

**Understanding the Antiretroviral (ARV) Treatment
Experiences and Adherence Outcomes of HIV Positive Men in
Jamaica: An Intersectionality Approach**

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**Understanding the antiretroviral (ARV) treatment experiences and
adherence outcomes of HIV positive men in Jamaica:
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Abstract

There is little research addressing men's health in Jamaica, in general, and more specifically, as it pertains to HIV positive men. Jamaican men are often placed at risk by a range of socio-cultural norms and processes that make them susceptible to contracting Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS), and affect how they engage with their treatment trajectory. Antiretroviral (ARV) treatment adherence is important in ensuring viral suppression, the reduced risk of HIV transmission, and the improved health and well-being of men. Yet, men continuously present late for testing and subsequently, linkage with treatment and care. The current study examined the treatment experiences and adherence outcomes of HIV positive Jamaican men, against the backdrop of their sexuality, gender, and HIV health status.

The study adopted an intersectionality-informed methodology to explicate the complexities surrounding sexuality, gender, and HIV status as interrelated dimensions of Jamaican men's identities that can impact their health outcomes. Twenty-four HIV positive men were recruited from an HIV-specialized clinic in Jamaica. Semi-structured interviews were conducted with all participants and six men were involved in follow-up interviews. Interviews with clinic staff, whose role directly related to men's access to ARV treatment, were conducted for detail about the clinic context. Data were coded using NVivo software and analysis conducted using an adaptation of the stepwise multi-level framework posited by Winker and Degele (2011).

Men's treatment trajectory comprised five phases: HIV diagnosis, acceptance, adjustment, treatment initiation, and treatment continuation. Receiving an HIV positive diagnosis proved traumatic for most participants, forcing them to consider the personal and social implications of living with an incurable and stigmatized illness. Some men grappled to come to terms with living with HIV as they perceived it to disrupt their lives, and destroy futuristic dreams and aspirations. Acceptance of a positive diagnosis became pivotal for men to progress into their treatment processes, as it encompassed an understanding of the need for lifelong and daily treatment and follow-up care. Adjustment, unlike the other four phases, was ongoing in response to the varying circumstances men experienced. The treatment phases were largely centred around the

clinic, which was deemed to minimize some men's autonomy and liberty. As a result, the clinic was positioned as both an enabler and barrier to men's access to optimal health care.

Throughout the treatment trajectory, men were often required to negotiate their personal identities against the benchmark of socially approved representations of a masculine self. The hegemonic representation of Jamaican masculinity is often predicated on the need to show sexual prowess, strength, and resilience. The incorporation of HIV as an aspect of men's identities and shifting HIV from the foreground to the background of men's sense of self were important aspects of men's reconstruction of their social identities. Some men engaged in gender performativity, where they exuded the defining qualities of masculinity that would ensure their safety, acceptance, and sense of belonging. Importantly, a number of men moved towards reconstructing new masculinities that supported their HIV identity and need for lifelong treatment. Nonetheless, some values pertaining to hegemonic masculinity were maintained or modified to suit their HIV status, such as being a leader, role model, father, and breadwinner.

The findings of this study have implications for the transformed approaches to addressing HIV positive men's health in Jamaica. Policy and programme recommendations are provided, including the need for gender-sensitive approaches, improved access to health services, and the provision of safe, supportive, and enabling health environments. The study contributes to the growing body of literature that utilizes intersectionality as a methodology, and more so in examining men's health issues.

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Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed:



Shakeisha Wilson

March 2016

Dedication

In memory of those I lost along the way,
and to whom I could not say farewell.

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I thank God, without whom none of this would have been possible. My faith has kept me grounded and focused, especially at my lowest and darkest points. I saw God's favour in the support, kindness, willingness, prayers and words of so many. You became the evidence of my faith – thank you.

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Ethics Approval

The Auckland University of Technology Ethics Committee (AUTEC) approved this research on November 29, 2012. AUTEC Reference number: 12/303.

The University of the Hospital West Indies (UHWI)/ University of the West Indies, Mona (UWI)/ Faculty of Medical Sciences (FMS) Ethics Committee approved this research on April 17, 2013. UHWI/UWI/FMS Ethics Committee Reference number: ECP 165, 2012/13.

Chapter 1 INTRODUCTION

I just love Steinbeck's *The Pearl*... in it the protagonist, he is just like me. He's a man, a surge of force... breaks down the walls, you know all the injustice that exist; bun down 'babylon system'. His wife she knows what 'babylon system' is all about she want to break down 'babylon system' but she also wants to preserve him. He knows she understands that. You know what, she understand that her husband, that man, will swim across the ocean and she knows too well that the ocean is too big for him to swim and he might kill himself doing it. But because he is a man she can't actually stop him but she knows it. And your question speaks to that. I know that my health should be the most important thing. My health is my ocean, really. My health is my ocean and I should try to deal with it and look after it. It's really a priority but when people look at the measure of my life, and I'm being... this is going to be my selfishness, my vanity whatever you call it, they don't want to look at my health, they are gonna see what Dan did as a [HIV] positive person to impact the lives of other persons in his community. (Dan)

1.1 INTRODUCTION

This study utilized an intersectionality-informed methodology to understand how Jamaican men infected with the Human Immunodeficiency Virus (HIV), engage with their antiretroviral (ARV) treatment and their subsequent adherence process. Central to the study was an examination of how the complexities of identity and the impositions of power and authority, embedded in socio-historical processes, help to define the health choices and outcomes of these men in light of their HIV infection. Such complexities surrounded ideas of maleness, sexuality and HIV health status, which are key facets of a masculine identity in Jamaica that are often reinforced by formal and informal social institutions, including the healthcare system. The process of engaging in treatment was not static for the men in this study, and unveiled situations where some men either challenged or negotiated the dominant discourses on acceptable masculine identity in addressing their health needs.

The intersectionality lens adopted for this study allowed for a micro-macro level analysis as proposed by Bowleg (2012) and Winker and Degele (2011). At the micro level, the research examined the complexity of men's identities as they contended with dominant discourses surrounding dimensions of their social identities, such as their gender roles. The research also assessed how some men were forced to deliberate and address macro-level, structural processes and norms surrounding their social identities, and in the context of their HIV illness and treatment. Guided by its roots in feminism

(Bowleg, 2008; Davis, 2008), this intersectionality-informed study aimed to provide policy and programme recommendations that could improve the health outcomes of HIV infected Jamaican men.

This chapter presents an overview of the research topic, rationale and aim of the study. Insight to the intersectionality theoretical lens and its underpinning critical theory research paradigm that informed the design and analysis of the study is offered. The process of developing the research focus is described, and my personal and cultural pre-understandings, as the researcher, examined. Finally, key definitions, the significance of the study and an outline of the thesis are provided.

1.2 BACKGROUND AND RATIONALE

Jamaican men are often pressured to engage in risky behaviours that can harm their health and well-being, such as not seeking healthcare until their ill-health has progressed significantly, and presenting for care later than women (Kempadoo & Dunn, 2001; Ministry of Health, 2012, 2014a; Morris, James, Laws, & Eldemire-Shearer, 2011). To illustrate, the Jamaica Health and Lifestyle Survey (JHLS) 2007-2008, reported that significantly more men than women in the 15 – 74 years age group used alcohol (80.1%), marijuana (22.9%), or smoked cigarettes (22.1%), which are identified as health risk behaviours (Wilks, Younger, Tulloch-Reid, McFarlane, & Francis, 2009). Though the JHLS 2007-2008 also indicated that more women than men self-reported having chronic illnesses, such as diabetes and hypertension, the accuracy of this data is questionable against the backdrop of men's unwillingness to acknowledge being ill as a sign of weakness (Addis & Mahalik, 2003; Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011). The health vulnerability of Jamaican men is further reinforced by men having a lower life expectancy than women, of approximately five to six years, despite the advances made in health over the years (Morris et al., 2011). Though data shows gender disparities that highlight men's health vulnerabilities, very little attention has been given to understanding the factors that impact men's health outcomes in general, and more specifically HIV infected men.

The marginalization and vulnerability of Jamaican men is evidenced in the HIV epidemiological patterns for Jamaica. Of the 780 persons reported as having advanced HIV in 2013, 54% were males, and higher incidences of Acquired Immune Deficiency

Syndrome (AIDS) was also reported for men in the same period (Ministry of Health National HIV/STI Programme, 2013). Since the emergence of the epidemic in Jamaica in 1982, men have accounted for the majority of AIDS-related deaths annually, which suggests that men either present late for testing and treatment, or fail to maintain their treatment and care (Ministry of Health National HIV/STI Programme, 2013). Men also account for the majority of the reported AIDS cases for persons ages 30 – 79 years (Ministry of Health National HIV/STI Programme, 2013), an age group that spans the working-age population and older people, which has implications for productivity and dependency concerns, especially in Jamaica where traditions of the male as breadwinner are maintained.

Despite the recognized vulnerability of men in Jamaica, it was only within the last decade that men who have sex with men (MSM), as a distinct subpopulation of men, were identified as an at risk population. A 2007 survey estimated that the HIV prevalence rate amongst the MSM population is 32% (J.P. Figueroa et al., 2013). This rate was fairly consistent with findings of a cross-sectional survey which was conducted in 2011 with 449 MSM (J.P. Figueroa et al., 2015). Currently it is estimated that one in three MSM in Jamaica are HIV infected (UNAIDS, 2014). These data provide evidence that support the conclusion that the MSM population is the most at risk group for HIV infection in Jamaica (Ministry of Health, 2014a). The risk associated with MSM extends to male inmates, who were estimated to have an HIV prevalence rate of 3.3% (Andrinopoulos et al., 2010). Though the practice of MSM relationships amongst prison inmates is acknowledged, Figueroa (2014) suggested that some of these men were already HIV infected prior to their incarceration.

There is a need to further assess the vulnerability of other men who are also at risk of contracting HIV, and whose sexual health behaviours may contribute to the HIV epidemic in Jamaica. Figueroa (2014) identified high-risk heterosexual men as another key population in the evolution of the HIV epidemic in Jamaica, on the basis of their risky sexual practices such as multiple partners, transactional sex, a history of sexually transmitted infections (STI) and substance usage. It was estimated that high-risk heterosexual men could represent approximately half of the number of men currently living with HIV in Jamaica (J.P. Figueroa, 2014).

Overall, it is recognized that a significant proportion of men consistently engage in risky behaviours that place them at a heightened risk of contracting and spreading HIV (Ministry of Health, 2012, 2014a). Men's vulnerability to HIV is heightened by the socio-cultural gendered norms that define appropriate masculine behaviours both in terms of appropriate sexual and health-seeking practices (Chevannes, 1993; J.P. Figueroa, 2008; Hope, 2010; Norman & Uche, 2003; Plummer, 2013). Proving masculinity necessitates that Jamaican men engage in sexual activity at an early age, demonstrate their sexual prowess by having multiple female partners, have children with a range of partners, and show their positions of authority by exuding dominance in and over their household (P. Anderson, 2012; Chevannes, 2001; J.P. Figueroa, 2014). This emphasis on a heterosexual masculinity helps to fuel the prevailing stigma attached to HIV and same-sex relationships which becomes a barrier to some men getting tested, learning their HIV status and progressing into treatment (R. Carr, 2002; Charles, 2011; R. White & Carr, 2005).

Where data on ARV treatment provision exists, very little is presented on retention in care and the data is generally not gender disaggregated (Ministry of Health, 2014a). One study was found that evaluated Jamaica's Adherence Programme; however, it failed to provide gender-specific data and the findings were found to be primarily descriptive rather than analytical (Harvey et al., 2008). The main findings of the study included a noted decline in adherence to ARV, engaging with adherence counsellors did not have a significant impact on adherence outcomes, and stigma was a key barrier to treatment as persons reported fearing others witnessing them taking their medication (Harvey et al., 2008).

Within the past decade, there has been a significant increase in the number of Jamaicans gaining access to ARV treatment (UNAIDS, 2008a, 2011b). Despite this, recent data shows that an increasing number of persons are defaulting care and treatment 12 months after treatment initiation (Ministry of Health, 2014a). It is expected that male treatment initiation patterns in Jamaica are consistent with global trends that show more women accessing ARV treatment than men (WHO, UNICEF, & UNAIDS, 2013). This disparity has been explained by the targeted effort to test and treat women as an aspect of the prevention of transmission from mother to child, as well as the poorer health-seeking behaviours of men (WHO et al., 2013).

Overall, there is a noteworthy gap in data and literature that 1) examines data on the HIV health risks of Jamaican men in general, and across sub-populations (for example heterosexual, transgender, bisexual and MSM); 2) provides an in-depth analysis of the health practices and outcomes of HIV infected Jamaican men; 3) assesses the treatment experiences and behaviours of HIV infected Jamaican men; 4) endeavours to focus on men's health as a priority area for health policy and practice.

This thesis aimed to address some of these gaps in knowledge by examining the ARV treatment experiences and adherence outcomes for HIV infected Jamaican men in general, and within the contours of gender, sexuality and the Jamaican culture. The interplay between gender and sexuality as defining characteristics of a hegemonic Jamaican masculinity were deemed to be intrinsic to this study (Chevannes, 2001; Hope, 2010; Lewis, 2003b). Though much is written on this typology of masculinity in Jamaica, no research has provided an in-depth assessment of how this construct interplays with HIV positive men's health status and their subsequent treatment experiences and outcomes.

1.3 AIM OF THE STUDY

The aim of this study was to understand the ARV treatment experiences and adherence outcomes for HIV infected Jamaican men, and to identify how these treatment experiences and outcomes are influenced by intersections of gender, sexuality and HIV status. The main research question asked was:

“How do the social identities of HIV positive Jamaican men intersect to influence their ARV treatment experiences and adherence outcomes?”

Following this were four sub-questions:

1. How do HIV positive Jamaican men perceive their ARV treatment and define their ARV treatment adherence process?
2. How do Jamaican men on ARV treatment self-identify against the backdrop of dominant discourses surrounding gender, sexuality and men's health status?
3. What are the social structures and processes that influence Jamaican men's identities and choices regarding their ARV treatment?

4. How might a better understanding of the ARV treatment experiences and adherence outcomes of HIV positive men inform HIV policy and program development in Jamaica?

1.4 METHODOLOGICAL AND THEORETICAL LENS

This study utilized an intersectionality-informed approach that was guided primarily by the perspective of Winker and Degele (2011). Intersectionality emerged from the work of Black feminists in the United States (Bilge, 2010). Since then it has evolved to being described as “the gold standard multidisciplinary approach for analysing subjects’ experiences of both identity and oppression” (Nash, 2008, p. 2). The focus of intersectionality theory on the multidimensionality of the lived experiences of marginalized groups positions it within the critical theory paradigm which maintains that social reality, and thus knowledge, is socially constructed (Guba & Lincoln, 2004; Holden & Lynch, 2004).

1.4.1 Research paradigm: Critical theory

Intersectionality is located within the critical theory paradigm which presents reality as historical and dynamic, having been shaped by a range of socio-cultural, political, economic and demographic factors (Guba & Lincoln, 2004). This suggests that the reality of living with HIV and adjusting to lifelong treatment for Jamaican men is entrenched in a history of social structural influences that are reproduced over time. Realists reject the notion of the existence of an objective reality, accepting instead the existence of varied interpretations and experiences of a particular social phenomenon (Maxwell, 2012). Thus whereas positivists view the world through a singular lens, realists perceive knowledge as “partial, incomplete, and fallible” (Maxwell, 2012, p.5), thus lending to its variable interpretations. This then gives space to the social construction of meaning or understanding, against the backdrop of the existence of a real social world. As Frazer and Lacey (1993) aptly explained, “Even if one is a realist at the ontological level, one could be an epistemological interpretivist . . . our knowledge of the real world is inevitably interpretive and provisional rather than straightforwardly representational” (p. 182). Thus, it was expected that within this study, men’s realities were influenced by deeply entrenched socio-cultural, historical, economic and political forces that often dictate how Jamaican men should identify and behave in the context of their HIV diagnosis and treatment. Despite the existence of

these structural forces, the men's understanding of these influences were anticipated to be varied, especially in lieu of their different experiences and responses to a positive HIV diagnosis and subsequent linkage to ARV treatment.

For the critical realist, meaning (and thus knowledge) is developed through a relational understanding of social structure or social phenomenon (Peters, Pressey, Vanharanta & Johnston, 2013). According to Peters, Pressey, Vanharanta and Johnston (2013), there are three layers at which understanding of a social phenomenon is produced within critical realism: "the real (the mechanisms that generate phenomena at the level of the actual), the actual (the events that occur), and the empirical (our experiences of those events)" (p. 338). This means that understanding men's ARV treatment experiences and adherence outcomes would take into account: 1) the issues that placed men at risk of contracting HIV, 2) men's HIV diagnosis, treatment progression and adherence outcomes, and 3) men's experiences surrounding their ARV treatment. This meant there were instances where information was descriptive and presented as factual (for example, the criteria for and importance of optimal adherence in ensuring men's health and well-being), but also interpretive (for example, the varying adherence outcomes being hinged on *how* men defined or understood their treatment regimen).

The meanings or knowledge emerging from data collected is considered to be transactional within the critical theory paradigm, and thus emerging from the interactions between the researcher and participants (Guba & Lincoln, 2004). This gives space to my voice and observation, in conjunction with the men, in exposing issues of power, dominance and subversion. It also gives space to my pre-existing values that would have been influenced by prior training and voluntary work with the HIV community in Jamaica. Being a Jamaican, it is also acknowledged that I entered the field with some familiarity of Jamaican society cultural dynamics, which celebrates a heterosexual hegemonic masculinity and subsequently abhors any other variations. Such familiarity underscored an awareness of how the participants' realities were likely socially constructed and shaped by power relations entrenched within the Jamaican society (Guba & Lincoln, 2004; Scotland, 2012). As a result, consideration was given to the influence of the socio-cultural norms surrounding HIV infection, men's health and masculinity in Jamaica, and their possible influence on the participants' treatment experiences and adherence outcomes.

1.4.2 An intersectionality-informed approach

The focus on the overlap between gender, sexuality and HIV illness within the Jamaican society helped shape the decision to adopt an intersectionality-informed framework for this study. Emerging from the feminist tradition, intersectionality allows for an unveiling of systems of power, domination, privilege and exploitation (Bilge, 2009; Griffith, 2012) that may affect the health experiences and outcomes of HIV infected men. It also enables an examination of how these systems of differentiation are entrenched in socio-culturally defined and reinforced norms that have been sustained for much of the country's history. Finally, the approach creates the space to argue for transformative outcomes, thus moving information from an academic space to one with practical implications and recommendations (Bilge, 2013; Carastathis, 2014).

Central to intersectionality theory is the notion that identity is complex, interdependent and multidimensional (Cuadraz & Uttal, 1999). This avoids the refuted additive approach that treats aspects of an individual's identity such as his race, gender and sexuality as conceptually separate, and are thus researched accordingly (Hancock, 2007). Hence, "attempting to understand or address health disparities via a single analytical category...elides the complex ways in which multiple social categories intersect with social discrimination based on those multiple intersecting categories to create disparity and social inequality in health" (Bowleg, 2012, p. 1268).

Whereas intersectionality theory primarily emerged to elucidate issues of discrimination, exclusion or oppression experienced by Black women, it is argued that the theoretical framework also lends itself to any group "whose microlevel and macrolevel experiences intersect at the nexus of multiple social inequalities and is broad enough to include populations who inhabit dimensions of social privilege and oppression simultaneously" (Bowleg, 2012, p. 1270). Therefore, it was felt that this lens would aptly suit a study on Jamaican men, a group that is traditionally privileged by their masculine identity, yet undermined by the health risks associated with proving or maintaining this hegemonic form of Jamaican masculinity.

The inherent value and suitability of intersectionality theory was challenged by the seeming absence of a clear methodological approach to conducting, analysing and presenting an intersectionality-informed study (McCall, 2005). A few theorists have

attempted to overcome this intersectional hurdle, including McCall (2005), Hancock (2007), Bowleg (2008) and Winker and Degele (2011). The intersectionality multi-level analytical model put forward by Winker and Degele was found to provide an apt stepwise process that could be adapted to guide the data analysis. According to Winker and Degele categories of inequality are categorized on three levels: 1) a micro level that addresses the processes of identity construction, 2) a level of representation which examines the influence of cultural norms and symbolisms, and 3) a macro/meso level comprising social structures such as social institutions and organizations. It is the interplay of inequality across these three levels that become the core of the analysis in understanding the treatment experiences and adherence outcomes of HIV-positive Jamaican men.

Overall the intersectionality lens used to inform this study was instrumental in understanding the treatment experiences and adherence outcomes of HIV positive Jamaican men. Though Jamaican men are not traditionally identified as an oppressed group, literature points to their vulnerabilities as it pertains their sexual health risks and adverse health outcomes, which are largely embedded in the socio-cultural terrains of the Jamaican society (P. Anderson, 2012; Chevannes, 2001; J.P. Figueroa, 2014; Kempadoo, 2004; Norman & Uche, 2003). As earlier data shows, more Jamaican men than women are likely to: 1) present with advanced HIV and AIDS, 2) be diagnosed late, 3) delay or fail to initiate treatment, and 4) default their care and treatment (Ministry of Health, 2012, 2014a). It is perceived that these disparate health outcomes are shaped by the micro-macro intersections of the men's gender, sexuality and HIV health status within the health system and other non-clinical contexts that determine how men approach their health in Jamaica.

1.5 DEVELOPING THE RESEARCH FOCUS

As a Jamaican, I am aware of the power, strengths and limitations of our culture. Jamaica is known globally for the rhythm and beat of its reggae music, the tropical climate that attracts many tourists annually and the warmth of its people. Yet Jamaica is also known for social ills such as increasing incidences of crime and a value system that ostracizes same-sex relationships. Each of these facets intertwine to help shape the history of HIV/AIDS in Jamaica; an illness that continues to impact the lives of both the infected and those around them.

The idea for the focus of the study emerged from my voluntary work with HIV infected women in Jamaica. This was the second HIV-focused NGO with which I worked, and though the second catered solely to the needs of HIV infected women, the first also maintained a population that was predominantly women. In addition, there were no known agencies that catered solely to the needs of HIV positive men in the parish in which the study was conducted. These personal observations implied the following: that more women than men are infected with HIV; mainly women are victimized (both infected and affected) by HIV; and more women than men need HIV services. A dialogue with a group of women living with HIV helped to narrow the research focus. When asked what research would prove most relevant to the work of the NGO, the general consensus was a better understanding of the role and importance of ARV in treating the illness. Though this ignited an interest in the topic of ARV treatment, there remained questions regarding the perceived absence and invisibility of HIV positive men. The final thrust occurred one day when the women had a family retreat to which they had the opportunity to take their partners and children. At the event one male asked, “Why is it that you don’t have these things for us men too?” That concretized the research focus. It became necessary to understand the experiences of men living with HIV in the socio-cultural context of the Jamaican society, particularly as it pertained their ARV treatment.

The research focus was seen to hold the potential of garnering new knowledge that could help to transform how Jamaican men living with HIV are perceived and treated. It was recognized that many Jamaican men are marginalized by the very institutions and structural processes that award them privilege. For example, the ideals of unprotected sex, early sexual initiation, multiple sexual partners and other risky practices characteristic of the dominant Jamaican masculinity (P. Anderson, 2012; Chevannes, 2001; Norman & Uche, 2003), continuously expose men to significant health and social malaise. The study built on this understanding of Jamaican masculinity by showing how the social construction of HIV positive Jamaican men’s identities and the impositions of these dominant discourses influenced HIV positive Jamaican men’s treatment experiences, choices, and adherence outcomes.

1.6 PERSONAL AND CULTURAL ASSUMPTIONS UNDERPINNING THE STUDY

Given the nature of the study, my role as a female researcher interviewing men, and the cultural norms surrounding both HIV and Jamaican masculinity, it was felt useful to engage in a presuppositions interview to identify my personal and cultural assumptions going into the study. This self-awareness of pre-conceived understandings of the research topic and the population of focus represents a key aspect of researcher reflexivity that enhances the quality and rigour of the study (Darawsheh, 2014; Jootun, McGhee, & Marland, 2009). Davison (2006) argued that research on men and masculinities that utilize a critical or feminist lens requires continuous reflexivity that “acknowledges the various ways the subjectivity of the researcher is intimately connected to research participants” (p. 1). This would be achieved:

by directing an analytical gaze into the self in an attempt to understand the dynamics between the researcher and the researched. This should extend beyond self-awareness to an in-depth understanding of the social context of the phenomena of interest and the participants of the study through examining the dynamics between them as research and the researcher. (Ibrahim & Edgley, 2015, p. 1671)

A pre-suppositions interview was facilitated by an experienced qualitative researcher familiar with my research focus. The questions surrounded my expectations of the research findings. Engaging in this process allowed me to become aware of my personal understandings of the issue of HIV/AIDS amongst Jamaican men and the cultural norms and values that helped to shape my outlook. Importantly, my personal and cultural assumptions spanned varying aspects of my identity: as a Jamaican, a female researcher, a previous HIV volunteer, a Christian, and someone who is HIV negative.

As a Jamaican, I am shaped by many of our cultural values that set us apart as a society. Some of these values surround gendered norms and expectations of manhood, though not in the extremities where men become harmed by the external and internalized pressure to prove masculinity. This is perhaps mediated by my training and professional background as a sociologist and an academic who has taught on aspects of our defining Jamaican, and by extension, Caribbean culture. My previous voluntary work as a technical advisor to two HIV-related NGOs made me aware of the sensitivities and challenges of engaging with persons living with a stigmatized illness, especially where

it is perceived that I cannot truly identify with them being HIV negative. As a Christian, I honour the family values reinforced by heterosexual relationships, a value that is also definitive of my 'Jamaican-ness'. As a female researcher, I carried with me certain skills and expertise of engaging with diverse groups, though I have never interviewed solely men.

Emerging from this exploration of my pre-understandings, based on these aspects of myself as the researcher, was another important question: How could my pre-understandings and assumptions impact the findings and outcome of the study? This process became an important avenue of reflecting on how well I was prepared to deal with the realities of interviewing HIV infected men. I had to determine how my own identity, as a female researcher who is HIV-negative, could influence the dialogue between myself and the men. My experience of working with the HIV community taught me the importance of transparency in allowing those I work with the choice of trusting me despite being HIV negative. My training and exposure to varying cultures had also reinforced the need to be non-judgemental and respectful of others' cultures, values and norms; thus I did not perceive my own values to be a threat to the men's rights and freedom. More importantly, my interest in the men's stories allowed me to adopt an approach that allowed them to introduce issues or concepts of interests which were then adopted and examined further in subsequent interviews. This method was felt to maintain the autonomy of the men, rather than allowing the study to be researcher imposed and directed.

1.7 DEFINITION OF KEY TERMS

Four key terms were identified as central to the study: Jamaican men, identity, HIV/AIDS and treatment adherence.

Jamaican men:

The term 'Jamaican men' is not defined primarily by the men's nationality but by their self-acknowledgement as Jamaicans. This was perceived to entail an association with the Jamaican society and culture. The notion of a Jamaican hegemonic masculine identity as a cultural construct is reinforced in the literature (Chevannes, 2001; Hall, 2011; Hope, 2010). The participants' identity as Jamaican was expected to be evidenced

in various cultural traits such as their dialect, demeanour, or the explicit acknowledgement of their cultural affinity within their narratives.

Identity:

Identity is deemed to be the labels that determine *who* an individual is, the roles he occupies in society and the premise by which he is either associated or distinguished from others (Jenkins, 2014). Thus identity is positioned as a social construct often defined in relation to existing socio-cultural norms, and reinforced through everyday interactions. Without contradicting the unidimensional approach which intersectionality rejects, this study focused on three main categories of identity: HIV health status, gender and sexuality. Though it is understood that the identities of men (as women) are complex, multidimensional and thus difficult to separate (Nash, 2008), it is believed that there is space to acknowledge these categories separately (Bowleg, 2008). Literature has shown that an individual has multiple identities, of which some can gain salience at particular points in the individual's life (McLeish & Oxoby, 2011). To illustrate, studies have shown where a chronic illness can result in greater salience being given to the new health status, thereby shifting illness to the foreground of someone's identity (Baumgartner, 2012; Baumgartner & David, 2009; Paterson, 2001; Tewksbury & McGaughey, 1998).

The social categories used in this study are generally dichotomous, that is, a person is either: HIV positive or negative; masculine or feminine; heterosexual or MSM. This presented the starting point for the data collection. However, it was expected that each category could be further re-defined by the men in the study, either directly in their self-identification or indirectly through their shared experiences.

- **HIV health status:** Studies have acknowledged the role of HIV as a health status that defines an individual's identity (Baumgartner & David, 2009; Brener, Callander, Slavin, & de Wit, 2013; Tsarenko & Polosky, 2011). For men to be included in this study, they had to be aware of their positive HIV diagnosis. The role of HIV as a social identity extended beyond the positive diagnosis to incorporate how the men perceived or treated being HIV positive, that is, whether or not it was linked to their self-identity. As such, it was anticipated that

some men could identify themselves as being in good health despite being HIV positive.

- **Gender:** In this study gender moved beyond a mere biological differentiation between male and female to instead treat gender as a social product of the interplay across socio-cultural norms and historical processes (Silberschmidt, 2004). The study commenced with a theoretically informed understanding of the hegemonic representation of Jamaican masculinity. However, it was expected that the men, upon being interviewed, would indicate whether their identities conformed or swayed from this dominant portrayal of manliness. The range of gendered distinctions emerging from the study included: male versus female; hegemonic masculinity versus subordinate masculinities; masculine MSM versus feminine MSM.
- **Sexuality:** This was identified as the labels of difference often given to differing sexual orientations, for example, heterosexual, bisexual, and MSM. Whereas there is general consensus in the meaning and use of the terms heterosexual and bisexual, some variation exists in the appropriateness of the terms MSM, and by extension homosexuality. For example, Young and Meyer (2005) argue that the term MSM undermines individuals' self-identification as lesbian or gay. Within the Jamaican context, the term MSM is still presented as a safe identity-free category that focuses on men's sexual practices rather than sexual identity. In addition, the term MSM is still widely used in Jamaica and the wider Caribbean, evidenced in a range of journal articles, public health reports and population briefs that are produced at the local, regional and international levels (See for example reports by UNAIDS). Further, the majority of men in this study self-identified as MSM, whilst only one male used the term interchangeably with gay. As such the term MSM is predominantly maintained within this study and refers to men who engage in romantic or sexual relationships with other men. The term homosexuality is incorporated at varying points in the thesis, particularly where it draws on existing literature or local policy documents that maintain the use of the term. This was used, for example, by the Ministry of Health National HIV/STI Programme in its outline of the country's HIV epidemiological profile in 2013.

HIV/AIDS:

HIV can be regarded as the most devastating disease that has impacted society in the history of mankind (UNAIDS, 2011a). HIV is a retrovirus that attacks and weakens an individual's immune system, making him susceptible to various opportunistic infections such as tuberculosis and pneumonia (World Bank, 2000). If left untreated, HIV can progress to its advanced stage, AIDS (Bronner, 2002).

HIV exists in bodily fluids and can be transmitted through unprotected sexual intercourse, blood transfusion, organ transplant, intravenous drug use, pregnancy, childbirth or breastfeeding (UNAIDS, 1999). Symptoms of HIV infection may take an average of 10 years to become evident. In poorer societies where health access and quality are limited, the symptoms will surface as early as within five years (World Bank, 2000). Despite the advancements made in the treatment of HIV, there is no known cure for the disease making its impact and treatment an enduring process.

Treatment adherence:

The current study adopts a two-fold definition of the term 'treatment'. At the forefront, it represents ARV treatment which is the medication prescribed to control the reproduction of HIV. Within this context, the WHO (2003) definition of adherence is maintained as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (p. 3).

Given the perception of treatment as largely clinical, being linked to the recommendations of the healthcare provider, it was felt that a space should be created to determine how the men defined their own treatment which might extend beyond simply taking ARV medication. This openness was aimed at allowing the men to safely present their interpretations of what is entailed in their own treatment journeys.

1.8 SIGNIFICANCE OF THE STUDY

In this study, specific attention is given to understanding the treatment experience and adherence outcomes for HIV positive Jamaican men, a group that until recently has received minimal focus in HIV program and policy development (UNAIDS, 2001). Though much research exists on masculinity in the Jamaican context (Hall, 2011;

Norman & Uche, 2003; Walcott et al., 2014), no noted research has sought to explore the link between Jamaican masculinities and the ARV treatment experiences and process for HIV infected men. As such, this study is deemed to contribute to the growing, though limited, body of literature on men's health in Jamaica, and makes a unique contribution to HIV positive men's ARV treatment experiences and adherence outcomes.

