



Local Tools for Global Change

The Second Annual Interscholastic
Student HIV Research Symposium

Meaghan Fisher and Mark Henrickson (Eds)



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F O R E W O R D

We are pleased to present the volume you hold in your hands, because it represents not only the brains but also the heart of human immunodeficiency virus (HIV) research of postgraduate research students in the Auckland region. For the past two years postgraduate students undertaking research in HIV in Auckland-area institutions, together with their supervisors, have been meeting and sharing their processes, findings, challenges and successes. This monograph is a product of the most recent gathering at Massey University, in May 2015.

Advanced research is a lonely process. The researcher is faced with canvassing the existing literature, recruiting participants, collecting and analysing data, making sense of those data, and writing it all down coherently for others to read and critique. Despite all the support and supervision that may be available, in the end the research student must undertake most of this process on their own. If the student is researching a highly complex or stigmatised subject, such as HIV and people living with or affected by HIV, this sense of isolation can be increased. It is important that we provide opportunities for these student researchers to come together and to recognise the valuable contributions they are making in New Zealand, in their communities and nations, and to knowledge.

The world is now well into the third decade of HIV, and we have learned an enormous amount about this virus and the communities it affects. Not only does HIV affect the health of individuals, but even more, it affects the wellbeing of communities and societies. Many of these affected communities are themselves stigmatised because of exclusionary laws and values: men who have sex with men, sex workers, gender minorities, people who inject drugs, and their partners and families are often forced to live hidden and marginalised lives because of social stigma. Telling their stories in order to challenge discriminatory laws and stigmatising attitudes and practices is an important part of creating inclusive and just societies and inspiring social change; this is important because the international evidence is incontrovertible that inclusion and just laws lead to

reduced discrimination, decreased transmission of infection, and increased access to care and treatment.

HIV is not only a medical and epidemiological problem, it is also a challenge to social and political infrastructures around the world. It is hard to imagine anything that has so radically transformed social and research agendas around the world in such a short period of time as HIV. It has required that medical and other healthcare practitioners, 'bench' researchers and pharmacologists, social workers and organisers from affected communities, policymakers and politicians work together at the local, regional, national and international levels to create effective and compassionate responses.

This monograph foreshadows the next generation of researchers and people who will work to realise the Joint United Nations Programme on HIV/AIDS (UNAIDS) vision of zero new infections, zero discrimination, and zero AIDS-related deaths.

The papers in this volume, all written by postgraduate students at Auckland-area universities, highlight how students are utilising local tools to effect global change. Shakeisha Wilson's paper, 'Pushing the boundaries of healthcare services for HIV-positive men in Jamaica', explores barriers to care faced by HIV-positive men in Jamaica. It highlights the intersectional nature of men's identities, including cultural expectations of stoic masculinity, and their effects on health-seeking behaviours. Balakrishnan Nair proposes to conduct a study investigating HIV counselling in one district in northern India, an HIV treatment tool that he argues receives inadequate government and financial support. This study will challenge the existing approaches

to HIV in India, where a preference is given to positivist approaches to HIV interventions, and to quantitative data over qualitative strategies. Dinar Lubis's contribution demonstrates the strengths and challenges of participatory action research (PAR) in her project on the use of social media as a vehicle for disseminating HIV-related information to young men who have sex with men in Indonesia. Finally, Fungai Mhlanga looks at the Black African migrant experience in New Zealand, and the effects of religion and culture on attitudes towards children's sex education. He explores how these important forces interact to limit knowledge of HIV and sexual health.

All of these papers have been peer-reviewed, and we thank Dr Peter Saxton, Director of the Gay Men's Sexual Health Research Group of the University of Auckland, and Dr Cath Conn, Head of Department of Public Health at the Auckland University of Technology, who assisted the editors in reviewing these papers. We acknowledge the Ministry of Health and the Health Research Council of New Zealand (Grant 11/965), which contributed funding for building African research networks on HIV in New Zealand.

