

The impact of comorbidity and clinical complexity on retention in HIV care

Ms. Shiraze Bulsara (Senior Clinical Psychologist; PhD Candidate)

Doctor of Philosophy (Clinical Psychology)

Graduate School of Health, University of Technology Sydney

Year of Submission: 2019

Primary Supervisor: A/Prof. Toby Newton-John (Clinical Psychology, GSH, UTS)

Secondary Supervisor: Prof. Milton Wainberg (Dept. of Psychiatry, Columbia University, NYC)

Word Count: 79,536

Certificate of Original Authorship

I, Shiraze Bulsara, declare that this thesis is submitted in fulfillment of the requirements for the award of Doctor of Philosophy (Clinical Psychology), in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all the information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature:

Production Note:
Signature removed prior to publication.

Original submission date: 04/12/2019

Date revisions submitted: 14/02/2020

Acknowledgements

My primary purpose in developing this research series was to further our understanding of factors which can impede the progress, well-being and QoL of people living with HIV (PLHIV). As a clinical psychologist who has worked with this population for over 12 years, I recognise how marginalised this cohort has been and continues to be. This has fuelled a passion to improve the way in which we support these, often vulnerable, clients with complex clinical presentations. I am also passionate about clinicians from varied disciplines working together in the best interests of the people we support. This body of work has highlighted just how important interdisciplinary, coordinated, and collaborative care is, especially within the public health system.

I must first acknowledge the traditional custodians of the land on which this research was conducted, the Gadigal people of the Eora nation, and convey my deepest respect to Elders past, present and emerging. This always was, and always will be, Aboriginal land.

I would also like to thank the research participants who offered their time and shared their experiences with me. Without their input, this work would not have been possible. I must also thank my colleagues at The Albion Centre, especially the Psychology unit who have supported this research throughout - Damien, Ben, Dion, Tracey, Katherine and Alesha. This really is the best team in the world, and I'd be lost without you. I must also especially acknowledge Ruth, who has allowed me so much flexibility and support, and Kim, who has always championed and mentored my research work. I also need to thank my colleagues Don and Tony for their humour and

support, and my beautiful friend and colleague Maggie, for picking me up and for the regular messages this last year to tell me I could do this.

My supervisors, Prof. Milton Wainberg and A/Prof. Toby Newton-John have been a pleasure to work with during this process. They have provided guidance, support, humour and friendship, and I am eternally grateful. I have always felt supported by them over the past few years, and not once have I felt I couldn't do this which is largely due to their unwavering faith in me and the research – thank you. I am also grateful to other collaborators on specific papers, especially A/Prof. Handan Wand and A/Prof. Kris Rogers, whose statistical genius and patience have been invaluable.

I must also thank the Health Education and Training Institute (HETI) for supporting me with a Mental Health Research Award – I am eternally grateful that you saw something in this research of value and have allowed me the opportunity to focus on it in 2019.

Lastly (but most importantly), my family and friends – without you in my life, I wouldn't have had the courage to embark upon this journey. In particular, my two loves – my husband John, without whom this would not have happened, and whose practical assistance in the final stages saved me! You've allowed me so much flexibility, support and love, especially this last year. I couldn't have done this without you. To my beautiful son Oliver – thank you for being the amazingly kind, caring and funny kid you are. You have kept me grounded, and have made sure I always laugh! You've both been interminably patient with me throughout this whole process and I can't thank you enough. You're my world and I adore you both – thank you.

Statement of Thesis Format

The present work is in the format of thesis by compilation, including a mix of published and unpublished works. The content of manuscripts of published papers is identical to the published versions.

List of publications, grants, awards, and presentations

Study 1 ([Chapter 2](#)) - Predictors of adult retention in HIV care: A systematic review

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2018). Predictors of adult retention in HIV care: A systematic review. *AIDS & Behavior*, 22(3): 752-764. doi: 10.1007/s10461-016-1644-y.

