (1996). Narrative mapping of social worlds: The voice of experience in alcoholics anonymous. *Symbolic Interaction, 19*, 203–224.

Pollner, M., & Stein, J. (2001). Doubled over in laughter: Humor and the construction of selves in alcoholics anonymous. In J. Gubrium and J. Holstein (Eds.), *Institutional selves* (pp. 46–63). New York: Oxford University Press.

Pound, P., Gompertz, P., & Ebrahim, S. (1998). Illness in the context of older age: The case of stroke. *Sociology of Health & Illness, 20*(4), 489-506.

Poynard, T., Ratziu, V., Charlotte, F., Goodman, Z., McHutchison, J. G., & Albrecht, J. (2001). Rates and risk factors of liver fibrosis progression in patients with chronic hepatitis C. *Journal of Hepatology, 34*(5), 730–739.

Pugh, J. (2006). *Controlling and constraining the participation of the hepatitis C-affected community in Australia: A critical discourse analysis of the first national hepatitis C strategy and selected news media texts.* Unpublished Doctoral thesis. Edith Cowan University. Australia.

Rabinow, P. (1996). Artificiality and enlightenment: from sociobiology to biosociality. In *Essays on the Anthropology of Reason* (pp. 91-111). Princeton: Princeton University Press.

Rabinow, P. (1999). *French DNA: Trouble in purgatory*. Chicago: University of Chicago Press.

Race, K. (2005). Recreational states: drugs and the sovereignty of consumption. *Culture Machine, 7*. Retrieved from http://culturemachine.net/index.php/cm/article/view/28/35

Race, K. (2009). *Pleasure consuming medicine: the queer politics of drugs*. Durham: Duke University Press.

Rafalovich, A. (1999). Keep coming back! Narcotics Anonymous narrative and recovering-addict identity. *Contemporary Drug Problems, 26*(1), 131-157.

Rapp, R. (1999). *Testing women, testing the fetus: the social impact of amniocentesis in America*. New York: Routledge.

Rappaort, J. (1993). Narrative studies and identity transformation in the mutual help context. *The Journal of Applied Behavioral Science, 29*(2), 239-256.

Reid, E. J. (1999). Nonprofit advocacy and political participation. In E. T. Boris & C. E. Steuerte (Eds.), *Nonprofits and Government: Collaboration and Conflict* (pp. 291-327). Washington, DC: Urban Institute Press.

Rhodes, C. (2000a). Reading and writing organizational lives. *Organization, 7*, 7-29.

Rhodes, C. (2000b), Doing knowledge at work: dialogue, monologue and power in organizational learning. In J. Garrick, & C. Rhodes (Eds.), *Research and Knowledge at Work*. London: Routledge.

Rhodes, T., & Treloar, C. (2008). The social production of hepatitis C risk among injecting drug users: A qualitative synthesis. *Addiction, 103*(10), 1593-1603.

Richmond, J. A., Bailey, D. E., Muir, A. J., & McHutchison, J. G. (2010). The use of mind-body medicine and prayer among adult patients with chronic hepatitis C. *Gastroenterology Nursing, 33*(3), 210-216.

Ricoeur, P. (1983/1984). *Time and Narrative (Temps et Récit)* (K. McLaughlin & D. Pellauer, Trans.). Chicago: University of Chicago Press.

Ricoeur, P. (1984/1985). *Time and Narrative (Temps et Récit)* (K. McLaughlin & D. Pellauer, Trans.). Chicago: University of Chicago Press.

Ricoeur, P. (1985/1988). *Time and Narrative (Temps et Récit)* (K. McLaughlin & D. Pellauer, Trans.). Chicago: University of Chicago Press.

Riessman, F. (1965). The 'helper' therapy principle. *Social Work, 10*, 27-32.

Riessman, C. K. (1994). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science Medicine, 30*, 1195-1200.

Riessman, C. K. (2002). Analysis of personal narratives. In J.F. Gubrium and J. A. Holstein (Eds.), *Handbook of Interviewing*. Sage.

Roberts, L. J., Salem, D., Rappaport, J., Toro, P. A., Luke, D. A., & Seidman, E. (1999). Giving and Receiving Help: Interpersonal Transactions in Mutual-Help Meetings and Psychosocial Adjustment of Members. *American Journal of Community Psychology, 27*(6,), 841-868.

Robinson, M. (1997). Privatising the voluntary sector: NGOs as public service contractors? In D. Hulme and M. Edwards (Eds.), *NGOs, states and donors: Too close for comfort*? (pp. 59-78). London: MacMillan.