We are especially grateful to these dedicated emerging researchers, and we celebrate their research. We hope you, the reader, will be inspired to tell their stories, and to share their important work.

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**Pushing the boundaries of healthcare services for
HIV-positive men in Jamaica**

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ABSTRACT

Jamaica has a reported adult HIV prevalence rate of approximately 1.8% (Ministry of Health, 2014). However, the epidemic remains concentrated amongst key populations, with men who have sex with men (MSM) comprising a significant proportion (32.8%) of the reported HIV cases (Ministry of Health, 2012). The heightened risk of infection for this group of men is extended to female partners of MSM and also to men who may be partners to either group but who do not identify as MSM. Overall, adult males are noted to account for over 60% of reported HIV cases for persons 30–79 years (Ministry of Health, 2014). Against this background, this study examined how HIV-infected men engaged with the antiretroviral (ARV) treatment adherence process in Jamaica. This working paper highlights some of the key findings surrounding the factors that impact HIV-positive men's health choices and outcomes, from the point of diagnosis to treatment. It also focuses on the need to push the boundaries of healthcare services for HIV-positive Jamaican men.

INTRODUCTION

Recent data suggest that approximately 1.8% of Jamaica's adult population is living with HIV (Ministry of Health, 2014). The epidemic is described as a low-level generalised epidemic as well as a concentrated epidemic. In particular, HIV prevalence is largely concentrated amongst key affected populations, such as commercial sex workers, men who have sex with men (MSM), male prisoners and the homeless, where sexual behaviours and socio-economic circumstances

continuously place them at risk of HIV transmission. Of this group, HIV prevalence rates are noted to be highest for the MSM population with an estimate of 32.8%, followed by a reported 12% for homeless persons (Ministry of Health, 2012). Adult males are noted to account for over 60% of reported HIV cases for persons 30–79 years (Ministry of Health, 2014).

These data reinforce the need to treat men, and in particular men living with HIV, as a key population in the spread and control of the HIV epidemic. This study has emerged from an interest in further developing the body of knowledge surrounding the HIV epidemic in Jamaica, as well as the recognised need to focus on the health needs of HIV-infected men, a group which has thus far been largely ignored within the literature. This working paper presents an aspect of the key findings emerging from a study that examined the antiretroviral treatment adherence process of HIV-infected men in Jamaica. At the centre of this rest the complexities of identity, which for the men in this study surrounded intersections of masculinity, sexuality and HIV status, which were further influenced by the socio-cultural context of Jamaican society.

MEN AT RISK

It is surprising that men are not recognised as an at-risk population, despite the evidence emerging from gender-comparative health data. Men are noted to have shorter life spans, estimated to be five years less than women's (Gast & Peak, 2011). As well, morbidity rates are reported to be higher for men for the more serious health conditions (Wilkins,

2010). Despite this, men are less likely to perceive themselves to be at risk of illness or injury, and are thus less likely to seek healthcare (Addis & Mahalik, 2003; Galdas, Cheater, & Marshall, 2005).

As with the wider literature, national data concur that Jamaican men engage in more risky health behaviours and are less likely to seek healthcare than women. In a study that assessed the high-risk health behaviours of adult Jamaicans, Figueroa et al. (2005) found that more men than women consistently engaged in high-risk health behaviours, such as cigarette smoking, marijuana smoking and alcohol use. Also, more men than women reported poorer health-seeking behaviour. This pattern of poor health-seeking behaviour among men was reinforced by another study that focused on the health of older Jamaican men (Morris et al., 2011). Here it was found that the majority of the participants (67.6%) had not visited a doctor or health facility in the year prior to the research. Further, half of the men reported not seeking medical assistance even when they were ill.

Importantly, men's approach to their health and illness has been intrinsically linked to their socio-cultural contexts (Courtenay, 2000). In particular, masculinity and related normative behaviours have been identified as key determinants of the health behaviours and outcomes of men (Addis & Mahalik, 2003; Cheatham, Barksdale, & Rodgers, 2008; Galdas, Cheater, & Marshall, 2005). Similarly, it is recognised that masculinity and male identity are key contributors to the sexual health behaviours and health outcomes of Jamaican men (Morris et al., 2011).