Journal: *AIDS & Behavior*

Journal Ranking: 2018 Impact Factor 2.908; Scimago rating Q1

Publication status: Published (Online, 2016; in print, 2018)

Google Scholar Citations: 26

Study 2 ([Chapter 4](#)) - Retention in HIV care in Australia: The perspectives of clinicians and clients, and the impact of medical and psychosocial comorbidity

Bulsara, S. M., Wainberg, M. L., Audet, C. M., & Newton-John, T. R. (2019). Retention in HIV Care in Australia: The Perspectives of Clinicians and Clients, and the Impact of Medical and Psychosocial Comorbidity. *AIDS Patient Care & STDs*, 33(10), 415-424. doi: 10.1089/apc.2019.0094.

Journal: *AIDS Patient Care & STDs*

Journal Ranking: 2018 Impact Factor 3.742; Scimago rating Q1

Publication status: Published (Online and in print, 2019)

Study 3 ([Chapter 6](#)) - The development of an HIV-specific complexity rating scale

Bulsara, S.M., Begley, K., Smith, D.E., Chan, D.J., Furner, V., Coote, K.V., Hennessy, R.M., Alperstein, D.M., Price, A., Smith, M., Wyson, A., & Wand, H. (2019). The development of an HIV-specific complexity rating scale. *International Journal of STD & AIDS*, 30(13): 1265-1274. doi: 10.1177/0956462419868359.

Journal: *International Journal of STD & AIDS*

Journal Ranking: 2018 Impact Factor 1.501; Scimago rating Q2

Publication status: Published (Online and in print, 2019)

Study 4 ([Chapter 8](#)) - Current definitions of retention in HIV care: The potential role of comorbidity

Bulsara, S.M., Wainberg, M.L., Rogers, K., McAloon, J., Grove, R., & Newton-John, T.R.O. (under review). Current definitions of retention in HIV care: The potential role of comorbidity. Manuscript submitted for publication. *AIDS Care*.

Journal: *AIDS Care*

Journal Ranking: 2018 Impact Factor 2.105; Scimago rating Q1

Publication status: Under Review

Research Grants, Awards and Scholarships

2018-2019 **Gilead Sciences Grant** (AUD \$27,000). 'The Fourth 90': Identifying and responding to clinical complexity to improve retention in care. CIA: Bulsara, S.M.

2019 **The Health Education and Training Institute (HETI), NSW Health** (AUD \$100,245.60). The HETI Mental Health Research Award; scholarship awarded to pay 0.8FTE salary for 12 months to complete PhD.

2019 **UTS Vice Chancellor's Conference Fund** (AUD \$3,000). Grant awarded to attend and present at the 12th International Symposium on HIV Neuropsychiatry in Barcelona, Spain, 14-15 June 2019.

Presentations relevant to PhD study series

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2015). *Substance use and sexual health: The roles of clinical practice and policy in risk-taking and engagement in HIV care in Sydney, Australia*. Oral presentation at the 34th International Congress of Law and Mental Health, Vienna Austria.

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2016). *The syndemic of psychosocial predictors of retention in care*. Oral presentation at the 14th HIV, Hepatitis and Related Diseases (HHARD) conference, UNSW, Sydney Australia.

Bulsara, S.M et al., (2017). *Navigating the cascade: An interdisciplinary approach to managing complex HIV care*. Poster presentation at the 2017 Australasian HIV/AIDS Conference, Canberra, ACT, Australia.

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2017). *A systematic review of predictors of adult retention in HIV care*. Poster presentation at the 2017 Australasian HIV/AIDS Conference, Canberra, ACT, Australia.

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2017). *The syndemic of psychosocial predictors of retention in care*. Poster presentation at the 2017 Australasian HIV/AIDS Conference, Canberra, ACT, Australia.

Bulsara, S.M et al., (2018). *Identifying and responding to clinical complexity in HIV: An interdisciplinary care model*. Oral presentation at the 2018 Australasian HIV/AIDS Conference, Sydney, NSW, Australia.

Bulsara, S.M et al., (2018). *Psychologists and the interdisciplinary team: Identifying and responding to clinical complexity in HIV*. Oral presentation at the 2018 SESLHD Psychology Study Day, Sydney, NSW, Australia.

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2018). *Re-examining our definition and estimates of retention in care*. Poster presentation at the 2018 Australasian HIV/AIDS Conference, Sydney, NSW, Australia.

Bulsara, S.M., Wainberg, M.L., & Newton-John, T.R.O. (2018). *What do they really think? Consumer and clinician perspectives on retention in care: A qualitative review*. Oral presentation at the 2018 Australasian HIV/AIDS Conference, Sydney, NSW, Australia.