Rogers, A., Bower, P., Kennedy, A., Gately, C., Lee, V., Reeves, D., Gardner, C., Richardson, G., Morris, F., Jerrim, S., & Chandler, C. (2005). *Process Evaluation of the EPP - Report II.* Manchester: National Primary Care Research & Development Centre. University of Manchester.

Rose, N. (1999). *Powers of freedom: Reframing political thought*. Cambridge: Cambridge University Press.

Rose, N. (2000). Community, citizenship, and the third way. *American Behavioural Scientist, 43*, 1395-1411.

Rose, N., & Novas, C. (2004). Biological Citizenship. In A. Ong & S. Collier (Eds.), *Blackwell Companion to Global Anthropology*, (pp. 228-259). London: Blackwell.

Rose, N., & Novas, C. (2005). Biological citizenship. In A. Ong & S. Collier (Eds.), *Global assemblages: Technology, politics, and ethics as anthropological problems*. London: Blackwell.

Rose, G., & Treloar, C. (2007). The C-een & Heard hep C speakers service - from the speakers viewpoint, *The Hep C Review,* (58). Retrieved from http://www.hep.org.au/index.php?article=content/hep-c-magazine/hep-review-index).

Rosenstock, I. M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly, 44* (3), 94–127.

Ross, J. (1989). Relation of implicit theories to the construction of personal histories. *Psychological Review, 96*, 341-357.

Ryan, M. L. (2005). Narrative. In D. Herman, M. Jahn & M. L. Ryan (Eds.), *Encyclopedia of Narrative Theory* (pp. 344-348). London: Routledge.

Rystrom, K. (1994). *The why, who, and how of the editorial page* (2nd ed.). Pennsylvania: Strata Publishing.

Salamon, L. M. (1987). Of market failure, voluntary failure, and third-party government: toward a theory of government–nonprofit relations in the modern welfare state. *Journal of Voluntary Action Research, 16*(1–2), 29-49.

Salamon, L. M., & Anheier, H. K. (1994). *The Emerging Sector—An Overview*. Baltimore: The Johns Hopkins University Institute for Policy Studies.

Salamon, L. M., & Anheier, H. K. (Eds.). (1996). *Defining the Nonprofit Sector: A Cross-National Analysis*. Manchester: Manchester University Press.

Sanders, C., Donovan, J. and Dieppe, P. (2002). The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Sociology of Health and Illness, 24*(2), 227–53.

Sandstrom, K. L. (1990). Confronting Deadly Disease: The Drama of Identity Construction Among Gay Men With AIDS. *Journal of Contemporary Ethnography, 19*(3), 271-294.

Sarbin, T. R. (1986). The narrative as a root metaphor for psychology. In T. R. Sarbin (Ed.), *Narrative psychology: the storied nature of human conduct*. New York: Praeger.

Scarlet Alliance (2010). *Scarlet Alliance Strategic Plan 2010-2013*. Retrieved 15 July, 2012, from http://www.scarletalliance.org.au/library/strat_plan1013/view

Schubert, M. A., & Borkman, T. J. (1991). An organizational typology for self-help groups. *American Journal of Community Psychology, 19*, 769-788.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed.) (pp. 189-214). Thousand Oaks, California: Sage.

Scrambler, G. (1998). Stigma and Disease: Changing Paradigms. *The Lancet, 352*(9133),1054-1055.

Sebranek, P., Kemper, D., & Meyer, V. (1999): *Write Source 2000 Revision*. Great Source Education Group Inc.

Sending, O.J., & Neumann, I.B. (2006). Governance to Governmentality: Analyzing NGOs, States, and Power. *International Studies Quarterly, 50*, 661-672.

Shalinsky, A., & Glascock, A. (1988). Killing infants and the aged in nonindustrial societies: Removing the liminal. *Social Science Journal, 25*(3), 277-287.

Shaw, I. (2003). Introduction: Themed Section on Consumerism and Social Policy. *Social Policy and Society, 2*(1), 33-34.

Shaw, I., & Aldridge, A. (2003). Consumerism, health and social order. *Social Policy and Society, 21*, 35-43.

Shephard, C. W., Finelli, L., & Alter, M. J. (2005). Global epidemiology of hepatitis C virus infection: epidemiology and vaccination. *The Lancet Infectious Diseases, 5*, 558-567.

Shields, R. (1990). *Places on the margin*. London: Routledge.

