

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

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## **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.

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## TABLE OF CONTENTS

CERTIFICATE OF ORIGINAL AUTHORSHIP.....	III
ACKNOWLEDGEMENTS .....	V
LIST OF FIGURES AND TABLES .....	XIII
ABSTRACT .....	XV
<b>CHAPTER ONE - INTRODUCTION.....</b>	<b>1</b>
Scope of thesis .....	3
Outline of thesis .....	5
Part One: Background and theory .....	5
Part Two: Methodology .....	9
Part Three: Findings and conclusion.....	11
<b>PART ONE: BACKGROUND AND THEORY</b>	
<b>CHAPTER TWO - UNDERSTANDING HEPATITIS C.....</b>	<b>17</b>
CHAPTER INTRODUCTION .....	17
HEPATITIS C BACKGROUND .....	18
Natural history .....	18
Prevalence .....	19
LIVED EXPERIENCE OF HEPATITIS C .....	22
Social stigma.....	22
Biographical adaptations.....	27
Narrative constitution of illness identity .....	35
SOCIAL RESPONSES TO HEPATITIS C.....	38
Public sector responses to hepatitis C .....	38
Civil society responses to hepatitis C .....	41
CONCLUSION.....	44
<b>CHAPTER THREE - UNDERSTANDING THE DISTINCT EXPERTISE OF HEALTH-ORIENTATED COMMUNITY-BASED ORGANISATIONS .....</b>	<b>47</b>
CHAPTER INTRODUCTION .....	47
UNDERSTANDING CIVIL SOCIETY ORGANISATIONS AND THEIR DEFINING DISTINCTION .....	48
The institutional and legal approach .....	49
The normative approach.....	51
The comparative advantage approach.....	53

UNDERSTANDING HEALTH COMMUNITY-BASED ORGANISATIONS BEYOND RATIONAL AND UTILITARIAN TERMS: THE IMPORTANCE OF PERSONAL EXPERIENCE.....	55
A NARRATIVE COMMUNITAS MODEL OF DISTINCT EXPERTISE .....	61
Level 1 – Narrative .....	63
1(a) Members’ hepatitis C lived experience as narrative identity .....	67
1(b) Hepatitis C community-based organisation as multiple-narrative organisations.....	68
Level 2 – Liminality .....	72
2 (a) Hepatitis C lived experience as in-between opposing categories.....	74
2. (b) Hepatitis C community-based organisations’ in-between the state and “community” .....	77
HEPATITIS C COMMUNITY-BASED ORGANISATIONS AND NARRATIVE COMMUNITAS	
SPACES .....	80
Linking multiple narratives of hepatitis C community-based organisations to structure and anti-structure .....	82
Hepatitis C community-based organisations and the production of state endorsed dominant narratives .....	83
Hepatitis C community-based organisations and the production of alternative and counter-narratives .....	85
Productive potential of narrative communitas spaces within a hepatitis C community-based organisations.....	89
CONCLUSION .....	93
<b>CHAPTER FOUR - SOCIO-POLITICAL ENVIRONMENT AND THE CONTAINMENT OF NARRATIVE COMMUNITAS SPACES .....</b>	<b>95</b>
CHAPTER INTRODUCTION.....	95
Emergence of “Third Way” centralist ideology .....	96
Impacts of state and civil society organisation relations .....	98
Culture governance.....	102
CONCLUSION .....	106
<b>PART TWO: METHODOLOGY</b>	
<b>CHAPTER FIVE - METHODOLOGY .....</b>	<b>111</b>
CHAPTER INTRODUCTION.....	111
Research goal.....	111
Conceptual framework .....	112
Research aim and question .....	113
Research objectives .....	114
Field site .....	115
Hepatitis New South Wales.....	116



METHODS .....	120
Data selection.....	120
(1) Hepatitis NSW secondary text - Hep C Review.....	121
<i>Procedure</i> .....	123
(2) Hepatitis NSW member data – Member Interviews.....	126
<i>Procedure</i> .....	126
(3) Hepatitis NSW key informant interviews.....	130
<i>Procedure</i> .....	131
(4) Literature .....	133
<i>Procedure</i> .....	133
Analysis.....	133
Hepatitis NSW text analysis .....	135
Member interview analysis .....	137
Hepatitis NSW key informant interview analysis.....	141
Organising and presenting findings .....	142

