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

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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.

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Signature:

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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.

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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The present work is in the format of thesis by compilation, including a mix of published and unpublished works.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.

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Journal: *AIDS Patient Care & STDs*

Journal Ranking: 2018 Impact Factor 3.742; Scimago rating Q1

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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

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

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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:

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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

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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

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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)

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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)

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

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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 = Untransmissable

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.