Shiner, M. (2003). Out of harm's way? Illicit drug use, medicalisation and the law. *British Journal of Criminology, 43*(4), 772-796.

Shomaker, D. J. (1989). Age disorientation, liminality and reality: The case of the Alzheimer's patient. *Medical Anthropology, 12*(1), 91-101.

Short, P. M., & Mutch, A. (2001). Exchange, reciprocity and citizenship principles of access and the challenge to human rights in the third sector: An Australian perspective. *Social Justice, 28*(4), 114-127.

Silverman, P. (1976). Mutual help. In H. R. Hirschowitz & B. Levy (Eds.), *The changing mental health scene*. New York: Spectrum.

Singer, J. (2001). Medicalisation: a "Third Way" to drug policy. In P. Basham (Ed.), *Sensible Solutions to the Urban Drug Problem*. Toronto: Fraser Institute Digital Publication.

Skultans, V. (2000). Narrative illness and the body. *Anthropology & Medicine, 7*(1), 5-11.

Skrabanek, P. (1994). *The Death of Humane Medicine and the Rise of Coercive Healthism*. Suffolk: The Social Affairs Unit.

Sladden, T. J., Hickey, A. R., Dunn, T. M., &, Beard, J. R. (1997). Hepatitis C transmission on the north coast of New South Wales: explaining the unexplained. *Medical Journal of Australia, 166*, 290-293.

Sladden, T. J., Hickey, A. R., Dunn, T. M., & Beard, J. R. (1998). Hepatitis C virus infection: impacts on behaviour and lifestyle. *Australian and New Zealand Journal of Public Health, 22*(4), 509-511.

Smart, B. (2003). *Economy, Culture and Society*. Open University Press: Buckingham, UK.

Smith, S. R., & Lipsky, M. (1993). *Nonprofits for hire: the welfare state in the age of contracting*. Cambridge, MA: Harvard University Press.

Smith, N. (1996). *The new urban frontier: gentrification and the revanchist city*. New York: Routledge.

Snyder, M., Omoto, A., Crain, A. L. (1999). Punished for their good deeds. *American Behavioral Scientist, 42*(7), 1171-1188.

Somers, M. (1992). Narrativity, narrative identity, and social action: Rethinking English working-class formation. *Social Science History, 16*, 591-630.

Somers, M. (1994). The narrative constitution of identity: A relational and network approach. *Theory and Society, 23*, 605-649.

Sommer, R. (2004). Beyond (Classical) Narratology: New Approaches to Narrative Theory. *European Journal of English Studies, 8*(1), 3-11

Sood, P. (2000). *Flowing upstream: The case for co-operative efforts between NGO-state relationships concerning the drinking water crisis in rural Gujarat (India).* Unpublished Master's thesis. Dalhousie University. Canada.

Southgate, E., Kippax, S., & Owler, K. (2002). *Social research needs analysis: Australian Intravenous League and Australian Hepatitis Council and member organisations* (Monograph 2/2002). Sydney: National Centre in HIV Social Research, University of New South Wales.

Spector-Mersel, G. (2010). Narrative research: Time for a paradigm. *Narrative Inquiry, 20*(1), 204-224.

Spooner, C., & Hetherington, K. (2004). Social Determinants Of Drug Use. Sydney: National Drug And Alcohol Research Centre, University Of New South Wales.

Srinivas, N. (2009). Against NGOs?: A critical perspective on nongovernmental action. *Nonprofit and Voluntary Sector Quarterly, 38*(4), 614-626.

St John, G. (2001). Alternative cultural heterotopia and the liminoid body:beyond turner at Confest. *The Australian Journal Of Anthropology, 12*(1), 47-66.

Stoller, E. P., Webster, N. J., Blixen, C. E., McCormick, R. A., Perzynski, A. T., Kanuch, S. W., & Dawson, N. V. (2009). Lay management of chronic disease: a qualitative study of living with hepatitis c infection. *American Jounral of Health Behaviour, 33*(4), 376-390.

Stone, M. M. (1996). Competing contexts: The evolution of a nonprofit organization's governance system in multiple environments. *Administration & Society, 28*(1), 61-90.

Stone, M. M., Hager, M. A., & Griffin, J. J. (2001). Organizational characteristics and funding environments: A study of a population of United Way-affiliated nonprofits. *Public Administration Review, 61*(3), 276-290.

Stryker, S., Owens, T. J., White, R. W. (Eds.) (2000). *Self, Identity, and Social Movements*. Minneapolis: University of Minnesota Press.