This study also extends the understanding of treatment adherence in the context of a resource limited setting. Though Jamaica has been re-classified as an upper-middle income country, the progress of the health sector has been known to be hampered by limited resources (D. Carr & McClure, 2014). These resources, whether staffing, expertise, finances or networking, culminate in limiting the effectiveness of programs that may cater to the needs of HIV infected men in Jamaica. It is important to understand how this impacts the health service provision and men's health outcomes.

Data arising from this study presents a significant opportunity to inform policies and programs in the development of a targeted response to the treatment needs of HIV infected Jamaican men. The importance of which is further reinforced by the recognized vulnerability of Jamaican men which contributes to their heightened sexual risk practices and their greater representation amongst those diagnosed with advanced HIV and AIDS, and those less likely to initiate and maintain treatment (J.P. Figueroa, 2014; Ministry of Health, 2014a). Altogether, the study responds to a recent call by the UNAIDS "for more work to be done to explore exactly how harmful gender norms and notions of masculinity may increase men's vulnerability" (UNAIDS, December 9, 2015). This vulnerability in the context of HIV/AIDS, crosses all aspects of the illness: risky practices, testing, linkage with care and access to treatment.

This study further makes a methodological contribution by adopting an intersectionality-informed approach. Despite intersectionality theory being in existence since the 1980s, its development as a methodology still remains in the teething stages. This study reinforced Bowleg's (2012) notion that intersectionality is a key tool in examining public health issues. It has also provided another illustration of the value of using intersectionality as a tool in understanding and addressing men's health issues.

1.9 STRUCTURE OF THE THESIS

This thesis comprises nine chapters. The current chapter provided an introduction and overview of the thesis, capturing the aim and rationale of the study, as well as its guiding theories.

The second chapter presents an in-depth situational context of the HIV epidemic in Jamaica with specific reference to the reported incidences for men and the data surrounding treatment. This situational analysis is captured in reference to both the regional and global epidemic of which there is often more current data.

The third chapter critically reviews the existing body of literature surrounding men's health in general, and specifically in relation to HIV/AIDS. The review is constructed within four main themes: The health of Jamaican men and their health-seeking behaviours; Men's health and intersections of identity; Men, masculinity and HIV/AIDS; and ARV treatment experiences and the adherence process for men.

The research methodology and study design are outlined in the fourth chapter and provides an in-depth discussion of the intersectionality-informed approach used to shape the design and analysis of the study. Details regarding ethical considerations, participant selection, demographic data on the study's participants, data collection and analysis, and the trustworthiness and validity of the study are discussed.

Chapters five through eight present the findings of the study across four main themes: "Discovering I'm positive": HIV testing and diagnosis; Transition: Moving from diagnosis to treatment initiation; Renegotiating self and identity; and lastly, Navigating treatment in clinical and social spaces: Issues of power, identity and stigma.

The final chapter presents a discussion of the study findings and draws on the existing body of literature. Perceived limitations of the study are indicated. Methodological implications and key recommendations for policy and practice are discussed. This chapter culminates with the researcher's concluding remarks.

Chapter 2 SITUATIONAL CONTEXT OF THE STUDY

2.1 INTRODUCTION

This chapter presents an overview of Jamaica and the HIV epidemic as a background for the research. General epidemiological patterns are presented in an effort to characterize and position the epidemic in Jamaica and relative to other societies, regionally and globally. Given the focus of the research, a more in-depth review of epidemiological and health service data on the male populace and antiretroviral (ARV) treatment in Jamaica and the wider Caribbean is presented. The chapter concludes with an examination of some of the main challenges that hinder optimal adherence in Jamaica, including implications of the WHO's recently amended treatment guidelines. These guidelines recommend earlier treatment initiation which is arguably an elusive gold standard for Jamaica as a developing and resource-limited country.

2.2 COUNTRY PROFILE

Jamaica, the largest English-speaking country in the Caribbean, is located 150km south of Cuba and 160km west of Haiti (Pan American Health Organization [PAHO], 2012b). The island comprises 14 parishes of which the capital is Kingston, located on the south east coast of the country. Other main urbanized areas include Spanish Town, Portmore and Montego Bay. The main industries for the country are tourism and mining which, along with information and communication technology (ICT), have accounted for most of the country's foreign direct investment since 2000 (Policy Planning Projects & Research Division, 2011). The main exports are bauxite and alumina, sugar, bananas and rum (PAHO, 2012b). The economy is described as being largely import-dependent (Planning Institute of Jamaica [PIOJ], 2014).

Jamaica's demographic, socio-economic, political, and health system profiles are important considerations in shaping the health behaviours and outcomes of the men in this study, whether directly or indirectly. In part, this information provides insight into the context of the country which may not be readily known. Further, these characteristics are important in assessing health behaviours and outcomes as they are often identified as determinants of health (PAHO, 2012b).

2.2.1 Demographic profile

At the end of 2014, the Jamaican population was estimated to be 2.72 million (PIOJ, 2014). The country is perceived to be at an intermediate stage of demographic transition due to declining birth and death rates (Ministry of Health, 2014a). Demographic trends showed a decline in the 0-14 age group (9%) and an increase in the working age population (52%) and dependent older population (11%) (Ministry of Health, 2014a). These demographic changes are noted to have implications for health care, education, social security and the welfare of the elderly (PIOJ, 2013). The annual population growth has consistently remained below 0.5% since 2001 and was reported to be 0.2% in 2014 (PIOJ, 2013).

In 2013 it was estimated that the population comprised approximately 49.5% (1, 345, 500) males and 50.5% (1, 372, 500) females (PIOJ, 2013). There has been a steady growth for both genders since 2010 though there is little variation in the proportional representation of males and females between 2010 and 2013 (see Figure 1). The sex ratio for 2013 was 98 males per 100 females, which suggests that the population is fairly even distributed on the basis of gender (PIOJ, 2013).

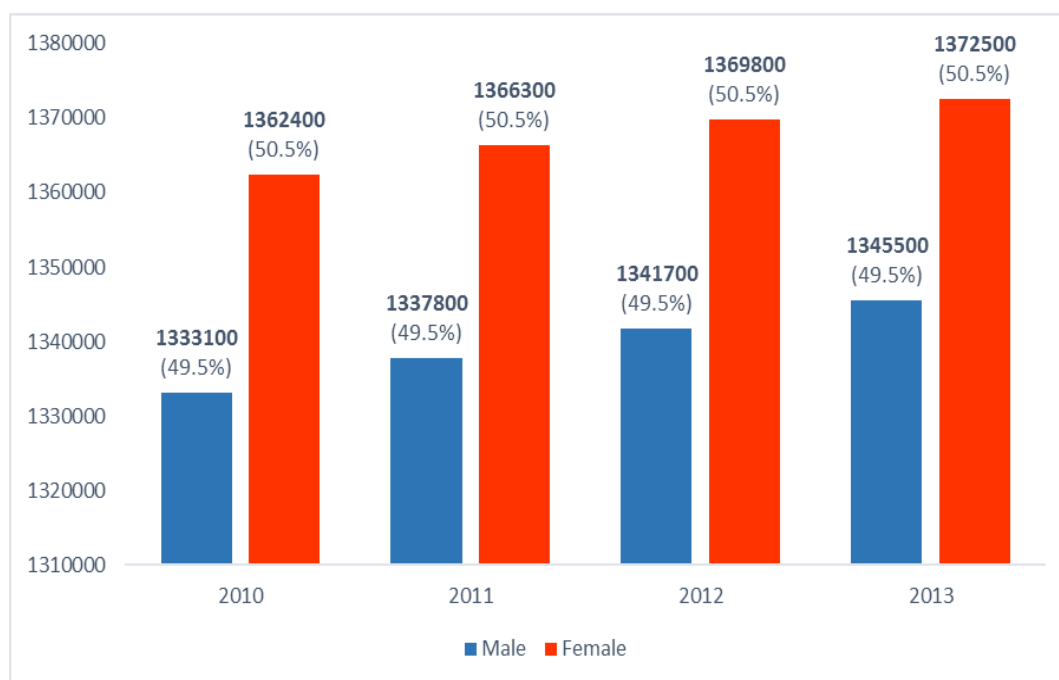


Figure 1: Gender distribution of Jamaica for 2010-2013

Source: *The Economic and Social Survey, 2013* (Planning Institute of Jamaica, 2013)

2.2.2 Political profile

The island has maintained a democratic political system since obtaining independence from Britain in 1962 (PAHO & World Health Organization [WHO], 2007). The executive branch of the government comprises a Cabinet of Ministers headed by the Prime Minister (PAHO & WHO, 2007). Since the country gained independence Jamaica has had a polarized political history with leadership fluctuating between either the People's National Party (PNP) or the Jamaica Labour Party (JLP). Much of this political history is marred by accounts of clientilism, garrison communities and politically related violence (Sives, 2002). This is one of the more definitive features of Jamaica's history which has been further linked to the incessant increase and spread of crime and violence in the country. As Anthony Harriott, one of the Caribbean's leading political scientist and criminologist, asserted:

if Jamaican politics is in some ways responsible for the extraordinarily high rate of violent criminality that the country is now experiencing then successive political administrations since the 1970s are even more responsible for the emergence and rise of organized crime. The political methodology of the political parties is profoundly and directly implicated in the rise of organized crime. (Harriott, 2008, p. 2)

At the time of data collection (2013), the ruling government was the PNP. However, the leadership of the country changed in 2016 to the JLP, led by the Most Honourable Andrew Holness.

2.2.3 Socio-economic profile

Jamaica has made gradual progress in its measured human development over the years, being currently ranked at 99 on the Human Development Index (HDI), advancing three positions above its ranking in 2014 (UNDP, 2015). The HDI presents a composite measure of human development by assessing a country's health, education and income levels. Jamaica was also re-classified as an upper-middle income country in 2010 by the World Bank (D. Carr & McClure, 2014).

The past few years have witnessed a persistent rise in Jamaica's poverty levels, further evidenced in Figure 2 (p. 21). The poverty rate was noted to be 19.9% in 2012 which was estimated to represent one-fifth of the Jamaican population (PIOJ & The Statistical

Institute of Jamaica, 2012). The reported 2.3% increase in poverty since 2010 has been attributed to the global economic recession, the resulting high exchange rates, growing debt burden, and high levels of unemployment (PAHO, 2012).

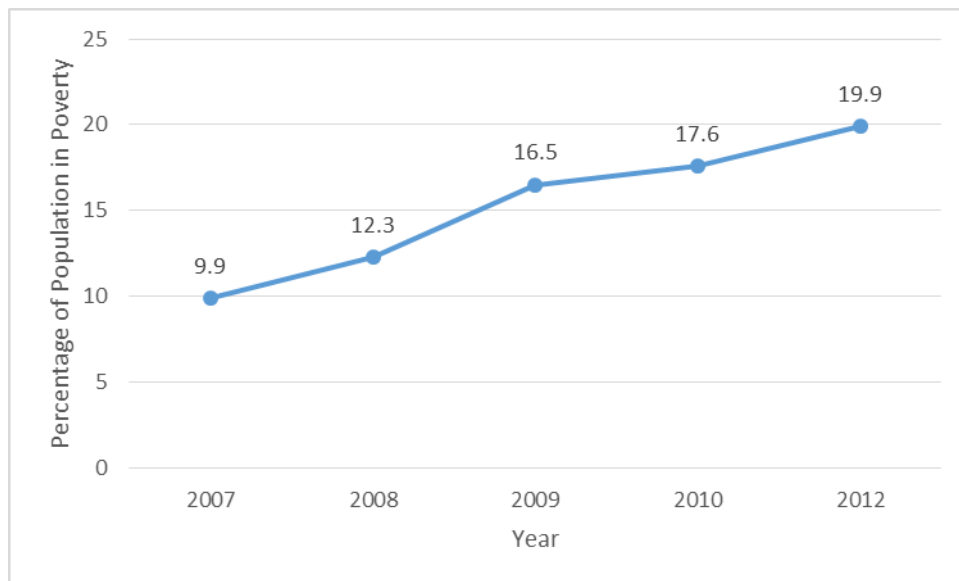


Figure 2: The percentage of population in poverty for 2007 – 2012

Source: *World Development Indicators*. Retrieved from data.worldbank.org/country/Jamaica

Jamaica has attained a relatively high literacy rate, reported to be 91.7% in 2014 (PIOJ, 2014). School enrolment rates are universal up to age 16 years, with an average enrolment of 98.4% being reported (PIOJ & The Statistical Institute of Jamaica, 2012). However, there is a significant gap between the enrolment rates at the secondary level and tertiary/university level of education (PIOJ, 2014). More males than females exit school at both primary (39.5%) and secondary (52%) levels (PIOJ & The Statistical Institute of Jamaica, 2012). This may have implications for the occupation, income and thus poverty levels, of males in comparison to females.

2.2.4 Health system profile

The health status of a country is perceived to be a key indicator of its developmental status. A summary of the key health indicators is provided in Table 1 (p. 22).

Table 1: Key health indicators 2014

Life expectancy at birth	74.13 years. [Males – 72; Females – 77] ⁺
Infant mortality rate	16.7/ 1000 live births
Crude birth rate	13.9/ 1000 mean population
Total fertility rate	2.4 children per woman in 15-49 age group
Maternal mortality rate	94.4/ 100, 00 woman in 15-49 age group
Immunization coverage	91.1%

Source: *Economic and Social Survey, 2014*; ⁺*WHO country statistics and global health estimates, 2012*.

There has been a general decline in the number of persons reporting ill since 2000. More men reported being in good health than women in a 2012 national survey (PIOJ & The Statistical Institute of Jamaica, 2012). However, the accuracy of these self-reports are questioned against the backdrop of men's general reluctance to admit illness (Addis & Mahalik, 2003; Brener, Billy, & Grady, 2003). The questioned accuracy of self-reporting is furthered by data from the recent Jamaican Economic and Social Survey that indicated an increase in admissions and length of stay in hospitals for both males which suggests the seriousness of illnesses with which men present for treatment (PIOJ, 2014). Overall mortality rates are reported to be higher for males than females (PAHO, 2012). In particular, men are identified as being 1.4 times more likely to die from cancer, and are at greater risk of dying as a result of homicides and transport accidents than women (PAHO, 2012).

There is a noted decline in the burden of communicable diseases and a surge in non-communicable diseases in recent years (Ministry of Health, 2014a). Despite the changes, HIV is still acknowledged as being partly responsible for the country's morbidity and mortality rates (Ministry of Health, 2014a). As a result, HIV/AIDS is still ranked as a priority in the country's move towards human capital development (Ministry of Health, 2014b).

Jamaica has employed a primary health care approach since the 1970s (PAHO & WHO, 2007). The Ministry of Health and Environment (MoH) has responsibility for monitoring the health status of the country. Its mandates include: "the enactment of health legislation; formulating, designing, and implementing health strategies and monitoring and evaluating programmes designed to protect and enhance the health

status of Jamaicans” (Ministry of Health, 2014b, p.1). Government expenditure on health as a percentage of GDP has shown a marginal increase in the past few years (see Figure 3) (WHO, n.d.). In 2013, government expenditure on health was reported to be 5.9% of the country’s GDP (WHO, n.d.). This rate appears comparable to other upper-middle income English-speaking Caribbean countries such as Antigua and Barbuda (4.9%), Dominica (6%) and Saint Vincent (5.2%) (WHO, n.d.).



Figure 3: Government expenditure on health as a percentage of GDP

Source: WHO Global Health Observatory Data Repository

There was a notable increase of 17% in the government’s budget allotment for health in the 2015/16 fiscal year ("Ferguson welcomes increase in health budget," March 29, 2015). A total of 49.09 billion was allotted for recurring expenses and 1.15 billion for capital projects, ranking the MoH as receiving the fourth highest budget allotment for the period (Barnes, February 19, 2015). A significant portion of the total expenditure on health is provided by private sources (42.8%), though the government maintains responsibility for the larger portion (see Figure 4).

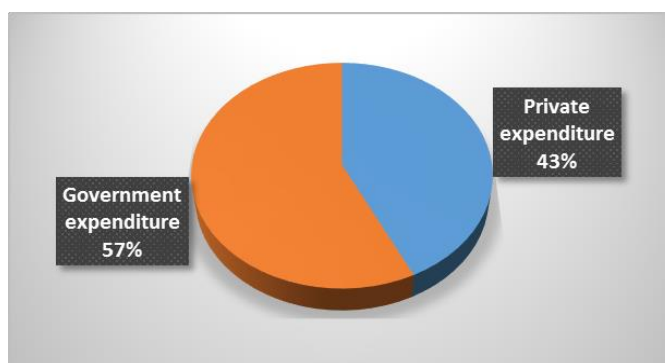


Figure 4: Government and private expenditure on health 2013

Source: WHO Global Health Observatory Data Repository

2.3 HIV/AIDS: A LOCAL SNAPSHOT

It has been over three decades since the first incidence of HIV was identified in Jamaica and the wider Caribbean. Since then, the epidemic has grown to position the Caribbean as second to Sub-Saharan Africa, having a prevalence rate of 1.1% (UNAIDS, 2014). There are currently an estimated 250 000 [230 000 – 280 000] persons living with HIV in the Caribbean (UNAIDS, 2014). Of this total, Jamaica accounts for the third highest proportion (12%), following Cuba and the Dominican Republic (UNAIDS, 2014). Jamaica is further positioned as having the largest number of persons living with HIV (PLWHIV) in the English-speaking Caribbean. Figure 5 below shows the distribution of the epidemic throughout the Caribbean.

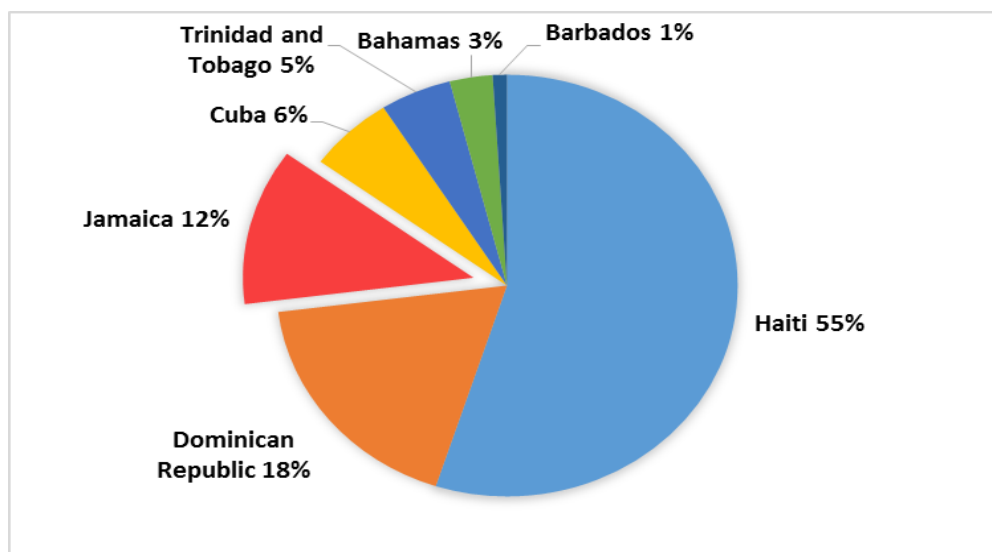


Figure 5: Persons living with HIV throughout the Caribbean

Source: *The Gap Report* (UNAIDS, 2014)

There are significant variations in the HIV prevalence rates throughout the region. Cuba is ranked the lowest with an HIV prevalence rate of 0.3% whilst the Bahamas is ranked the highest with a prevalence rate of 3.2% (UNAIDS, 2014). Table 2 (p. 25) outlines data on adult HIV prevalence rate for select Caribbean countries for the periods between 1990 and 2013. Though there is a noted decline in HIV prevalence for some countries, in others there is a steady increase. These variations are due to the differences between concentrated and generalized epidemics.

Table 2: Adult HIV Prevalence in the Caribbean

Country	1990	2000	2007	2013*	Estimated * PLHIV 2013
Bahamas	3.8	3.1	3.0	3.2	7, 600
Haiti	1.2	2.2	2.2	2.0	130, 000
Jamaica	0.3	1.4	1.6	1.7	30, 000
Trinidad and Tobago	0.2	1.4	1.5	1.6	14, 000
Barbados	0.5	1.2	1.2	0.9	1, 700
Dominican Republic	0.6	1.3	1.1	1.0	43, 000
Cuba	-	<0.1	0.1	0.3	15, 000

Source: *The 2008 Report on the global AIDS epidemic* (UNAIDS & WHO, 2008).

*From *UNAIDS 2013 estimates*.

It is estimated that approximately 30,265 persons are currently living with HIV in Jamaica, of which 30% are perceived to be unaware of their status (Ministry of Health, 2014a). A total of 30,620 incidences of HIV/AIDS have been reported to the Ministry of Health since the first case was identified in 1982 (Ministry of Health, 2014a). There has been a steady increase in the HIV prevalence rate which was noted to be 1.6% in 2008, 1.7% in 2012, and is currently 1.8% (Ministry of Health, 2012, 2014a). This is attributed to the reduced number of AIDS-related deaths and the extended lifespan of PLWHIV due to the successes of ARV treatment (WHO, UNAIDS, & UNICEF, 2011).

HIV incidences exist in all parishes, though the rates are notably higher in the most urbanized parishes (St. James, St. Catherine and Kingston and St. Andrew) and the tourist destinations (Trelawny, Westmoreland and St. James) (Ministry of Health National HIV/STI Programme, 2013). Kingston and St. Andrew, St. James and St. Catherine, which collectively contains 50% of the population, accounted for 56% of reported HIV cases in 2013 (Ministry of Health National HIV/STI Programme, 2013). Figure 6 (p. 26) shows cumulative HIV/AIDS cases for each parish for the period 1982-2013 in comparison to reported HIV/AIDS cases in 2013.

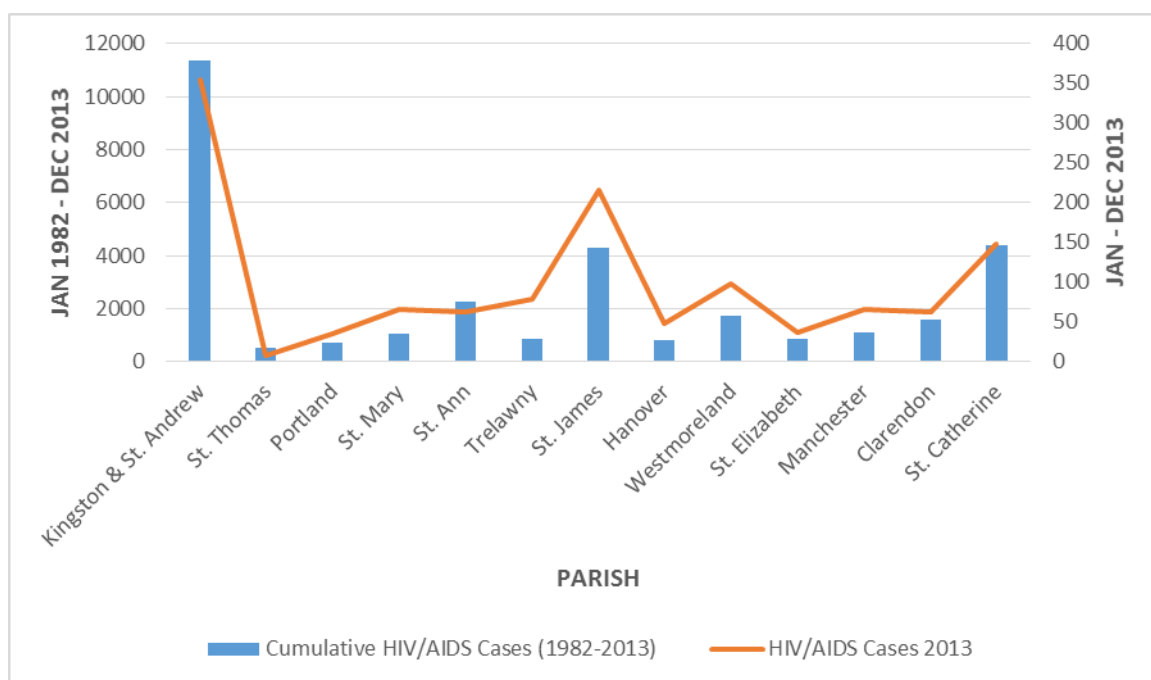


Figure 6: HIV/AIDS cases by parishes, 1982 – December 2013

Source: *Jamaica HIV/AIDS Epidemic Update, January to December 2013* (Ministry of Health, 2013).

There is a cumulative number of 18, 142 AIDS cases for the period January 1982 to December 2013 (Ministry of Health National HIV/STI Programme, 2013). A total of 9, 056 AIDS-related deaths were also noted for the same period (Ministry of Health National HIV/STI Programme, 2013). Overall, there has been a decline in AIDS-related deaths since peaking with 692 cases in 2002 (J. P. Figueroa et al., 2008). There has been a 76% decrease in the number of AIDS-related deaths since the introduction of universal access to ARVs in 2004 (Ministry of Health National HIV/STI Programme, 2013). This decline has also been attributed to increased awareness, access to testing, promotion for behaviour change and improved HIV surveillance (Ministry of Health, 2014a). Even with the progress made, there remains a need to further improve the surveillance system as a significant number of cases continue to remain undiagnosed or unreported until the disease has progressed to the advanced stage.

2.3.1 Population of focus: Jamaican men

In general, men account for approximately 50% of the number of PLWHIV in the Caribbean (UNAIDS, 2010). This trend differs slightly for Jamaica as more males than females are noted to report with HIV, advanced HIV or AIDS (Ministry of Health National HIV/STI Programme, 2013). This has been attributed to the increased likelihood of men (rather than women) engaging in unprotected sex with a number of partners (J. P. Figueroa et al., 2008). Jamaica started monitoring cases of advanced HIV only in 2005 as an indicator for the earlier initiation of treatment. Of the 780 persons diagnosed with advanced HIV in 2013, over half the cases (n = 423) were men (Ministry of Health National HIV/STI Programme, 2013). The consistent trend in the proportion of men being impacted by the illness, outweighing women is evidenced in Figures 7 and 8 (p. 28).

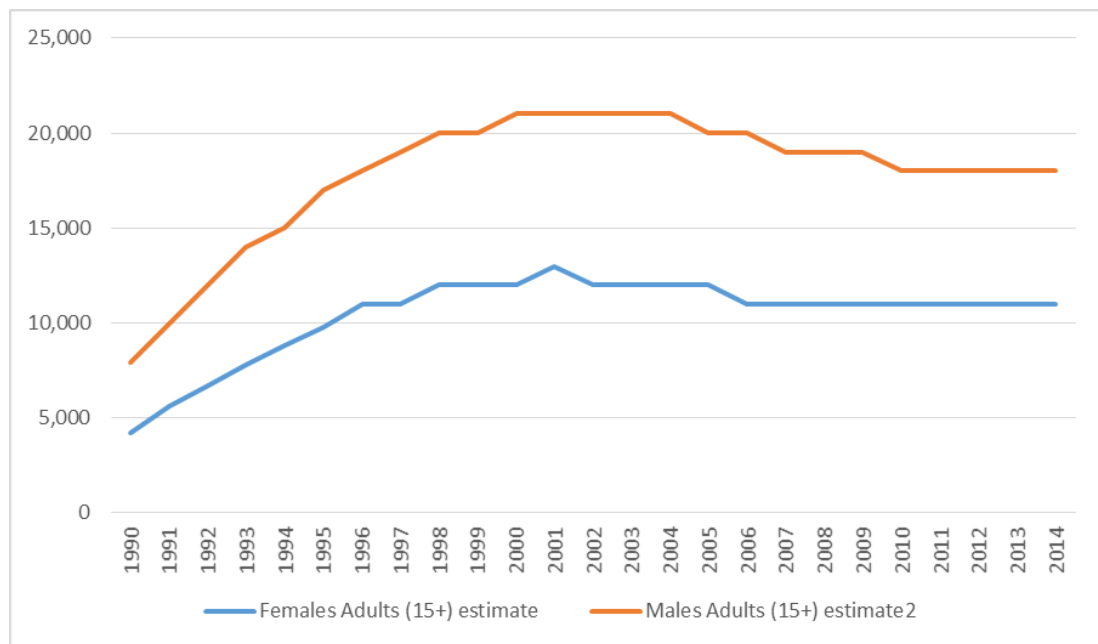


Figure 7: Gender distribution of adult HIV prevalence in Jamaica

Source: Generated from UNAIDS AIDSinfo data

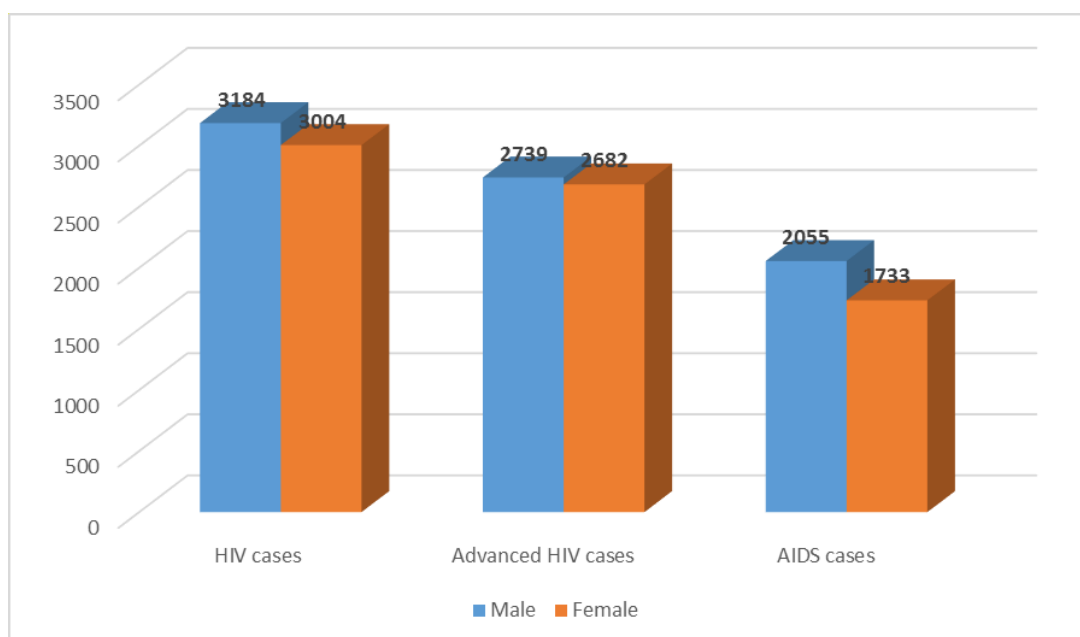


Figure 8: Gender distribution of HIV, Advanced HIV and AIDS cases, 2010 – 2013

Source: The Ministry of Health, *Jamaica HIV/AIDS Epidemic Update, January to December 2013*.

There is some variation in the gender distribution across age groups. Whereas females account for the greater portion of cases in the 10 to 29 age group, males account for the larger proportion of AIDS cases for the 30 to 79 age group, (Ministry of Health National HIV/STI Programme, 2013). Cumulatively, for the period 1982 – 2013, the reported AIDS cases for the 15 to 19 age group was four times higher for females than males (Ministry of Health National HIV/STI Programme, 2013).

Men are also noted to represent the greater portion of reported AIDS-related deaths despite the general decline in incidences (Ministry of Health National HIV/STI Programme, 2013). Figure 9 (p. 29) shows that more men than women have died from AIDS-related illnesses since the first HIV case was identified in 1982. This may be indicative of the late stage at which men present with the illness, as well as the delay or unwillingness to access and maintain care and treatment.

