BY VIRTUE OF CIRCUMSTANCE:

HIV/AIDS IN MOBILE AND RURAL POPULATIONS IN WESTERN AUSTRALIA, AN ETHNOGRAPHIC STUDY

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This thesis is presented for the degree of Doctor of Philosophy of Murdoch University

Supervisor: David Nolan
DECLARATION

The research presented in this thesis is my own work unless otherwise stated and contains as its main content work which has not previously been submitted for a degree at any tertiary education institution.

Susan Elizabeth HERRMANN

Signature

Date
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And in the end, loving thanks to my family for their unflagging support.

This work is dedicated to my beloved parents

Hugh Davey
17th October 1927 – 30th June 2011

& Jean Davey
24th April 1932 – 29th April 2012

Voici mon secret. Il est très simple: on ne voit bien qu’avec le cœur. L’essentiel est invisible pour les yeux

Here is my secret. A very simple secret. It is only with the heart that one can see rightly. What is essential is invisible to the eye

From Le Petit Prince (1943), a novel by Antoine de Saint Exupéry (1900-1944)
ABSTRACT

HIV/AIDS is an incurable, infectious condition that, without access and adherence to lifelong treatment with specific antiretroviral drugs (ARVs), leads to declining immune-competence and death, usually within ten years of acquiring the infection. Australians have benefited from universal access to ARVs under patent through the national health care access scheme, Medicare. Since 2005 there has been a steady rise in notifications, dispersed across Western Australia (WA), indicating HIV infection in women, and men who have sex with women, against the previous trend of risk and transmission in men who have unprotected sex with other men. Many people diagnosed hold temporary visas and come to WA with their families to work or study and are ineligible for Medicare. This compromises their access to effective antiretroviral treatment by virtue of their visa status.

Between 2007 and 2008, one hundred and seventeen people living with HIV in WA participated in an international, mixed methods study of health-related quality of life. This thesis describes and references those findings to examine, through an ethnographic perspective, and within the context of current epidemiology: (1) the experience of managing HIV in a rural or remote environment; (2) the effect of visa status in mediating the experience of HIV; and (3) aspects of access and adherence to ARVs that influence the outcome of treatment. In 2010 and 2011 data were gathered from interviews with thirty participants (nine women) with HIV-infection: twenty-two had been granted temporary work or student visas, fourteen were current business or student visa holders, and nineteen lived or worked in rural areas. Group data from two rural-based cohorts is referenced and twenty-one key informants were interviewed to augment context, and contribute thick description.
Limited access to ARVs posed by non-citizen status and/or distance from dispensing pharmacies was overcome largely by motivation to accept treatment and support from key health professionals (HPs), which resulted in high levels of adherence and engagement with care. However, there were differences in approaches to HIV supportive care between indigenous and non-indigenous cohorts with more intense involvement of HPs in the former group. The data showed a pattern of stigma characterised by persistent fear of disclosing HIV serostatus and infecting others. This was nuanced by the particular circumstances of individuals, for example, non-citizen status, and living and/or working in regional areas. In particular HIV-positive serostatus affected, and frequently limited, social relationships, employment and the likelihood of successful migration.

These data indicate, firstly, that the immunopathological consequences of HIV infection can and should be avoided by policies that facilitate unfettered access to treatment and medical care; and secondly that the psychosocial aspects of HIV disease that limit the lives and livelihoods of people with HIV infection require intervention.

**Key Words:** HIV/AIDS, Access, ART, Medication Adherence, Health-Related Quality of Life, Stigma, Visa Status, Rural, Employment, FIFO, Immigration, Ethnography
ACADEMIC OUTPUT DURING CANDIDATURE