Sulik, G. A. (2009). Managing biomedical uncertainty: the technoscientific illness identity. *Sociology of Health & Illness, 30*(7), 1059-1076.

Sutton, R., & Treloar. C. (2007). Chronic illness experiences, clinical markers and living with hepatitis C. *Journal of Health Psychology, 12*, 330 -340.

Tabar, L. (2007). Memory, agency, counter-narrative: testimonies from Jenin refugee camp. *Critical Arts, 21*, 6-31.

Taylor, C. (1989). *Sources of the Self: The Making of the Modern Identity*. United States: Harvard University Press.

Taylor, K., Durant, R., & Boje, D. (2007). Telling the story, hearing the Story: Narrative co-construction and Crisis Research. *American Communication Journal*, *9*(1), 1-13.

Taylor, S., & Littleton, K. (2006). Biographies in talk: A narrative-discursive research approach. *Qualitative Sociology Review, II*(1), 22-38.

Teamey, K. (2007). *Whose Public Action? Analysing Inter-sectoral Collaboration for Service Delivery: Literature Review on Relationships between Government and Non-state Providers of Services*. Birmingham: International Development Department School of Public Policy.

Temple-Smith, M., Gifford, S., & Stoove, M. (2004). The lived experience of men and women with hepatitis C: Implications for support needs and health information. *Australian Health Review, 27*(2), 46-56.

Terrault, N. A. (2002). Sexual activity as a risk factor for hepatitis C. *Hepatology, 36*(Supplement 1), S99-105.

Terry, J., & Urla, J. (Eds.). (1995). Deviant bodies: critical perspectives on difference in science and popular culture. Indiana: Indiana University Press.

Texter, L. A., & Mariscotti, J. M. (1994). From Chaos to New Life: Ritual Enactment in the Passage from Illness to Health. *Journal of Religion and Health, 33*(4), 325-332.

Toman, N. (2011). *Lost boys? lost narratives? The potential for narrative identity methodologies to facilitate an understanding of the under-representation of young working-class Protestant males within Northern Ireland Higher Education.* Paper presented at the Conference on Contributions and challenges for educational research, Portugal.

Toscano, A. (2003). Art against empire: On Alliez and Negri's "Peace and War"'. *Theory Culture Society, 20*(2), 103-108.

Touraine, A. (1985). An introduction to the study of social movements. *Social Research, 52*, 749-787.

Treloar, C., & Fraser, S. (2007). Public opinion on NSPs: avoiding assumptions for policy and practice. *Drug and Alcohol Review, 26*(4): 355-361.

Treloar, C., & Rhodes, T. (2009). The lived experience of Hepatitis C and its treatment among injecting drug users: Qualitative synthesis. *Qualitative Health Research, 199*(9), 1321-1334.

Turner, V. (1969). *The Ritual Process*. London: Aldine.

Turner, V. (1974). *Dramas, Fields, and Metaphors: Symbolic Action in Human Society*. Ithaca, NY: Cornell University Press.

Tyler, C. (2011). Power, alienation and performativity in capitalist societies. *European Journal of Social Theory, 14*(2), 161-179

van Gennep, A. (1909). *The Rites of Passage* (M. B. Vizedom & G. L. Caffee, Trans.). London: Routledge & Kegan Paul.

van Til, J. (2000).*Growing civil society: From nonprofit sector to third space*. Bloomington: Indiana University Press.

van Til, J. (2009). A Paradigm Shift in Third Sector Theory and Practice: Refreshing the Wellsprings of Democratic Capacity. *American Behavioral Scientist, 52*(7), 1069-1081

Vertovec, S. (1999). Social cohesion and tolerance. In J. Hjarno (Ed.), *From Metropolis to Cosmopolis* (pp. 94-134). Esbjerg: South Jutland Unviersity Press.

Viney, L. L. and Bousfield, L. (1991). Narrative analysis: A method of psychosocial research for AIDS-affected people. *Social Science Medicine, 32*, 753-765.

Violi, P. (1992). Gender, subjectivity and language. In G. Bock, & S. James (Eds.), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity* (pp. 64-176). New York: Routledge.

Walder, A. G. (2009). Political Sociology and Social Movements. *Annual Review of Sociology, 35*, 393-412.

Walzer, M. (1995). The Civil Society Argument. In R. Beiner (Ed.), *Theorizing Citizenship* (pp. 153-174). New York: SUNY Press.