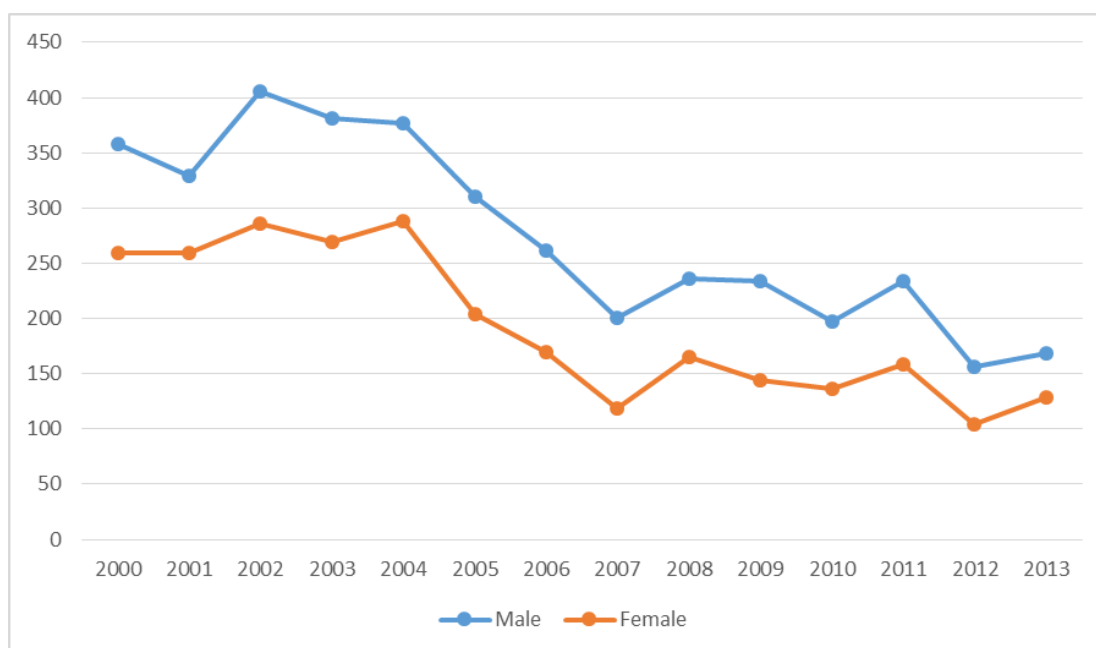


Figure 9: AIDS deaths in Jamaica, 1982 – 2013

Source: *HIV Epidemiological profile 2013* (Ministry of Health National HIV/STI Programme, 2013)

2.3.2 Modes of transmission

The main mode of HIV transmission in Jamaica is through unprotected sexual intercourse (Ministry of Health National HIV/STI Programme, 2013). Of the reported HIV cases, 95% reported engaging in heterosexual practices (Ministry of Health National HIV/STI Programme, 2013). Cumulative data for HIV shows that more women than men state their sexual practices, with less than 1% of women not stating their sexual practice in comparison to 44% for men (Ministry of Health National HIV/STI Programme, 2013). Similarly, 41% of men diagnosed with AIDS did not indicate their sexual practices (Ministry of Health, 2014a). This was attributed to the stigma attached to same-sex relationships that often hinder MSM from talking about their sexuality (J.P. Figueroa, 2014; R. White & Carr, 2005). This is further reinforced by the small percentage of HIV infected men who reported engaging in either MSM (4%) or bisexual (4%) practices (see Figure 10, p. 30) (Ministry of Health National HIV/STI Programme, 2013).

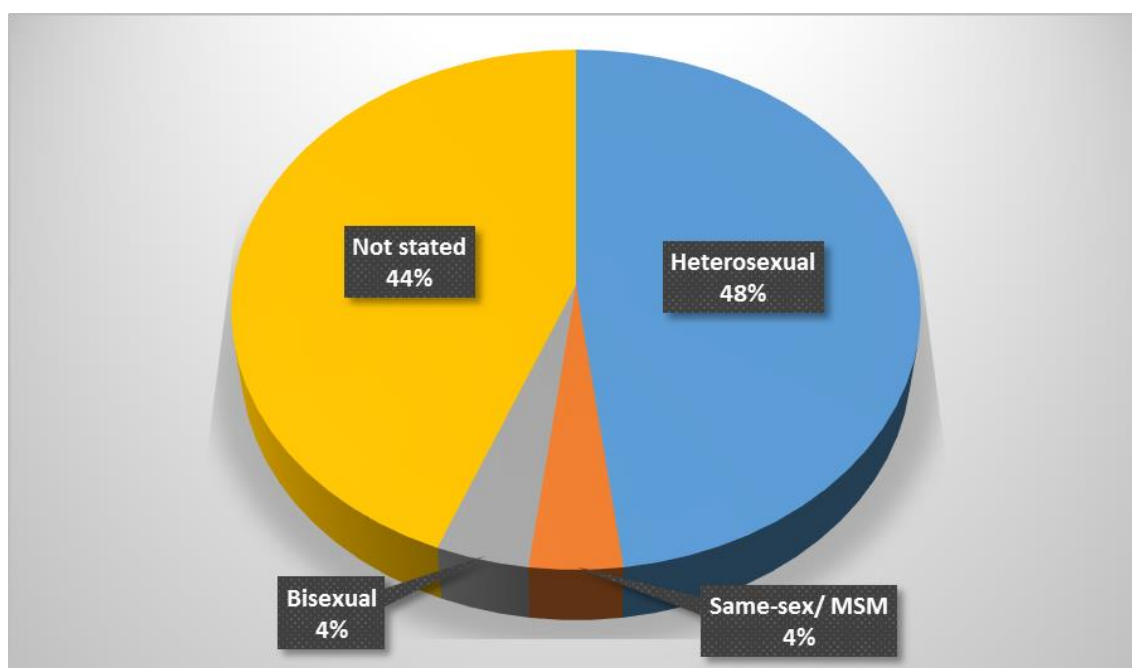


Figure 10: HIV infected male sexual practices, 1982 - 2013

Source: *HIV Epidemiological profile 2013* (Ministry of Health National HIV/STI Programme, 2013)

Similar to the wider Caribbean, intravenous (IV) drug usage is not a common mode of HIV transmission in Jamaica. However, in recent years, there has been a noted increase with 73 cases being reported for the period 2008 – 2012, which represents 43% of total IV-drug incidences since 1982 (Ministry of Health, 2014a). This has been attributed to widened programme coverage that assesses the risks and practices of the homeless population, as well as the increasing number of forcibly returned migrants from regions where IV-drug use is more widely practised (Ministry of Health, 2014a). As Jamaica maintains full screening of blood related products, blood transfusion and occupational exposure are not significant modes of HIV transmission (Ministry of Health, 2014a).

The main risk factors for HIV infections to date are people having unprotected sex with multiple partners, engaging in commercial sex, and a history of STIs and crack or cocaine use (J.P. Figueroa et al., 2008; Ministry of Health, 2010a). A significant proportion of people who are HIV positive report that they had sex with one partner only (28.6%) and thus it was concluded that their partner was infected by another partner (Ministry of Health, 2010a). This shows a pattern of increased HIV transmission amongst perceived monogamous relationships.

2.3.3 Most at risk populations

The HIV epidemic in Jamaica is characterized as both a low-level generalized epidemic as well as a concentrated epidemic, indicated by the low general adult prevalence rates and higher prevalence rates for at risk populations, namely MSM, commercial sex workers (CSW), inmates and the homeless (Ministry of Health, 2014a). In 2013, HIV prevalence rates were reported to be 4.02% for homeless persons/ drug users and 1.9% for prison inmates (Ministry of Health, 2014a). Though 2013 data was not available for CSW and MSM, they were reported to have HIV prevalence rates of 4.2% and 32% respectively in 2011 (Ministry of Health, 2014a). The prevalence rates for these at risk populations have declined in recent years with the exception of MSM, perhaps due to the prevailing stigma surrounding same-sex relationships (R. White & Carr, 2005). The high HIV prevalence rate reported for MSM is also attributable to the high probability of HIV transmission associated with unprotected receptive anal intercourse (J.P. Figueroa et al., 2015).

Throughout the Caribbean, MSM are noted to have high levels of HIV prevalence (UNAIDS, 2014). Jamaica was identified as having the highest HIV prevalence rate for this population in the Caribbean in 2014 (UNAIDS, 2014). Approximately 30% of new infections that occurred in 2012 were amongst the MSM population (See Figure 11, p.32) (Ministry of Health, 2012). This highlights that the MSM population in Jamaica is the most at risk group. As noted earlier, these higher incidences of HIV/AIDS for this population is attributable to a range of factors including the heightened risk of transmission through unprotected anal sex, having unprotected sex with multiple partners, and the attached taboo or stigma that prevent these men from openly seeking information and accessing health services (J.P. Figueroa, 2014; J.P. Figueroa et al., 2015; Halkitis et al., 2013; Pantalone, Tomassilli, Starks, Golub, & Parsons, 2015; R. White & Carr, 2005). Men are also becoming increasingly involved in the sex work industry; thus positioning male sex workers as an emerging vulnerable group (UNAIDS, 2008b). National surveillance data has failed to capture the incidences of HIV for MSM sex workers despite their emergence as an at risk group. One study found that HIV prevalence rate for MSM sex workers was 41% in 2011 (J.P. Figueroa et al., 2015).

Though the remaining data in Figure 11 does not specifically distinguish men within the categories, research indicates that they are highly represented amongst casual heterosexual sex (CHS), partners of those who engage in CHS, low-risk heterosexuals, and clients of CSW (J.P. Figueroa, 2014; J.P. Figueroa et al., 2015; Ministry of Health, 2014a). This highlights the need to capture data on that group of men who are broadly classified as ‘high-risk heterosexual men’ (J.P. Figueroa, 2014). High-risk heterosexual men are perceived to include “men who have multiple sexual partners...have sex with female sex workers, participate in casual and transactional sex, frequent sites where persons go to meet new sex workers such as night clubs and bars, drink alcohol, and develop a sexually transmitted infection” (J.P. Figueroa, 2014, p. 161). It is likely that this group includes MSM who maintain their privacy on the issue given the prevailing social norms and taboos (R. Carr, 2002; Charles, 2011; Cowell, 2011; R. White & Carr, 2005).

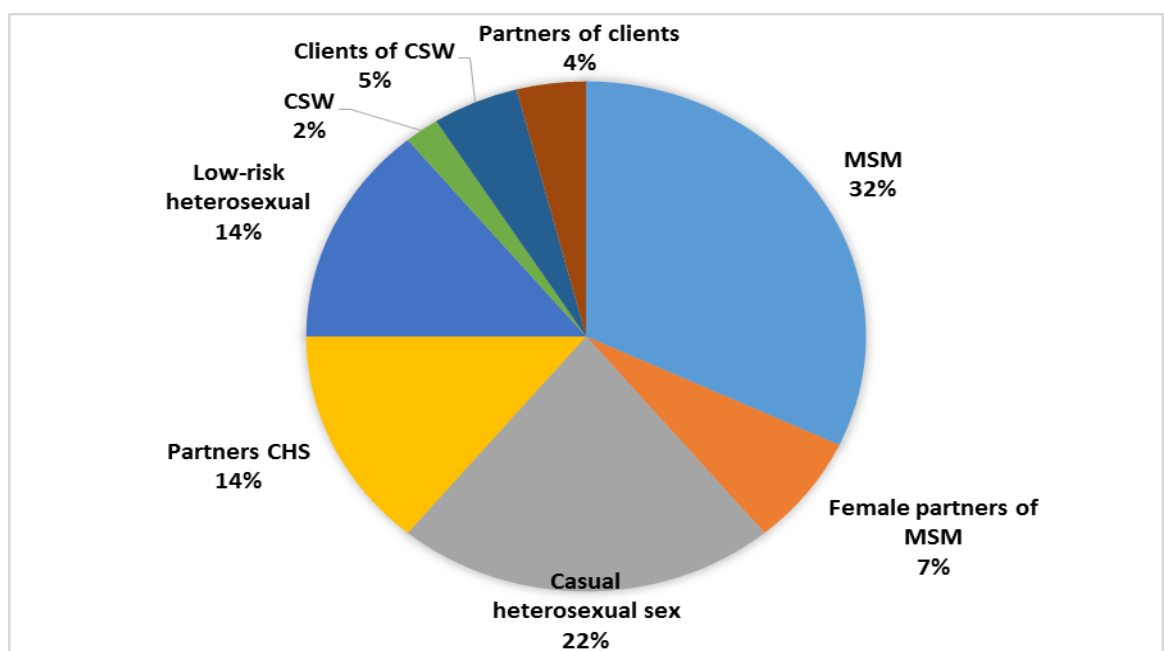


Figure 11: New incidences of HIV infection, 2012

Source: *Jamaica Country Progress Report* (Ministry of Health, 2014)

2.3.4 Social Drivers of the Epidemic

The HIV epidemic in Jamaica is compounded by social, cultural and structural factors (J.P. Figueroa, 2014; UNAIDS, 2010). As outlined in a key UNAIDS (2010) report:

The social drivers of the epidemic are those norms and beliefs that guide our interpretation and response to HIV. They determine the lens through which we view HIV/AIDS and the frameworks which guide our response. (p. 11)

A distinction is made between the ‘risk’ model and ‘vulnerability’ model in identifying factors that predispose an individual to HIV infection. The ‘risk’ model points to factors such as unsafe sexual practices, inconsistent condom use and multiple sex partners. The ‘vulnerability’ model, on the other hand, addresses issues such as gender inequities, stigma, discrimination and social exclusion (UNAIDS, 2010).

Multiple sexual partnerships, early sexual debut, high levels of transactional sex, commercial sex, and inadequate condom use have been identified as key factors that shape the HIV epidemic in Jamaica (J. P. Figueroa, 2008; National HIV/STD Control Programme & UNAIDS, 2012). Cumulative data since 1982 shows that the majority of persons (80%) diagnosed with HIV noted that they engaged in multiple sexual partnerships (National HIV/STD Control Programme & UNAIDS, 2012). Traditionally the rate is higher for men than women, as well as highest amongst young males (HOPE Enterprises Ltd, 2012; Olukoga, 2004). The 2012 Knowledge, Attitudes, Values and Practices (KAVP) survey revealed that 41% of sexually active respondents had more than one sexual partner in the past 12 months and that of these, 35.4% did not use a condom at their last sexual encounter (HOPE Enterprises Ltd, 2012). Significantly more men (60.5%) than women (19.4%) reported having multiple sexual partners during this period (HOPE Enterprises Ltd, 2012). The men in this sample reported an average of 6 partners in the past 12 months (HOPE Enterprises Ltd, 2012).

Some of the high risk sexual behaviour is attributed to the socio-cultural norms that pervade the Jamaican society, including gendered norms that prescribe appropriate masculine behaviour (P. Anderson, 2012; Chevannes, 2001; Hope, 2010). These socio-cultural norms are seen to promote male dominance, male promiscuity, early sexual debut and limited condom use (Brown & Chevannes, 1998; National HIV/STD Control Programme & UNAIDS, 2012; Norman & Uche, 2003). Such norms impact the age of

sexual debut (Kempadoo & Dunn, 2001), the mean age of which was noted to be 16.1 years for females and 14.5 years for males in 2010 (PIOJ, 2010). Persistent levels of poverty and high levels of unemployment are also significant in the formation of transactional relationships and engagement in sex work activity (National HIV/STD Control Programme & UNAIDS, 2012). HIV stigma and discrimination remain key barriers to status disclosure and access to treatment and care (Abell, Rutledge, McCann, & Padmore, 2007; R. Carr, 2002).

2.4 NARROWED LENS: THE ISSUE OF ANTIRETROVIRAL TREATMENT

Universal access to ARV treatment remains one of the main global targets towards ending the public health threat of HIV/AIDS. Global programmes aimed at increasing the number of persons accessing treatment worldwide, have contributed significantly to the accelerated rate of access in the region. Such programmes included the “3 by 5” initiative to provide ARV treatment to 3 million persons in low and middle income countries by 2005 (UNAIDS, 2013). The UNAIDS recently celebrated the success of its Treatment 2015 (“15 by 15”) initiative that ignited global action towards targeting 15 million HIV infected persons by 2015 (UNAIDS, 2015a). Specifically, the Treatment 2015 initiative surrounded increased ARV provision, reaching the most in need, and the development of innovative diagnostic and treatment options (UNAIDS, 2015a). According to the UNAIDS, the success of this initiative was made possible through

strong and sustained leadership and commitment, community engagement, robust funding, increased knowledge of HIV status, a reliable supply of effective and affordable medicines, improved efficiency and quality of treatment services, innovation, and progress in reducing HIV-related stigma and discrimination. (UNAIDS, 2015a, p. 5)

Subsequently, the UNAIDS has launched a new target: the 90-90-90 target. This surrounds governments’ commitment to ensure that by 2020 90% of people living with HIV will know their HIV status; 90% of people who know their status will receive treatment; and 90% of people on HIV treatment will have a suppressed viral load (UNAIDS, 2015a). Critical to the success of these targets in Jamaica is the identification of innovative ways to promote earlier diagnosis (UNAIDS, 2015b), especially amongst those most at risk or hidden populations. Success further entails ensuring that persons in need are receiving and sustaining treatment, especially if viral suppression is to be achieved (UNAIDS, 2015b). A crucial challenge faced by Jamaica in adopting the

proposed targets, is reducing its reliance on diminishing external funding in its response to the national epidemic. Figure 12 (p. 36) provides a timeline of some of the key milestones locally and internationally that have impacted ARV treatment provision in Jamaica.

2.4.1 Treatment financing in Jamaica

The majority of Jamaica's HIV/AIDS services and programmes are funded by external donors (Pan American Health Organization, 2012a; Pan American Health Organization & WHO, 2013). It was estimated that over 90% of funding for Jamaica's the National HIV/STI Programme (NHP) for the period 2008 to 2013, came from external donors such as the Global Fund, The United States President's Emergency Plan for AIDS Relief (PEPFAR), USAID and the World Bank (D. Carr & McClure, 2014; Ministry of Health, 2014a). In 2014, the Global Fund disbursed US 2.7 million to support a range of HIV-related services including the strengthening of the legal and policy framework, the provision of ARVs, capacity building to reach the most at risk populations and public education to reduce practices that promote HIV transmission (PIOJ, 2014). UNAIDS funded a range of projects and national activities that concluded in 2014. This included the drafting of the National Gender-Based Strategic Plan and support for the preparation of the Global AIDS Response Progress Report (PIOJ, 2014).

It is estimated that over 75% of Jamaica's ARV provision is funded externally (PAHO & WHO, 2013). The past 10 years has seen some Caribbean countries transition from high to medium dependency (such as Dominican Republic and St. Lucia), or from medium to no dependency (such as Anguilla and Monserrat) (PAHO & WHO, 2013). However, Jamaica has maintained its high dependency throughout this period (PAHO & WHO, 2013).

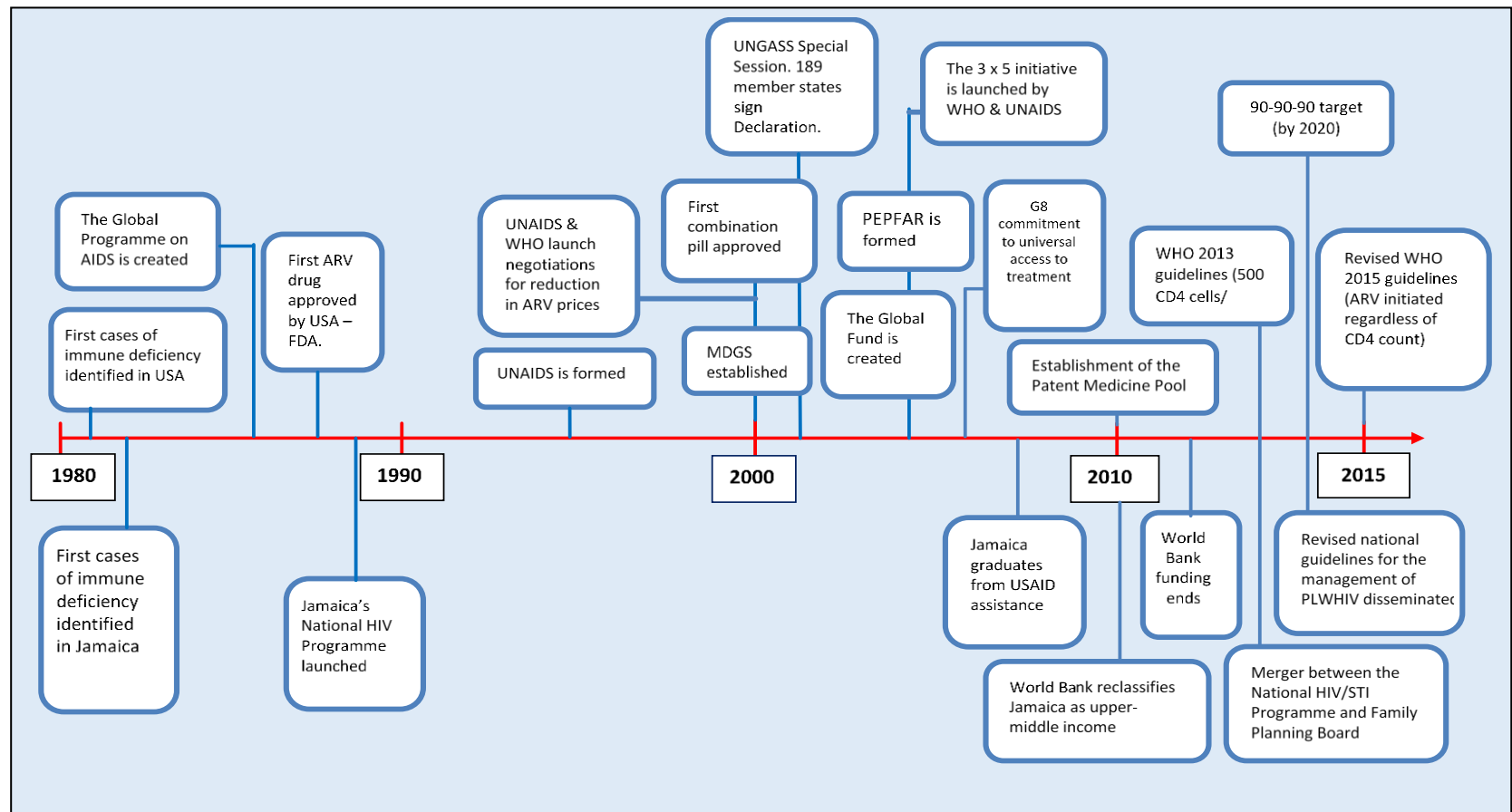


Figure 12: Timeline showing key local and global milestones in shaping Jamaica's ARV treatment provision

Sources: *WHO in 60 years: A chronology of public health milestones* (WHO, 2008); *Global HIV/AIDS timeline* (Kaiser Family Foundation); *AIDS at 30: Nations at the crossroads* (UNAIDS, 2011); *National Family Planning-HIV Programme Integration in Jamaica: Creating a new sexual health agency* (Carr & McClure (2014); *Jamaica country progress report. Global AIDS response progress report* (Ministry of Health, 2014).

Funding from some external donors has ceased with Jamaica's reclassification as an upper-middle income country by the World Bank in 2010 (D. Carr & McClure, 2014). This means that Jamaica is now only eligible for funding that targets most at risk populations, thereby reducing the financial support of other aspects of the country's HIV response (Ministry of Health, 2014a). This has forced the government to look internally to cut costs and identify creative solutions to support its HIV response (D. Carr & McClure, 2014). The government has made the commitment to absorb the costs associated with maintaining the ARV provision and clinical management of PLHIV given the changed funding options (Ministry of Health, 2014a). In 2014, the then Minister of Health, reported at a Global Fund press briefing that approximately 46% of the country's HIV/AIDS programme was funded locally ("Jamaica increasing funding for HIV/AIDS programmes," April 11, 2014). This is, however, contestable given Jamaica's capacity to invest in its health programmes is strongly limited by the country's excessive debt burden of at least 140% of its GDP (D. Carr & McClure, 2014). Thus servicing the debt does not allow the Jamaican government much space to further invest in its health system or other social services (D. Carr & McClure, 2014; Ministry of Health, 2014a).

The cost of implementing the current phase of the National HIV and AIDS Programme (2013-2016) was estimated to be US 116.8 million, with an average annual outlay of US 29.2 million (Ministry of Health, 2014a). Current funding has been received from the Global Fund of US 14.9 million for the period 2016 – 2018, and PEPFAR, of US 5 million for the period 2015 – 2016 (Gilpin, July 15, 2015). Prevention remains the area of priority, thus receiving the largest portion of funding (Ministry of Health, 2014a). Allocation of resources for ARV treatment is expected to increase by 75% in the short-term, given the expanded enrolment of persons with advanced HIV who will need to initiate treatment (Ministry of Health, 2014a).

2.4.2 Jamaica's treatment guidelines

Since 2002, the WHO has provided evidenced-based scientific recommendations to guide countries in developing their national guidelines on ARV (PAHO & WHO, 2013). These guidelines are largely driven by a public health perspective that focuses on the collective health status of a population, rather than the health of individuals (WHO, 2008). Thus the WHO recommendations largely surround the benefit of early treatment initiation in reducing the incidences of HIV infection at the population level (WHO, 2013) and forms the basis of the goal for large scale provision of ARV as a strategy for the prevention of HIV transmission (Grubb, Perriens, & Schwartländer, 2003). It is expected that this public health approach will

ensure the widest possible access to high-quality services at the population level, based on simplified and standardized approaches, and to strike a balance between implementing the best-proven standard of care and what is feasible on a large scale in resource-limited settings. (WHO, 2013, p. 42)

The WHO published a revised guideline for treatment the same year the study was conducted. The 2013 publication presented a consolidated document that covered the use of ARV as treatment and prevention for all sub-populations and across the broad spectrum of HIV care (WHO, 2013). The 2013 guidelines expanded the group of persons considered eligible for treatment to include all adults with CD4 counts between 350 and 500 cells/mm³, all HIV-infected pregnant women, individuals with HIV and TB, HIV-infected individuals with Hepatitis B infection and chronic liver disease, all HIV-infected children between the age 2-5 years, children above 5 years with CD4 counts between 350 and cells/mm³ and serodiscordant couples (WHO, 2013). A summary of these recommendations are outlined in Table 3 (p. 39). These amended guidelines were projected to shift the total number of persons requiring treatment globally from 17.6 million in 2010 to 28.6 million in 2013 (Stover et al., 2014).

Table 3: Evolution of WHO treatment guidelines for HIV adults

TARGET POPULATION	RECOMMENDATIONS		
	2010	2013	2015
HIV infection (WHO clinical stages 1 or 2)	Initiate ARV if CD4 count is ≤ 350 cells/mm ³	Initiate ARV if CD4 count is ≤ 500 cells/mm ³ Priority given to patients with CD4 count ≤ 350 cells/mm ³	Initiate ARV regardless of CD4 count Priority given to patients with advanced HIV or having CD4 count ≤ 350 cells/mm ³
Advanced HIV infection (WHO clinical stages 3 and 4)	Initiate ARV regardless of CD4 count	Initiate ARV regardless of CD4 cell count	Initiate ARV regardless of CD4 cell count
Patients with active tuberculosis	Initiate ARV regardless of CD4 count	Initiate ARV regardless of CD4 cell count	Initiate ARV regardless of CD4 cell count
Patients with Hepatitis B with severe chronic liver disease	Initiate ARV regardless of CD4 count	Initiate ARV regardless of CD4 cell count	Initiate ARV regardless of CD4 cell count
Pregnant women	Initiate ARV if CD4 count is ≤ 350 cells/mm ³	Initiate ARV regardless of CD4 cell count	Initiate ARV regardless of CD4 cell count
HIV serodiscordant couples	N/A	Initiate ARV regardless of CD4 cell count	Initiate ARV regardless of CD4 cell count
HIV-negative individuals at substantial risk of infection such as serodiscordant couples, MSM and transgender women.	N/A	N/A	Oral PrEP should be offered as an additional prevention choice

Note. From: *Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV* (WHO, 2015b); *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendation for a public health approach* (WHO, 2013); *Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach* (WHO, 2010).

Despite the substantial benefits to be achieved with increased ARV coverage, the associated costs and burden of provision made the recommendations difficult to attain in the short to medium term in Jamaica. As such, Jamaica has not fully adopted all the recommendations posed in the WHO 2013 guidelines. Instead, Jamaica maintains the WHO 2010 recommendations of initiating ARV treatment for adults whose CD4 counts are ≤ 350 cells/mm³ (See Figure 13, p. 41) (PAHO & WHO, 2014). However, modifications were made to national guidelines to ensure that all pregnant women received ARV treatment regardless of their CD4 counts (PAHO & WHO, 2014).

The more recent 2015 WHO guidelines now recommend initiating ARV treatment for all persons diagnosed, regardless of their CD4 counts. Priority is, however, given to adults with CD4 counts ≤ 350 cells/mm³ (WHO, 2015b). In addition, it is recommended that oral prophylaxis (PrEP) be offered as an additional preventative choice for HIV-negative persons deemed at high risk of infection, such as persons in serodiscordant relationships, MSM and transgender women (WHO, 2015b). Table 3 (p. 39) shows how the recommendations within the 2015 WHO guidelines compare with the previous two published guidelines.

As with the earlier 2013 guidelines, there remain challenges in Jamaica's ability to adopt all the recommendations. The WHO's move to provide ARV treatment for all persons, irrespective of their CD count, is largely a preventative approach (Vitoria, Vella, & Ford, 2013). Studies show that the benefit of initiating treatment at high CD4 count levels can result in early viral suppression, an optimal adherence level of at least 95% over time, and a low probability of developing drug resistance (Lima et al., 2015). However, adopting these new guidelines will mean that a significantly larger number of persons will require ARV treatment soon after diagnosis. The WHO predicts that the persons needing treatment in Jamaica will increase by 35% if the 2015 guidelines are adopted (WHO, 2015b). Beyond the increased demand, these recommendations mandate an efficient and bolstered health system that provides for an increased uptake in HIV testing, accessible and affordable viral load testing, and effective procedures to ensure patient treatment adherence, rapid response

to treatment failure and retention in care (Vitoria et al., 2013). These areas have posed challenging for Jamaica's health system even prior to the increased demand for ARV provision (Ministry of Health, 2014a). Adopting the guidelines would require an increase in technical expertise, acquisition of new technologies, and perhaps an expansion of existing facilities or the services provided (Eholie, Vella, & Anglaret, 2014; Vitoria et al., 2013).

Altogether, adopting the 2015 WHO guidelines will require a strengthened health system, additional staffing and a strong financial capacity. Despite being re-classified as an upper-middle income country, Jamaica remains challenged by an excessive debt burden (D. Carr & McClure, 2014). Jamaica's capacity to undertake these guidelines is further hindered by socio-cultural barriers that prevent key populations from accessing HIV testing services (Ministry of Health, 2014a), and the success of this strategy is hinged on an early detection of HIV (Eholie et al., 2014; Vitoria et al., 2013). Figure 13 shows Jamaica's current guidelines in respect to the 2015 WHO recommendations.

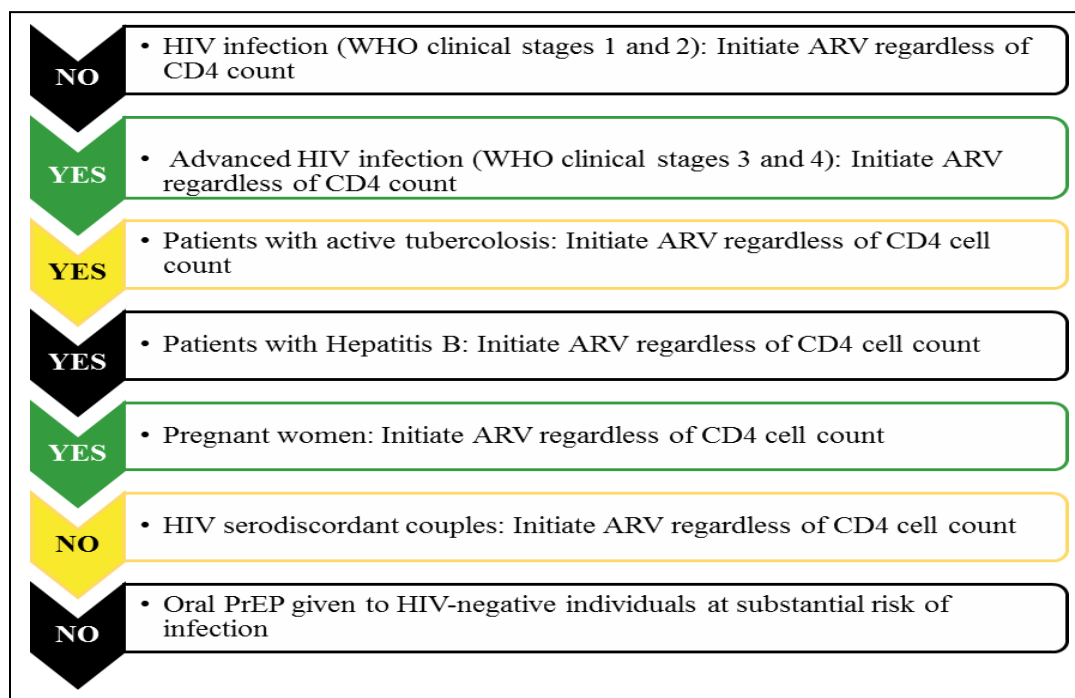


Figure 13: Jamaica's adoption of the WHO 2015 treatment guidelines

Source: *Antiretroviral treatment in the spotlight: a public health analysis in Latin America and the Caribbean* (PAHO & WHO, 2014).