Publications


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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AFAO</td>
<td>Australian Federation of AIDS Organisations</td>
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<tr>
<td>ART</td>
<td>Anti Retroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>BBV</td>
<td>Blood Borne Virus</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>Doha</td>
<td>WTO Declaration on TRIPS and Public Health</td>
</tr>
<tr>
<td>DIDO</td>
<td>Drive in Drive Out</td>
</tr>
<tr>
<td>FDC</td>
<td>Fixed-dose Combination</td>
</tr>
<tr>
<td>FIFO</td>
<td>Fly in Fly Out</td>
</tr>
<tr>
<td>Generic Drug</td>
<td>A bioequivalent of a propriety (brand name) drug</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People with HIV/AIDS</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>MHS</td>
<td>Mental Health Summary</td>
</tr>
<tr>
<td>NAPWA</td>
<td>National Association for People Living with HIV/AIDS</td>
</tr>
<tr>
<td>NRTI</td>
<td>Nucleoside/tide Reverse Transcriptase Inhibitor</td>
</tr>
<tr>
<td>NNRTI</td>
<td>Non-Nucleoside Reverse Transcriptase Inhibitor</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
</tr>
<tr>
<td>PHU</td>
<td>Population Health Unit</td>
</tr>
<tr>
<td>PHP</td>
<td>Public Health Physician</td>
</tr>
<tr>
<td>PHS</td>
<td>Physical Health Summary</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living With HIV</td>
</tr>
<tr>
<td>PI</td>
<td>Protease Inhibitor</td>
</tr>
<tr>
<td>RPH</td>
<td>Royal Perth Hospital</td>
</tr>
<tr>
<td>RRN</td>
<td>Rural and Remote Clinical Nurse Specialist</td>
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<td>TRIP Agreement</td>
<td>Trade Related Intellectual Property Agreement</td>
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<td>WAAC</td>
<td>Western Australian AIDS Council</td>
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<tr>
<td>WACHS</td>
<td>Western Australian Country Health Service</td>
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<tr>
<td>WAHCS</td>
<td>Western Australian HIV Cohort Study</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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</tbody>
</table>
# TABLE OF CONTENTS

**ABSTRACT** .................................................................................................................. iii

**ACADEMIC OUTPUT DURING CANDIDATURE** .............................................................. v

**ABBREVIATIONS** ........................................................................................................ vii

**INTRODUCTION** .......................................................................................................... 1

- Origins and Context of the Study .................................................................. 2
- Uptake and Adherence to Treatment .............................................................. 3
- Current Epidemiology: Regional Spread ......................................................... 4
- HIV and Migration Status in Australia ............................................................. 6
- HIV Diagnosis, Treatment and Care ................................................................. 8
- Contribution to the Field of HIV Social Research ........................................... 9
- Research Purpose ............................................................................................... 14
- Organisation of the Thesis ............................................................................... 14

**CHAPTER ONE LITERATURE REVIEW** ..................................................................... 19

- Overview ............................................................................................................. 19
- HIV and AIDS in Context .............................................................................. 21
- The Origins of HIV .......................................................................................... 22
- Life Cycle of the Virus ..................................................................................... 24
- Chronic Infection ............................................................................................. 27
- Treatment for HIV/AIDS ............................................................................... 30
- Antiretroviral Drugs ....................................................................................... 33
- Potency of antiretroviral therapy ................................................................. 36
- Adherence to and Persistence with Antiretroviral Drugs ............................ 38
- Raising the Alarm: Medication Nonadherence in HIV .............................. 42
- The Pharmacokinetics of Commonly Prescribed Antiretroviral Drugs ...... 44
- Measurement of Adherence ......................................................................... 45
- Factors that Influence Adherence to and Persistence with ART .............. 47
- Health-related Quality of Life ....................................................................... 50
- Health-related Quality of Life and Adherence ............................................. 54
- Medication Adherence in the WA HIV Cohort ............................................ 57
- The Critical Role of Antiretroviral Drug Access ........................................ 59
- AIDS Activism Influenced Drug Access ..................................................... 59
- Access to Medication: the Socio-Political Context and TRIPS ................. 61
- Delivery of Antiretroviral Drugs to the People ........................................... 63
- Migration, Mobility and HIV .......................................................................... 69
- Immigration and HIV in Australia ................................................................. 74
- Australian HIV/AIDS Organisations Action on Behalf of Immigrants with HIV ........................................................................................................... 76
- Applications for Temporary Visas for Work or Study ................................ 77
- Temporary Visa Holders and HIV in Australia ............................................. 79
- Summary ........................................................................................................... 80

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**Summary**
CHAPTER TWO  METHODS ................................................................. 85
Introduction...................................................................................... 85
Methodological Considerations ...................................................... 86
Qualitative Research ........................................................................ 86
Ethnography .................................................................................... 87
Research Problem, Purpose and Aims.............................................. 92
The Research Setting: HIV Services in Western Australia .......... 94
Services to PLWH in Regional Western Australia ................. 97
Accessing the Research Setting ..................................................... 98
Data Collection ............................................................................... 102
Interviews with Key Informants .................................................... 102
Recruitment of ‘Patient’ Participants ............................................. 104
Interviews with ‘Patient’ Participants ............................................. 107
Use of Diverse Forms of Data: The Reflective Diary and Field Notes 109
Clinical Data .................................................................................. 109
Antiretroviral Medication History, Access and Adherence to Treatment 110
Data Analysis ................................................................................. 111
Sample size or How Many Interviews Are Enough? .................. 114
Ethical Considerations ................................................................ 115
Summary ....................................................................................... 119