Bulsara, S.M., Wainberg, M.L., Rogers, K., & Newton-John, T.R.O. (2019). *Revising retention in HIV care guidelines: Addressing multi-morbidity to allocate resources and achieve the UNAIDS 90-90-90 targets*. Oral presentation at the 12th International Symposium on HIV Neuropsychiatry, Barcelona, Spain.

Contribution of authors

Paper 1 ([Chapter 2](#)) - Published

Contributors:

Ms. Shiraze Bulsara (SB)

Prof. Milton Wainberg (MW)

A/Prof. Toby Newton-John (TNJ)

The conceptual design was developed by all authors. SB was responsible for executing the search strategy, and reviewed articles to be included with TNJ. SB prepared the manuscript, which was reviewed and edited by MW and TNJ.

Paper 2 ([Chapter 4](#)) - Published

Contributors:

Ms. Shiraze Bulsara (SB)

Prof. Milton Wainberg (MW)

Dr. Carolyn Audet (CA)

A/Prof. Toby Newton-John (TNJ)

The conceptual design was developed by SB, MW, and TNJ. SB was responsible for conducting and coding the focus groups, and coding was reviewed with TNJ. SB prepared the manuscript, which was reviewed and edited by MW, CA, and TNJ.

Paper 3 ([Chapter 6](#)) - Published

Contributors:

Ms. Shiraze Bulsara (SB)

Dr. Kim Begley (KB)

Prof. Don Smith (DS)

A/Prof. Derek Chan (DC)

Dr. Virginia Furner (VF)

Ms. Katherine Coote (KC)

Ms. Ruth Hennessy (RH)

Dr. Dion Alperstein (DA)

Mr. Anthony Price (AP)

Ms. Maggie Smith (MS)

Mr. Anton Wyson (AW)

A/Prof. Handan Wand (HW)

All authors involved in the conceptual underpinnings of the study. DS, VF, and DC were involved in scoring datasets. SB, HW, DS, and KB involved in statistical analyses. SB prepared the bulk of the manuscript, although all authors contributed and were involved in reviewing and editing the manuscript.

Paper 4 ([Chapter 8](#)) – submitted for publication (under review)

Contributors:

Ms. Shiraze Bulsara (SB)

Prof. Milton Wainberg (MW)

A/Prof. Kris Rogers (KR)

Dr. John McAloon (JM)

Dr. Rachel Grove (RG)

A/Prof. Toby Newton-John (TNJ)

The conceptual design was developed by SB, MW and TNJ. KR assisted with statistical analyses, and JM and RG assisted with the interpretation of data. SB prepared the manuscript, which was reviewed and edited by MW, KR, JM, RG, and TNJ.

Remaining chapters ([Chapter 1](#), [Chapter 3](#), [Chapter 5](#), [Chapter 7](#), [Chapter 9](#), [Chapter 10](#), and [Chapter 11](#))

Contributors:

Ms. Shiraze Bulsara (SB)

Prof. Milton Wainberg (MW)

A/Prof. Toby Newton-John (TNJ)

All chapters written by SB and reviewed by TNJ, some reviewed by MW.

TABLE OF CONTENTS

Certificate of Original Authorship	ii
Acknowledgements	iii
Statement of Thesis Format	v
List of publications, grants, awards, and presentations	vi
Study 1 (Chapter 2) - Predictors of adult retention in HIV care: A systematic review	vi
Study 2 (Chapter 4) - Retention in HIV care in Australia: The perspectives of clinicians and clients, and the impact of medical and psychosocial comorbidity.....	vi
Study 3 (Chapter 6) - The development of an HIV-specific complexity rating scale	vii
Study 4 (Chapter 8) - Current definitions of retention in HIV care: The potential role of comorbidity.....	vii
Research Grants, Awards and Scholarships.....	vii
Presentations relevant to PhD study series.....	viii
Contribution of authors	ix
Paper 1 (Chapter 2) - Published.....	ix
Paper 2 (Chapter 4) - Published.....	ix
Paper 3 (Chapter 6) - Published.....	ix
Paper 4 (Chapter 8) – submitted for publication (under review).....	x
Remaining chapters (Chapter 1, Chapter 3, Chapter 5, Chapter 7, Chapter 9, Chapter 10, and Chapter 11)	x
List of illustrations and tables	xviii
Chapter 1	xviii
Chapter 2	xviii
Chapter 4	xix
Chapter 5	xix
Chapter 6	xix
Chapter 8	xx