2.4.3 Antiretroviral treatment provision and outcomes

There are 23 treatment sites that provide comprehensive care for PLHIV across the island, majority of which are located in the Kingston and St. Andrew parishes (see Figure 14) (Ministry of Health, 2014a). There remains a need for additional treatment sites throughout the country, especially given the modified guidelines for treatment initiation resulting in more persons being eligible to commence ARV (Ministry of Health, 2014a). Treatment within public health facilities exists as part of an integrated health system, as these facilities also provide non-HIV related health services (Ministry of Health, 2014a). Treatment and care is further provided through the private health system. The Ministry of Health partnered with DrugServ, a private pharmaceutical company, to provide ARV medication free of cost to private sector patients (Ministry of Health, 2012). ARVs are also supplied by select private pharmacies (Ministry of Health, 2014a).

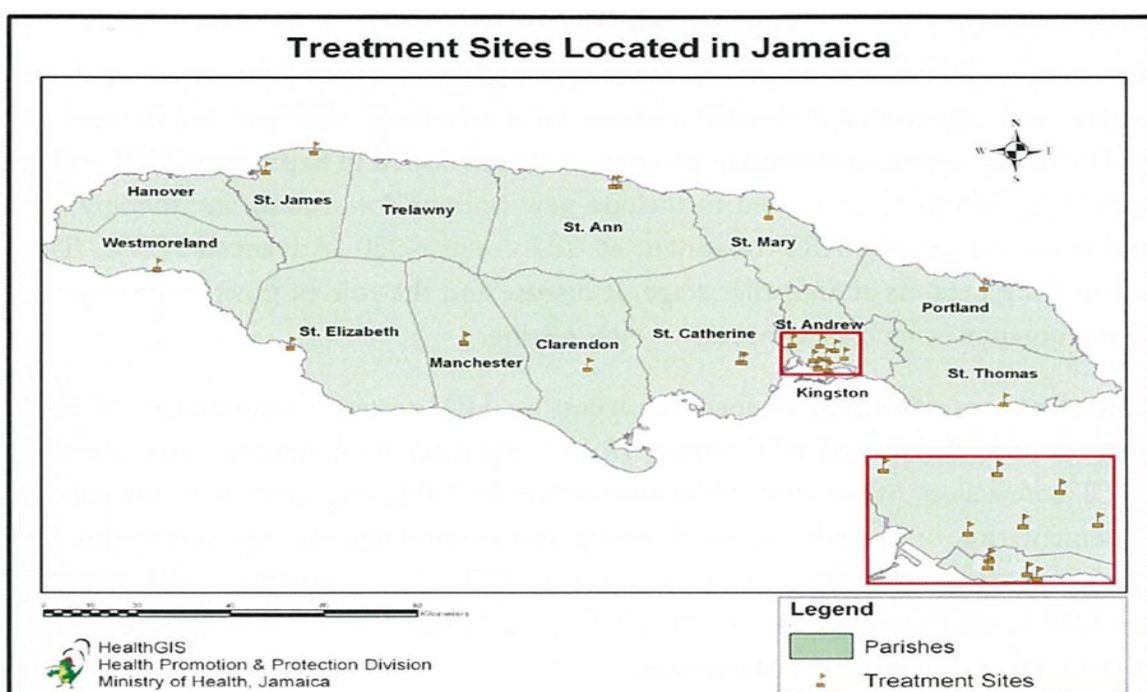


Figure 14: Treatment sites located in Jamaica

Source: Jamaica Country Progress Report, 2008

CD4 testing, used to determine when ARV treatment should be initiated, is facilitated at a few institutions across the island (Ministry of Health, 2014a). The provision of additional Pima machines has further improved access to CD4 testing (Ministry of Health, 2014a). Viral load testing, however, is facilitated solely by the National Public Health Laboratory (Ministry of Health, 2014a). This indicates a significant burden on the resources of one facility in processing viral loads for the entire country.

There has been a noteworthy increase in the number of persons accessing ARV therapy in the Caribbean (PAHO & WHO, 2014). ART coverage was reported to have increased from 37% in 2008 to 48% in 2009 (WHO, UNAIDS, & UNICEF, 2010) and current UNAIDS estimates indicated that 120,369 persons in the Caribbean were receiving ARV treatment in 2014. Much of this increased provision is attributable to the declining cost of ARVs, particularly those used in first and second line regimens (Pan American Health Organization & WHO, 2013). Increased access to ART has resulted in a decrease in AIDS-related deaths (UNAIDS, 2010). However, the proportion of persons who remain in need of ARV therapy continues to be a grave concern for the region. Despite the steadily increasing ARV coverage rates, they remain below the benchmark for universal access which is ensuring that at least 80% of the persons in need of ARV receive treatment (WHO et al., 2010).

Jamaica, as with many other Caribbean territories, has reported significant improvement in the longevity and quality of life of PLHIV in recent years (Ministry of Health, 2012). There has been a gradual increase in the number of persons receiving ARV treatment since 2004 (Figure 15, p. 44). It was reported that at the end of 2011, 8675 adults and 487 children with advanced HIV or with CD counts ≤ 350 cells/mm³, were receiving ARV treatment (Ministry of Health, 2012). The consistent increase is likely due to ARV treatment, including ARV medication, being provided free of cost within the public health system since 2004 (Ministry of Health, 2012).

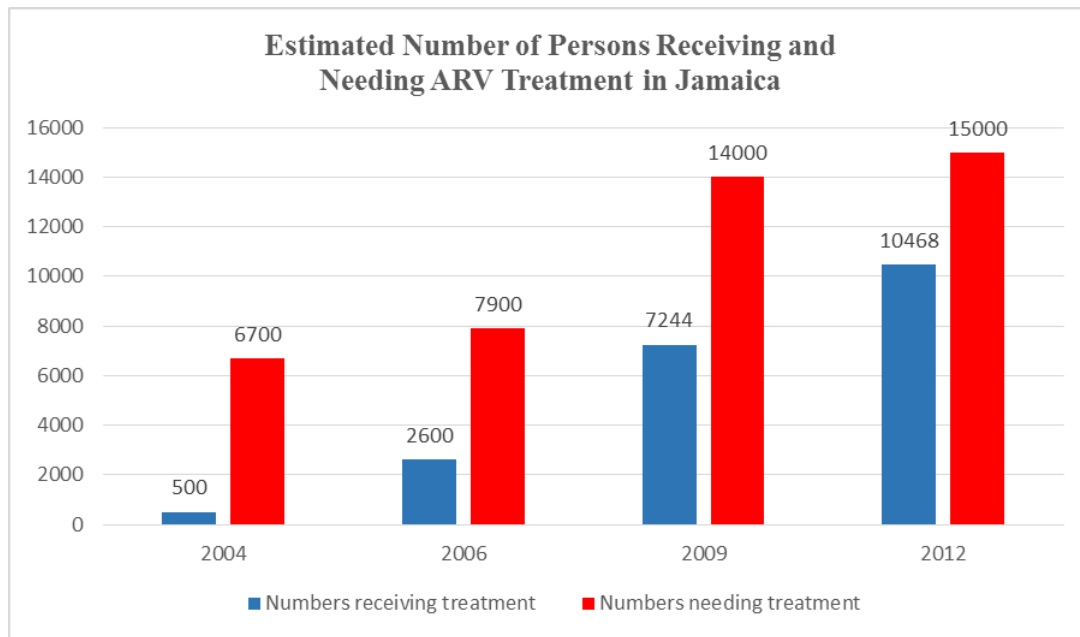


Figure 15: Persons Receiving and Needing ARV Treatment, 2004 - 2012

Source: *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector* (WHO, UNAIDS & UNICEF, 2010); *UNAIDS Progress Report, 2010*.

Despite the increase in coverage, a significant number of persons are still in need of ARV treatment (Ministry of Health, 2014a). In 2013, of the 16, 811 PLWHIV deemed eligible for ARV, only 52% (n = 8689) had initiated and maintained treatment (Ministry of Health National HIV/STI Programme, 2013). Therefore 48% of this group were deemed to either be unaware of their HIV status or had defaulted from treatment (Ministry of Health National HIV/STI Programme, 2013). At the time of this study, national guidelines for the initiation of treatment was at count is ≤ 350 cells/mm³ (Ministry of Health National HIV/STI Programme, 2013), and has remained at that level despite the WHO's subsequent recommendations to initiate treatment at CD4 count is ≤ 500 cells/mm³ in 2013 and for all persons diagnosed with HIV in 2015 (WHO, 2013, 2015). Importantly, Jamaica has incorporated some of the recommendations posed in the WHO 2013 revised guidelines (see Figure 13, p. 41).

In 2013, over 50% of the reported 30, 265 PLHIV were in need of treatment (Ministry of Health, 2014a). In addition, of those persons who have been diagnosed, 25% have never been linked to care and treatment (Ministry of Health National HIV/STI Programme, 2013). Furthermore, of those linked to care, only 56.5% were retained in care after 12 months (Ministry of Health National HIV/STI Programme, 2013). There has been a consistent decline in the number of persons retained in care (Figure 16); highlighting a key challenge for the country, especially in ensuring adherence post treatment initiation (Ministry of Health, 2014a).

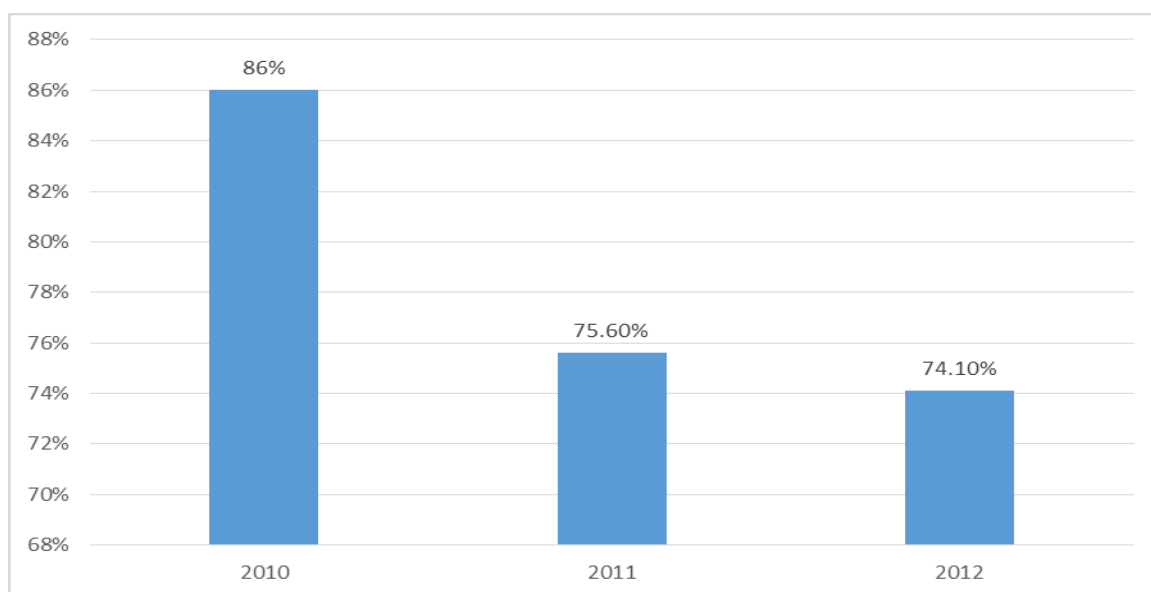


Figure 16: Persons retained in care and treatment after 12 months

Source: *Jamaica Country Progress Report, 2014* (Ministry of Health, 2014)

2.4.4 Adherence patterns

A study conducted in 2007 provided key insights into adherence patterns for individuals accessing services from non-governmental organization related to the Caribbean Regional Network of PLHIV (CRN+) across three Caribbean countries (Allen, Simon, Edwards, & Simeon, 2011). The cross-sectional survey indicated that of the 394 respondents, 69.5% were taking ART at the time of the study and that of this amount approximately 70% were

reported to have a 95% - 100% adherence rate over a seven-day period. The results further showed that there was no significant association between ART adherence and demographic variables including age, gender, educational level and marital status. It was, however, highlighted that social factors such as fear of ridicule and stigma and discrimination appeared to be important determinants of patients' adherence behaviours. These variables were not examined in-depth in the study and emerge as a scope for further work. It is important to note that the authors acknowledged the limited generalization of the findings of the research as the sample was not randomly selected and was based on a unique sub-population that accessed services from a non-governmental organization (Allen et al., 2011).

The results from the study by Allen et al. (2011) were incongruent with the findings of a Jamaica specific cross-sectional survey of individuals with advanced HIV and on highly active ARV therapy (HAART). Further, unlike the study by Allen et al., that reported high levels of adherence, Harvey et al. (2008) found low adherence levels based on both a 24-hour (59%) and 7-day (55%) period of recall of taking medication as prescribed. The 24-hour and 7-day recall measures are methods used to assess patients' medication adherence based on recall data for either a day (24 hour) or a week (7 day). Importantly, the survey noted that there was no significant difference in adherence levels based on gender and educational status for both the 24-hour and 7-day recall measures. For the 7-day recall, however, there was a distinction in adherence levels for those residing in urban and rural areas. More urban dwellers maintained their prescribed doses in the seven days prior to the survey (Harvey et al., 2008).

Another study by Williams, Clarke, Williams and Barton (2007) that aimed to determine the mean level of adherence and factors contributing to non-adherence of patients on HAART at a specialized institution, found that adherence levels were again sub-optimal. As with the previous studies by Allen et al. (2011) and Harvey et al. (2008), age, gender, employment status and level of education were not identified as significant factors in the analysis of self-reported adherence to medication. Low adherence was reported both in

terms of the self-reported number of tablets taken (58.4%) and the dosing frequency (56.4%) (M. Williams, Clarke, Williams, & Barton, 2007).

The above studies indicate the need for further research and improved monitoring to better establish and assess the adherence patterns of PLWHIV. Data provided through Jamaica's national surveillance systems (Figure 10, p. 30) clearly indicate a trend of increasing default from care and treatment, given both systems are intricately related. This poor adherence pattern was reflected in the findings of Harvey et al. (2008) and Williams et al. (2007). However neither of these studies were able to provide clear explanations of these trends, beyond reporting that these were not significantly related to gender, age, educational level and employment status.

2.5 PREVAILING CHALLENGES IN ENSURING OPTIMAL TREATMENT AND CARE

Treatment adherence remains a notable concern especially for countries with prevailing or escalating epidemics (WHO et al., 2010). Even with increased provision of ARV, the success of treatment can only be achieved with patients' retention of their prescribed treatment plan. Monitoring of patients' retention is a key aspect of ensuring the complete success of ARV programmes. Patient attrition tends to occur within the first year of commencing ARV therapy after which retention rates will stabilize (WHO et al., 2010). Despite the successes noted in the increased treatment coverage since 2004 (Ministry of Health, 2014a), there remains notable gaps that continue to hinder the overall progress of stemming and addressing the HIV epidemic. These challenges span issues of retention and adherence, stigma and discrimination, surveillance and technical resources.

2.5.1 Sub-optimal coverage

Despite the increased provision of ARVs, treatment coverage remains low for most countries in the Caribbean (UNAIDS, 2008a). Ideally countries are expected to attain, at minimum, an 80% treatment coverage rate to be considered as having universal access (AVERT, n.d.). Jamaica was noted to have attained only a 52% ARV coverage rate in

2013, which has been attributed in part to the increased demand due to the re-definition of persons identified as being in need of ARV (Ministry of Health, 2014a).

Sub-optimal coverage is also attributable to Jamaica's inadequate health infrastructure, the absence of sensitization of health personnel, insufficient treatment sites, inequities in ARV coverage within the country and recurrent transportation costs and user fees (Hardon & Daniels, 2006; Ministry of Health, 2014a). There have also been reported incidences of ARV stock-outs (Pan American Health Organization & WHO, 2013). It was noted that in 2010, 87% of the institutions dispensing ARV medication experienced stock-out episodes. In 2011, all ARV dispensing institutions in Jamaica experienced stock-out episodes (Pan American Health Organization & WHO, 2013). Only one reported ARV stock-out was reported for 2013 (Ministry of Health, 2014a).

Altogether, Jamaica remains significantly hindered by its limited financial resources. The country's reclassification as an upper-middle income country, amidst its excessive debt burden, IMF obligations and prevailing social issues, all act as barriers to the country's effort to expand and improve its treatment services (Ministry of Health, 2014a; PIOJ, 2014).

2.5.2 Treatment adherence and retention

Individual adherence behaviour remains a key challenge to attaining viral suppression, and minimizing the negative repercussions associated with the illness. Only 43% of persons reported to be on ART in 2013 had obtained viral load suppression (Ministry of Health National HIV/STI Programme, 2013). This suggests that a portion of the remaining 57% on ART may not be effectively adhering to their medication. It also highlights the need for better sequencing of ARVs by doctors, as well as increased training to improve the counselling capacity of adherence counsellors (Ministry of Health, 2014a). The declining rate of persons being retained in care after 12 months has the potential to further debilitate existing strides in controlling the HIV epidemic in Jamaica (Ministry of Health National HIV/STI Programme, 2013). Thus linkage, retention and adherence to treatment and care remain critical areas for future redress (Ministry of Health, 2014a). In response to the

prevailing challenges, a linkage and retention protocol was developed that outlined the linkage and retention process, as well as the roles of key staff member in ensuring optimal outcomes (Ministry of Health, 2014a). No information regarding the implementation and evaluation of this protocol is yet available.

2.5.3 Stigma and discrimination

A key challenge to countries attaining universal coverage is the reluctance of individuals to get tested and subsequently commit to treatment due to the stigma and discrimination associated with the disease (Katz, Ryu, Onuegbu, Psaros, & Weiser, 2013). HIV-related stigma is often reflected in key institutions in the society, including the health sector (Ministry of Health, 2014a). Studies have documented HIV-related stigma amongst health workers in Jamaica and the wider Caribbean, which are more pronounced towards MSM and CSW (Abell et al., 2007; Rogers et al., 2014; R. White & Carr, 2005). HIV-related stigma and discrimination also prevents PLWHIV from disclosing their status to their partners (M. Anderson et al., 2008). Further, where persons may opt to engage in treatment, the fear of stigma forces them to access care outside their communities (Ministry of Health, 2014a). Importantly, this stigma is further aggravated for the MSM population in Jamaica (Charles, 2011; Cowell, 2011; R. White & Carr, 2005). This stigma has been noted to drive the population underground, where they fail to be tested and, where diagnosed, fail to initiate or maintain their treatment (J.P. Figueroa, 2014; J.P. Figueroa et al., 2015; R. White & Carr, 2005).

2.5.4 Data surveillance

There are recognized challenges surrounding data reporting on ARV treatment adherence throughout the Caribbean. Standardized measures are often developed using the Spectrum programme¹ which are noted to be difficult to use with small populations, as exists in many small island Caribbean countries (UNAIDS, 2008a). This challenge of data reporting is

¹ Spectrum is a suite of policy models used by UNAIDS to ensure consistency in global reporting.

further amplified by variations in the format of reporting and the disaggregation of data reported. In some instances, countries fail to report the requisite information for the appropriate tallying of regional data (WHO et al., 2010). Overall this hinders the production of a comprehensive review of adherence coverage and retention rates that remain crucial areas for policy and programme redress.

It is also acknowledged that the absence of standardized techniques to measure adherence at the local level is a key barrier to understanding treatment adherence (M. Williams et al., 2007). In the past, surveillance data on adherence was collated from reports prepared by social workers, adherence counsellors, or nurses, which was partly based on patients' self-reported adherence levels of dosing frequency and number of tablets taken (M. Williams et al., 2007). Patient self-reports are cheap and simple to execute; however, they are largely subjective, where the accuracy of information reported is affected by poor recall, failure to acknowledge and account for mistimed doses (Patel, Hirschorn, Fullem, Ojikutu, & Oser, 2010). As a result, patients often overestimate their adherence levels (Patel et al., 2010). Nonetheless, studies have shown that patient self-report of adherence has a significant, though weak, relationship with viral load test results (Simoni et al., 2006).

The Ministry of Health has also acknowledged the absence of disaggregated data on key indicators which are important in addressing service access for some key populations (Ministry of Health, 2014a). Some work has been done to train staff at treatment sites across the island which has led to an improvement in the quality and accuracy of data being captured (Ministry of Health, 2014a). The developed linkage and retention protocol is also expected to help improve data surveillance (Ministry of Health, 2014a).

2.6 RESPONSES TO THE HIV EPIDEMIC

Jamaica's response to the HIV epidemic incorporates collaborations between governmental and non-governmental organizations at both the local and regional levels (Ministry of Health, 2014a). The national response is also multi-sectoral, suggesting that all sectors should integrate HIV-related strategies in their policies and daily operations (Ministry of

Health National HIV/STI Programme, 2011). History shows a strong partnership with international development agencies (IDA) such as the World Bank, UNAIDS and PEPFAR (PIOJ, 2014). Currently, the national response is guided by a 5-year national strategic plan (2012-2017) that identifies six priority areas: prevention, treatment, care and support, enabling environment and human rights, empowerment and governance, monitoring and evaluation, and sustainability (Ministry of Health, 2014a). Given the scope of this current study, two main aspects of the country's response to the epidemic will be highlighted: the merger of the National HIV/STI Programme with the National Family Planning Board and the National HIV/AIDS Policy.

2.6.1 National HIV/STI Programme

The National HIV/STI Programme was established in 1986 within the Ministry of Health to coordinate and implement a national response to the disease (National HIV/STD Control Programme & UNAIDS, 2012). Since the launch of the Programme, HIV surveillance was incorporated into existing STI control programmes. In 2010, interventions were designed to specifically target the most-at-risk-populations. However, Jamaica's reduced access to external funding, given its new upper middle income classification, has forced the government to evaluate the feasibility of some HIV programs and to determine more cost-effective approaches (D. Carr & McClure, 2014). The integration of the National HIV/STI Programme (NHP) into the National Family Planning Board (NFPB) to create a single statutory agency for sexual health was deemed effective in cutting costs allotted to financing the two separate agencies (D. Carr & McClure, 2014). The new entity, labelled the NFPB-Sexual Health Agency (SHA), operates as an independent statutory agency under the auspices of the Ministry of Health (D. Carr & McClure, 2014). The idea of combining the country's reproductive health and HIV/AIDS programmes, services and agencies is not new, and is felt to improve a comprehensive response to clients who seek HIV-related services and reproductive health services (Ministry of Health, 2014a). In addition, these integrated services are expected to:

Ensure that the reproductive health needs and aspirations of all people, including people living with HIV, are met. Integrating family planning services into HIV prevention, treatment, and care services provides an opportunity to increase access to contraception among clients of HIV services who do not want to become pregnant, or to ensure a safe and health pregnancy and birth for those who wish to have a child. Integrating HIV services into the existing family planning infrastructure is an opportunity to expand HIV prevention efforts and increase the use of care and treatment services. (Ministry of Health, 2014a, p. 29)

2.6.2 National HIV/AIDS Policy

The National HIV/AIDS Policy was officially launched in May 2005. The policy is premised on the need to effectively respond to the epidemic, whilst upholding the rights and freedom of all in accordance with the Jamaican Constitution and existing international rights and standards. The policy has four main objectives: the prevention of new HIV infections; treatment, care and support for persons living with and affected by HIV/AIDS; mitigation of the socio-economic impact of HIV/AIDS; and ensuring a supportive policy, regulatory and legislative environment (Ministry of Health, 2005). Much of the country's response to date has been in tandem with the policy though there were noteworthy gaps. The policy was reviewed in 2014 with the aim of identifying its strengths and weaknesses, and to address the gaps in its response to the current HIV epidemic (PIOJ, 2014). It was further deemed necessary to revise the policy to better align it to the recent 90-90-90 targets, and ensure the inclusion of the Post-2015 Development Agenda (PIOJ, 2014). Though not yet published, this revised policy has the potential to inform effective responses to the epidemic by various sectors and the country's leaders. This could aid significantly in ensuring earlier testing and diagnosis, as well as effective linkage to treatment and care for Jamaican men.

2.7 CONCLUSION

It has been over 30 years since the first incidence of HIV/AIDS, yet Jamaica's government officials and policy makers still grapple to control the epidemic and its effects. The resistance and spread of the disease has forced various stakeholders to collaborate across

state boundaries to effect change at national, regional, and international levels. Despite the advances made, issues concerning ARV coverage, treatment adherence and risk behaviours remain key areas of concern for Jamaica (Ministry of Health, 2014a; Ministry of Health National HIV/STI Programme, 2013). A significant proportion of PLHIV still do not have access to ARV treatment (Ministry of Health, 2014a). Additionally, there is an increase in the number of infections identified amongst MSM, highlighting the importance of understanding the adherence patterns and related issues for Jamaican men. Jamaica's HIV epidemic appears to have plateaued instead of continuing its steady decline, potentially impeding the social and economic development of the country (Planning Institute of Jamaica, 2014). These issues underscore the importance of HIV/AIDS in Jamaica and, more specifically, amongst most at risk populations in shaping the country's research and policy agenda.

Chapter 3 LITERATURE REVIEW

3.1 INTRODUCTION

In recent years increased attention has been given to the need to research and address men's health. This is primarily due to the recognized disparity between the health outcomes of males and females within many societies (P. Baker et al., 2014). Within the past decade, much of the research done on men's health has focused on assessing the health disparities for men and women (P. Baker et al., 2014), explaining patterns of male health and health seeking behaviours (Addis & Mahalik, 2003; Pearson & Makadzange, 2008), and determining men's experiences with chronic illnesses such as cancer (B. Anderson, Marshall-Lucette, & Webb, 2013; Mesquita, Moreira, & Maliski, 2011), diabetes (Hawkins et al., 2015; O'Hara, Gough, Seymour-Smith, & Watts, 2013), mental illness (Loue, Daugherty-Brownrigg, Heaphy, Mendez, & Sajatovic, 2012; Montgomery, Brown, & Forchuk, 2011; Ward & Besson, 2012) and HIV/AIDS (M. Anderson et al., 2010). Despite this increased attention to research on men's health, there are some significant gaps in the literature, and little attention has been given to improving the policy and programme responses to men's health in Jamaica.

Though men in general are deemed to have greater privilege, status and opportunities than women, this does not translate into their health status, and there are significant health disparities between men and women globally (P. Baker et al., 2014). For many societies, men are generally reported to have a lower health status than women (Leonard, 2005); are more likely to experience chronic illnesses (Galdas, Cheater, & Marshall, 2005; Plowden, 2003); are more likely to engage in health risk behaviour (Mahalik, Burns, & Syzdek, 2007); and are more likely to delay seeking healthcare (Jarrett, Bellamy, & Adeyemi, 2007; Noone & Stephens, 2008).

Some of these health practices and outcomes have contributed to the lower life expectancy of men in both developed and developing countries, despite the progress in increasing life

expectancy for all in the past few decades (WHO, 2014). Men in developing countries are currently expected to live until age 60 years, three years younger than their female counterparts and 19 years younger than men in developed countries (WHO, 2014). Baker et al. (2014) found that data from the Global Burden of Disease Study showed a widening gap between the life expectancy of men and women between 1970 and 2010. The Global Health 2035 report led by the Lancet Commission reported that the mortality rates of women decreased more rapidly than that of men in UN defined less and least developed countries between 1992 and 2012 (Jamison et al., 2013). The findings of these two studies suggest that the health of men has not received sufficient attention to ensure equitable health outcomes for men and women.

In embarking on the review of literature, it was recognized that studies that examine male health and health-seeking behaviours tended to fall in one of two categories: gender comparative and gender specific. Gender comparative studies focus on comparing the difference in health behaviours for men and women (Jarrett et al., 2007), whilst gender-specific studies tend to examine the health behaviours of men within the context of their own biological, psychological or social differences (Galdas et al., 2005). The latter is perceived to be a more recent movement in studies on men and masculinities (Lohan, 2007). Gender-comparative studies have been argued to be methodologically flawed in adequately explaining men's health help seeking behaviour (Galdas et al., 2005). The range and frequency of illnesses vary for men and women and thus alter the normalized base for true comparison of the groups (Galdas et al., 2005). Men can be seen as seeking health care less than women as a result of women over-reporting mild illnesses such as frequent headaches, backache and swollen ankles (Corney, 1990). This is in part due to the biological differences of the genders that would make women more perceptive of, or sensitive to, physiological changes, discomfort or pain (Jarrett et al., 2007). Further, medical consultation rates are noted to be higher for women than men during their reproductive years (O'Brien, Hunt, & Hart, 2005). Gender-comparative studies are also perceived to fail to acknowledge the variability within gender groups (Galdas et al., 2005;

O'Brien et al., 2005). In addition, they are considered at risk of reinforcing the essentialist approach to gender, which treats each attribute as fixed rather than variable across and within groups (Addis & Mahalik, 2003). This analysis supports the view that where such studies may highlight gender differences, their findings are more speculative rather than conclusive (Addis & Mahalik, 2003). Nevertheless, gender-comparative studies maintain some value, especially in the relative positioning of men and women. Studies that focus solely on men have been critiqued for making women invisible, which is further perceived to be regressive and contradictory of history (Brod, 1994). Instead, it is suggested that a “consistently relational approach to gender” be maintained (Connell & Messerschmidt, 2005, p. 837). Consequently, both gender-specific and gender-comparative studies are included in this review as they both possess intrinsic value in helping to shape the understanding of men’s health behaviour, independently and in contrast to other groups of men, as well as in relation to women.

This literature review aimed to provide a critical analysis of literature deemed relevant in understanding the health of Jamaican men, particularly HIV positive Jamaican men. A multi-database search was conducted, using the terms ‘Jamaican men’, ‘Jamaican men’s health’, ‘Jamaican men and health (help) seeking behaviours’, ‘Jamaican masculinities’, ‘Jamaican men and HIV/AIDS’, and HIV or antiretroviral treatment in Jamaica’. It proved necessary to broaden and vary the scope of these search terms, and thus core themes were extended to the wider English-speaking Caribbean and the Caribbean diaspora. The literature search was also guided by emerging themes, for example, some generalized information on male health-seeking behaviour was ascertained given the consistency of themes across articles. The main themes arising from the literature search, along with ideas central to the research focus, were used to determine the four broad themes that guided the review of the literature. These main themes were: “The health of Jamaican men and their health-seeking behaviours”; “Men’s health and intersections of identity”; “Men, masculinity and HIV/AIDS”; and “ARV treatment experiences and the adherence process for men”.

Though journal articles were primarily consulted, this review also draws on books and reports deemed important in generating a thorough awareness of the body of knowledge available to inform this study. A critical review of these scholarly works moves beyond a general synthesis of key insights to identify certain antagonisms, inconsistencies or gaps which further help to inform the focus and parameters of the study.

3.2 THE HEALTH OF JAMAICAN MEN AND THEIR HEALTH-SEEKING BEHAVIOURS

3.2.1 Men's health and health-seeking behaviours

Significant literature exists on men's health-seeking behaviours which generally acknowledge men's health outcomes to be directly related to a number of socio-cultural factors. Hooper and Quallich (2016) quite aptly acknowledged that health-seeking behaviours are shaped by a number of social, cultural and intellectual influences, which vary across gender and cultural circumstances thereby hindering the emergence of a universalistic understanding of the issue. This lack of a universalistic understanding of men's health behaviours and outcomes have contributed to the development of a range of perspectives in the literature that explain the poor health outcomes of men in both developing and developed countries (Galvan, Bogart, Wagner, Klein, & Chen, 2014; Mahalik et al., 2007; O'Brien, Hart, & Hunt, 2007; Silberschmidt, 2004; Skovdal et al., 2011). For example, Addis and Mahalik (2003) found that male health-seeking behaviours in America were driven by both internal factors (surrounding the physiological or psychological qualities attributed to men), and external factors (relating to socio-cultural factors such as gender role expectations). Overall, much of the literature acknowledges the influence of socio-cultural gender norms and perceptions of masculinity in defining how men perceive and respond to their ill-health (Jarrett, Bellamy, & Adeyemi, 2007; Mahalik et al., 2007; O'Brien et al., 2007; Siu, Seeley, & Wight, 2013; Siu, Wight, & Seeley, 2015; Tyler & Williams, 2014). Though some studies give greater weight to the role of gendered norms and stereotypes, there are those who argue that male poor health choices and outcomes are attributable to both the physiological effects of testosterone and the cultural

implications of gender role expectations (Yin, 2007). Yet, there are others who argue that these approaches represent distinct historical explanations of men's health (Creighton & Oliffe, 2010). Creighton and Oliffe (2010) posited that the early biological explanations of men's health was replaced by the social constructions of masculinity in the 20th century, given "biology's overly deterministic way of interpreting masculinity" (p. 411).