Anderson (2012), in her study on masculinity in the Afro-Caribbean context, found that men's self-perceptions were predominantly defined by the social norms surrounding masculinity. Thus, gender role expectations were inculcated at an early age through gender socialisation. Here, young boys are taught to adapt particular machismo attitudes, such as sexual risk-taking, sexual prowess, aggression and impregnation, as proof of being a man (Brown & Chevannes, 1998). Altogether, these factors contribute to the heightened vulnerability of men to HIV infection. This, paired with the patterns of adverse health outcomes and poor health-seeking behaviours, highlight the need to research and prioritise the health of Jamaican men.

METHOD

This study utilised an intersectionality-informed qualitative approach to ascertain the in-depth stories of 24 HIV-positive Jamaican men regarding their antiretroviral (ARV) treatment adherence process. Data were collected using primarily face-to-face interviews, although telephone interviews were conducted in a few instances to facilitate either convenience or preferred measures of anonymity. All interviews were tape-recorded and subsequently transcribed for analysis.

Intersectionality has been described as 'an analytical tool for studying, understanding and responding to the ways in which gender intersects with other identities and how these intersections contribute to unique experiences of oppression and privilege' (Symington, 2004, p. 1). The classification of identities includes gender, race, class,

sexuality, disability and any other characteristic that might be deemed a distinguishable faction for individuals in a society. Intersectionality has been demonstrated to be an important tool in researching men's health (Bowleg, et al., 2013; Griffith, 2012), and thus was seen as the ideal lens to adopt in examining the intersections of identity, HIV and ARV treatment choices and outcomes. Following this, intersectionality was used primarily as the guiding theoretical framework for the data analysis. An intersectional lens was also adopted during the data collection phase, where the researcher allowed the men to expose those dimensions of their identity deemed significant in understanding their experiences. These introduced ideas were then explored in subsequent interviews to determine whether these experiences were shared by other men.

This research approach was felt to respect the autonomy of the men in choosing how to identify themselves in their particular contexts. The strength of this approach arose from the variability noted in how some of the men presented themselves, as their perception and/or presentation of self were at times dependent on their environment and the individuals with whom they were interacting. Two main dimensions of identity were put forward by the men as key in shaping their health outcomes: masculinity and sexuality. Importantly, these were recognised as deeply intertwined and almost inseparable constructs. Additionally, these constructs were further shaped by the cultural environment and the socio-political contexts of the men (Schwalbe & Wolkomir,

2003). This revealed the power dynamics surrounding the intersections of self and the health outcomes of HIV-positive Jamaican men.

Ethical approval was obtained from both the Auckland University of Technology Ethics Committee (AUTEK) and the University Hospital of the West Indies (UHWI)/Faculty of Medical Sciences (FMS) Ethics Committee. The former relates to obtaining ethical approval for all studies conducted as part of a programme of study within the institution. The latter was required given that the participants were recruited from a clinic setting that is governed by the UHWI.

The ages of the participants ranged between 20 and 56 years. The majority ($n = 13$) were classified as older adults, falling within the age range of 40 years and older. This was followed by younger adults aged 25–39 years ($n = 7$). Only four participants were noted to be aged 20–24 years, a group often classified as being the upper echelon of youth. The educational levels of the men varied, with most having attained a secondary level of education. Only 16 men indicated that they were employed, although this varied across part-time, full-time and self-employment. This proportion is not indicative of the overall employment rate for the population, as statistics collated in the period following the study revealed an employment rate of 89.5% for Jamaican males (Statistical Institute of Jamaica, n.d.).