Chapter 9	xx
Chapter 10	xx
Glossary.....	xxi
Abstract.....	xxv
Chapter 1: Introduction.....	1
1.1 The early years.....	1
1.2 The biology of HIV.....	2
1.3 HIV Today.....	4
1.3.1 The global epidemic.....	5
1.3.2 HIV in countries with advanced economies	6
1.4 Priority populations	7
1.5 The public health response to managing HIV	8
1.6 Treatment as Prevention (TasP)	8
1.7 The biomedicalisation of the HIV response	9
1.8 HIV as a chronic disease.....	11
1.8.1 An ageing cohort of PLHIV	12
1.9 Comorbidity and complex clinical presentations.....	14
1.10 The HIV Care and Treatment Cascade and 90-90-90 targets	16
1.10.2 Do current targets represent optimal service delivery?.....	17
1.11 Optimal holistic care: Moving beyond viral suppression to include ‘a fourth 90’?	19
1.11.3 Quality of Life (QoL).....	22
1.12 What is ‘retention in care’ and why does it matter?	23
1.13 Comorbidity in the context of VL and Retention.....	28
1.14 Theoretical underpinnings.....	30
1.14.1 The biopsychosocial model and chronic disease.....	31
1.14.2 Syndemic Theory	43
1.14.3 The Andersen Behavioral Model of Health Service Use.....	46
1.15 The present study series.....	50
1.16 Study 1	53

1.17 Chapter 1 References.....	54
Chapter 2 – Predictors of adult retention in HIV care: A systematic review ...	73
2.1 Abstract.....	73
2.2 Introduction	74
2.3 Methods.....	76
2.3.1 Systematic literature search	76
2.4 Results.....	83
2.4.2 Developed Countries	88
2.4.5 Developing Countries	95
2.5 Discussion	97
2.5.1 Conclusions.....	105
2.5.2 Conflict of Interest	106
2.5.3 Acknowledgements and funding	106
2.6 Chapter 2 References.....	107
Chapter 3: Synthesising the literature to understand barriers to retention in Australia	114
3.1 Results from the systematic literature review	114
3.2 Epidemiological differences in countries with advanced economies.....	115
3.3 The local epidemic and the public health response	116
3.4 The role of comorbidity	118
3.5 Accessing expert local opinion.....	120
3.6 Study 2	120
3.6.1 Goals	121
3.6.2 Research questions.....	121
3.6.3 Methodology	121
3.6.4 Analysis	122
3.7 Chapter 3 References.....	123
Chapter 4 - Retention in HIV care in Australia: The perspectives of clinicians and clients, and the impact of medical and psychosocial comorbidity	125

4.1 Abstract.....	125
4.2 Introduction	127
4.3 Methods.....	129
4.3.1 Participants	129
4.3.2 Focus group questions and data analysis	130
4.4 Results.....	132
4.4.2 Barriers to retention	134
4.4.3 Potential solutions to improve retention	146
4.5 Discussion	152
4.5.1 Conclusions	161
4.6 Acknowledgements and Disclosures	161
4.7 Chapter 4 References.....	163

Chapter 5 – Identifying clinical complexity to assess its impact on retention 169

5.1 Results from the preceding study.....	169
5.2 Comorbidity	172
5.2.1 Syndemics	173
5.2.2 Clinical complexity	174
5.2.3 Measuring comorbidity/complexity using a screening tool	174
5.2.4 Challenges to measuring comorbidity/complexity.....	176
5.3 The pros and cons of clinician assessment	178
5.3.1 Quantifying clinician assessment.....	179
5.4 Study 3	180
5.4.1 Rationale for developing the scale	181
5.4.2 Consumer Engagement	181
5.4.3 Early development of the scale	182
5.5 Chapter 5 References.....	183