In general, men tend to delay in seeking healthcare due to their perceptions of manhood and masculinity (Courtenay, 2000; Galdas et al., 2005; Jarrett et al., 2007), which frames the relationship between gender and health as being socially constructed (Noone & Stephens, 2008). According to Courtenay (2000), a man who ascribes to the socially prescribed notions of masculinity

would be relatively unconcerned about his health and well-being in general and would place little value on health knowledge. He would see himself as stronger, both physically and emotionally than most women. He would think of himself as independent, not needing to be nurtured by others. (p. 10)

This argument suggests that some men are largely driven by external social forces that prescribe notions of strength and independence, even in the context of ill-health. The perceived need to be stoic, resilient, and self-reliant, therefore, prevents some men from seeking healthcare even with the onset and recognition of symptoms (Jarrett et al., 2007). This is perceived to be an avoidance of sick roles that would prevent a male from fulfilling his traditional social roles (Jarrett et al., 2007).

There are various factors that could differentiate the health-seeking choices and behaviours of men from women. Literature indicates that the health of some Black men are impacted by their socioeconomic status, issues of masculinity, lack of awareness of the need for preventative health care, racism and distrust of medical institution and practice, religion and spirituality and a criminal background (Cheatham, Barksdale, & Rodgers, 2008). Galdas et al. (2005) acknowledged that socioeconomic status, age and occupation are key factors to be considered in the analysis.

There remains a general consensus across studies that men's health-seeking behaviours are predominantly learnt through the process of gender-role socialization which, for many cultures, prescribes that men should be strong, self-reliant and emotionally composed (Mansfield, Addis, & Mahalik, 2003, Galdas et al., 2005). Therefore, evidence of being unwell and expressions of seeking the help of others, whether professional or non-professional, could be considered as gender-role conflict (Addis & Mahalik, 2003; Courtenay & McCreary, 2011). Gender-role conflict is explained as "a condition in which rigid or overly restrictive male gender roles conflict with incompatible situational demands and lead to negative consequences for men and those around them" (Vogel & Wester, 2013, p. 61). It is expected that such gender-role conflict can predispose men to a heightened risk of ill-health especially where they risk ridicule or other negative repercussions due to their failure to live up to the expectations of hyper-masculinity within their respective cultures (Courtenay & McCreary, 2011).

Power relations amongst men and between men and women are also important in understanding how masculine normative health behaviours are shaped. Such perceptions are in part formed through a male's understanding of the expectations and habits of his male role models. Mahalik, Burns and Syzdek (2007) gave the example of the male who recalls that his father never visited the doctor and thus followed suit. Women or female associated characteristics also play a key role in determining men's health behaviours. A systematic review by Teo, Ng, Booth and White (2016) found that female partners played an integral role in supporting men's uptake of health screening. Despite this, the research also showed men's reluctance to access healthcare in an effort to avoid behaviours that could be perceived as feminine or weak. The need to avoid anything that appears feminine reinforces the notion that masculinity exists in direct opposition to feminine portrayals (Courtenay, 2000, 2009; Mahalik et al., 2007). The acceptance of a sick role challenges the masculine notion of self-control, self-reliance and maintained social roles and responsibilities (Jarrett et al., 2007). Further, the acknowledgement of ill-health "can reduce

a man's status in masculine hierarchies, shift his power relations with women, and raise his self-doubts about masculinity" (Charmaz, 1995, p. 268).

Yet not all men opt to conform to these social ideals of perceived masculinity. In fact, the notion of masculinity and likely its relationship to men's health has evolved and varies across societies (Connell, 2005; Jarrett et al., 2007). Just as women's roles have changed in relation to the household and workplace, so have men's roles (Jarrett et al., 2007). This shift in men's role across some social classes in Jamaica was noted by Anderson (2012). Further, Lewis (2003a) has lobbied for the need to move away from outdated homogenous categorizations of the Caribbean male which erroneously presents all Caribbean men as promiscuous and irresponsible. This disrupts taken-for-granted notions of masculinity, and accepts that there are multiple masculinities that vary across and within space, time and cultures, and presents further nuances where masculinities vary across intersections of identity such as race, class, sexuality and disability (Creighton & Oliffe, 2010; Griffith, 2012). However, there remain some aspects of the traditional notions of masculinity that have persisted over time and continue to influence the health of some men (Jarrett et al., 2007). Thus this output of multiple, historical, variable and persistent masculinities creates a space to acknowledge and question pre-existing notions of a dominant Jamaican masculinity that help to determine men's health choices and outcomes.

3.2.2 Assessing the health-seeking behaviours of Jamaican men

Self-reported health approaches have been widely used to determine men's health status in Jamaica (Galvan et al., 2014; Harvey et al., 2008; Morris, James, Holder-Nevins, & Eldemire-Shearer, 2013; Morris et al., 2011; Norman & Uche, 2002). This may be considered unreliable as men could either over-report or under-report their symptoms depending on the social or cultural acceptance of the perceived health problem being assessed (Brener et al., 2003). However, some authors justify the place of self-reported health studies as they give insight to health conditions that may otherwise not be addressed (Weinhardt, Forsyth, Carey, Jaworski, & Durant, 2008). Studies have also shown a

correlation between patients self-reported treatment adherence and the results of monitoring devices which validates self-reported health studies as reliable proxy measures of men's health status (Shi et al., 2010).

Biomedical analyses of illnesses, particularly prostate cancer, have been the primary focus of men's health research in Jamaica in the past decade (Jackson, McFarlane-Anderson, Simon, Bennett, & Walker, 2010; Ritch et al., 2007; Shivappa, Jackson, Bennett, & Herbert, 2015). This focus is largely due to the steady increase in the incidences of prostate cancer since the late 1980s and the increasing testing and diagnosis amongst young men (Gibson, Hanchard, Waugh, & McNaughton, 2011). It is also likely attributed to prostate cancer being the leading cause of cancer-related deaths in Jamaica (Aiken & Eldemire-Shearer, 2012).

Sexual health literature was found to focus primarily on behavioural risk analyses, many of which acknowledged Jamaican men's risk of contracting HIV/AIDS (J.P. Figueroa, 2014; J.P. Figueroa et al., 2015; Kempadoo & Dunn, 2001; Ministry of Health, 2014a; Plummer, 2013). These studies are important in showing the higher vulnerability of Jamaican men across all stages of the disease (Ministry of Health, 2012, 2014a). A few studies were found that described Jamaican men's involvement in other health threatening activities such as smoking or alcohol usage (Welsh, Duff, Campbelle-Taffe, & Lindo, 2015; Wilks et al., 2009), which were also influenced by socio-cultural norms surrounding masculinity.

Social and cultural factors were identified as significant drivers of men's health access and outcomes in Jamaica. Gendered norms were noted to influence if, when and how, men present for care and treatment (J.P. Figueroa et al., 2015; Walcott et al., 2014). In their study, Bourne, Charles, and McGrowder (2011), found that Jamaican men's unwillingness to seek healthcare was due to the feminization of such health seeking behaviour. In addition, much of the literature on the HIV epidemic in Jamaica and the English-speaking Caribbean point to the role of social and cultural norms, particularly those surrounding gender roles, sex and sexuality, in explaining the health risk behaviours of men, which

place them at risk of contracting HIV (J.P. Figueroa, 2014; Olukoga, 2004; Walcott et al., 2014). As Walcott et al. (2014) reported, “Gender expectations that result in masculinity, inequitable gender norms, masculine ideologies such as risk-taking, control over women, sexual prowess and violence can shape the pathway for increased vulnerability to HIV acquisition” (pp. 47-48). This suggests that there are deeply embedded cultural norms in Jamaica that perpetuate men’s predisposition to practices that either cause or prolong their ill-health. A study that sought to assess the relationship between the attitudes towards gender norms and risky sexual behaviours of 549 men in western Jamaica found that the support for masculinity and inequitable gender norms promoted health risk behaviours (Walcott et al., 2014). Such behaviours included the unwillingness to seek health information, as well as accessing health services (Walcott et al., 2014).

More men than women generally report poorer health-seeking behaviour in Jamaica. Morris, James, Holder-Nevins and Eldemire-Shearer (2013), in their study on the self-reported health status of older men, found that men generally did not perceive themselves to experience poor health. Men diagnosed with chronic illnesses such as diabetes and hypertension were more likely to indicate having good health than the men who were not diagnosed with an illness. This could be indicative of these men being in denial of their illnesses and the repercussions of lifelong treatment. The authors also suggested that men’s tendency to over-estimate their level of good health was to present an image that was more aligned to the culturally accepted notions of masculinity in Jamaica (Morris et al., 2013). Only 5% of the study’s participants perceived that regular visits to a doctor contributed to good health. In this way the study demonstrated that men do not associate the clinic or the doctor with maintaining good health. It also suggested a possible reason why some Jamaican men delay in seeking medical attention until their illnesses have become advanced. Thus healthcare for Jamaican men is more curative than preventative (Bourne et al., 2011). Morris et al. further highlighted the cultural resistance of men having prostate examinations. In this study, 65% of the men reported never having a prostate examination. This was explained as “Jamaican men perceive[ing] prostate examination as ‘de-

masculinizing” and highlighted how some Jamaican men’s health behaviours are shaped by prevailing gender norms (Morris et al., 2013, p. 118).

The same study showed that older Jamaican men were likely to display poor health-seeking behaviours, as the majority of the participants (67.6%) did not visit a doctor or health facility in the year prior to the research (Morris et al., 2011). Further, half the participants reported not seeking medical assistance even when ill. Less than 50% of the men diagnosed with chronic illnesses reported having accessed healthcare in the year preceding the study. Again, norms surrounding masculinity and male identity were identified as key explanations for the men’s health-seeking behaviours. These norms, which included the men’s independence, the need to portray machismo, and the social expectation of men being ‘tough’, all contributed to men’s perceptions and responses to their health.

The findings of the study by Morris et al. (2011) were consistent with that of another study that analysed secondary data from the 2002 Jamaica Survey of Living Conditions, a national cross-sectional survey (Bourne et al., 2011). Bourne et al. (2011) found that the culture surrounding Jamaican masculinity contributed to the poor health-seeking behaviours of Jamaican men. Such norms contributed to majority of the men (52%) being unlikely to complete a full course of medication prescribed by their doctors. In addition, they identified the socio-economic status and thus the financial capabilities of the men to also be determinants of their health behaviours. It was noted that 57% of the men prescribed medication were unable to fill the entire prescription due to lack of funds. This holds significant implications for the point in which men present for medical care and their retention in care/ treatment.

The findings of studies specific to Jamaican men are consistent with the general literature that assesses the health behaviours of men. Jamaican men delay in seeking healthcare and thus often present late with an illness; as noted for the higher proportion of men diagnosed with advanced HIV and AIDS (Ministry of Health, 2012). Further, they tend to either deny being unwell, over-rate their state of good health and fail to either initiate or sustain

treatment in avoidance of sick roles that question their traditional masculine identities (Jarrett et al., 2007). Thus the health behaviours of Jamaican men diagnosed with chronic illnesses appear to be largely defined by perceptions and impositions of sociocultural notions of appropriate masculinity (P. Anderson, 2012; Hall, 2011; Norman & Uche, 2003). These norms have been institutionalized through gender socialization which commences during childhood and is reinforced throughout adult years (P. Anderson, 2012). However, there is an absence of literature that contests this prevailing influence of a set of masculinity norms that persist over time. More recent research and masculinity theorizing has lobbied for the move away from a monolithic assessment of masculinity within and outside the context of men's health (Creighton & Oliffe, 2010). Such writers argue for the need for more critical approaches that challenge ahistorical perceptions of masculinity, as presented in the Jamaican literature. Instead, there is a need to acknowledge the multiple masculinities that vary across time, space and cultures. Despite post-structuralist frameworks showing how some elements of masculinity have been retained or re-constructed over time (Wetherell & Edley, 1999), it is undoubted that aspects of these have surpassed being contested especially with increased awareness, the growing severity of chronic illnesses, and important role of social support in encouraging good health (Jarrett et al., 2007).

3.3 MEN'S HEALTH AND INTERSECTIONS OF IDENTITY

3.3.1 Social constructions of masculinity

Masculinity is a multidimensional social construct that defines manhood or the criteria for being a man (Connell & Messerschmidt, 2005). Silberschmidt (2004) presented masculinity as an achieved identity that extends beyond the mere biological or innate features of maleness to be the outcome of cultural and social processes. Masculinity is also described as the demonstration of specific qualities such as aggression, strength, stoicism, heterosexuality and sexual prowess (P. Anderson, 2012; Connell & Messerschmidt, 2005; Connell, 2005). Though the construction of masculinity changes over time and space, the need to prove manhood remains constant in many societies (Griffith, 2015). Lewis (2004)

presented an apt definition of the concept which he explained as “a socially constructed set of gendered behaviours and practices of men, which are not frozen in time or culture and which are mediated by notions of race, class, ethnicity, religion, age and sexual orientation, among others” (p. 245). Thus the social construction of gender and gender relations results in multiple masculinities within and across societies (Connell & Messerschmidt, 2005). These social constructions are further varied amongst men and in relation to women (Connell & Messerschmidt, 2005).

The representations of masculinity are arguably similar across societies, though the cultural peculiarities and the symbols or evidence of such masculinity may vary (Lewis, 2003a). To illustrate, in some societies the symbolism of masculinity may rest in cars, guns, size of the penis, number of children or a behavioural indication of sexual prowess (Chevannes, 2001; Flood, 1996; Lewis, 2003a). These constructions of what it is to be a ‘man’ are fostered within social interactions, whether with a pre-existing cultural system or the gendered expectations of others. Thus the need to publicly demonstrate manhood is based on the socially constructed expectations of male appropriate behaviour (Lewis, 2005).

The imposition of labels, meaning and power through this interactive process reinforces the values inherent in social constructivism. In fact, masculinity is also posited as an ideological position “by which men become conscious of themselves as gendered subjects” (Lewis, 2005, p. 2). As Lewis (2005) further explained:

Masculinity is therefore an ontological process of becoming aware of societal roles and expectations that are inscribed on the text of the body. Men are not born with this awareness of themselves. Society must impose this understanding on them...For not only does society play a determining role in shaping the consciousness of subjectivity, but it proceeds by sanctions and rewards to police the boundaries of the identities it establishes. (pp. 2-3)

The broad interplay of social, cultural and historical factors has generated a multiplicity of masculinities that are further distinguished by race, class, age and sexuality (Lodge & Umberson, 2013; Pompper, 2010; Slevin, 2008). The evidence of this across societies and

throughout history nullifies the notion of men being a homogenous group and masculinity being a fixed ahistorical concept (Connell, 2012). The power imbalances inherent in this differentiation of masculinities produce a hierarchy of masculine identities that reinforce a system of inequality. In its simplest form, it delineates between a dominant masculinity and a subordinate masculinity which exist in relation to each other. Traditionally, dominant masculinity is based on the embodiment of white, middle-class, heterosexual men (Kimmel, 2007). Subordinate masculinity, in comparison to the dominant typology, is largely characterized by effeminate and infantile behaviours (Nurse, 2004) that seemingly align these men to the perceived 'weaker' gender. Connell (2005) also proposed a third category of complicit masculinity, where some men enjoy the benefits of patriarchy without participating in the portrayals of masculinity and male dominance (Connell & Messerschmidt, 2005).

A key term emerging in the history of understanding this hierarchy of masculinities is 'hegemonic masculinity' which was introduced in Connell's early work *Gender and Power* in 1987. Hegemonic masculinity was presented as a universal description of specific behaviours of dominant masculinity. In a later work, Connell defined hegemonic masculinity as "the masculinity that occupies the hegemonic position in a given pattern of gender relations" (Connell, 2005, p. 76). It was identified as a social position that was distinguishable from other subordinated or complicit masculinities, existing in relation to the subordination of women, and could only be attained by a minority of men (Connell & Messerschmidt, 2005). Since its emergence, Connell's approach to classifying men's identities has received extensive critique and has since been revisited (Connell & Messerschmidt, 2005). One such critique described the perspective as having "explanatory limitation in that it abstracts from a 'false cultural universalism' which legitimizes and normalizes certain forms of masculinity (hegemonic ones) and marginalizes others (subordinate ones)" (Nurse, 2004, p. 6). Such critique challenged an apparent fixed notion of a hierarchy of masculinities and a prescribed status quo between men. Later revisions to the theory acknowledged shifts in power, where subordinate masculinities can influence

dominant masculinity (Connell & Messerschmidt, 2005). Notwithstanding the value of these criticisms, the differentiation between types of masculinities which centre on positions of power and inequality holds tremendous value in understanding how men are socially constructed and how these socially imposed values impact their health choices and outcomes.

More contemporary explanations of masculinity existing in relation to multiple intersecting identities hold greater relevance to understanding the complexities within masculine identities and the shaping of health outcomes. As Knight et al. (2012) noted, “masculine identities can be subordinated by virtue of their other intersecting and mutually constitutive social identities” (pp. 1247-1248), which accounts for the complexities of intersecting lines of gender, socioeconomic status, sexuality and race. The value of research that treats masculinity as one dimension of the complex and dynamic milieu of intersectional identities is evidenced in a number of research on men’s health (Bowleg, Teti, Malebranche, & Tschann, 2013; Griffith, 2012; Hankivsky, 2012). As Griffith (2012) stated,

Men’s health is based on understanding the social and health implications of gender, a socially-defined construct, but it is critical to consider that gender depends on other social categories for meaning. Analyses that focus on gender without consideration of other identities and group memberships implicitly assume other social statuses that go unnamed: race, ethnicity, heterosexuality, social class, economic status, ability status and others. (p. 106)

3.3.2 Understanding Jamaican (hegemonic) masculinity

Much of the work on masculinity in Jamaica, and by extension the Caribbean, has been foreshadowed by the extensive feminist traditions of Caribbean gender research (Hope, 2010). Thus, Caribbean men were shadowed in literature that focused on women’s disadvantage or marginalization, an output of a system that emphasized patriarchy, hegemonic masculinity and heterosexuality (Lewis, 2003b). As a result, literature that addressed men either did so either as a backdrop to women (for example the effects of a

patriarchal system or domestic violence) or in the context of men's sexuality and the negative repercussions. This arguably biased focus is perhaps due to the main ownership of the discourse being attributed to key female academics who have also contributed to the development of a Caribbean feminist perspective (Lewis, 2003b).

There has also been a series of works that chart the historical and ideological underpinnings of Caribbean masculinity (Barrow, 1998; Beckles, 2004; Lewis, 2003a, 2003b), as well as more ethnographic portrayals of Caribbean masculinity and manhood (Brown & Chevannes, 1998; Chevannes, 1993, 2001, 2003). More recent works have sought to examine Jamaican masculinity within specific spaces such as the family (P. Anderson, 2012), educational system (M. Figueroa, 2004) and dancehall (Hope, 2006, 2010). Much of these documentations have maintained some consistency regarding the characterization and analysis of Caribbean masculinity over the years, where masculinity is seen as a historical, socio-cultural and gendered construct that is influenced by notions of power.

Early work on Jamaican masculinity characterized manhood as fulfilling three specific criteria: proof of sexuality/heterosexual identity, financial stability and a position of headship over his household (Brown & Chevannes, 1998). According to Brown and Chevannes (1998), sexuality resonated around the need to prove sexual prowess where boys were encouraged to initiate sexual activity at an early age. This was reinforced by the number of serial or concurrent female partners a male would have, and strengthened by the number of children he would have across unions (Brown & Chevannes, 1998). Therefore, the male with multiple children across different partnerships was likely to be revered as 'a real man'. The mandate of the man being provider required men to show evidence of their financial standing and thus ability to provide for his family. This was linked to particular masculine roles such as father and partner which are important portrayals of a boy moving into manhood (Brown & Chevannes, 1998). The notion of the male as head of his household correlates with a patriarchal system that deems men to be authoritarians in the home. Within the Caribbean context, this is seen to be an ordained scriptural position and is thus upheld by women (Brown & Chevannes, 1998).

Lewis (2003b) added to the analysis of masculinity by stating that it is both a biological and cultural concept that is quite difficult to separate. As he explained,

The determination of the biological is itself culturally coded. In other words, there is imbricated, in what is regarded as purely biological, a specific cultural meaning of biology and the body. The body which is the principal signifier of the biological, is rendered comprehensible in cultural and historical terms. (p. 11)

Therefore, the biological differentiation between male and female is supplanted by the cultural, which assigns specific gendered expectations of what is masculine and feminine. As such, it becomes difficult to escape the societal imposition of gender-specific norms that mandate that all Jamaican men should be heterosexual, stoic, financially stable and demonstrate a sense of authority within his household. These socially constructed qualities help to underscore the biological determination that men tend to be aggressive and risk-taking (Yin, 2007).

Jamaican masculinity is also considered to be performative, where the evidence of one's masculine identity is duly performed in order to obtain social recognition and acceptance. Whereas womanhood is postulated to be attained and fixed through biological changes (Griffith, 2015), it is argued that manhood is earned and requires continuous public demonstrations for the status to be retained (Vandello & Bosson, 2013). It is perceived that "it is in this acting out that we exteriorize that gender-specific behaviours which we have been taught" (Lewis, 2004, p. 245). Thus public demonstrations of heterosexuality, hypersexuality, strength and stoicism offer evidence that the social lessons of masculinity have been duly learnt.

Historical explanations

The defining nature of Jamaican masculinity can be linked to the region's history of slavery and colonialism (Beckles, 2004; Hall, 2011). Beckles (2004) argued that masculinity is "a socially produced script" (p. 226) which was birthed through the enslavement, subordination and marginalization of black men, in comparison to white slave masters.

Though this framework for masculinity has evolved and is variable, it remains important to acknowledge what is considered the origin of this masculine ideology within the Caribbean. The historical legacy of this system of oppression and exploitation has contributed significantly to the current constructions and distinctions between masculinity and femininity (Ramchand, 2004). The historical and cultural influences on this social construct suggest a persistent classification of maleness which remains malleable to the forces of changing social and cultural norms. It also suggests a sense of fragility based on an individual's ability to follow a scripted ideology of maleness that seemingly alters across social and historical contexts (Silberschmidt, 2004). As aptly explained by Beckles (2004),

It is important to recognize that the ideology of masculinity is largely “a socially produced script” on which historical notions of role fulfilment have been coded. This feature of the process dictates that the script is under constant revision; it is therefore unstable even though the continuity of certain fundamental elements can be discerned. These elements, collectively, constitute the rollers on which masculinities evolve as sites of cultural power within changing social realities. As male role fulfilment changes over time, ideological representation of masculinities are revised, an indication of the interactive nature of ideology and institutional power. (p. 226 – 227)

The emergence of Caribbean masculinity against the backdrop of slavery justifies the forcefulness in which this identity is maintained and propelled. Beckles (2004) described this period as a dialectical process (and struggle) between the “differentiated, marginalized, subordinated and stigmatized” masculinity of enslaved blacks and the hegemonic dominance of white masculinity (p. 227).

Within the contemporary Caribbean society, masculinity is less about comparability to the dominant white masculinity that was characteristic of the periods of slavery and indentureship; suggesting that the positions of power and privilege amongst Caribbean men are no longer restricted to terrains of race or colour. Instead it is likely that this hierarchy of masculinity is now also distinguished along other intersecting lines of identity such as class, sexuality, disability and religion. For instance, Miller (1994) referred to Black

Jamaican men being subordinate to Jewish, White and Chinese men who were more aligned to the upper echelons of wealth in society (Miller, 1994). However, education attainment and the resulting increased material wealth, offered an opportunity for social mobility for Black men (Hope, 2010), therefore changing the composition of men within the hierarchy of masculinity.

Despite these historical changes, evidence of a hegemonic masculinity remains that differentiate men who reflect this ascendant classification from other subordinated and marginalized groups of men and women (Hope, 2010). According to Hope (2010), Jamaica's hegemonic masculinity continues to be defined on the basis of material wealth, which translates into power and control. This line of commonality across varying historical epochs does not suggest that the ideal hegemonic masculinity has been the same throughout Jamaica's history. As Connell (2005) noted, hegemonic masculinity is not fixed and is always contestable. As such, the hegemonic masculinity during slavery was characterized as white slave owners who monopolized wealth, power and denigrated all enslaved black men (Beckles, 2004). This was notably distinct to the hegemonic masculinity of the 1980s which, despite the retained position of wealth, was further characterized by "middle-class background/status, tertiary education, white collar career, economic wealth, ability to provide for/control immediate family, (polygamous) heterosexuality, access to leisure, access to/ ownership of expensive cars, and domination of women" (Hope, 2010, p. 9).

The role of gender socialization

The norms surrounding masculinity in Jamaica are largely engendered through the process of gender socialization which outlines clear specific and quite distinct roles for males and females (P. Anderson, 2012; Chevannes, 2001). Thus the process of learning masculinity as distinct and comparable to feminine traits begins in the home at a tender age (P. Anderson, 2012; Hope, 2010). These gender-based child rearing practices are largely protective where boys are being raised to be independent and economically stable, whilst girls are protected from early exposure to sexual activity that could impact their future if they were to become

pregnant (Brown & Chevannes, 1998). Boys become indoctrinated by father or other male role models through sexualized conversations or exposure to pornographic material or any other relevant source that cultivates the promiscuous heterosexual masculinity (Chevannes, 2001; Hope, 2010).

An ethnographic study by Chevannes (2001) examined male socialization in five communities across three Caribbean countries: Jamaica, Guyana and Dominica. He found that the process of becoming a socially acceptable male was intrinsically related to the positioning of women. This was due to the power or positioning of the male being established or reinforced in direct relation to the subordinate positioning of the female. Thus males learn their role expectations against “the backdrop of female behavioural norms and values, against which and in relation to which male role expectation and performance are played out” (Chevannes, 2001, p. 67).

The reflection of gender stereotypes throughout the main forces of socialization in society produce a system of social conformity whereby those who fail to comply can experience mild to extreme punitive measures (Lewis, 2003a). The culture of the street which played a major role in socializing adolescent Jamaican boys to ascribe to socially prescribed rules of manhood was also the space that ridiculed, ostracized or bullied them where non-conformity was seen (Chevannes, 2003). This system of control was also replicated by women and some of the communities, especially inner-city communities, in which the men resided (Hope, 2010).

Representations of current Jamaican masculinity

The representations of Jamaican masculinity are varied, and are largely dependent on the audience from which these men may seek approval. Jamaican masculinity is perceived to be represented on three levels: how men perceive themselves against the backdrop of prescribed norms; how men perceive each other which builds on the need for masculine approval; and how men are perceived by women which highlights the importance of heterosexuality as an integral aspect of Jamaican masculinity (Chevannes, 2001; Lewis,

2003a). Each of these require Jamaican men to engage in gender performance against the prescribes of normative ideals and with the need to attain social approval to avoid potentially severe social sanctions (Hall, 2011). Thus masculinity is largely an acting out of maleness and an exteriorizing of gender-specific behaviours that are taught and maintained by social institutions (Lewis, 2004).

The idea of gender being based on performativity is not a new concept. Hall (2011) postulated that Jamaican masculinity is the output of identity performances that are influenced by the experiences of slavery, colonialism and globalization. Importantly, performativity underscores the centrality of social constructions in the negotiation of Jamaican masculine identities (Hall, 2011). An apt definition of gender performativity was presented by White (2015):

The concept of gender performativity asserted that gender is the result of reiterated acting which produces a normal or static gender whilst masking the contradiction and volatile nature of any individual's gender act. This produces a 'true gender', a narrative sustained by the collective commitment to perform, sustain, and produce polar and discrete genders as a cultural fiction and punishments resulted from not 'playing your part' and agreeing with these fictions. (E. White, 2015, p. 318)

Thus, for Jamaican men, this 'true gender' often exists in relation to their sexuality (heterosexuality and hypersexuality), their overt display of aggression and their familial roles (Chevannes, 2001; Hope, 2010; Lewis, 2003a).

A significant portion of what comprises Jamaican masculinity surrounds the representation and performance of sexuality (Hope, 2010). This promotes a sense of hypersexuality that emphasizes an excessive and insatiable male sexual drive where the Jamaican male is expected to be a sexual expert, should always be ready to engage in sex, must never lose his erection and must be able to please his partner (Flood, 1996). Much of this is attributable to the legacy of slavery, where black slaves were stripped of their pre-existing identities and apart from their forced labour, were relegated to the role of studs – the deliberate breeding of slaves (Higman, 1995). Elements of this identity was therefore seen to survive post

emancipation, independence and beyond, as the Jamaican male was continuously described and expected to be virile, promiscuous and heterosexual (Chevannes, 2001; J.P. Figueroa, 2014; Hope, 2010). This perception of Jamaican and Caribbean masculinities has contributed to growth in sex tourism in the Caribbean region (Kempadoo, 2004; Mullings, 1999) and has been a noted driver of the region's HIV epidemic (Boxill et al., 2005; Padilla, Guilamo-Ramos, Bouris, & Reyes, 2010).

Another key aspect of sexuality is the need for men to prove that they are heterosexual especially given Jamaica's cultural intolerance of same-sex relationships (Charles, 2011; Cowell, 2011; Kempadoo, 2004; Rheddock, 2004; R. White & Carr, 2005). This emphasizes how gender is interwoven with sexuality in Jamaica. Homophobia is not simply about the fear or resentment of MSM. Rather, it represents the fear of being acknowledged as less than the ideal man and becoming ranked amongst more lowly status of "others" (Kimmel, 2007). It is this fear that forces some men to perform exaggerated versions of masculinity, to ensure a particular image of self is protected (Kimmel, 2007). Thus masculinity becomes "the dragon at the gates of an alternative masculinity [that] polices the boundaries of conventional masculinity" (Flood, 1996, p. 2). As such, some men "take enormous risks to prove [their] manhood, exposing [themselves] disproportionately to health risks, workplace hazards, and stress-related illnesses" (Kimmel, 2007, p. 80).

Some authors also account for representations of aggression in proving Jamaican masculinity. According to Hall (2011) this was characteristic of the "rude boy" phenomenon which surrounded the male enactment of "insolence, violence and other transgressive social performances" (p. 39). It also represented the essence of being a 'hardcore' Jamaican man who is powerful, strong and untouchable. Much of these representations of aggression occurred on the streets which became a mainstay for the socialization and policing of this aspect of Jamaican masculinity (Chevannes, 2003). Other representations are noted in some inner-city communities where donmanship can only be attained through proof of being the most feared aggressor in the community.

These representations of masculinity have been suggested to place men at risk where they become displaced or marginalized in the society. To illustrate, the need to prove ‘badness’ through heightened expressions of aggression has contributed to high male truancy rates and low levels of academic achievement (Miller, 1994), as well as their role in the increasing rate of crime in Jamaica (Brown & Chevannes, 1998). This marginalization thesis was later challenged, and instead these issues were identified as products of gender socialization and the privileging of males in society (Chevannes, 1999; M. Figueroa, 2004).

Hope (2011) showed how Jamaican dancehall has emerged as a definitive space for the “promotion of a promiscuous and polygamous male heterosexuality” which has been acknowledged as largely characterizing the hegemonic Jamaican ideal (p. 16). Yet this space is also noted to exaggerate other qualities of the hegemonic Jamaican ideal, where the dancehall typology must display excessive aggression and at times gun violence, excessive contra-homosexuality attitudes and a hyper-performance of the masculinity pose (in terms of fashionable dress) (Hope, 2010). As with earlier representations of Jamaican masculinity, this dancehall hegemonic character exists in comparison to women and other marginalized men (Hope, 2010).

It is clear that Jamaican hegemonic masculinity, as with classifications of hegemonic masculinity elsewhere, is both a historical and social construct. Thus changes have occurred over the years in the characterization and representation of this Jamaican ideal. However, the salience of a particular typology of the ideal Jamaican man has persisted, which marginalizes or disempowers ‘others’, a group comprising both men and women. Change has also occurred in how Jamaican masculinities are represented. Though the streets, inner-city communities and the audience of women remain current spaces for this representation or performance of masculinity, other spaces such as the dancehall have emerged in recent years.