FINDINGS

It was found that the treatment journey for HIV-infected men commenced with the period surrounding their HIV

diagnosis. Prior to this point, many of the men were not aware of the conditions and implications of living with HIV. Thus, the factors that led to them being tested and their responses to their diagnosis were pivotal in determining how well they transitioned into treatment. It was also recognised that system-based and social factors affected the men's progression throughout their treatment journey. Issues such as social stigma and discrimination, and the absence of social support, were consistently highlighted by most of the men interviewed. As such, this paper focuses primarily on the factors that have affected the health of the men in relation to their HIV testing and diagnosis, and the subsequent progression into their ARV treatment. This information provides the foundation on which the early recommendations for enhancing healthcare services for HIV-infected men are subsequently made.

Factors impacting on HIV testing and diagnosis

Examination of the period surrounding the men's HIV diagnosis identified key concerns regarding the role of HIV literacy and the awareness of healthcare services in promoting earlier HIV testing and diagnosis. Of the 24 men interviewed, 15 were identified as being symptomatic at the time of diagnosis. This suggested that most of the men presented late for diagnosis and testing. The description of opportunistic illnesses and the recollection of extremely low CD4 counts at the time of diagnosis suggested that a number of the men had already progressed to the advanced stages of HIV infection. Some of the men delayed seeking medical attention despite the onset of symptoms, as these were perceived to be due to

minor or self-remedied ailments such as a 'persistent cold'. This contributed to the prolonged period between the onset of symptoms and the seeking of medical care. Importantly, this posed implications not just for the health outcome and requisite care and treatment of the men post-diagnosis, but also for the health of those who may have been exposed to the virus prior to the men learning of their HIV status.

Eight men indicated that they were hospitalised at the time of their diagnosis. Most of them had developed opportunistic infections which required extended periods of hospitalisation and treatment. The delay in seeking healthcare was again attributed to the symptoms being perceived as due to minor or more familiar illnesses. Thus, the flu-like symptoms and rashes were simply treated as a common cold or a mild skin condition. This tendency to misdiagnose symptoms raised questions about the HIV-awareness levels of the Jamaican populace, specifically in relation to recognising the symptoms of HIV infection. Significant public awareness has occurred in the past decade to generate an awareness of the risks of transmission, but the findings of this study may indicate that a greater focus needs to be directed towards recognising the signs of infection. The findings also highlighted the tendency of men to delay seeking healthcare in response to their ill health. Again, this presents another area for further policy or programme redress.

Some men also delayed testing for HIV even when recommendations to do so were made, as they did not perceive themselves to be at risk of contracting the virus. This

often occurred where the men were engaging in occasional risky sexual practices, such as multiple sexual partners and sex without a condom. This denial of risk of exposure further hindered some men in accepting their positive HIV test results. In these instances, the HIV tests were repeated at a later stage when the men's health had further deteriorated and warranted urgent medical attention.

Factors impacting on healthcare access

A majority of the men expressed satisfaction with, or gratitude for, the services provided by the HIV clinic. However, some key challenges were identified that affected the quality of the care received by the men. One concern expressed was the frequent rotation of doctors, preventing the development of an established patient–doctor relationship to enable a developed sense of comfort and trust.

In addition, there were complaints regarding the lengthy waiting periods for appointments. The frustration of waiting for lengthy periods to be seen by a doctor was further exacerbated when the men visited the affiliated pharmacy for their medication refills. There, they were often required to wait for lengthy periods, which proved problematic for those men who were employed full-time and were only able to access their healthcare during short work breaks. Thus the extended time lapse surrounding clinic visits and medication refills could also impact on the men's ability to maintain their treatment regimen, especially where the time requirement conflicted with other obligations such as their jobs. Overall, there was a resounding discontent with the mandated clinic

visits to obtain prescription renewals. This approach had been developed to ensure that patients visited their physicians and did the requisite tests, such as the CD4 and viral load tests, which could impact on the treatment regimen being prescribed. There were some, however, who felt constrained by the process, especially given the extensive time allotted to the clinic visits and subsequent pharmacy refills.