Chapter 6 - The development of an HIV-specific complexity rating scale 187

6.1 Abstract.....	187
6.2 Introduction	189
6.3 Methods.....	192

6.3.1 Development Phase.....	192
6.3.2 Validation of the screening tool	196
6.4 Results.....	197
6.4.2 Deriving the complexity screening tool	200
6.4.4 Performance of the complexity screening tool	202
6.5 Discussion	205
6.5.1 Conclusions.....	210
6.5.2 Ethical approval	211
6.5.3 Acknowledgements	211
6.6 Appendix A.....	213
6.7 Appendix B – The Clinical Complexity Rating Scale for HIV (CCRS-HIV)	214
6.8 Chapter 6 References.....	215

Chapter 7 – The role of comorbidity and clinical complexity in understanding and defining retention 220

7.1 Understanding results from the preceding study.....	220
7.1.1 Strengths and limitations.....	220
7.1.2 The role of stigma and QoL.....	223
7.2 Changes to clinical practice as a result of the development of the CCRS-HIV.....	225
7.3 How identifying complexity assists retention.....	225
7.4 Understanding retention	226
7.5 Testing syndemic theory.....	231
7.6 Study 4	232
7.6.1 Study goals.....	232
7.6.2 Initial study design.....	233
7.6.3 Relevant methodological issues within the present study design	234
7.7 Chapter 7 References.....	237

Chapter 8 – Current definitions of retention in HIV care: The potential role of comorbidity 242

8.1 Abstract.....	242
8.2 Introduction	244

8.3 Methods.....	247
8.3.1 Participants.....	247
8.3.2 Outcome variable	248
8.3.3 Client characteristics and predictors	250
8.3.4 Analyses	251
8.4 Results.....	253
8.4.1 Descriptive statistics	253
8.4.2 Comorbidity predictors of retention	256
8.4.3 Exploratory analyses.....	257
8.5 Discussion	259
8.6 Acknowledgements and Compliance with Ethical Standards.....	265
8.7 References	266

Chapter 9 – Adapting definitions and measurement of retention in the context of comorbidity and clinical complexity 270

9.1 Results from the preceding study.....	270
9.1.1 Discrepancies in estimates of retention	270
9.1.2 Understanding comorbidity and its impact on retention.....	271
9.1.3 The role of syndemics.....	274
9.2 Implications of the results	275
9.3 Chapter 9 References.....	277

Chapter 10 – Research Impact..... 279

10.1 Translational research	279
10.1.1 Changes to clinical practice	279
10.1.2 Integration to Electronic Medical Records (eMR)	282
10.2 Requests from other services for the CCRS-HIV	284

Chapter 11 – Discussion 285

11.1 The problem.....	285
11.1.1 The biomedical response to HIV	285
11.1.2 Comorbidity	287

11.1.3 Ageing	288
11.1.4 The Cascade, retention in care, and optimal service delivery: Beyond viral suppression.....	289
11.2 The study series	295
11.2.1 Study 1	295
11.2.2 Study 2	296
11.2.3 Study 3	296
11.2.4 Study 4	297
11.3 Comorbidity, VL, and Retention in the present study series	298
11.4 Current results in the context of theoretical models	303
11.4.1 HIV and the Biopsychosocial Model	303
11.4.2 Comorbidity and Syndemic Theory	304
11.4.3 Retention in care and The Andersen Behavioral Model of Health Service Use ..	306
11.5 Strengths of the study series	307
11.6 Limitations of the study series.....	312
11.7 Practice priorities and future research	314
11.7.1 Retention in the Cascade.....	314
11.7.2 Expanding definitions of retention	315
11.7.3 Recognising the role of comorbidity.....	316
11.7.4 Moving beyond viral suppression for optimal holistic care.....	317
11.7.5 Reviewing State and Federal public health HIV strategies within Australia.....	318
11.7.6 Future research.....	319
11.8 Conclusion.....	320
11.9 Chapter 11 References.....	323