Wamai, R. (2004). *Recent International Trends in NGO Health System Organization, Development and Collaborations with Government in Transforming Health Care Systems: The Case of Finland and Kenya.* Unpublished Doctoral thesis. University of Helsinki, Department of Social Policy/Institute of Development Studies. Helsinki.

Welle, K. (2001). *Contending discourses on 'Partnership'. A comparative analysis of the rural water and sanitation sector in Ghana*. London: Occasional Paper, Water Issues Study Group, SOAS, University of London.

White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. New York: Norton.

Wyhte, S. R. (2009). Health identities and subjectivities: The ethnographic challenge. *Medical Anthropology Quarterly, 23*(1), 6-15.

Williams, G. H. (1984). The genesis of chronic illness: narrative reconstruction. *Sociology of Health and Illness, 6*, 175-200.

Williams, J., Diego, G-M,. Quan, L. (2011). Infectious diseases and social stigma. *Applied Technologies & Innovations, 4*(1), 58-70.

Williams, S. J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness, 22*(1), 40-67.

Wilson P. M., & Mayor V. (2006). Long-term conditions. 2: supporting and enabling self-care. *British Journal of Community Nursing, 11*, 6-10.

Winter, R., Fraser, S., Booker, N., & Treloar, C. (2011). *Technical review of hepatitis C health promotion resources* (Monograph 5/2011). Sydney: National Centre in HIV Social Research, The University of New South Wales.

Wolch, J. (1990). *The Shadow state: government and the voluntary sector in transition*. New York: The Foundation Center.

Woolford, A., & Curran, A. (2012). Community positions, neoliberal dispositions: managing nonprofit social services within the bureaucratic field. *Critical Sociology, 39*(1), 45-63.

WHO. (1986). Ottawa Charter for Health Promotion. Geneva: World Health Organization.

WHO. (2012). *Hepatitis C Fact Sheet*. Geneva: World Health Organization.

Wozniak, L., Prakash, M., Taylor, M., & Wild, T. (2007). Everybody's got it, but ... : Situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *International Journal of Drug Policy, 18*(5), 388-396.

Yang, G. (2000). The liminal effects of social movements: Red Guards and the transformation of identity. *Sociological Forum, 15*(3), 379-406.

Zappalà G, & Lyons, M. (2009). *Approaches to Measuring Social Impact*. Sydney: CSI Background Paper 5, The Centre for Social Impact, University of New South Wales.

APPENDICES

Appendix A

Participant recruitment letter published in the Hep C Review

<u>Making sense of hepatitis C</u>

My name is Paul Simpson. I am a PhD student at the University of NSW conducting research on hepatitis C. In particularly, I am interested in how people make sense of living with hepatitis C, be that though the help of one's family, friends, the health system or associations like the Hepatitis C Council of NSW.

I would like to interview people living with hepatitis C who are members of the Hepatitis C Council of NSW. Interviews will consist of asking participants to talk about their thoughts and feelings when they were first diagnosed with hepatitis C, as well as participants' views of living with hepatitis C now.

Interviews are expected to run for an hour and can be held at a place convenient to you. Complete anonymity and confidentiality will be upheld at all stages of the research process. Participants will be given $20 to cover for any transport costs.

If you would like to participate, or have any questions in regards to the study please feel free to call me on: [redacted] or alternatively email me at [redacted]

Kind regards

Paul Simpson

Appendix B

Participant information statement and consent form – Hepatitis NSW members

You are invited to participate in a study looking at how members of the Hepatitis C Council of NSW make sense of living with Hepatitis C. We hope to learn whether, and in what ways, your membership with the Hepatitis C Council of NSW has helped you address the impacts of living with Hepatitis C. You were selected as a possible participant in this study because you are a member of the Hepatitis C Council of NSW. Some members were sent a letter from the Hepatitis C Council of NSW inviting them to participate. Alternatively, you may have responded to an advertisement you saw in the 'Hep C Review'.

If you decide to participate, we will be conducting confidential interviews that will ask about the thoughts and feelings you experienced when you were first diagnosed with hepatitis C and how those experiences compare to how you think and feel about living with hepatitis C today.

Interviews will be conducted at a time and place that is convenient for you. Interviews are expected to take 60-90 minutes. We do not anticipate that you will experience any undue stress as a result of taking part in this interview. However, we will provide information on services and support in case participants require so.