It was also perceived that HIV healthcare largely catered more to the needs of women than men. This perception was further reinforced by the obvious disparity between the clinic attendance rates of males and females. During the five months surrounding data collection it was observed that the clinic was predominantly attended by women, with only a few men visiting on those days. The lower utilisation of healthcare facilities and services is congruent with the literature that examines male health-seeking behaviour. It also highlights a clear need to improve efforts to target a population whose health status holds significant implications for their partners and families.

Concerns were also expressed regarding the absence of empathy demonstrated by some of the support staff members within the clinic. It was felt that the approach of clinic staff to the male patients was notably different to the quality of care offered to women. This may be entrenched in the perception and expectation that men should be strong and invincible, even in the context of ill health. Thus, the absence of empathy reinforced the imposition of masculine stoicism and resilience, which threatens the male's ability to freely and effectively lobby for appropriate healthcare. However, it

could also suggest the labelling of women as victims and men as villains in the transmission of HIV, whereby the former are more likely to attract empathy.

HIV-related stigma also acted as a barrier to the men's access to healthcare. However, this was more often a perceived stigma or the fear of stigma which resulted in the men being particularly cautious in accessing their health needs. This at times involved strategies such as accessing healthcare outside of residential communities and disguising their appearance to avoid unintentional disclosure. It was also perceived that men who were readily identified as MSM were treated quite differently to heterosexual male and female clients. This reflected the prevailing stigma surrounding MSM relationships within Jamaica.

It also exposed a possible hierarchy of access to services for women, men and men identified as MSM by the clinic personnel. It was perceived by some men that women were treated with compassion and empathy at the clinic, whereas men were at times treated with scant regard. Further, those men who were deemed to be MSM were treated with obvious scorn and disrespect. This displaces men in general, but particular isolates MSM, and can likely hinder them from accessing healthcare and treatment services.

DISCUSSION AND RECOMMENDATIONS

There are obvious gaps in the healthcare delivery system that caters to the needs of HIV-infected men in Jamaica. These span the treatment process for the men, which commences at the point of HIV diagnosis, and as such

have great implications for the health status of the men and also their partners. It is evident that there is a need to unmask the unique health needs of men which place them at risk of poor health conditions and also of becoming lost within a healthcare system that appears largely focused on the wellbeing of women and children. In doing so, it is paramount that consideration be given to men as a diverse and heterogeneous population. This further challenges the future of healthcare service delivery in Jamaica to ensure that the needs of all men, irrespective of their sexuality or any other defining quality, are equally met.

In light of this, it is proposed that key changes be made to transform the clinical, policy and programme environment surrounding the health needs of HIV-infected men in Jamaica. Central to these changes is an expanded approach that recognises and treats men living with HIV as a key affected population whose health needs must be prioritised, alongside those of other identified at-risk groups. In so doing, sufficient attention must be given to training the health personnel who are directly or indirectly involved in providing healthcare for HIV-infected men.

Further, it is necessary that all sectors involved in healthcare service delivery promote the need to understand and respect the rights and dignity of all individuals living with HIV, irrespective of their gender or sexuality. This calls for measures that challenge the imposition of the socio-cultural norms surrounding masculinity and sexuality in the provision of fair, equitable and quality healthcare.

It is understood that the socio-cultural terrains of a

society that emphasises a dominant masculinity, where men are seen as tough, strong, stoic and hypersexual, may be a barrier to the transformations needed to effectively improve the health approaches and outcomes of HIV-infected men. Nonetheless, it is anticipated that a drive to increase awareness at all levels within the society will result in the transformation of the clinical, policy and programme environment to ensure that the health needs of all HIV-infected men are effectively addressed.

C O N C L U S I O N

This paper has highlighted the need to pay particular attention to the health needs of HIV-infected men. There are noted gaps in the quality of service provision offered to HIV-infected men, especially where they are treated as distinct from other key populations, such as women and children. The relationship of this population to other at-risk populations highlights the importance of effectively targeting and responding to the health needs of men as both a responsive and a preventative approach.

A C K N O W L E D G E M E N T

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