3.3.3 Intersections of gender, sexuality and Jamaican culture

Though many Caribbean studies have traditionally treated gender, sexuality, and race, amongst other identity constructs, as separate or compartmentalized, it is recognized that greater work is needed to analyse the complexities and nuances within Caribbean identities (Lewis, 2003b). Further, the health outcomes of men are not impacted by any one dimension of their identity. Instead, “men’s lives and health are rooted in opportunity structures that are shaped by race, ethnicity and other characteristics that have important social, political, economic and cultural meaning” (Griffith, 2012, p. 106). This point reinforces the need to assess how the health experiences of Jamaican men are influenced by their relative positioning to dominant categorizations of Jamaican masculinity. The importance of adopting an intersectional approach to understanding men’s health experiences and outcomes in Jamaica was aptly explained by Lewis (2003b) who stated

issues of gender, sexuality and culture are not disembowelled concepts but have important material consequences for how we live our lives, under what conditions we reproduce our means of existence and how we relate to each other as social beings. (p. 3)

Thus it is difficult to effectively understand what is meant by ‘being’ a man, and his health outcomes, outside the context of that man’s national identity (and thus culture), race, class, religion and even health status.

It is difficult to separate gender from sexuality in understanding the perceptions and expectations of men in Jamaica or the wider Caribbean. The inseparable connection between gender and sexuality is largely evidenced in the Caribbean’s popular culture, especially its music and some literary work that often reflect scripted intersections of masculinity and heterosexuality. To illustrate, Ramchand (2004) highlighted excerpts from renowned literary texts written by Sam Selvon, Jamaica Kincaid, Seepersad Naipaul and Earl Lovelace. Within his work he cited a quote from Selvon’s *A Brighter Sun*, which highlighted the reconstructions of hegemonic masculinity:

Tiger had never smoked. He had only seen his father and the others. But he had decided that he was not going to appear a small boy before his wife. Men smoked: he would smoke. He would drink rum, curse, swear, bully the life out of her if she did not obey him. Hadn't he seen when his father did that? (Sam Selvon, *A Brighter Sun*)

Here, portrayals of masculinity surrounded the need to prove masculine dominance in relation to a woman, as well as other expressions of aggression such as cursing, swearing, bullying or even abuse.

The core of the ideal Jamaican male's identity is predicated on both his biological sex and his socially constructed masculine behaviours which must include a demonstration of his 'straightness' or rather heterosexuality. This is perhaps best illustrated in Cowell's (2011) description of the Jamaican man, being biologically male, displaying masculine behaviours and being sexually oriented to women. It could be argued that at the core of Jamaican maleness must be the evidence of a man's heterosexual identity, as anything outside of this domain becomes classified as non-masculine, or perhaps more derogatory – "chi chi man" or "batty man" – terms which acknowledge different and more subordinate types of masculinities (Kempadoo, 2004).

The antagonism towards this marginalized representation of masculinity has attracted significant negative sentiment and response in various social arenas including popular culture (Cowell, 2011; Hope, 2010). These subtle and overt condemnations of same-sex relationships are also seen in laws surrounding buggery, dominant religious movements such as Pentecostalism and Rastafari, and an educational system that emphasizes the role of the nuclear family in procreation and the progress of our society (Charles, 2011; Cowell, 2011; Hope, 2010; Kempadoo, 2004). As Kempadoo (2004) explained,

Male homosexuality is explicitly and violently renounced and defined as a corruption of masculinity, where anything considered feminine is seen to damage the "Real Man" identity of Caribbean men...Heterosexual conquests and a hatred of homosexuality are then a way that men "access their entire cache of masculinity and manhood." (p. 46)

The need to portray or emphasize heterosexuality as an intrinsic aspect of Jamaican masculinity exposes divisions of power amongst Jamaican men. Though the general literature suggests that men are powered beings within a patriarchal system, this sense of power is only experienced as a part of the aggregate body of men (Kimmel, 2007). Further, the fact that only a minority of men are able to fully attain the qualities of the ideal hegemonic masculinity (Connell, 2005) suggests that a majority of Jamaican men will have a sense of feeling powerless or disempowered. Undoubtedly this will impact the health choices and outcomes of these men, especially where their masculinity is further influenced by other dimensions of their identity surrounding, for example, race, class, sexuality and disability status. These other variations of masculinity must therefore grapple with their sense of self in comparison to the hegemonic standard established, and in relation to other men and women (Kimmel, 2007).

The stigma attached to both HIV/AIDS and same-sex relationships in Jamaica further compounds the health experiences of HIV infected men. These can be seen as intersecting markers of men's social identity that can further result in discrimination at varying levels in the society (Brinkley-Rubinstein, 2015), including health facilities. One study suggested that the linkage between masculinity and heterosexuality in Jamaica marginalizes gay men who may be HIV infected and in need of treatment and care, thus compromising the progress of the country's ARV programme (Charles, 2011). According to Charles (2011), "The government's policy to provide anti-retroviral treatment is failing because the human rights abuse against gay men causes gay men infected with the AIDS virus not to reveal their HIV status and their sexual orientation to health workers" (Charles, 2011, p. 13). Thus the stigma attached to homosexuality or same-sex relationships prevents MSM from being tested, diagnosed, treated and retained in care (J.P. Figueroa et al., 2015; Ministry of Health, 2014a; R. White & Carr, 2005).

Within the Jamaican culture, the social construction of masculine identity not only intersects with sexuality but also class and race. Again, much of this intersectionality is evidenced in the lyrics of some of the country's most celebrated reggae artistes. For

example, Beenie Man's song *Ole Dawg*, captures the essence of how the ideal masculinity is shaped by notions of promiscuous, heterosexuality and a distinction between men from the lower and middle to upper class levels (Hope, 2010). A few excerpts from the song are given:

Ole dawg like we, wi haffi have dem inna twos and threes
[Old dogs like us, we have to have them (women) in twos and threes]

From mi see a gal whey look good mi haffi fool har (An get whey mi want)
[Once I see a girl who looks good, I have to trick her to get what I want]

Cause mi nuh live over Shortwood so mi haffi bounce har (Mek she drop inna mi paw)
[Because I don't live in Shortwood, I have to have sex with her to ensure she falls into my clutches]

Five six seven eight gal a whey mi waan
[Five, six, seven, eight girls is what I want]

One burner business a nuh me dat yaah
[The one girl commitment, that's not me at all]

(Beenie Man - Old Dog Lyrics)

These excerpts show the emphasis on multiple sexual relationships as well as a subordination of women, where they need to be tricked or coerced sexually. Shortwood is recognized as an upscale middle class community in Jamaica. Middle and upper class men are often reputed to have sexual drives and prowess that are less than that of their lower class counterparts (Hope, 2010). Thus this song shows the contestation of the space of superiority of masculinity as an overlap with sexuality, class and gender comparability.

3.3.4 Jamaican masculinity as a sexual health risk

Masculinity and related normative behaviours in societies 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). This is

largely due to masculinity being equally a focal point of men's self-construction as it is their health construction (Saltonstall, 1993). Jamaican male sexuality is noted to be intrinsically shaped by the social construction of masculinity (Chevannes, 2001, 2003; Flood, 1996; Hope, 2010; Kempadoo, 2004; Lewis, 2003a). Certain prescribed notions of Jamaican masculinity increase the risk of the spread of HIV/AIDS and other sexual transmitted illnesses (J.P. Figueroa, 2014; Kempadoo, 2004; Kempadoo & Dunn, 2001; Ministry of Health, 2012, 2014a). Some literature refers to Jamaican men's need to prove their sexual prowess by overtly engaging in multiple sexual relationships which place both the male and his partners at risk of HIV infection (J.P. Figueroa, 2014; Kempadoo, 2004; Ministry of Health, 2012, 2014a). As well, the need to portray male strength negates the acceptance of being sick and hinders male health-seeking behaviours (Morris et al., 2011).

As seen in earlier cited studies, the engagement in high risk behaviours and the delayed approach to seeking healthcare are key indicators of 'maleness' across many societies. Similarly, studies examining the health or sexual risks of Jamaican men have found that the norms surrounding Jamaican masculinity are key in defining the sexual health behaviours and health outcomes of Jamaican men (J.P. Figueroa, 2014; Kempadoo & Dunn, 2001; Morgan et al., 2012; Morris et al., 2011; Norman & Uche, 2002; Walcott et al., 2014). In Jamaica, risky sexual practices such as engaging in sexual intercourse 'bareback' (without a condom) and having multiple concurrent or sequential partners have increased the likelihood of unwanted pregnancies and the transmission of HIV/AIDS amongst other STIs (Kempadoo & Dunn, 2001; Ministry of Health, 2014a; Morgan et al., 2012; Norman & Uche, 2002). Figueroa (2008) acknowledged that the higher incidence of AIDS for men was due to their greater risky behaviours.

A number of studies have examined the issue of young males being pressured to prove their masculinity either through early sexual initiation, having sex with multiple partners or having children (Bailey, Wynter, Jackson, Lee, & Hamilton, 1999; Eggleston, Jackson, & Hardee, 1999; Norman & Uche, 2003). Boys are encouraged to prove their masculinity and sexual prowess from an early age resulting in sexual initiation occurring quite early for both

males and females (Ishida, Stupp, & McDonald, 2011). The most recent *Reproductive Health Survey* reported that the mean age of sexual initiation was 14.5 years for males and 16.1 years for females (National Family Planning Board, 2010). In addition, only 57% of males indicated using condoms at first intercourse (National Family Planning Board, 2010). These data show the correlation with the heightened risk of teen pregnancies and STIs amongst Jamaican youth. Analysis of data from the 2008–2009 Jamaican Reproductive Health Survey found that the risky sexual practices of young males (ages 15-19) increased with age (Ishida et al., 2011). So whereas only 37.5% of boys aged 15 years reported having multiple sex partners, this figure was almost doubled for the 19 year olds of which 67.3% reported having multiple partners (Ishida et al., 2011). This trend was similar for those reporting inconsistent condom usage. Importantly, 82.7% of 19 year old males reported being sexually active which underscores the norms around proving sexual virility during early adolescence (Ishida et al., 2011). Thus Jamaican masculinity norms expose males to numerous health risks at an early age. This means that a number of youth are at risk of contracting STDs including HIV, which may hold serious socio-economic and developmental implications.

3.4 MEN, MASCULINITY AND HIV/AIDS

3.4.1 Men and masculinity in the advent of chronic illness

The onset of chronic illnesses such as cancer, depression and HIV/AIDS, has been noted to result in biographical disruptions, “where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982, p. 169). Many studies have chronicled how the onset of chronic illnesses disrupt the lives of individuals, whether male or female and across age groups (Asbring, 2001; Bury, 1982; Charmaz, 2002; Kralik, Brown, & Koch, 2001; Kvigne, Kirkevold, Martinsen, & Bronken, 2014). Serious chronic illnesses are seen to challenge men’s “taken-for-granted masculinity identities” (Charmaz, 1994, p. 270). According to Charmaz (1994), the suddenness, intensity and period during the life course at which men become chronically ill can impact the extent to which they experience identity dilemmas. These identity dilemmas pertain to significant changes to the

general routines of daily living such as employment, relationships, recreational activities and future aspirations (Charmaz, 1994). One study which included Jamaican men as their participants, found that the treatment for prostate cancer and the continued effects of the illness challenged the men's masculine identities in areas of work, strength, sexual performance and independence (Maliski, Rivera, Connor, Lopez, & Litwin, 2008). Thus chronic illness can become difficult for men to embrace and overcome in trying to achieve a new sense of self or in re-defining an existing identity (Asbring, 2001).

Charmaz (1991) provided critical insight to the meaning of living with chronic illnesses and the impact it has on the construction of self. Importantly, she theorized that living with a chronic illness was a subjective, personalized, yet public experience that required the chronically ill to often re-construct their sense of self. Thus living with a chronic illness was seen as entailing "overcoming stigmatised judgements, intrusive questions, and feeling of diminished worth" (Charmaz, 1991, p. 2). Another important aspect of Charmaz's work that proves relevant to this study is her development of the trajectory by which persons experience chronic illness. According to Charmaz chronic illness can be experienced in three ways: as an interruption of lives, as an intrusive illness, or as an immersion in illness. The onset of a chronic illness, usually experienced through its symptoms, result in a disruption of daily routines and futuristic plans or dreams. The intrusiveness of the illness tends to be experienced in perceived bad days, where dreams for the future are abandoned as health deteriorates. Immersion in illness occurs when daily routines are structured around the illness and the experience of *living* with the experience becomes ingrained. The three ways of experiencing illness also represent an illness trajectory as it can show how individuals progress over time, especially with interventions such as treatment or support (Charmaz, 1991). Critically, this is not a linear process and is largely dependent on the subjective interpretations of the illness (Charmaz, 1991).

Studies have found that the onset of chronic illnesses have forced some men to renegotiate their masculinity (Bokhour, Powel, & Clark, 2007; Kvigne et al., 2014; Maliski et al., 2008; Mathieson & Stam, 1995; O'Brien et al., 2007). Maliski, Rivera, Connor, Lopez and Litwin

(2008) found that this process of renegotiating masculine identity comprised varying stages including: normalizing the effects of the illness, balancing hope with acceptance and moving on, a critical examination of masculine values, and finally, shifting priorities. This last stage showed how varying masculine values were shifted to suit the men's circumstances. The process of renegotiating masculinity in the context of illness was also found in a study by Mesquita, Moreira and Maliski (2011). Here the study assessed the experiences of Brazilian men receiving cancer treatment. The authors found perceptions of masculinity emerging in three phases: prior to cancer, during treatment and post treatment. At each of these phases, the definition of the men's masculine identities differed which was key in showing how they negotiated and prioritized their masculine identities.

Some men tend to pursue approaches that maintain or improve their health in an effort to preserve their masculinity (Mesquita et al., 2011; Siu et al., 2015). Thus, being or appearing healthy was also an important component of some men's masculinity. An example of this is seen in Siu et al.'s (2015) study where males reported a restoration of their masculine identities after experiencing the benefits of adhering to their ARV treatment. The medication contributed to a restoration of health that allowed them to resume their normative duties instead of being "weak and useless" (Siu et al., 2015). This was further reinforced when participants in the study by Mesquita et al. (2011) indicated that men who failed to access health care are weak and ignorant. These findings suggest that masculinity is a complex and dynamic construct that can be re-shaped given the circumstances of individuals (such as becoming ill) and their determination to surpass or overcome the social constraints of identity constructions. Thus becoming unwell can result in symptoms that challenge the masculinity identity being maintained by some men. These can however be contested or negotiated in the face of the illness and with the emergent benefits of effective healthcare and treatment (Siu et al., 2015).

3.4.2 The male experience of diagnosis and living with HIV/AIDS

Hearing of one's HIV diagnosis is often a traumatic experience especially where the outcome is unexpected (M. Anderson et al., 2009). The responses to testing HIV positive vary but largely include expressions of shock, denial, depression and suicidal ideation (M. Anderson et al., 2010; Hult, Maurer, & Moskowitz, 2009; Stevens & Doerr, 1997). Anderson et al. (2010), however, found that gay men were less shocked at learning of their positive HIV diagnosis as they were aware of their potential risk of infection. Often, a positive diagnosis results in a sense of loss, suffering or imminent death (M. Anderson et al., 2010; Leyva-Moral, de Dios Sánchez, Lluva-Castaño, & Mestres-Camps, 2015; Stevens & Doerr, 1997). Doyal, Anderson and Paparini (2009) found that many of the men reported the fear of dying and loss of future aspirations, and the loss of relationships. Some men reported that their diagnosis resulted in the termination of their partnerships and relationships with their children (Doyal, Anderson, & Paparini, 2009).

Chesney and Smith (1999) noted that the prevailing stigma around HIV contributes to the psychological trauma experienced upon learning of a positive HIV diagnosis. This also contributes to some persons' delay in being tested for HIV and uptake of treatment services (Smith & Baker, 2012). Some authors perceive that this stigma has existed since the early years of the HIV epidemic, given its then association with deviant behaviours such as homosexuality, prostitution, promiscuity and injecting drug use which tend to evoke sentiments of social disapproval, contempt or other moralistic denunciations (Herek, 2002). According to White and Carr (2005) the extent of HIV/AIDS-related stigma in Jamaica often propels some persons to become suicidal upon learning of their HIV status. This is likely due to the fear of isolation and the potential discrimination if others become aware of their HIV positive status (R. White & Carr, 2005). This fear of stigma is found to be particularly great for Jamaican men, given the associations between HIV infection and homosexuality or same-sex relationships (Bain, 1998; R. Carr, 2002). Research, however, indicates that the association between the two are waning as more heterosexual married women are diagnosed with HIV, and more families and communities become affected by

the illness (R. White & Carr, 2005). Nonetheless the fear of stigma often forces men to not disclose their HIV status, even when they are knowingly placing their partners at risk of infection (Carricaburu & Pierret, 1995; Sikweyiya, Jewkes, & Dunkle, 2014). Carricaburu and Pierret (1995) found that once men became symptomatic, they created alternate explanations to explain the symptoms as well as their need to visit the doctor. This maintenance of HIV as a secret then became a key aspect of these men's management of their daily lives.

Roth and Nelson (1997), upon conducting an ethnographic study comprising mainly men, found that the point of an HIV diagnosis was a “mutually constituted” experience between the patient and his healthcare provider (p. 162). They noted that patients often played a passive role in the moment of being advised of their diagnosis (Roth & Nelson, 1997). The authors also found that this juncture was significant for patients, even many years post diagnosis. Other studies suggest this period also retains its importance, given the less than ideal circumstances by which patients are advised of their HIV status (Stevens & Hildebrandt, 2006); suggesting that the point of HIV diagnosis, which usually involves the patient and a healthcare professional, is a crucial point for appropriate psychosocial intervention (M. Anderson et al., 2010; Roth & Nelson, 1997).

Receiving a positive HIV diagnosis is acknowledged as a life changing event for persons (P. Stevens & Hildebrandt, 2006). Roth and Nelson (1997) described it as “the gateway for the patient into a new phase of life with a new HIV-positive identity” (p. 166). The extent of the impact of an HIV positive diagnosis is further dependent on the timing both in the historical context of the epidemic and in the context of the personal lives of men (Roth & Nelson, 1997). The former identifies distinct epochs in the history of the HIV epidemic for countries, which would likely result in different experiences. For instance, Roth and Nelson found that patients' accounts of their experience around diagnosis varied across the nascent days of the epidemic, the 1980s, before HIV information was widely distributed, and post this period when there was increased awareness and access to services. The latter takes into consideration the other events occurring in the lives of men at the time of their diagnosis,

which corresponds with notions of a biographical disruption (Carricaburu & Pierret, 1995). As such the onset of an HIV infection was seen to hinder persons from achieving future goals and aspirations (Leyva-Moral et al., 2015).

Men's acceptance of their HIV positive diagnosis is seen as a key turning point in men's experiences with the illness (Sikweyiya et al., 2014). Sikweyiya et al. (2014) highlighted that acceptance of an HIV diagnosis is not immediate and that some men in their study were still struggling to accept their diagnosis. Once the men accepted their status, however, men propelled into a phase of empowerment where they were able to seek healthcare and initiate treatment (Sikweyiya et al., 2014). Some men also repositioned themselves as leaders in the HIV community, becoming activists and advocates (Sikweyiya et al., 2014).

Much of the male experience of moving beyond diagnosis to living with HIV surrounds the incorporation of HIV as an aspect of his identity (Carricaburu & Pierret, 1995). According to Roth and Nelson (1997) this new "HIV-positive personhood is not a singular entrance. The entrance is effected not only in relationship to the physician, but in relationship to other in the community and an understanding of community norms" (p. 170). This shows how the incorporation of an HIV identity as an aspect of the masculine self is an ongoing, non-linear and perhaps disruptive process that is further imprinted by a range of actors including HIV-infected men, their health practitioners, their family/peers and the wider socio-cultural norms of the Jamaican society. It also shows the power of others in potentially influencing, whether positively or negatively, the experiences of men post their HIV diagnosis. These factors help to reinforce the notion of an uncertain future where men feel like they are no longer in control of their lives and are unclear of their future (Leyva-Moral et al., 2015; Sikweyiya et al., 2014).

Carricaburu and Pierret (1995) found that men in their study spent much of their everyday lives post diagnosis adjusting to and fitting their HIV status into their personal biographies. This included adjusting to the constraints imposed by being infected, such as those surrounding sexual practices and intravenous injections (Carricaburu & Pierret, 1995).

These constraints were intended to contain the virus and thus prevent the transmission to others. Importantly, these adjustments were both clinical recommendations and personal choices for some men. So instead of practicing safe sex, some men opted to abstain from sex altogether (Carricaburu & Pierret, 1995; Doyal et al., 2009). Some men also isolated themselves from others which limited their network of support at various points in their illness journey (Doyal et al., 2009). Other life-changing habits included changes in diet, intake of vitamins, and an increased immersion in spirituality, which were perceived to give men a sense of control over their bodies, lives and their future (Carricaburu & Pierret, 1995; Doyal et al., 2009).

A sense of continuity or regained hope for the future is obtained when some men recognize the importance and benefits of their ARV treatment (Sikweyiya et al., 2014; Siu et al., 2013; Siu et al., 2015). This was reinforced when sustained treatment, along with access to other resources, allowed men to resume some of their previous roles such as work and socializing with peers (Carricaburu & Pierret, 1995; Sikweyiya et al., 2014; Siu et al., 2013). This move into *living* with HIV also occurred as the ARV medication helped men to regain their physical strength and appearance, thus removing them from a dismal sick role (Siu et al., 2015).

Studies indicate that the journey of living with HIV is often complex, relational and significantly structured around the health professional (R. Carr, 2002; Leyva-Moral et al., 2015; Roth & Nelson, 1997; Siu et al., 2015). Importantly, men's experiences of living with HIV are largely impacted by the quality of healthcare received, especially given its centrality post HIV diagnosis (Leyva-Moral et al., 2015). Thus, from the point of diagnosis, the quality of the patient-doctor interaction can determine how well men progress into other stages such as being connected to care and treatment (M. Anderson et al., 2010; Leyva-Moral et al., 2015; Roth & Nelson, 1997). Leyva-Moral et al. (2015) found that poor quality of service provision such as the frequent change of doctors resulted in sentiments of distrust that acted as a barrier to care. Further, the absence of resources beyond the biomedical treatment of HIV left other important aspects of wellbeing unattended (Leyva-

Moral et al., 2015). This accounts for the absence of psycho-social support that is reported by some men (Siu et al., 2015).

3.4.3 The impact of HIV/AIDS on identity

The onset of chronic illnesses has been noted to have significant effects on the pre-existing identities of individuals (Baumgartner & Niemi, 2013). The incorporation of a chronic illness into the re-definition of self has been noted to impact other aspects of an individual's identity, such as their work identity or relational identity (Baumgartner & Niemi, 2013). Chronic illness can impose statuses that assume the incapability of individuals, thus resulting in a devaluation of their function or contribution to the work environment (McGonagle & Barnes-Farrell, 2014).

The impact of HIV/AIDS on an individual's sense of self and identity is arguably greater given the stigmatized nature of the illness. Some authors report HIV diagnosed individuals referring to HIV as “an aspect of who I am”, “a part of me” or being “central to my sense of self” (Bartos & McDonald, 2000, p. 302). Other studies reported that an HIV-positive status was more destructive, tarnishing the social image or reputation of persons, or simply destroying futuristic aspirations (M. Anderson et al., 2010; Leyva-Moral et al., 2015; Siu et al., 2015). These changes are likened to biographical disruptions (Bury, 1982) or identity dilemmas (Charmaz, 1994) wherein individuals evaluate their lives on the premise of what is lost due to the onset of the illness. Bury (1982) posited that there are three aspects of disruption that can occur due to becoming chronically ill:

First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries [...] Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation. (pp. 169-170)

These three stages of biographical disruption could be perceived to be three stages which a chronically ill person goes through in response to their illness. For Bury, the first aspect entailed a developed consciousness of bodily (dys)functions that were previously taken-for-granted or unacknowledged. Hence, the onset of HIV symptoms can force men to suddenly acknowledge and value certain physiological attributes that were not thought of before. In the second aspect, there is a personal reflexivity and redefinition of self that is enshrined in both the biomedical and social conversations on the illness and the person's identity. Here it becomes important to remember that a personal understanding of self is often shaped by social constructions (Charmaz, 1994). The third aspect represents a practical response to being ill. By mobilizing resources, chronically ill men become responsive to both their illness, and the social, cultural, economic and temporal contexts in which their illness occurred (S.J. Williams, 2000).

Becoming HIV infected also produces a series of conflicting positions which Charmaz (1994) described as including "risking activity vs. forced passivity, remaining independent vs. becoming dependent, maintaining dominance vs. becoming subordinate, and preserving a public persona vs. acknowledging private feelings" (p. 270). Each of these conflicting positions represents the choices men must make either in relation to traditional masculinity norms or in response to becoming chronically ill. Charmaz gave the illustration of the male who engages in risky behaviour to maintain his sense of independence, dominance and public image. Conversely, the male who becomes seriously ill is faced with the dilemma of becoming passive, dependent, subordinated to others and forced to reckon with personal emotions. As such, these conflicting positions can become important considerations for men diagnosed and living with HIV.

Having an incurable illness means that individuals are often forced to incorporate being HIV positive as a part of their identity. Thus "because HIV disease influences how individuals see themselves and act, disease becomes a part of self-identification both personally and socially for those individuals who are aware of their infection" (Tewksbury & McGaughey, 1998, p. 215). This redefining process requires taking on a sick identity that

is affiliated with the need for constant care and treatment, whilst relinquishing certain futuristic ideals (Tewksbury & McGaughey, 1998).

The incorporation of an HIV identity into a redefined sense of self begins for some persons upon diagnosis (Baumgartner & David, 2009). This stage of diagnosis was perceived to be one of the possible turning points at which individuals are forced to face and subsequently accept their HIV diagnosis (Baumgartner & David, 2009). Some authors suggest that the initial turning point for HIV positive men either leads to them becoming involved in the HIV community or gaining an awareness of the illness (Baumgartner & David, 2009; Roth & Nelson, 1997), which are avenues deemed essential in encouraging acceptance of an HIV diagnosis. Such awareness indicated the symbolism of the passing of time in the adjustment process (Baumgartner, 2012; Charmaz, 1991). The incorporation of HIV as an aspect of a person's identity is perceived to be an ongoing process, and thus does not end at the point of diagnosis (Roth & Nelson, 1997). Further it is seen as a socially situated process that involves not just the PLWHIV, but also his family, healthcare providers, peers and the wider community of HIV positive persons (Roth & Nelson, 1997).

3.4.4 HIV infection and masculinity as key aspects of men's identities

HIV/AIDS, as with other chronic illnesses, has been noted to impact men's self-perception, especially as it pertains their masculinity (Maliski et al., 2008). Becoming HIV infected results in a diminished masculinity wherein men are seen as weak, unmasculine, and in need of care and pity (Sikweyiya et al., 2014). Despite some types of masculinity promoting sexual virility and multiple sexual partners, men are still expected to be knowledgeable as sex experts and responsible (Siu et al., 2013). These almost contradictory expectations result in HIV-positive men being seen as failures or weak (Siu et al., 2013). The impact on identity is worsened where illnesses can impact a man's sexuality, which is seen as an integral aspect of their masculine identity; more so the Jamaican hegemonic masculine identity (Chevannes, 2001; Hope, 2010; Kempadoo, 2004; Kempadoo & Dunn, 2001; Lewis, 2003a; Norman & Uche, 2003). Some men report becoming incapable of

engaging in sex or to a lesser extent than prior to becoming infected (Mfecane, 2008; Siu et al., 2015). Studies have also reported men experiencing a lower sexual libido, erectile dysfunction or simply losing interest in sex due to being consumed with the realities of being seriously ill (Mfecane, 2008; O'Brien et al., 2007). This seeming acquired asexual identity was also reinforced by some doctors who encouraged abstinence in light of the infection (Siu et al., 2015).

The extent of ill-health at the time of HIV diagnosis can render some men helpless and thus reliant on others for care. This is claimed to make men powerless, as they lose their sense of authority as head of household and thus relinquish control of their family and the affairs of the household (Siu et al., 2015). Siu et al. (2015) gave accounts of men who experienced mistreatment, disrespect, subjection and ridicule due to their reliance on their wives and children for care. Other men become emasculated as a result of HIV-related illness forcing them into unemployment and dependence on others (Mfecane, 2008). Thus HIV infection results in a disempowerment of men in spaces that traditionally respect their positions of authority (father, partner, and breadwinner) and dominance.

Some of the challenges experienced by men in adjusting to their HIV diagnosis surround the perception and response of others to their masculinity. This fear of stigma, ridicule, rejection or loss prevents some men from disclosing their positive HIV status (R. White & Carr, 2005), especially where physical manifestations of the infection are not present (Carricaburu & Pierret, 1995; Gaskins et al., 2011). Literature points to HIV disclosure leading to unemployment, broken relationships, and loss of family ties (M. Anderson et al., 2010), all of which reinforces the biographical disruptions that occur at the onset of chronic illnesses, especially illnesses that are stigmatized and thus hold greater social implications. Anderson et al. (2010) also pointed to an HIV-positive diagnosis leading to a sense of loss of future aspirations which causes some men to further detach and isolate themselves from others.

Sikweyiya et al. (2014) found that men who adhered to the social constructions of hegemonic masculinity, prior to being diagnosed, struggled with notions of their masculine self post diagnosis. Some men were reported to grieve past representations of their 'youthful masculinity' which surrounded multiple sexual partners, unprotected sex and being in control of sexual relationships. This was compared to a more mature 'traditional masculinity' position which focused on a man's role as provider, head of household and father. The authors seemingly configure these two variations of masculinity along a continuum which was aligned to but not restricted to age. Importantly, the men who were noted to grieve their youthful masculinity due to their HIV status, also grieved the unattainability of the traditional masculinity, as their HIV positive status was seen as a barrier to finding a steady partner and bearing children. As the authors noted

Men who had no biological children showed strong emotions of sadness and regret when discussing this topic. For them, having HIV meant that they would not leave anyone behind to perpetuate their family name, proving them to be failures in the eyes of their families. (Sikweyiya et al., 2014, p. 5)

Whereas some studies report that a positive HIV status results in diminished masculine identities (Sikweyiya et al., 2014; Siu et al., 2015), White and Carr (2005) found that some HIV positive Jamaican men retained their masculinity status post-diagnosis because representations of their heterosexual masculinity were still reinforced. The men's sustained habits of "male-oriented activities such as playing dominoes, drinking, hanging out at bars and fathering children" (R. White & Carr, 2005, p. 350) allowed the men to maintain the prestige attached to their masculinity, despite being HIV infected. This reiterates the emphasis given to a hegemonic heterosexual identity within the Jamaican society, which can supersede perceptions and responses of stigma, shame and isolation.

In response to the onset of chronic illness, some individuals develop "preferred identities" in an effort to reconstruct a sense of self outside their illness which offers an opportunity to regain hopes and aspirations for the future (Charmaz, 1987). These preferred identities symbolize the men's hopes, desires and aspirations for their future (Charmaz, 1994). Thus HIV infection is perceived to result in men redefining their identities to regain a sense of

their previous masculine self that existed prior to becoming HIV infected. This would allow these men to maintain a socially privileged status instead of succumbing to the denigration attached to being HIV infected. As Mfecane (2008) aptly stated, “It seems that when men are in crisis, they become willing to rethink their masculinities and accommodate new ideas with respect to what it is to be a man” (p. 56). It is therefore expected that one such crisis includes the reality of living with an illness that requires life-long treatment. This suggests that in rethinking their masculinities, Jamaican men would reprioritize and accommodate the idea of taking their medication as an aspect of the new conceptualization of their masculine self.

There are instances where an individual accepts his HIV diagnosis and progresses into a responsive phase that “cultivate[s] a self-perception of being pro-active and ‘choosing to live’” (Katz et al., 2013, p. 10). Thus a new identity in lieu of the HIV status is construed as a proactive measure to enhance the process of *living* with the illness. This means that the definition of masculinity is re-constructed to support the healthier lifestyle needed in response to being HIV infected (Sikweyiya et al., 2014). In order to regain or protect this identity, a man is likely to engage in health promoting behaviour such as maintaining his clinic visits or adhering to his treatment regimen (Siu et al., 2015). Research has proven that individuals who move into this phase of accepting their HIV status as an aspect of their identity are able to adhere to their ARV treatment regimen (Nam et al., 2008).