Chapter 12 – Complete Reference List..... 331

List of illustrations and tables

Chapter 1

1.10.1 Figure 1: The HIV Care and Treatment Cascade, Australia

1.10.3 Figure 2: The continuum of HIV services and retention cascade

1.11.1 Figure 3: Inclusion of the “Fourth 90”

1.11.2 Figure 4: Updated model including the “Fourth 90” for all PLHIV

1.12.1 Figure 5: WHO proposed interaction of factors which impact retention in paediatric and adolescent cohorts

1.14.1.1 Figure 6: The Biopsychosocial Model

1.14.2.1 Figure 7: The Syndemic Model

1.14.3.1 Figure 8: The Andersen Behavioral Model of Health Service Use

Chapter 2

2.3.1.2 Figure 1: PRISMA-P Flowchart of article selection

2.3.1.5 Table 1: Review of methodological strengths and weaknesses of included studies

2.4.1 Table 2: Predictors of retention in HIV care – developed and developing countries

2.4.3 Table 3: Summary of predictors of retention in care, and associated articles – Developed countries

2.4.4 Table 4: Summary of predictors of retention in care, and associated articles – Developing countries

Chapter 4

4.4.1 Table 1: A summary of demographic characteristics of client participants

4.4.2.1 Table 2: Potential barriers to retention identified by clinicians and clients through the thematic analysis

4.4.3 Table 3: Potential solutions identified by clients and clinicians to improve retention rates

4.5.1 Figure 1: A schematic representation of the proposed relationship between the barriers to retention identified by clients and clinicians through the thematic analysis

Chapter 5

5.1.1 Figure 1: WHO proposed interaction of factors which impact retention in paediatric and adolescent cohorts

5.1.2 Figure 2: Results of the previous study in the context of the Andersen Behavioral Model of Health Service Use

Chapter 6

6.3.1.1 Table 1: List of variables used to assess clinical complexity in the present study

6.4.1 Table 2: The distribution of all variables in the development dataset. Shaded items denote HIV-specific items added to the original scale

6.4.3 Table 3: Results from multivariable logistic regression analyses for the development and validation datasets

6.4.5 Table 4: Performance of the development and validation models (shaded line denotes chosen cut-off)

6.7 Appendix A: Definitions of each of the 17 variables assessed during the development phase of the study. Scoring denotes evident functional impairment based on various factors at the time of assessment.

6.8 Appendix B: The Clinical Complexity Rating Scale for HIV (CCRS-HIV)

Chapter 8

8.3.1.1 Figure 1: Client flow after applying inclusion and exclusion criteria

8.3.3.1 Table 1: Summary of variables and associated complexity domains in the CCRS-HIV

8.4.1.3.1 Table 2: Summary of outcome and covariate variables and descriptive statistics

8.4.2.1 Table 3: Binary logistic regression results for covariates, PH and PSY complexity domains, as well as their interaction (PH*PSY)

8.4.3.1. Table 4: Exact likelihood ratio tests with Firth Bias correction for exploratory interaction analyses

8.5.1 Figure 2: A syndemic model of the synergistic effect of combined PH and PSY complexity domains on retention in care, as outlined in Tsai et al.

Chapter 9

9.1.2.1 Figure 1: The potential bidirectional relationship between comorbidity and retention

Chapter 10

10.1.2.1 Figure 1: Deidentified screenshot of the CCRS-HIV on the Statewide electronic Medical Record (eMR)

Glossary

90-90-90 - Global targets relating to 90% of people living with HIV being aware of their status, 90% of those on treatment, and 90% of those virally suppressed

ABM – Andersen Behavioral Model of Health Service Use

ADLs – Activities of Daily Living

AIDS - Acquired immune Deficiency Syndrome

Albion - The Albion Centre; A tertiary Interdisciplinary HIV Clinic in Sydney (NSW), AUSTRALIA

AMO - Attending Medical Officer

aOR - Adjusted Odds Ratio

ART - Antiretroviral Therapy

ATSI - Aboriginal or Torres Strait Islander; Indigenous Australians

AUC - Area Under the Curve

BBV - Blood Borne Virus

BMI - Body Mass Index

CALD - Culturally and Linguistically Diverse

Cascade – The HIV Care and Treatment Cascade

CCRS - Clinical Complexity Rating Scale

CCRS-HIV - Clinical Complexity Rating Scale for HIV

CD4 - Cluster of Differentiation 4 cells; Cells involved in the immune response, and implicated in HIV-infection