## **PART THREE: FINDINGS AND CONCLUSION**

<b>CHAPTER SIX - DOMINANT HEPATITIS C IDENTITIES.....</b>	<b>147</b>
CHAPTER INTRODUCTION .....	147
Public sector as hepatitis C relational setting.....	147
Public sector narratives of hepatitis C.....	149
MEDICALISATION OF HEPATITIS C IDENTITIES.....	151
Contemporary expression of medicalisation.....	157
HEPATITIS C HEALTH CONSUMER IDENTITIES.....	159
Consumerism .....	159
Healthism .....	160
The hepatitis C expert health consumer.....	163
Expert health consumer identities (re)produced within Hepatitis NSW.....	165
Expert health consumer identities (re)produced by Hepatitis NSW members.....	170
LIMITATIONS OF DOMINANT HEPATITIS C IDENTITIES .....	175
(Re)producing hepatitis C as liminal identity .....	178
Hepatitis NSW members: Bree and Jacqui .....	180
CONCLUSION.....	185
 <b>CHAPTER SEVEN - ALTERNATIVE HEPATITIS C IDENTITIES .....</b>	<b>187</b>
CHAPTER INTRODUCTION .....	187
Addressing medicalisation concerns.....	187
Biosociality .....	189
HEPATITIS C SOCIAL ADVOCACY IDENTITIES.....	190

Social advocacy identities produced in Hepatitis NSW text .....	190
Editorial text .....	191
Reader stories .....	195
HEPATITIS C SOCIAL LIMINAL IDENTITIES .....	203
Social liminal identities produced by Hepatitis NSW members.....	203
Liminality and volunteering .....	206
HEPATITIS C COMMUNITY-MUTUALIST IDENTITIES .....	209
Community-mutualist identities produced by Hepatitis NSW members.....	209
Mutual help.....	210
Community .....	213
CONCLUSION .....	219
<b>CHAPTER EIGHT - BETWIXT AND IN-BETWEEN STATE AND COMMUNITY: EXPRESSION AND CONTAINMENT OF PROSPECTIVE NARRATIVE COMMUNITAS SPACES IN A HEPATITIS C COMMUNITY-BASED ORGANISATION .....</b>	<b>221</b>
CHAPTER INTRODUCTION.....	221
HEPATITIS NSW DISTINCT EXPERTISE AS PROSPECTIVE .....	222
NARRATIVE COMMUNITAS SPACES .....	222
NARRATIVE COMMUNITAS EXPRESSIONS THROUGH MEMBER IDENTITY WORK.....	228
Social-liminal identities indicative of Hepatitis NSW narrative communitas elements....	228
Community-mutualist identities as an effect of Hepatitis NSW narrative communitas spaces?.....	232
HEPATITIS NSW NARRATIVE COMMUNITAS CONTAINMENT.....	236
CONTEMPORARY SOCIAL-POLITICAL ENVIRONMENT AND NARRATIVE COMMUNITAS CONTAINMENT.....	250
Culture governance and reinstating utilitarianism.....	255
CONCLUSION .....	260
<b>CHAPTER NINE - CONCLUSION.....</b>	<b>263</b>
Investigating the notion of the distinct expertise of a hepatitis C community-based organisation .....	266
In what ways does a hepatitis C community-based organisation facilitate the construction of responsive hepatitis C identities among those who engage with it?.....	268
Investigating the factors that help express and constrain the distinct expertise of a hepatitis C community-based organisation.....	270
Implications and directions for future research .....	271
Hepatitis C identities .....	272
Conceiving distinct expertise of a health-orientated community-based organisations.....	274

REFERENCES .....	281
APPENDICES .....	309
Appendix A.....	309
Appendix B.....	310
Appendix C.....	312
Appendix D.....	314
Appendix E.....	316



## **LIST OF FIGURES AND TABLES**

### **List of figures**

- Figure 1      Narrative communitas model of HCV CBO distinct expertise
- Figure 2      Narrative communitas model of health CBO distinct expertise (2 X 2 level model)
- Figure 3      Narrative communitas model of health CBO distinct expertise (2 X 3 level model)
- Figure 4      Organisational structure of HNSW
- Figure 5      Narrative communitas model of HCV CBO distinct expertise

### **List of tables**

- Table 1      Types of data collected according to research objectives
- Table 2      Participant demographics, reported HCV and treatment status and mode of hepatitis C transmission
- Table 3      Types of analysis according to data type
- Table 4      Organising and presenting findings according to research objectives



## 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.