It is hoped that the findings from this study will help non-profit health-based associations like the Hepatitis C Council of NSW better address the needs of their members. We cannot and do not guarantee or promise that you will receive any benefits from this study.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or except as required by law. If you give us your permission by signing this document, we plan to discuss and present the findings to the Hepatitis C Council of NSW and the National Centre in HIV Social Research. Information discussed and presented will include a summary of the themes identified from the interviews. In any publication of the findings, information will be provided in such a way that you cannot be identified.

Participants will receive $20 to cover their time and travel costs that may be incurred by participating in this study.

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au).

Summary of research findings will be published in the 'Hep C Review' after the completion of the study. The study is expected to be completed in December 2007.

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales and the Hepatitis C Council of NSW. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without question and prejudice.

If you have any questions, please feel free to ask us. If you have any additional questions later, Dr Kylie Valentine on (02) 9385 6948, Dr Carla Treloar on (02) 9385 6959, or Mr Paul Simpson on [redacted] [redacted], will be happy to answer them.

You will be given a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

………………………………………………… …………………………………………………..
Signature of Research Participant Signature of Witness

………………………………………………… …………………………………………………..
(Please PRINT name) (Please PRINT name)

………………………………………………… …………………………………………………..
Date Nature of Witness

…………………………………………………
Signature(s) of Investigator(s)

……………………………………………………
Please PRINT Name

REVOCATION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with The University of New South Wales and the Hepatitis C Council of New South Wales.

………………………………………………… …………………………………………………
Signature Date

…………………………………………………
Please PRINT Name

The section for Revocation of Consent should be forwarded to either Dr Kylie Valentine, Dr Carla Treloar, or Mr Paul Simpson, National Centre in HIV Social Research Centre, Level 2, Robert Webster Building, University of New South Wales, Sydney NSW 2052.

Appendix C

Participant information statement and consent form – Hepatitis key informants

My name is Paul Simpson and I am a doctoral student at UTS under the supervision of Professor Jenny Onyx. You are invited to participate in a study looking at what makes a community-based organisation unique in terms of the kinds of help it provides to people affected by hepatitis C.

The first part of the study interviewed people affected by hepatitis C to hear what they valued about their engagement with Hepatitis NSW. The second part of the study looks at what senior Hepatitis NSW staff value about Hepatitis NSW.

You were selected as a possible participant for part 2 of this study because of your knowledge and experience working with Hepatitis NSW.

If you decide to participate, we will be conducting interviews that will ask about your thoughts regarding what makes Hepatitis NSW unique in terms of the kinds of help Hepatitis NSW provide to people affected by hepatitis C. The interview will also look at how funding agreements with NSW Health over the past 5 years have helped and/or challenged the unique work Hepatitis NSW undertakes.

Interviews will be conducted at a time and place that is convenient for you. Interviews are expected to take 45-60 minutes. We do not anticipate that you will experience any undue stress as a result of taking part in this interview.

It is hoped that the findings from this study will help health-orientated community organisations like Hepatitis NSW better address the needs of their members and others who engage with such organisations. We cannot and do not guarantee or promise that you will receive any direct benefits from this study.

You may be identifiable due to the small number of participants recruited for this study, however, you will be contacted beforehand for approval of the use of any information you provide to this study, and every effort will be made to de-identify you. No-one other than the researchers will have access to the information.

If you give us your permission by signing this document, we plan to discuss and present the findings from both part 1 and part 2 of this study to Hepatitis NSW, the Cosmopolitan Civil Societies Research Centre and, the National Centre in HIV Social Research. The study is expected to be completed in December 2012.

Your decision whether or not to participate will not prejudice your future relations with The University of Technology, Sydney. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without question and prejudice.

If you have any questions, please feel free to ask us. If you have any additional questions later, Mr Paul Simpson (doctoral candidate, ID: [redacted]) on [redacted] or Professor Jenny Onyx on (02) 9514 3633 will be happy to answer them.

You will be given a copy of this form to keep.

NOTE: This study has been approved by the University of Technology, Sydney Human Research Ethics Committee. If you have any complaints or reservations about any aspect of your participation in this research which you cannot resolve with the researcher, you may contact the Ethics Committee through the Research Ethics Officer (ph: +61 2 9514 9772 Research.Ethics@uts.edu.au). Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

…………………………………………………	…………………………………………………
Signature of Research Participant	Signature of Witness
…………………………………………………	…………………………………………………
(Please PRINT name)	(Please PRINT name)
…………………………………………………	…………………………………………………
Date	Nature of Witness

…………………………………………………

Signature(s) of Investigator(s)

…………………………………………………

Please PRINT Name

REVOCATION OF CONSENT]

I hereby wish to **WITHDRAW** my consent to participate in the research described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with The University of Technology, Sydney.