The engagement with ARV treatment has been shown to allow men the opportunity to regain a sense of their masculine identity (Sikweyiya et al., 2014; Siu et al., 2015). In the study by Siu et al. (2015), one male shared that his consistent ARV treatment, along with working closely with his physicians, allowed both him and his wife to have a child after a series of miscarriages and stillbirths. Thus the importance of being a father as a symbol of his masculinity outweighed the diminished worth that initially occurred when others learnt of his HIV status. Additionally, some men who were already husbands and fathers before their diagnosis, tapped into these pre-existing roles as motivation to seek and maintain treatment (Siu et al., 2013). Thus being a husband and father requires men to take their

medication so that they may live longer to ensure their families are provided for. Initiating treatment also allowed some men to regain their physical strength which is an important aspect of their masculine identity, especially where it concerns the engagement with work (Siu et al., 2013; Siu et al., 2015).

Conversely, being HIV infected amidst the need to protect a masculine identity hinders some men from engaging in treatment and care, as medication or other forms of treatment (such as doctor visits) are seen as markers of a man's health status (Bartos & McDonald, 2000). Thus being HIV infected (along with its associated stigma), taking ARV medication or visiting a physician are regarded as compromising the traditional masculine position of strength, independence and resilience (Galvan et al., 2014; Mburu et al., 2014; Sikweyiya et al., 2014; Siu et al., 2013). Studies have found that some men ascribing to these traditional forms of masculinity were able to retain their masculine identity by delaying or avoiding the initiation of their ARV treatment (Galvan et al., 2014; Siu et al., 2013). One male reported delaying his treatment initiation as he was still physically strong and thus his body was able to fight the infection independent of treatment (Siu et al., 2013). Siu et al. (2013) found that this tendency to avoid treatment, due to the focus on masculine strength and independence, was more characteristic of younger men (below 40 years) who were more intent on proving a particular masculinity. This notion of masculinity and treatment being further impacted by the age of men was also supported by Sikweyiya et al. (2014). Additionally, these authors also found that some men were reluctant to take their medication in the presence of their partners or family members which further contributed to their poor adherence. This reluctance was hinged on non-disclosure and the fear that if their status became known, they would be blamed for infecting their partners or be labelled as weak (Sikweyiya et al., 2014).

Men's choices to initiate, maintain or default their treatment is largely determined by the representations of masculinity they choose to portray. These masculine representations can focus on either characteristics of independence and strength (thus avoiding a sick role) or responsibility and roles as father and husband (which require extended life) (Siu et al.,

2013). This is further impacted by their socio-cultural context which bears on the definition of the ideal masculine identity. It is recognized that a range of individual, social and health system factors could also affect men's choices regarding their treatment (Siu et al., 2013).

3.5 ARV TREATMENT EXPERIENCES AND THE ADHERENCE PROCESS FOR MEN

3.5.1 Defining adherence

Throughout the literature, the seminal work cited for the origin of understanding patient treatment adherence is the book *Compliance with therapeutic regimens* by David Sackett and R. Brian Haynes (1976). Here the authors introduced and defined compliance as the extent to which the patient's behaviour coincides with medical or health advice (Haynes, Taylor, & Sackett, 1979). Compliance relates to the extent to which taking medications, following diets or executing other lifestyle changes follow the directives of health professional (Haynes et al., 1979). The term compliance has been criticized for being paternalistic as it focuses on the patient's ability to submit to, obey, or follow the instructions of his healthcare provider (Bissonnette, 2008; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Thus the healthcare provider is seen as an authoritarian in the process, knowing what is best for the patient without need to incorporate the patient's perspective (Gearing, Townsend, MacKenzie, & Charach, 2011). Further, patient compliance requires that the treatment prescribed be implemented and followed exactly as intended by the healthcare provider; any deviations would render the patient non-compliant (Gearing et al., 2011; Kalogianni, 2011).

Noting the limitations of the concept compliance and the need to present the patient as an active player in the determination of his treatment regimen, the term adherence was introduced. The WHO (2003) publication *Adherence to long-term therapies: Evidence for action* was a landmark in defining the term and establishing a framework for understanding the factors that impacted the adherence outcome. Here, adherence is defined as "the extent to which a person's behaviour – taking medication, following a diet, and/ or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider"

(WHO, 2003, p. 3). This definition was argued to be necessary in generating and recognizing patient autonomy and maintaining a collaborative relationship between the patient and the healthcare provider (Gearing et al., 2011; World Health Organization, 2003). The term was noted to present patients as “independent, intelligent, and autonomous people who take more active and voluntary roles in defining and pursuing goals for their medical treatment (Lutfey & Wishner, 1999, p. 635).

Subsequently, and as a result of ongoing criticism of the concepts compliance and adherence (neither of which adequately reflect patient-provider collaborative approaches), the term ‘concordance’ was introduced to present greater emphasis on the collaboration between patient and healthcare provider (Bissonnette, 2008). This was to be evidenced in a mutually agreed upon treatment regimen that suggested a level playing field between patient and doctor (Bissonnette, 2008; Vrijens et al., 2012). It is important to note that there is limited reference to this term in healthcare literature (Bissonnette, 2008). Further, despite the proclaimed evolution of terms, current literature still varies in the use of compliance and adherence, whether interchangeably or synonymously (Vermeire et al., 2001). It is further suggested that the terms ‘patient compliance’ and ‘medication adherence’ are the most widely used terms (Vrijens et al., 2012). For the purposes of this research the term adherence, as coined by the WHO (2003), will be adopted and maintained throughout the discussions primarily as the study endeavours to understand the treatment adherence *process* which is perceived to extend beyond the mere taking of medication to encompass other crucial and related behaviours.

3.5.2 The process of adherence

Adherence studies often create a dichotomous divide for adherence behaviour between the adherent or non-adherent based on the frequency of taking medication as prescribed (Hill, Kendall, & Fernandez, 2003). Some studies have further disaggregated these two groups, acknowledging that there are further distinguishing features specific to how well or how poorly someone follows his prescribed treatment (Gearing et al., 2011; Rand, 1993; Vrijens

et al., 2012). As Rand (1993) noted, “For the patient, there may be many shades of gray in their adherence pattern, and many complex factors that influence their medication use on a given day” (p. 70D).

Rather than classifying the patient as being either adherent or non-adherent, some studies have generated and explained processes of adherence which identify the degree to which a patient has engaged his treatment (Gearing et al., 2011; Vrijens et al., 2012). This approach to understanding adherence is seen to be aligned to a process-oriented definition as against an outcome-oriented definition as previously discussed (Vermeire et al., 2001). Understanding adherence as a process allows healthcare providers to trace the progress of an individual, noting that their position in their treatment journey may not be static. It also provides an opportunity to re-assess the patient and introduce additional interventions at varying stages in the process, to improve the overall adherence and health outcomes of the patient.

Gearing, Townsend, MacKenzie and Charach (2011) identified six phases of medication adherence: treatment initiation; treatment trial; partial treatment acceptance; intermittent treatment adoption; premature discontinuation following treatment adoption; and adherence. Treatment initiation is noted to occur once the healthcare provider prescribes a medication regimen for the patient. The treatment trial phase commences when the patient begins taking the medication. Partial treatment acceptance occurs when the patient begins taking the medication but fails to take it consistently as prescribed. In the fourth stage the patient, having started treatment, takes the medication as prescribed for a specific period, discontinues and then resumes. The fifth stage is similar to the fourth except the patient chooses to discontinue treatment altogether. The final adherence stage occurs when full or optimal adherence occurs, evidenced in the patient taking the medication as prescribed. Though a useful taxonomy, the stages identified in this model appear to be very distinct from each other rather than sequential. Indeed, the authors acknowledged that the process is more iterative than linear. It proves useful in identifying the specific stage of the adherence process.

Another useful classification of the process of adherence was presented by Vrijens et al. (2012) in their article “*A new taxonomy for describing and defining adherence to medications*”. The authors defined the process of adherence as comprising three stages: initiation, implementation and discontinuation. Initiation occurs when the patient takes the first dose of his prescribed medication. The second stage, implementation, measures the extent to which the patient adheres to the prescribed regimen, from initiation to the recommended last dose. Discontinuation occurs when the patient ceases to follow the prescribed treatment. This model recognizes that non-adherence can occur prior to initiation (non-initiation) or at any stage in the process. It further acknowledges the role of the patient, the healthcare provider, social support systems and health care policy in determining the outcome of the adherence process.

Unlike the previous model put forward by Gearing et al. (2011), the structure proposed by Vrijens et al. (2012) presents a more linear process between the points of commencing to choosing to discontinue treatment. However, it fails to acknowledge that some patients adhere intermittently. Nonetheless, these models and the evolution of terminologies used to capture a more patient-centred approach to treatment have helped to enhance the understanding of treatment adherence as a process rather than an outcome. This understanding of the *process* of adherence offers a useful guideline for understanding the individual adherent behaviour that may be reflected in the study. As ARV therapy is a recommended lifelong treatment, it is anticipated that the process of acceptance, adjustment and adherence will vary for each individual due to the impact of factors as identified by the WHO (2003).

3.5.3 Factors that impact or predict adherence outcomes

Treatment adherence is a multi-dimensional phenomenon that encompasses a range of factors across multi-levels (Kalogianni, 2011). A range of factors have been identified as impacting patients’ adherence to prescribed treatment regimen. Such factors are inclusive of: medication side effects, complexity of treatment regimen, available social support,

patients' healthcare beliefs, patient-physician relationship and substance abuse (Bissonnette, 2008; Hill et al., 2003; Rand, 1993). The WHO presented five sub-classifications of factors/dimensions that impact adherent behaviour: social/ economic factors, health system/ healthcare team factors, condition-related factors, therapy-related factors and patient-related factors (WHO, 2003). These factors, whether individually or collectively, can impact on how an individual approaches his treatment process.

Social/ economic factors

According to the WHO, social and economic factors are inclusive of poverty, illiteracy, social support networks, transportation costs, unstable living conditions, culture and beliefs surrounding illness and treatment, each of which have been identified as significant determinants throughout the literature (Ingersoll & Cohen, 2008; Kalogianni, 2011; Mehta, Moore, & Graham, 1997). The WHO also accounted for demographic variables such as race and age, though the former was seen as directly related to country of origin and prevailing cultural beliefs (Ammassari et al., 2002; Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007; WHO, 2003). Gender is also argued to be a key demographic variable in understanding adherence behaviour (Kempf et al., 2009).

Patient-related factors

Patient-related factors are identified as those “resources, knowledge, attitudes, beliefs, perceptions and expectations of the patient” (WHO, 2003, p. 30). Depression and psychological illness are noted to contribute to treatment non-adherence (Moosa, Jeenah, & Kazadi, 2007; Vervoort et al., 2007). The patient's acceptance and perception of their illness and the effectiveness of the medication are key considerations (Mehta et al., 1997). Such factors contribute to patient readiness for long-term treatment which has also been found to be a significant determinant of adherence outcomes (Harvey et al., 2008). Research has further found that fear of stigma and isolation due to status disclosure can impact adherence behaviours (Gebrekristos, Lurie, Mthethwa, & Karim, 2009).

Health system/ healthcare team factors

The location of the treatment site, its accessibility, the cost of treatment and the relationship between the health-care practitioner and the patient are recognized determinants of treatment adherence (Mehta et al., 1997). The latter is important in ensuring that patients are comfortable and that they receive sufficient information about their illness and their prescribed treatment, which includes appropriate health management systems. Undoubtedly patients who do not accept and understand their illness and who do not own their treatment process will exhibit greater difficulty adhering to their treatment.

The cost of ARV treatment has been significantly reduced in many Caribbean countries (Osorio-de-Castro, Crisante, Miranda, Oliveira, & Oliveira, 2009). However, there remains related cost factors that may impact the accessibility of treatment such as the cost of general healthcare and the cost of transportation to the requisite health facility.

Condition-related factors

Condition-related factors refer to the illness-specific conditions that may be experienced by the patient (WHO, 2003). Such factors may include the severity of symptoms, the presence and severity of a disability, the presence of other illnesses, the severity or progression of the chronic illness and the availability of treatment (WHO, 2003).

Therapy-related factors

Therapy-related factors are specific to the treatment regime of the patient and may include treatment complexity, duration of treatment, immediacy of positive effects, previous drug failures, side effects and the availability of medical support to address concerns where necessary (Stone et al., 2001; WHO, 2003).

3.5.4 Treatment adherence: the masculinity perspective

No research has been done to understand Jamaican men's process of engaging and adhering to ARV treatment. Limited attention has been given to this issue within the wider literature on men's health, particularly from a qualitative research perspective. However, a study by

Welsh, Duff, Campbelle-Taffe and Lindo (2015) that focused on hypertensive Jamaican men, found that optimal medication adherence was a challenge despite the men having high knowledge scores (Welsh et al., 2015). Both hypertension and HIV/AIDS are chronic illnesses that require long-term treatment, thus this information provides some insights to the behaviours of HIV positive men. Welsh et al. reported that financial constraints impacted the men's ability to obtain their medication and were also identified as a main source of stress. The study failed to provide an in-depth analysis of the men's adherence patterns.

As noted earlier, men's identities are often affected with a positive HIV diagnosis (Baumgartner & David, 2009; Tewksbury & McGaughey, 1998). Research has found that social constructions of masculinity act as a barrier in men accessing HIV-related care, including their ARV treatment (Nyamhanga, Muhondwa, & Shayo, 2013; Siu et al., 2013; Skovdal et al., 2011). A quantitative study that examined the association between masculinity and medication adherence amongst HIV-positive Latino men in the USA found that 'machismo' was associated with lower levels of ARV treatment adherence (Galvan et al., 2014). Taking ARV medication was perceived to be a constant reminder of the illness which countered the cultural notions of masculinity. Thus "non-adherence to medications can become a way to exert control over their situation, as well as a denial of a perceived sense of weakness or vulnerability to being HIV-positive" (Galvan et al., 2014, p. 704). This is consistent with studies that assess the impact of masculinity on accessing treatment for other chronic illnesses (Hawkins et al., 2015). Nyamhanga, Muhondwa and Shayo (2013) found that the men in their study were reluctant to publicly access HIV health services as this challenged their "superior social status". Thus accessing and taking ARV would publicly confirm a health status which disrepute some men's masculinity, especially where those socio-cultural contexts embrace healthy and strong as defining characteristics of masculinity. HIV-related stigma further acts as a barrier to men accessing healthcare services and maintaining their treatment, especially where it threatened social ties and support (Katz et al., 2013).

Studies show that the advent of ARV and the increased access across societies has changed the impact of HIV on masculine identities. Some studies indicate that the provision of ARV medication offers men a sense of hope in regaining their lost masculinity (Siu et al., 2015). This is due to the advance in treatment shifting HIV from a perceived death sentence to a chronic and thus treatable illness (Nyamhanga et al., 2013). By improving their health, ARV medication offers men an opportunity to regain a sense of independence and strength to re-engage in activities as prior to becoming infected. However, there are some men who link ARV treatment to their HIV diagnosis and thus see them both as having negative repercussions, resulting in “dented masculinities” (Siu et al., 2015).

In some instances, access to information and involvement in an HIV support group were noted to be integral in helping men to understand and subsequently adhere to their treatment regimen (Mfecane, 2011; Westerfelt, 2004). However, some of the health messages of support groups can run contrary to the masculine image, especially those that reinforced a sick identity that required men to be disciplined, always travel with their ARV medication and give up certain manly habits such as drinking (Mfecane, 2011).

The absence of literature that present an in-depth analysis of the treatment processes and experiences of men underscores the important contribution of the current study. There also remains a need to understand how these processes and experiences are shaped by social constructions of gender, sexuality and men’s health. These issues become paramount in an era of the HIV epidemic that emphasizes *living* with HIV due to the successes of ARV treatment. Thus it is necessary to garner further insight to the experiences of HIV infected Jamaican men as this could further inform policy and program response that can improve men’s health outcomes in Jamaica.

3.6 SUMMARY AND CONCLUSION

Four main themes were examined in this review of existing literature: the health of Jamaican men and their health-seeking behaviours; men’s health and intersections of identity; men, masculinity and HIV/AIDS; and ARV treatment experiences and the

adherence process for men. Each of these sections provided useful insight to understand issues surrounding the health of Jamaican men, especially those living with HIV/AIDS and generated awareness of gaps and limitations in the literature. Though significant work was done in the early years to conceptualize Caribbean and Jamaican masculinities, none of the discourse on Jamaican masculinity has been explicitly applied to assessing the health of Jamaican men beyond HIV/AIDS. In addition, no literature was found that offered an in-depth qualitative assessment of how these (re) constructions of Jamaican masculinity influence the health experiences, health behaviours and health outcomes of Jamaican men. There is also a paucity of literature on the health of Jamaican men and an absence of literature that examines Jamaican men's experiences of being diagnosed and living with HIV/AIDS, as well as their treatment experiences.

The use of literature from an international context has helped to reinforce the multidimensional nature of masculinity that varies across time, space and cultures. Consistently, the literature showed how men consider and, at times, negotiate or transform their masculinities within the context of their positive HIV diagnosis and treatment regimen. At these junctures, men do not consider only the socio-cultural norms that define their masculine identity, but are also impacted by a range of personal, social and health-system factors. This gives credence to the WHO (2003) five sub-classification of factors that impact adherent behaviour. Thus it is anticipated that social/ economic factors, health system/healthcare team factors, condition-related factors, therapy-related factors and patient-related factors could likely impact the treatment adherence behaviours of HIV-positive Jamaican men. Given the qualitative design and the focus of this study on the treatment adherence process of HIV infected Jamaican men, it is likely that each of these factors will emerge in the study. It is, however, anticipated that social/economic, patient-related and health-system factors will take some pre-eminence given the study aims to assess men's treatment experiences against the backdrop of dominant discourses on gender, sexuality and men's health. This is also due to the focus on assessing the role of social structures and process in influencing the men's treatment experiences and outcomes.

Chapter 4 RESEARCH METHODOLOGY AND DESIGN

*The actuality of our experience is multiplicative. Multiply each of my parts together, 1 x 1 x 1 x 1 x 1, and you have **one** indivisible being. If you divide one of these parts from one you still have **one**.* (Wing, 1990, p. 194)

4.1 INTRODUCTION

This study utilized an intersectionality-informed qualitative research design. Intersectionality was birthed within Black feminist theory and is thus largely informed by some of the main tenets of the feminist epistemology. The main ideas characterizing intersectionality theory, along with the focus on HIV/AIDS as a public health issue, helped to shape the research question and guided the data collection and analysis process. The qualitative nature of the study allowed an in-depth understanding of the complexities and richness of the participants' experiences of HIV treatment adherence (Denzin & Lincoln, 1994).

Intersectionality theory provides an understanding of “the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power” (Davis, 2008, p. 68). The perspective has been described in the literature as providing a valuable basis for research that examines the “interlocking systems of oppression” that surround particular social identities (Cuadraz & Uttal, 1999, p. 159). Though the theory formally emerged within Black feminism, a number of researchers have since utilized the framework to inform studies on men and men's health (Bowleg et al., 2013; Griffith, 2012; Hankivsky, 2012; Mburu et al., 2014). Thus, it was perceived that intersectionality theory provided a useful and relevant lens through which the issue of treatment adherence for HIV positive Jamaican men could be interrogated, especially given its value in assessing issues of power, inequality and marginalization. The marginalization of Jamaican men is not a new concept, being largely examined in the context of gender socialization and education in Jamaica (M. Figueroa, 2000; Miller, 1994). However, the

current study has endeavoured to move beyond the general periphery of the marginalization of Jamaican men, by using an intersectionality lens to unveil the issues of difference, inequality, and dominance that often interact in defining the identities of, and health outcomes for, Jamaican men. At the centre of this research process, was an interrogation of how the different dimension of the men's identities intersected at varying levels to influence their ARV treatment experiences and adherence outcomes.

The research question addressed in the study was *“How do the social identities of HIV positive Jamaican men intersect to influence their ARV treatment experiences and adherence outcomes?”* This question aimed to investigate how issues surrounding gender, sexuality, and men's HIV health status were experienced by the men. It further endeavoured to examine how the men responded to such issues in the context of their ARV treatment. Four sub-questions were generated to further guide the research focus and design:

- i. *How do HIV positive Jamaican men perceive their ARV treatment and define their ARV treatment adherence process?*
- ii. *How do the men self-identify against the backdrop of dominant discourses surrounding gender, sexuality and men's health status?*
- iii. *What are the social processes and structures that influence the men's identities and choices regarding their ARV treatment?*
- iv. *How might a better understanding of the ARV treatment experiences and adherence outcomes of HIV positive men inform HIV policy and program development in Jamaica?*

This chapter begins with an overview of feminism as the epistemological underpinning of intersectionality theory. The main tenets of intersectionality are then discussed and its usefulness as a methodology evaluated. Some of the forefront contributions to an

intersectionality research framework are presented, after which an in-depth discussion of Winker and Degele's (2011) multi-level framework, as adapted in this study, is provided. The research design is then outlined, charting the research process from its inception through to the data analysis and presentation of findings.

4.2 INTERSECTIONALITY: BLACK FEMINISM AND BEYOND

Intersectionality theory was birthed during the 1980s in response to a critique of feminist scholarship's primary focus on gender in explaining women's subordination (Cuadraz & Uttal, 1999; Trahan, 2011). The term is credited to Kimberlé Crenshaw (1989) who, in her early work, challenged the feminist tradition of treating gender and race as mutually exclusive categories. It was argued that feminist scholarship, in attempting to privilege issues of gender, failed to examine the importance and roles of other factors that equally impacted the realities of women's lives (Cuadraz & Uttal, 1999). Crenshaw's work, though foundational, was noted to be limited in her focus on the intersection of race and gender in defining the experiences of Black women. Further, the emphasis on the 'double jeopardy' of Black women was seen to epitomize the additive approach that intersectionality theorists have increasingly endeavoured to avoid (Grollman, 2014). This prompted the Black feminist movement of deconstructing issues of gender, race and class as interdependent rather than distinct constructs (Bowleg, 2008; Trahan, 2011).

White, Russo and Travis (2001) identified four fundamental principles of feminist research: "inclusiveness and diversity, the importance of social and historical context, combating power and privilege, and social activism" (p. 267). Feminists perceive gender to be constructed by the social and historical contexts in which men and women live (J. White, Russo, & Travis, 2001). These socio-historical contexts influence a range of power dynamics that result in experiences of inequality, oppression, and the subjugation of women (Beckman, 2014). The effect of gender is, however, intermediated by other dimensions of identity such as race, class, sexuality and disability or any "other social dimensions that involve differential access to power and privilege, and that may carry stigma and elicit prejudice and discrimination" (J. White et al., 2001, p. 272). It is in recognizing these

multiple identities and their interactions/ intersections that intersectionality was developed (Beckman, 2014). As Beckman (2014) elaborated, “those conducting feminist research not only recognize that the person is composed of many intersecting socially constructed identities, but also understand that these interacting multiple identities are fluid and complex” (p. 168). Finally, feminism is based on the principle of activism directed at creating a system of equality that removes differential lines and hierarchical positions (Hesse-Biber, 2014; J. White et al., 2001).

Men have traditionally been a subject of critique in feminist theory (Holmgren & Hearn, 2009). However, over the years the scope of feminism has broadened to examine how men have also been impacted by historical, political and socio-cultural processes (Sabo & Gordon, 1995). This theorized “inclusive feminism” is seen to encompass a range of studies on men (Sabo & Gordon, 1995) and masculinity such as those emerging in critical studies of men (CSM). Some of these studies have recognized the importance of rethinking men’s approach to health and illness through appropriate research lens (Sabo & Gordon, 1995). Intersectionality offers an additional perspective through which to analyse how men simultaneously experience privilege and disadvantage, and the implications for their health outcomes. This was aptly captured by Griffith (2012) who stated:

Men’s lives and health are rooted in opportunity structures that are shaped by race, ethnicity and other characteristics that have important social, political, economic and cultural meaning. Within men’s health, there is a need to consider how structural factors and men’s socially-defined characteristics affect the relationship between sex, gender and health. The goal of an intersectional approach is to simultaneously examine the social and health effects of several key aspects of identity and context in ways that create a new understanding of these factors and that are a more accurate reflection of the lived experiences of the populations of interest. (Griffith, 2012, p. 106)

Thus an intersectionality approach supports a critical interrogation of the role of socio-cultural and historical forces in shaping men’s identities, health approaches and subsequently, health outcomes.

4.3 THEORISING INTERSECTIONALITY

Intersectionality as a theoretical framework allows us to understand how multiple, layered and intersecting categories of difference are shaped by socio-historical contexts (Bowleg, 2012; Crenshaw, 1991; Davis, 2008). Further, it exposes ‘systems of oppression’ that help to position individuals within a hierarchy of power and privilege (Carastathis, 2014). According to Bilge (2009), these “multiple social relationships structured in dominance...reinforce each other and co-constitute subject positions and shape life experiences” (p. 3). Intersectionality highlights an interactive process that exists not just at the individual level, but in relation to others and across varying levels in the society (Bowleg, 2012). It also points to the impact these processes have in shaping the life experiences of persons.

The ‘multidimensionality’ nature of identity is one of the hallmark characteristics of intersectionality (Crenshaw, 1989). Here, intersectionality analysis regards intersections of class, race and gender, and lends itself to examining other categories of difference such as sexuality and disability (Grollman, 2014; Guittar & Pals, 2014). Importantly, these multiple identities are not examined as independent constructs but are analysed simultaneously to understand the complex nature of identity. As Nash (2008) asserted, “intersectionality has worked to disrupt cumulative approaches to identity (i.e. race + gender + sexuality + class = complex identity)” (p. 6). Here, the additive approach implies that social inequality increases with each added category of difference (Bowleg, 2008). Thus, as Bowleg (2008) illustrated, a Black lesbian is deemed to experience triple jeopardy as a result of her ethnicity, sexuality and gender. Rather than this additive approach, intersectionality theorists maintain that a *multiplicative* relationship exists across the various categories that shape the social experiences of disenfranchised groups (Hancock, 2007; Nash, 2008). Thus intersectionality as a methodology and theoretical perspective is celebrated as offering the vantage point of addressing the “simultaneity, complexity, irreducibility and inclusivity” required in understanding the multidimensional nature of identity (Carastathis, 2014, p. 304).

Another key facet of intersectionality is the acknowledged role of socio-historical contexts in informing the power dynamics that influence identity. This stems in part from intersectionality being grounded in the feminist tradition which gives credence to history and politics as drivers of power imbalances in social relations (Hancock, 2007; Symington, 2004). As Hancock (2007) further stated, within intersectionality

[t]he domains of power thesis elaborates upon these theoretical roots by delineating a shared, integrated terrain upon which various categories of difference intersect. It identifies the hegemonic (ideas, cultures and ideologies), structural (social institutions), disciplinary (bureaucratic hierarchies and administrative practices), and interpersonal (routinized interactions among individuals) playing fields upon which race, gender, class, and other categories or traditions of difference interact to produce society. (p. 74)

The intersectionality approach is noted to give precedence to the voice of those being researched as opposed to methodologies where the researcher's voice and agenda is central (Cuadraz & Uttal, 1999). Thus intersectionality is one product of the shift away from the perceived Eurocentric, masculine and positivist domain (Cuadraz & Uttal, 1999). Intersectionality theory's endeavour to focus on the "experiences of subjects whose voices have been ignored" (Nash, 2008, p. 3), gives credence to its use in this study for understanding the experiences of HIV positive men in Jamaica; a group largely silenced by the norms that dictate appropriate maleness. This benefit exists in tandem with the other main tenets of the approach that would chart the experiences of Jamaican men as a socio-historical and political process, and the importance of a move towards empowerment and social transformation.

Beyond being a 'buzzword' (Davis, 2008) or 'catchall phrase' (Phoenix, 2006), as it has been described by earlier writers, intersectionality lends itself to being a transformative tool that exposes visages of dominance and oppression whilst presenting an opportunity for redress. Here intersectionality endeavours to overcome multiple oppressions by "generating counter-hegemonic and transformative knowledge production, activism, pedagogy and non-oppressive coalitions (Bilge, 2013, p. 405), which is achieved in part by facilitating an

awareness that questions taken-for-granted norms that have been treated as universal (Dant, 2003). It is anticipated that an intersectionality approach will inform policy and practice changes that will help to foster an inclusive society (Carastathis, 2014).

4.4 ARGUING FOR AN INTERSECTIONALITY METHODOLOGY

Some authors have challenged the value of intersectionality as a methodological approach stating that it has failed to present a clear pathway for doing intersectionality research (Chang & Culp, 2002; Nash, 2008). This has been primarily based on the perceived gaps between the discourse of intersectionality theory and its application as a research paradigm and methodological practice (Bilge, 2009; Bowleg, 2008; Nash, 2008). The methodological challenge has been further attributed to “the complexity that arises when the subject of analysis expands to include multiple dimensions of social life and categories of analysis” (McCall, 2005, p. 1772). Despite these methodological concerns, there have been increasing efforts to clarify and validate intersectionality as a valid research methodology, especially in examining issues of power imbalances, inequality, oppression and injustice (Bilge, 2009; Bowleg, 2008; Cuadraz & Uttal, 1999; Hancock, 2007; McCall, 2005; Winker & Degele, 2011). Of these efforts, a few intersectionality theorists were recognized as being more prevalent in the literature, particularly McCall (2005), Hancock (2007), Bowleg (2008), and Winker and Degele (2011).

4.4.1 Leslie McCall

McCall (2005) advanced three distinct intersectional methodological approaches for studying the complex and multidimensional nature of identity. McCall posited that a noteworthy strength of intersectionality, as a methodology, is its ability to assess the complexities or “multiple dimensions of social life and categories of analysis” (p. 1772). McCall’s work is widely cited in intersectionality literature; though this is not an indication of its usage in informing intersectionality studies. The three methodological approaches: anticategorical complexity, intercategorical complexity and intracategorical complexity revolve around how categories are treated in a particular research design. Anticategorical complexity rejects the use of categories as these are seen to oversimplify and embody

notions of exclusion and inequality. The second approach, intracategorical complexity, is positioned as a mid-point between the polar anticategorical and intercategorical approaches. It facilitates the strategic use of categories whilst being critical of their “boundary-making and boundary-defining process” (McCall, 2005, p. 17736). At the end of the continuum, intercategorical complexity (also referred to as the categorical approach) is noted to support the strategic use of categories “to document relationships of inequality among social groups and changing configurations of inequality along multiple and conflicting dimensions” (McCall, 2005, p. 1773). Here categories are used strategically to unveil issues of inequality that may also rest within these predefined categories.

Though McCall’s (2005) three typologies of intersectionality methodologies have been instrumental in the development of intersectionality research methodology, they have also been identified as having significant limitations. For instance, McCall’s intracategorical complexity was criticized for its danger of eroding the significance of group identification which holds some importance in determining difference (Winker & Degele, 2011). It is also cautioned that McCall’s focus on a “single primary axis of social inequality” risks cultural reductionism (Walby, 2007). In addition, McCall’s anticategorical approach has been charged for doing the very thing intersectionality proclaims to avoid by focusing on deconstructing single categories of difference, despite the rationale of exposing relationships of inequality within the categories themselves. Another noted limitation has been her failure to embrace a multi-level approach which examines issues of differentiation and inequality across levels of identity, social structure and representation (Winker & Degele, 2011).

4.4.2 Ann Marie Hancock

Hancock (2007) argued that intersectionality’s value as a research paradigm was based on the significance given to multiple categories of analysis, whilst locating them against the backdrop of particular socio-political and historical contexts. As Hancock further indicated:

intersectionality posits an interactive, mutually constitutive relationship among these categories and the way in which race (or ethnicity) and gender (or other relevant categories) play a role in the shaping of political institutions, political actors, the relationships between institutions and actors, and the relevant categories themselves. (p. 67)

Hancock further justified her position by charting how intersectionality addressed key methodological questions such as the conceptualization of each category and the levels of analysis. Despite Hancock's contribution in characterizing some important methodological qualities of intersectionality theory, it is recognized that a methodological approach needs to provide "a theory and analysis of how research does or should proceed" (Harding, 1987, p. 3). This would require extending the discussion beyond key principles, to outline the procedures and process involved in engaging in intersectionality research (Carter & Little, 2007).