CDC - Centers for Disease Control and Prevention

CI - Confidence Interval

CMA - Crystal Methamphetamine

CNS - Central Nervous System

CVD - Cardiovascular Disease

DSP - Disability Support Pension; Welfare payment in Australia for those with an assessed disability which prevents them from working

eMR – Electronic Medical Record

EACS – European AIDS Clinical Society

EU - European Union

GP - General Practitioner

HAART - Highly Active Antiretroviral Therapy

HAV - Hepatitis A Virus

HBV - Hepatitis B Virus

HCV - Hepatitis C Virus

HETI - Health Education and Training Institute

HIV - Human Immunodeficiency Virus

HIV-DNA - HIV Deoxyribonucleic Acid

HIV-RNA - HIV Ribonucleic Acid

HPV - Human Papilloma Virus

HREC - Human Research and Ethics Committee

HRSA - The U.S. Health Resources and Services Administration

IVDU - Intravenous Drug Use

LDCs – Least developed countries

LTFU - Lost to Follow Up

MSM - Men who have sex with men

MTCT - Mother to child transmission

NSP - Needle and Syringe Program

NSW – New South Wales; a State within Australia, whose capital city is Sydney

OI - Opportunistic Infection

OR - Odds Ratio

PBS - Pharmaceutical Benefit Scheme; an Australian government program which provides subsidised prescribed medications to Australian residents

PD - Personality Disorder

PH – Physical Health (complexity domain; CCRS-HIV)

Phlebotomy Test - Blood test

PLHIV/PLHIV - People living with HIV

PrEP – Pre-Exposure Prophylaxis

PSY – Psychosocial (complexity domain; CCRS-HIV)

PTSD - Posttraumatic Stress Disorder

QA/QI - Quality Assurance/Quality Improvement

QoL - Quality of Life

SESLHD - South East Sydney Local Health District; a local health district (LHD) within NSW Health

SMI - Severe Mental Illness

STI - Sexually Transmitted Infection

T Cells - Lymphocyte developed in the thymus gland, central to the immune response, and implicated in HIV-infection

TAFE - Technical and Further Education Institutes; Tertiary educational facilities in Australia

TasP - Treatment as prevention

TB - Tuberculosis

U.K. - United Kingdom

U.S. - United States of America

U=U - Undetectable = Untransmissible

UDVL - Undetectable Viral Load

UNAIDS - Joint United Nations Program on HIV/AIDS

UTS - University of Technology Sydney

Viraemia - The presence of virus in the blood

VL - Viral Load

WHO - World Health Organization

Abstract

Significant advances in the medical management of HIV have heralded a new era of treatment which acknowledges psychosocial, as well as medical, comorbidity factors. However, policy guidelines, reporting requirements and directives are yet to be revised accordingly, with metrics for successful treatment continuing to be considered in medical terms alone. The importance of medical and/or psychosocial comorbidity in impacting well-being, quality of life, and optimal holistic HIV management has arguably been under-represented in reporting outcomes.

At present, biomedical markers such as viral load are used to measure treatment 'success'. Optimal holistic care should transcend viral load alone and include other measures such as overall functioning and health-related quality of life. Retention in care is a current metric within the HIV Care and Treatment Cascade, and the only one which allows for holistic monitoring or medical review by HIV specialists; however, at present, its full potential is not realised. Consistent definitions and means to measure retention are elusive, with differences within and between regions making comparisons difficult. However, retention remains an important component of the Cascade, as it affords the opportunity for optimal monitoring and timely intervention for biopsychosocial comorbidities which may ultimately impact disease progression and quality of life.

In the context of three key theoretical models (the Biopsychosocial Model, the Syndemic Model, and the Andersen Behavioral Model of Health Service Use), the present study series aims to review current definitions of retention in HIV care and understand its specific antecedents through a series of four empirical studies. A systematic literature review considers the global literature on the subject, while a local qualitative analysis of both clinician and client perspectives provides context within the Australian public health landscape. A third study describing the development of an HIV client complexity rating scale, to assess for comorbidity, is outlined. These results are then used to assess the impact on retention in an Australian cohort of people living with HIV, in the fourth and final study.

Results suggest a complex interplay of individual and contextual biological, psychological and social factors which impact retention in HIV care. Further, they suggest that particular interactions, or syndemics, beyond biomedical markers alone are implicated in poor retention in HIV care.

The results are discussed in the context of appropriate theoretical models to understand the factors and the nature of the relationships between them. Implications for future research, as well as policy and reporting guidelines, are discussed.