…………………………………………………	…………………………………………………
Signature	Date

…………………………………………………

Please PRINT Name

The section for Revocation of Consent should be forwarded to either Professor Jenny Onyx or Mr Paul Simpson, room CM05D.04.14, 1-59 Quay Street, University of Technology, Sydney Haymarket, NSW 2001

Appendix D

Hepatitis NSW members by demographics, themes and identity template table

Participant	Demographics	Reason for joining, or value from engaging with, HCCNSW		Clinical and (biomedical) treatment status	HCCNSW engagement & identity work related theme(s)	Assignment to primary identity work cluster
		Receiving help	Giving help			
Aaron	Male, 40-50 yo, Anglo-Australian, disability pension	Receive information (research and news items)		HCV+ Unable to undergo biomedical treatment (as advised by his doctor due to bipolar diagnosis and alcohol use)	Primacy of HCV related health concerns & biomedical agents/knowledge. Critical of newsletter genre's and narratives that are not "serious" (that stray away from more formal & medicao-scientific discourses)	(expert health consumer?)
Andrew	Male, 40-50 yo, Anglo-Australian, drug and alcohol counsellor	Receive information (research and news items), vocation support	(previous) HCCNSW volunteer ('Ceen & Heard' program volunteer)	Cleared HCV	Mutualism, sense of 'community' & volunteering	Community-mutualist volunteer
Bre	Female, 30-35yo, father Anglo-Australian, other is Sri-Lankan Australian, Artist, government benefits.	Reader stories & to receive information (research and news items)	Would like to volunteer in the future (e.g. in art based projects)	HCV+ Last days of biomedical treatment	Reader stories help guide/inform liminality/relation to HCV	Liminal guidance consumer
Chris	Male, 40-50 yo, Anglo-Australian, disability pension	Reader stories & to receive information (research and news items) & reader stories	Would like to volunteer but health status prevents this	HCV+ Does not currently want biomedical treatment	Primacy of HCV related health concerns and stigma - supersedes HCCNSW engagement	(Lack of HCCNSW engagement talk)
Gina	Female, 70-80 yo, Anglo-Australian, retiree	Reader stories & to receive information (research and news items)		HCV+ Unable to undergo biomedical treatment (as advised by his doctor due to age)	Age and biomedical agents/knowledge inform relation to HCV – supersedes HCCNSW engagement	(Lack of HCCNSW engagement talk)
Jacki	Female, 35-40 yo, Anglo-Australian, government benefits	Reader stories & to receive information (research and news items)		HCV+ Last days of biomedical treatment	Reader stories help guide/inform liminality/relation to HCV	Liminal guidance consumer
Jen	Female, 30-35 yo, Greek-Australian, government benefits	Sometimes likes to read reader stories		HCV+ Does not currently want biomedical treatment	Critical of newsletter being too formal/scientific – minimal HCCNSW enagement	(Lack of HCCNSW engagement talk)
	Female, 40 yo,	Receive	Would like	HCV+	Research and news	Expert health

Josie	Anglo-Australian, tertiary educated, artist and health professional	information (research and news items)	to do more volunteer work (has distributed HCV awareness bookmarks	States she can not currently undergo biomedical treatment (due to lack of support for her child)	help inform consumer agency Critical of biomedical treatment focus.	consumer
Kate	Female, 50-60 yo, Anglo-Australian, home duties (& hospital volunteer)	Receive information about research		HCV+ Underwent biomedical treatment which did not clear HCV. Currently awaiting better treatment options	Research and news help inform consumer agency Lack of commonality with reader story text	Expert health consumer
Nick	Male, 35-40 yo, Anglo-Australian, government benefits (& HCCNSW volunteer), tertiary educated	Receive information (research and news items) & reader stories	HCCNSW volunteer (e.g. newsletter data base work)	Cleared HCV	Mutualism, 'community'/(shift in) association identification & volunteering	Community-mutualist volunteer
Pete	Male, 40-50 yo, Anglo-Australian, government benefits	Receive information (research and news items) & reader stories		HCV+ Does not currently want biomedical treatment	Critical of lack of 'street based' feel of newsletter but likes medico-scientific presentations in newsletter	(Lack of HCCNSW engagement talk)