CHAPTER THREE HEALTH-RELATED QUALITY OF LIFE ............ 123
Introduction...................................................................................... 123
Background .................................................................................... 123
Specific Methods .......................................................................... 124
Results ............................................................................................ 128
Results of Interviews (Stage One) ................................................ 128
Results of the Psychometric Testing of HRQL (Stage Two) ....... 134
Discussion ....................................................................................... 142

CHAPTER FOUR  PEOPLE IN RURAL AND REMOTE ENVIRONMENTS .... 151
Background .................................................................................... 151
A Tale of Two Cohorts: The North-West and Goldfields HIV-Outbreaks 153
The Service Model ........................................................................ 153
Methods Specific to this Chapter ................................................ 155
Interviews with Health Care Providers ........................................ 155
Interviews with Participants ........................................................ 156
Part One ......................................................................................... 157
Clinical Data .................................................................................. 157
Access to Antiretroviral Drugs in Regional Areas ...................... 158
Interviews with Key Informants .................................................. 159
Managing HIV in the North-West: Engaging with PLHV .......... 166
Adherence to Antiretroviral Drugs .............................................. 167
Summary of Part One .................................................................. 176
The Role of HIV Support Services .............................................. 178
Conclusion ...................................................................................... 179
Part Two: Participants Living or Working in Regional Western Australia .... 179
Introduction ................................................................................... 179
Results ............................................................................................ 182
CHAPTER FIVE  TEMPORARY VISA HOLDERS……………………………...211

Introduction ....................................................................................... 211
Specific Methods .............................................................................. 212
Results ............................................................................................. 213
Results of Interviews ........................................................................ 217
Impact of an HIV Diagnosis .............................................................. 217
Disclosure of HIV Status: “Is she Black?” ........................................ 220
Fear of Transmitting HIV ................................................................... 223
Physical Impact of HIV ....................................................................... 224
Complementary Medicine and Use of Substances ............................... 225
Treatment and Side Effects .................................................................. 225
Adherence to Antiretroviral Drugs .................................................... 229
Returning to Country of Origin .......................................................... 232
Relationships and Support .................................................................. 233
People With and/or Wanting to Have Children .................................. 234
Outpatient Care: Social Support ......................................................... 235
Employment ..................................................................................... 237
Culture: Anonymity and Visibility ....................................................... 240
Adaptation and the Future ................................................................... 243
Discussion ......................................................................................... 244

CHAPTER SIX  DISCUSSION ................................................................. 255

Introduction ....................................................................................... 255
The PROQOL-HIV Study ..................................................................... 258
HIV/AIDS and Employment ............................................................... 259
Stigma and Health Seeking Behaviours .............................................. 260
Treatment Access, Adherence, Attitudes and Literacy .......................... 263
Methodological considerations in the assessment of health-related quality of life...... 272
Summary ........................................................................................... 273
The Construction of Stigma ............................................................... 274
Stigma in HIV/AIDS .......................................................................... 275
Recommendations .............................................................................. 287
Limitations ........................................................................................ 291
Conclusion ........................................................................................ 292

REFERENCES .................................................................................... 295
APPENDICES .................................................................................... 353
TABLE OF FIGURES

Figure 1: Increasing number of PLWH in regional areas between 1998 and 2009 .......... 5

Figure 2: Movement of people, 19th Century migration vs 20th Century movement.....12

Figure 3: Schematic of population of interest ................................................................. 15

Figure 4: CD4 T cell count predicts risk of opportunistic infections and AIDS-related malignancies................................................................. 22

Figure 5: Lifecycle of HIV................................................................................................ 25

Figure 6: The natural stages of HIV infection .................................................................... 28

Figure 7: Therapeutic schema of the determinants of drug efficacy .............................. 32

Figure 8: How drug resistance arises ................................................................................ 36

Figure 9: Chronology of adherence and or persistent pill taking behaviour as measured by electronic event monitoring cap technology ........................................................................ 39

Figure 10: Relation between individual drug classes, levels of adherence and risk of resistance mutations............................................................................................. 43

Figure 11: Adherence correlates with pharmacy refill data ............................................. 46

Figure 12: Schematic of fundamental domains which encompass factors influencing adherence to medication ................................................................................................. 47

Figure 13: Schematic of adherence management .............................................................. 50

Figure 14: The impact of treatment regimen and lifestyle on medication adherence...55

Figure 15: Countries with highest purchase volumes of generic ARVs ......................... 64
Figure 16: Countries, territories that have some form of HIV-related restriction on entry, stay or residence ................................................................. 73

Figure 17: A map of designated regions ................................................................. 151

Figure 18: The social and structural elements that support relationships and engagement with HIV care .............................................................................. 178

Figure 19: Continuum of HIV care .............................................................................. 270

Figure 20: Model of HIV-related stigma, theory, manifestations and outcomes ....... 277
TABLE OF TABLES

**Table 1:** Classical concepts shaping medication adherence behaviour: changes in Western Australia 2002-2010 .................................................................................................................. 11

**Table 2:** Sampling frame of key informants and stakeholders/constituents ..............103

**Table 3:** Evolution of themes derived from the PROQOL-HIV Study..........................108

**Table 4:** Topics and themes drawn from the interviews .................................................113

**Table 5:** Characteristics of the 15 interviewees who participated in Stage One ..........130

**Table 6:** Themes emerging from narratives........................................................................133

**Table 7:** Characteristics of participants : psychometric testing....................................138

**Table 8:** Linear regression estimates of univariate predictors........................................139

**Table 9:** Pearson correlations of PROQOL subscale scores with the global PROQOL 8-factor score; and the MOS Mental health and Physical Health Scales..............................141

**Table 10:** Audit data for cohorts in the North-West Town and the Goldfields ............157

**Table 11:** Kalgoorlie-Boulder regional information..........................................................162

**Table 12:** The Kalgoorlie-Boulder Outreach Clinic.............................................................165

**Table 13 (a,b):** Demographic and clinical characteristics of the participants either living or working in regions designated as rural and/or remote .........................................181

**Table 14:** Rural case study ................................................................................................193

**Table 15 (a,b):** Demographic and clinical characteristics of the participants ..........216
THE CONTRIBUTION OF OTHERS TO THIS WORK

I acknowledge the contribution of others to this thesis. The Quality of Life Study presented in Chapter Three grew from my organisation’s contribution to an international project (PRO-QOL HIV) which developed a psychometric instrument to assess the health-related quality of life impacts of HIV. The study was designed and coordinated by Dr Martin Duracinsky and funded by Sidaction. In accordance with the research contract, the Western Australian data remained under the governance of the Australian investigators to be published independently of the larger project. The manuscript, which I wrote during my candidature, is presented as a single chapter in the thesis in the form of a manuscript as it complements and informs the two subsequent sections concerning HIV infection in regional Western Australia and the growing epidemic in non-citizens. Therefore, I acknowledge the considerable contribution of others to that original work.

My contribution to the work was as follows: I led the two-stage Australian arm of the study; wrote and managed the ethics submission; conducted the majority of the interviews; and the face to face questionnaire administration in stages one and two of the study; and analysed the qualitative data. I assisted with the presentation of the preliminary findings of the international study at international conferences, and prepared and presented the Western Australian data at two national ASHM conferences and local branch meetings. I liaised closely with co-author Noel Hyland (Clinical Psychologist, Sexual Health and Communicable Diseases at Royal Perth Hospital), who conducted four of the fifteen interviews and we reviewed the data together, and independently. Statisticians Christophe Lalanne (Assistance Publique–Hopitaux de Paris, Saint-Louis Hospital, Department of Clinical Research, PRO unit,
Paris, France), and Bethy McKinnon in the Institute of Immunology and Infectious Diseases (IIID), worked on the data at some stage. However, Bethy conducted the most recent and thorough data analysis for the Western Australian manuscript; and we explored the quantitative data iteratively, and in consultation with Martin Duracinsky, Christophe Lalanne and Noel Hyland. Bethy also wrote the results section and prepared some of the tables. As the primary author of the manuscript, I wrote the majority of the paper and am responsible for the interpretation of the analyses. I chose to present the qualitative and quantitative results in stages one and two of the study, as a single manuscript in order to provide a clear, rich and thick description of the work. The PROQOL-HIV study provides the reference data for the subsequent studies presented in this thesis.

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