Appendix E

Hep C Review readers story theme table

Ed	**Author**	**Title of Story**	**Theme & topics**	**Demographic**	**Vector mode**	**Clinical status**	**Discourse Types**	**Message to reader's**
51	Lily	Lily's Treatment Story	Not enough information about a treatment side effect (i.e. retinopathy)	tertiary educated ("ex-social worker-cum-artist") / mother (35 yo +)	undisclosed	HCV+, cirrhosis of the liver. Combination treatment for 6 months	Biomedical, alternative	"Please everyone be vigilant if you are on therapy as it seems to me that we are really on our own when this stuff doesn't work."
51	Snake	Article writing competition – Snake	Discrimination & drug use associated with Hepatitis C: More education is needed	not disclosed (assumption: indigenous Australian, male, ex-prisoner, some education)	not disclosed (assumption: IDU)	hepatitis C positive ("for some time")	Biomedical Health promotion and education Military Drug Legal	- "Politicians and social commentators MUST change their strategies and attitudes towards drugs". - Address and treat drug use as a complex "interwoven" issue. - Education (include those affected by hepatitis C in this)
51	Grenville	Article writing competition – Grenville	Discrimination & drug use associated with Hepatitis C: "treating problem injecting drug use as a disease rather than a crime".	"background in market research" (assumed female, some education, employed)	not disclosed (assumed through IDU)	not disclosed (assumed hepatitis C positive or previously positive)	Biomedical (Drug use as a disease or voluntary act?) Marketing discourse Drug discourse and citizenship	Treating problem drug use as a medical problem rather than a legal problem would lead to a better outcome for society and individuals affected by drug use and hep C.
51	Anna	Article writing competition - Anna	Concerns living with hepatitis C (Pros and cons of disclosing to friends but mostly health professionals)	Female, married, past (present?) drug user	Needle stick or IDU	Hepatitis C positive ("LFT's are always normal)	Biomedical "LFT's" Everyday Spiritual	Honesty wins re disclosure
52	Magdalena	Hepatitis C, Interferon and the Medical Profession	Limitations of the medical profession re issues of treatment & costs of alternative treatment	Female, 30s, educated, city/urban	IDU?	HCV+	Metadiscourse? Biomedical critique	Patient as a whole person not just someone who has to take responsibility to have treatment
52	Jewells	My Dream for a Healing Centre	Treat illness holistically & awareness and costs of alternative treatment	Female, 40-60s, country/rural, educated (alternative)	IDU or medical?	HCV+	Alternative medicine, biomedicine, psy-discourse, spiritual	"A dream" to have both complimentary/alternative and biomedicine available and affordable to all
52	Dinesh	Treatmen	Experiences	Country/rural,	Not	Cleared	Biomedicin	Resources needed to

		t in an Isolated Area	of treatments living in an isolated area	educated?	disclosed	HCV	e, psy-discourse, alternative/ eastern	make the best from treatment and its side effects
53	Julie	Blood Blues	Lack of help/support from health system. Rights not informed/ignored	Female, 43 yo, mother	Blood transfusion	18 yrs HCV+	Life world, biomedicine	Injustice and lack of empathy/sympathy from health/medical system
53	Sharon	Heal Thyself	Confusing and conflicting process/journey in finding the treatment path that is right for the individual	Female, 40-50yo	IDU	2 yrs HCV+	Alternative medicine, biomedicine, Californian concepts of the self, military-chemical warfare, individualism, life world	Understand one's unique and individual journey in handling HCV, "have faith"
53	Margaret	Access and Quality of Hep C Treatment	Experience in living with and seeking treatment	Female, 70+ yrs	Blood transfusion	HCV+	Life world, biomedicine	Accepting the limits of treatment as it relates to aging
54	Glenda	Just Do It	Experience and journey through treatment	Female 40+, mother, TAFE student	Not disclosed (IDU?)	HCV-	Life world, biomedicine	Despite all the "sufferance" treatment is worth it so "just do it"
54	John ("not his real name")	Twenty Down and One to Go	Experience of HCV in prison (lack of rights and dignity)	Male, 45yo, in prison,	John does not know (non-IDU)	5yrs HCV+	Life world,	.critical of the treatment of prisoners and thankful of HCCNSW
54	Dave ("not his real name")	Using Outside Using Inside	Looking after one's health (associated with past drug use, prison and HCV)	Male, 40 yo, in prison,	IDU	15-20 yrs HCV^{+}	Life world, health	How vital your health is (don't leave it until it's too late)