4.4.3 Lisa Bowleg

Bowleg (2008) offers further insight to doing qualitative and quantitative intersectionality research. In particular, she asserted that intersectionality research requires an evaluation of individuals' experiences across both micro and macro levels. As such, "multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socioeconomic status) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level" (Bowleg, 2008, p. 1267). Bowleg (2008) draws on Cuadraz and Uttal's (1999) recommendation of first examining the participants' experiences surrounding a particular phenomenon, after which these experiences can be further examined to assess the role of historical processes and social hierarchies in shaping these experiences. Bowleg's (2012) approach is recognized as offering some value to health research that aims to expose health disparities that occur as an outcome of interlocking systems of oppression across micro and macro levels.

4.4.4 Gabriele Winker and Nina Degele

Winker and Degele (2011) proposed that intersectionality research be analysed across three levels that subsume the micro-macro duality and introduced a space to assess the role of cultural norms, values and ideologies. They suggested an analysis of “interrelated categories of inequality on various levels... [comprising] social structures, including organizations and institutions (macro and meso level), as well as processes of identity construction (micro level) and cultural symbols (level of representation)” (Winker & Degele, 2011, p. 52). This approach is aligned to feminist theorist, Sandra Harding’s (1986) discourse on the symbolic, structural and individual aspects of social genders (Winker & Degele, 2011).

As with other intersectionality theorists, Winker and Degele (2011) recognized that a person’s identity is often constructed in reference to, and delineated from, others. This “doing difference approach” shows the interrelatedness of categories and complexity surrounding identity construction (Winker & Degele, 2011, p. 54). Thus Winker and Degele proposed that the first level comprise identifying all categories of differentiation surrounding an individual’s identity. The outcome of this process is either an identity that creates a sense of belonging or differentiates an individual from other reference groups.

At the second level, symbolic representations are noted to comprise “norms, ideologies and representations, used as hegemonically verified justifications [and] are based on naturalizing and/ or hierarchy-creating assessments” (Winker & Degele, 2011, p. 54). Here, symbolic representations are identified as norms and values surrounding categories of difference. These norms and values often support and are reinforced by social structures (Winker & Degele, 2011).

For Winker and Degele (2011) the third level of analysis is at the social structure level and involves “identifying concrete relations of power and then analysing their interrelatedness and changes” (p. 54). The identification and description of these relations of power and inequality can be informed theoretically; however, their interrelatedness must be based on

empirical research that documents the historical, observed and investigated (Winker & Degele, 2011). Race, class and gender are identified as the starting points for this structural analysis given intersectionality traditionally “understands gender, ethnicity/ race and class as oppressive structural categories, since history has shown how unequal allocation of resources (and consequently also of life chances) run alongside these three lines of difference (Winker & Degele, 2011, p. 55). The authors treat gender as subsuming a person’s sexuality, thus not warranting sexuality being listed as a separate social category. They justified this by arguing that “heteronormativisms denote power relations that are grounded in hierarchical gender relations as well as in unquestioned assumptions about naturalized heterosexuality and a binary gender order” (Winker & Degele, 2011, p. 55). In addition, Winker and Degele proposed including body as a fourth structural category, which was perceived to be “less as a fact of nature, and more a product of culture, due to the fact that it can be manipulated mechanically, genetically, mentally and physiologically” (Winker & Degele, 2011, p. 55). The sense of ‘bodily productivity’ could impact a person’s employability and thus resources and quality of life (Winker & Degele, 2011). This body category is noted to include a range of terminologies or conditions affiliated with the physiological nature of the human body, such as age, appearance, ability and disability.

Altogether, Winker and Degele’s (2011) focus on the powered relations that emanate from social categories (class, gender, race and body), and that are represented at the structural level, for example: classism, racism, sexism, heteronormativism and bodyism. Further, they are concerned with the interrelatedness of power relations which are underscored by historical processes (Winker & Degele, 2011). These structural level factors are interconnected through social practices that also interrelate with the construction of identity and symbolic representations. According to Winker and Degele, “through social practices like social action and speech, individuals delineate themselves in social contexts, construct identities, process symbolic representation, support social structures or challenge them” (p. 56).

4.4.5 Identifying a framework for this study

Winker and Degele's (2011) three-layered analysis across identity, social structure and symbolic representation was deemed to be valuable for this study given its contribution of a multi-level framework that encompassed the general micro-macro levels, but also provided a third level that assessed the role of cultural norms, values and ideologies. The incorporation of this third level of analysis sets Winker and Degele's framework apart from other intersectionality researchers' focus on either one, or at most two of these interwoven layers. Absent in these two-tiered approaches is the specified focus on norms, values or prevailing ideologies that are often reinforced by social institutions, imprinted on the identity construction process of individuals, and ultimately shape their personal experiences. It is the added dimension of analysing the influence of culturally embedded processes that signalled the usefulness of Winker and Degele's framework for the current study. It is recognized that Jamaican men's health approaches are impacted by their identity constructions, social-structural forces such as stigma and discrimination, as well as prevailing norms, symbolisms and values surrounding their identity and often embedded in socio-historical processes.

Winker and Degele's framework was deemed particularly relevant in guiding the data analysis, which is discussed in-depth in section 4.12. Though useful, it was adapted to incorporate some of the ideas put forward by Bowleg (2008) and Cuadraz and Uttal (1999) in developing the research design. Altogether, Winker and Degele's multi-level approach was seen to enable the researcher to capture how HIV-positive Jamaican men's treatment experiences and practices are influenced by overlapping layers of their identity constructions, prevailing socio-cultural and historical norms and values, as well as the social structures and institutions within which these men function daily.

4.5 THE INTERSECTIONALITY APPROACH USED IN THIS STUDY

4.5.1 Applying Winker and Degele's multi-level framework to this study

Level 1: Identity constructions

The study commenced with the researcher deductively identifying three social categories of difference to be examined: gender, sexuality and HIV health status. Though Winker and Degele (2011) suggested that the number of social categories to be used remains open, this was not deemed feasible given the nature and scope of a doctoral project. Instead, the social categories examined in this study were informed by the literature reviewed that indicated the interlocking roles of men's gender, sexuality and acquired HIV status in shaping their health experiences and outcomes (Doyal et al., 2009; Siu et al., 2013; Sikweyiya et al., 2014; Siu et al., 2015). The definition of these categories were not fixed; instead room was given for the participants to define and delineate these social categories in their narratives. As a result, sexuality broadened from the typical dichotomy of heterosexual or MSM (or gay) to include heterosexual, feminine MSM and masculine MSM.

Whereas Winker and Degele conceptualized gender to subsume sexuality, it was determined that this naturalized linkage between sexuality and gender is patriarchal, universalistic and thus contestable against the backdrop of an openness of categories maintained within intersectionality. As Anthias (2014) postulated,

There has been a tendency (at the risk of over-simplifying quite complex arguments) to see gender as a product of the social organisation of sexuality and to regard sexuality as expressive of gender with differential and varied forms of causality implied. (p. 154)

The decision was taken to maintain sexuality as a separate social category to avoid an over-simplification or reduction of the significance of sexuality. This was deemed to better capture the complexities that could emerge in assessing the interrelatedness across social categories that may adhere to the preconceived linkage proposed by Winker and Degele.

Level 2: Symbolic representations

Symbolic representations were identified as norms and values surrounding the participants' gender, sexuality and HIV status that helped to shape their identity construction, treatment experience and adherence outcomes. These norms and values often support and are reinforced by social structures (Winker & Degele, 2011), unveiling the subliminal top-down process of hegemonic and socio-historical ideologies being passed on through everyday conversations. As a result, the researcher endeavoured to expose and examine the overt and subtle tendencies of domination and oppression buried in the norms, values and ideologies surrounding gender, sexuality and HIV health status in Jamaica, and their interwoven impact on the participants ARV treatment experiences and adherence outcomes.

Level 3: Social structures

Though Winker and Degele (2011) proposed that race, class and gender should be included initially as starting points for the structural analysis, it is maintained that this is largely dependent on the population of focus. Thus it is not expected that irrelevant social categories be imposed on the understanding of certain populations. This would erroneously repeat the mistake of a unidimensional thinking that assumes a certain trajectory for the reality of groups, including HIV-positive Jamaican men, and the issue under investigation: treatment adherence. As alluded earlier, the demographic composition of Jamaica currently does not present race/ ethnicity as a centralized social category though this is largely dependent on the issue being investigated.

It was acknowledged that class could be an important consideration in both the identity construction and health outcomes of the men. Given the clients who access the services of the research clinic are predominantly from a low socio-economic background, it was not expected that class distinctions would add to the complexity of the participants' identities. Rather, issues of poverty, which exists at the structural level, were expected to impact some men's health choices and access to certain services, including their choice to seek treatment from a public rather than private treatment facility. The role of men's socio-economic status

in shaping their health approaches and outcomes is also reinforced in the literature (Cheatham, Barksdale, & Rodgers, 2008; Galdas et al., 2005). Overall, effort was made to be guided by the most paramount social categories chosen for this study which were gender, sexuality and HIV status, whilst giving space to those constructs that emerged as important in the men's narratives.

Following the illustrations provided by Winker and Degele (2011), the powered relations emerging from the social categories chosen for this study included heteronormativity, HIV-related stigma and MSM-related stigma. These structural level factors are interconnected through social practices that also interrelate with the construction of identity and symbolic representations. According to Winker and Degele, "through social practices like social action and speech, individuals delineate themselves in social contexts, construct identities, process symbolic representation, support social structures or challenge them" (p. 56). For this study, social practices were identified as the treatment experiences and adherence behaviours of HIV-positive Jamaican men. Following the guidelines put forward by Winker and Degele, these treatment experiences and behaviours that would determine the men's adherence outcomes, became the starting point of the data collection and analysis. As they further explained: "This means...beginning with our analysis in the everyday life of people. Starting out from the social practices of a person, we are able to reconstruct identities they construct, as well as the structures and norms they draw on" (Winker & Degele, 2011, p. 57).

The notion of commencing with the everyday life of people is quite similar to Cuadraz and Uttal's (1999) and Bowleg's (2008) recommendation of commencing with the personal biographies or experiences of each individual and thereafter enquiring of the extent to which a particular phenomenon is impacted by structural forces such as race, class and gender. This strengthens the "strategy of fluctuation and comparison" used by Winker and Degele (p. 57), which maintains a stepwise though iterative process of analysis.

Thus, applying Winker and Degele's (2011) approach to this study first required having an understanding of the men's experiences surrounding their HIV diagnosis and treatment. An in-depth understanding of how the men experienced their HIV diagnosis and subsequently approached their treatment provided the base for the following questions to be asked:

- Which categories of difference or inequality do the men relate to? How do they identify in light of their gender, sexuality and HIV health status? Do any other categories of difference emerge in their narratives?
- Which norms, principles and interpretive patterns affect them?
- What are the structural and historical contexts that influence their identities, recognized norms or cultural symbolisms, and agency in terms of their treatment adherence behaviours and outcomes?

Following the pathway provided by Winker and Degele (2011), answering these questions would allow a correlation of the three levels of analysis in the study, whilst addressing the interrelationship between the noted categories of difference.

4.6 CHALLENGES IN USING THE INTERSECTIONALITY APPROACH

Despite the apparent usability of intersectionality, given its popularity across varying disciplines (Hancock, 2007), there remains noteworthy criticisms that are important to address, especially within the contours of the current study. Four main criticisms will be presented and justifications or responses of how these have been overcome in this study will also be discussed. These criticisms emerge primarily from the main merits for which intersectionality has been credited.

4.6.1 The simultaneity of intersectionality

Perhaps the main pillar of intersectionality is the notion that it allows for the simultaneous analysis of multiple, intersecting categories of difference (Carastathis, 2014). However, as noted in section 4.4, there has been a failure to present an explicit research pathway on "researching simultaneous oppressions without reducing them to unitary categories or

merely reverting to an additive model” (Carastathis, 2014, p. 308). This ambiguity is likely due to the recognized difficulty, if not impossibility, of simultaneously examining multiple intersecting categories of difference.

In response, some authors have argued for the necessity of separating categories for analysis. As Bowleg (2008) asserted, “addition is often a critical step in preliminary analysis” (p. 319). Cuadraz and Uttal (1999) generated a process where the researcher would first analyse “each experience, each structure and biography relationship, separately before asking about their intersectionality” (p. 177). Thus intersectionality analysis commences with analysing categories in relation to individual accounts of their experiences, after which it is determined how these identified categories and their impact on individual experiences are further shaped by cultural, norms, values and ideologies, and structural processes such as heteronormativity, classism, ableism and sexism (Winker & Degele, 2011). Thus, “by understanding how the current moment and historical processes both shape how individuals view their experiences and live their lives, a bridge between individual experience and social context is made” (Cuadraz & Uttal, 1999, p. 179).

In this study, HIV-positive Jamaican men’s experiences surrounding their ARV treatment were examined within the context(s) in which they are presented. Next, these accounts were examined in relation to cultural norms and ideologies, and socio-historical constructs of difference and domination that could have shaped the treatment experiences, practices and adherence outcomes of the participants. The categories of difference examined focused on gender, sexuality and HIV status, which were informed by the review of the literature and reinforced in the men’s narratives.

4.6.2 The realm of complexity and irreducibility

Intersectionality is argued to tackle an ‘insurmountable complexity’ in its bid to address an indefinite list of categories of difference (Ludvig, 2006). As a result, “it is impossible to take into account all the differences that are significant at any given moment” (Ludvig,

2006, p. 246). This seemingly infinite list of categories of difference makes doing intersectionality analysis difficult, if not clumsy. As Butler (1990) stated:

Theories of feminist identity that elaborate predicates of colour, sexuality, ethnicity, class and able-bodiedness invariably close with an embarrassed 'etc.' at the end of the list. Through this horizontal trajectory of adjectives, these positions strive to encompass a situated subject, but invariably fail to be complete. (p. 143)

Thus the questions are asked: Who determines which categories are salient? How can this be done or on what basis? Or as Ludvig (2006) pondered: "*Who* defines when, where, which and why particular differences are given recognition while others are not?" (p. 247).

Though clear responses to these questions were not identified in the intersectionality literature examined, it was felt that for the purposes of this study, that salient categories of difference be identified through the review of existing literature. From the review, it was determined that gender, sexuality and HIV health status were three important categories of difference given the nature and scope of this study. This choice was further evaluated by allowing the participants to identify (directly or indirectly) the categories of difference that are salient to their identity, which allowed an opportunity to either corroborate or modify the initial choice of categories. Bowleg (2008) suggested that, by asking the respondent to simply share his experience, this would allow him the opportunity to identify the categories of difference perceived as central to his experience. This can then be used to validate the researcher's initial selection of categories. Cuadraz and Uttal (1999) and Bowleg (2008) acknowledged the space for the researcher to further interrogate the narratives of participants by identifying how their accounts are shaped by socio-historical positions on the basis of relevant categories of difference. Presumably, this relevance would be identified by an informed awareness of the 'situational location' ("contemporary moment about which the account reports") and social location ("histories of race, class, and gender stratification (and other structural forms of domination)" of these individuals (Cuadraz & Uttal, 1999, p. 179).

Following the guidelines provided by Bowleg (2008), initiating questions asked about men's experiences with their treatment which commenced with their HIV diagnosis. An opening was made for the men to tell *their* stories in an unhindered way. This became an easy platform for some men to move beyond a mere description of their experience, into more detailed narratives about aspects of themselves that predisposed them to experiences of inequality or discrimination. Such narratives were not always explicit and thus it became necessary, at times, for the researcher to go further, as asserted by Cuadraz and Uttal (1999), in explicating how certain structural and socio-historical processes further impacted the men's treatment experiences and adherence outcomes. This move was not done independent of the men, but was rather corroborated either later in the interview or in a follow-up interview, and further interrogated in reference to the literature. This approach is supported by both the epistemological and ontological viewpoints underpinning the study, which acknowledge the role of the researcher, and creates space for the interpretation of more hidden meanings (Guba & Lincoln, 2004; Maxwell, 2012). Overall, this method avoided the challenges surrounding both the simultaneity and complexity of intersectionality.

4.6.3 The scalar reach of intersectionality

Carastathis (2014) identified that intersectionality is critiqued for its noted scalar reach across micro-, meso- and macro- levels. Davis (2008) alluded that there is some uncertainty about "whether intersectionality should be limited to understanding individual experiences, to theorizing identity or whether it should be taken as a property of social structures and cultural discourses" (p. 68). Such a statement likely returns to the variations of the intersectionality approach, some of which have focused on micro-level analysis and some that have focused on the structural influences.

The move to provide a micro-macro scope of analysis is not as elusive as suggested by Carastathis (2014) and Davis (2008). According to Hancock (2007), "Most intersectionality scholars share the logic that multiple marginalizations of race, class, gender, or sexual

orientation at the individual and institutional levels create social and political stratification, requiring policy solutions that are attuned to the interaction of these categories” (p. 65). Further, a number of scholars, such as McCall (2005), Bowleg (2008), and Winker and Degele (2011), have embarked on intersectionality research or theorizing that explicitly outline how intersectionality is achieved across varying levels. For this study, Winker and Degele’s multi-level analysis was deemed appropriate to guide the data analysis given the aim to understand how the treatment experiences and adherence outcomes of HIV-positive Jamaican men (micro-level) are impacted by their socio-historical positions and related cultural norms and ideologies, due to particular categories of difference (meso- and macro-level). The stepwise process adopted from Winker and Degele is discussed in section 4.12 of this chapter.

4.6.4 Intersectionality as a transformative tool

It is questioned whether intersectionality can truly achieve its normative goal of social transformation that ensures the inclusion of historically marginalized groups. There is the perception that intersectionality may result in a further fragmentation of persons (Carastathis, 2014). Thus there is a fear of a reification of a hierarchy of difference which intersectionality endeavours to diminish. Perhaps a useful example is the recognition that developed policies often focus on target populations that are based on the very stereotypes that intersectionality aims to dismantle (Hancock, 2007). As Hancock (2007) noted, “These social constructions of target populations are based on stereotypes about particular groups from political, culture, the media, and history, among other influences” (p. 65). How then does intersectionality escape the trap of reinforcing labels and stereotypes that highlight groups of difference? This question remains perhaps as a cautionary note in determining the outputs of intersectionality studies and projects.

Some assurance is taken from Bilge (2013) who asserted that intersectionality was originally intended as

an analytical and political tool elaborated by less powerful social actors facing multiple minorizations, in order to confront and combat the interlocking systems of power shaping their lives, through theoretical and empirical knowledge production, as well as activism, advocacy and pedagogy. (p. 410)

It is not the researcher's intent to merely contribute to a growing body of literature on intersectionality or the paucity of same as it surrounds HIV-positive Jamaican men. It is intended that the findings of the research contribute to an increased awareness at the micro- and meso- levels that could lead to individual and organizational changes. To this end, an interim report was developed and submitted to the study clinic that shared some of the key findings but focused primarily on the recommendations emerging from the men and those identified early in the data collection and analysis phases. Further, the researcher has and continues to engage in critical discussions and dissemination of the research in a range of academic and non-academic forums.

4.7 REAFFIRMING THE VALUE OF AN INTERSECTIONALITY APPROACH TO THIS STUDY

Overall, the use of intersectionality theory as the theoretical lens informing the study, is justifiable on multiple grounds: 1) its focal population, HIV positive men whose behaviours and identities are largely shaped by the prescribed socio-cultural norms that determine manhood; 2) the experience of living with HIV is intertwined with experiences of stigma that are hinged on being HIV positive, and may extend to assumptions surrounding other categories of difference such as sexuality and gender; 3) the recognition that treatment adherence behaviours and outcomes for these men are not determined solely by their individual choices. Rather such choices are shaped by a range of social, cultural, economic and political factors; and 4) the potential for change rests in the men's recognition and rejection of the dominant ideologies that define their medication adherence behaviours.

The researcher endeavoured to engage the research critically, allowing the men to share their treatment experiences and identify issues that impacted their adherence outcome. Further, this lens allowed the researcher to infer areas of overt and covert injustices,

hegemony and power dynamics across intersecting areas of HIV health status, gender, sexuality and, in some instances, economic well-being. Beyond this, the researcher had the opportunity to engage with some of the men on ways to improve their health outcomes. Such discussions built on their recommendations or expressions of interest and included their participation in a male HIV support group, being more committed to their treatment regimen, and researching medical concerns and discussing these openly with their doctors.

4.8 RESEARCH DESIGN

This section outlines the specific methods/techniques used in the data collection and analysis processes. It presents a demographic profile of the participants included in the study, describes the participant recruitment procedures, discusses the ethical considerations and outlines the data analysis techniques employed.

4.8.1 Research site

The researcher obtained the permission and support of the Centre for HIV/AIDS Research, Education and Services (CHARES) to access their patient population for the recruitment of study participants. The CHARES is located at the University Hospital of the West Indies (UHWI), which is situated in the parish of Kingston, Jamaica. CHARES is one of the few clinics that offer HIV specialized care in Jamaica. As a non-governmental organization, it provides both clinical and psychosocial services to persons living with HIV/AIDS in Jamaica and thus represented a useful access point for HIV positive Jamaican men (Clarke et al., 2010).

The clinic has a small staff complement comprising two social workers, three administrators, one adherence counsellor and one permanently appointed clinical practitioner. This staffing is supplemented by residential doctors attached to the training hospital, and graduate level students from surrounding universities on practicum placement. A range of staffing issues were noted during the period of data collection including the resignation of both social workers in short succession.

4.8.2 Researcher reflexivity

Feminist research, from which intersectionality is birthed, identifies the research process as dialogic, thus making it important for the researcher to also acknowledge her role in shaping the dialogue and the emergent data (Beckman, 2014; Jones et al., 2014). This was done through a process of research reflexivity which is defined as “the continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions” (Darawsheh, 2014, p. 560). Reflexivity functions to enhance the rigour and thus credibility of qualitative research findings (Darawsheh, 2014; Jootun, McGhee, & Marland, 2009). It also gives space to the researcher’s critical self-reflection that could help to unveil patterns of privilege or disadvantage, as well as contribute to an enhanced awareness of the participants that could lead to more egalitarian relationships (Beckman, 2014). Researcher reflexivity in this study was maintained by engaging in a presuppositions interview, maintaining researcher memos and debriefing with a supervisor especially at the most difficult junctures in the data collection process. Each of these approaches has been identified as useful strategies in the researcher reflexivity process (Berger, 2015; Birks, Chapmen, & Francis, 2008; Darawsheh, 2014; Ibrahim & Edgley, 2015).

Reflexivity is noted to occur throughout the research process, such as during the research design, data collection or analysis stages (Berger, 2015; Darawsheh, 2014). The research process commenced with the researcher engaging in a presuppositions interview with an occupational therapist familiar with her study. This allowed the researcher to explore her suppositions of her personal values, cultural awareness, and sensitivities going into the field (See section 1.6, p. 11, for a detailed discussion of this process). A presuppositions interview helps to position the research within the subjectivism epistemology which acknowledges the impact of the researcher’s value system in the research process and development of the data (Guba & Lincoln, 1994; Holden & Lynch, 2004). This awareness then allowed the researcher to be cognizant of her personal values, and thus limit the potential biases that could emerge in the data collection and analysis process. To illustrate,

the researcher was cognizant of the need to ‘couch’ her religious values surrounding morality, that could potentially influence her perception of the lifestyles and choices of the participants. This was not difficult to achieve given her prior years of working with PLHIV and personal belief in respecting the rights of all persons. Nonetheless, this process of reflecting on one’s own personal values in a research was noted to enhance the credibility of the research process (Berger, 2015; Jootun et al., 2009). Thus,

By bringing to consciousness the researcher’s beliefs, he or she is in a better position to approach the topic honestly and openly. Exploration of personal beliefs makes the investigator more aware of the potential judgements that can occur during data collection and analysis based on the researcher’s belief system rather than on the actual data collected from participants. (Jootun et al., 2009, p. 43)

Research memos were maintained throughout data collection and analysis and formed an important aspect of the researcher’s reflexivity. Memos were written that documented the researcher’s insights and critical reflections on the research process, the data emerging from the participants and developing insights from the literature. In general, memo writing is perceived to “aid...in linking analytic interpretation with empirical reality” (Charmaz, 2003, p. 261). It is seen as an intermediate step in data collection and the production of draft (Charmaz, 2006), and represents the base for which the researcher becomes a co-author of the data collected. Memos acknowledge the role of the researcher, whether directly or indirectly, in weaving the data produced from the interviews.

The supervisory relationship also offered an opportunity to reflect and interrogate aspects of the data collection process that could have been potentially problematic. By discussing these issues with a supervisor, the researcher was able to attain a sense of resolve regarding the next steps in the research process. As Darawsheh (2014) noted, this type of reflexivity “enables the researcher to provide a rationale for their research decisions, and in turn alter the research process to generate relevant findings” (p. 562). An example of this relates to the initial question, “What does treatment adherence mean to you?” The first few men interviewed struggled to respond to this question immediately, and the researcher realized

that she was then required to define or explain what was meant by adherence, which was felt to then impact on a more focused response. Through discussions with her supervisor, this question was altered to “Tell me about your treatment”, after which a series of sub-questions could be introduced to generate a story around what, when, how and how often the men took their prescribed medication.

4.8.3 Insider/Outsider and the gendered nature of research

The gendered nature of the research had to be considered quite early in the research design. As a female researcher, it was necessary to consider the implications and potential challenges (if any) of engaging a population of men in the study. This consideration was furthered by the sensitivity of the focus of the research and the criteria that all participants had to be diagnosed with HIV. Berger (2015) asserted that reflexivity of a researcher’s position should include personal characteristics such as gender, age and sexual orientation as all can impact the research process. For instance, Berger indicated that the personal characteristics of the researcher could influence the researcher-participant relationship, and subsequently impact the quality of the data collected. The example was given of a woman feeling more comfortable discussing her sexual experiences with another woman instead of a male researcher (Berger, 2015). As with this illustration, it was important for me to consider the potential influence of my role in this study as an HIV-negative woman interviewing HIV-positive men. Would the men feel comfortable talking to me about their HIV diagnosis and treatment practices? Would they want to know if I am HIV infected? How do I identify a common pathway to generate a sense of trust and openness? These were some of the questions that were deliberated before commencing data collection.

It was also necessary to consider issues of safety and representations of power. As Hearn (1997) noted,

With women interviewing men there may be a range of additional questions, for example, threat and safety, heterosexual definitions of the situation, including flirting and dualist complementary. There is also the question of to whom the interviewer owes allegiance. Interviewing the

powerful is itself not one-dimensional. Women interviewers may be subject to gender power from men interviewees but may themselves be more powerfully placed in terms of, say, race, disability, class and education. (p. 53)

Issues of safety were addressed by developing a safety protocol surrounding venues for interviews and contact procedures. It was also necessary to remain cognizant of the overt behaviours of the men during the interview. As Schwalbe and Wolkomir (2003) suggested, “*How men answer questions and how they behave in an interview* are potentially valuable sources of data when the research has to do with gender or topics related to gender” (p. 56). Thus both verbal and non-verbal cues were considered important aspects of the data collected. These cues were noted at relevant points in transcripts which helped in understanding the tones or emotions that could alter the meaning of information presented. An example of a non-verbal cue that was worthwhile noting was one participant’s prolonged silence and discreet gesture to wipe tears from his eyes, which suggested the extent of the emotional pain experienced at that particular point in his narrative.

Remaining cognizant of the potential impact of gender on the research process was also important given the use of an intersectionality lens. This extended beyond the differences surrounding gender to other categories that helped to differentiate the researcher and the participants. Being HIV negative also had the potential of positioning the researcher as an outsider who could not personally identify with the experiences of the men (Berger, 2015). To ameliorate some of these issues, the researcher was open about her familiarity with the topic given her prior voluntary work with HIV-related NGOs. However, being ‘an outsider’, as a woman who is HIV negative, meant that the researcher was not familiar with certain language cues that emerged during some interviews. The researcher asked participants to clarify in instances where they used particular codes to ensure that she understood what was being shared. To illustrate, some males referred to their ARV medication as vitamins, thus it was necessary to consistently clarify at these points of reference as some men were taking both ARV medication and vitamins. Her willingness to learn also helped in strengthening a sense of interest, openness and collaboration with the

participants. Arising from this process was one male's observation that the researcher needed to extend her research to capture the views of another distinct group of men (men who identify as either masculine MSM or feminine MSM), which was unknown by the researcher. He subsequently assisted the researcher in recruiting men who he identified as belonging to the group he introduced, thereby enhancing the complexity and authenticity of the study.

4.8.4 Trustworthiness

A number of approaches were adopted to establish the rigour and trustworthiness of the study. Lincoln and Guba (1985) established four criteria for establishing the trustworthiness of qualitative research, of which this study drew on two: confirmability and credibility. The previously discussed strategies used in ensuring researcher reflexivity contributed to confirmability, a process that shows steps taken to minimize researcher bias (Amankwaa, 2016). In addition, rich contextual quotes were provided to support the findings of the study, thereby showing evidence of a true representation of the participants' voices.

The researcher also engaged in member-checking, a process that enhances the credibility of the data (Lincoln & Guba, 1985), and in which the findings of the study are shared with the participants to determine if they concur (Ryan-Nicholls & Will, 2009). Member-checking occurred along the research process where new themes introduced by some men were further explored at the end of subsequent interviews with other participants. This allowed the researcher to identify if there was congruence that would reinforce the significance of the issue. Emerging ideas from early data analysis were also shared with some of the men who were involved in follow-up interviews. Again this presented an opportunity to both validate some of the earlier responses of these men, and explore ideas that emerged within other men's narratives and early themes from the data analysis.

4.9 PARTICIPANT RECRUITMENT AND DESCRIPTION

Participants in the study were adult Jamaican men who are HIV positive and aware of their status. To be included in the research, the men had to be 20 years of age or older, diagnosed as HIV positive and prescribed ARV treatment at least 6 months in advance of the data collection process. It was perceived that six months was an adequate time period after which to assess the participants' experiences with adhering to their prescribed treatment regimen.

4.9.1 Participant recruitment

The CHARES was instrumental in the recruitment of participants. This meant that all, except one participant, were registered patients at the clinic. The one non registered patient indicated initially accessing healthcare from the attached hospital. This may hold implications for the pool of persons from which the participants were selected. However, it was deemed useful to utilize this access point given the feasibility of the clinic's location, the ease of access for the researcher, as well as the reduced timeline for ethical approval for the clinic as against other health facilities. Further, it was indicated that the clinic caters to a diverse population including persons who reside in varying parishes across the island and with income levels across the lower to middle income levels. It was anticipated that upper class persons would opt for the privacy and convenience of private care and would thus not be accessible through the clinic.

Introductory meetings were held with members of staff who were identified as key to the data collection process. One of the clinic's social workers was assigned the responsibility of making initial contact and inviting select patients to participate in the study. The details of the study were discussed with the social worker and the Participant Information Sheet (See Appendix A, p. 335) along with letters for the participants were provided (See Appendix B, p. 339). A contact consent form was also provided to indicate the men's consent to have the researcher contact them directly (See Appendix C, p. 341). Using the specified criteria of inclusion, an initial pool of potential participants was identified and invited to participate in the study. Some persons contacted the researcher directly to indicate their interest in the

study. Others granted the social worker permission to have the researcher contact them directly to further discuss the study.

A poster was also generated and displayed in the waiting area of the clinic. It provided information on the study's aims and the inclusion criteria for participants. Copies of the researcher's contact details were presented on ready-to-take leaflets in a pocket holder on the poster. One male contacted the researcher in response to the poster and was subsequently recruited as he met the inclusion criteria. The researcher frequently visited the clinic during the specified times for clinic rotations which afforded interested persons an opportunity to meet her and discuss information pertaining to the study. A few patients took the opportunity to discuss the study, of which one later agreed to participate in the study. The others indicated a potential willingness but subsequently declined to being included in the study.

The strategy used to recruit participants was modified due to staff changes that involved the clinic operating without a full-time social worker. As an alternative, the researcher attended all clinic days for existing patients (held three days each week) and asked the receptionist to introduce her to potential participants. This allowed the researcher to introduce the study to prospective participants and schedule interviews with any expressing an interest in participating in the research. This mode of recruitment proved beneficial as majority of the men approached subsequently participated in the study. In addition, three men were identified through snowballing after one participant proposed that the study also include men belonging to a particular group.

Over 30 men were invited to participate in the study; however only 24 were subsequently recruited and included in the research process. Interviews with two participants ended prematurely as the men were required to see the doctors, and subsequently did not return to conclude the interviews. These interviews were excluded from the analysis given the early stage in the interviews at which the men had to leave. The remaining men declined to participate at the point at which they were contacted to schedule an interview.

The background and procedures of the study were discussed with each male before commencing the interview and the opportunity given for questions and concerns to be addressed. The men were advised of their right to withdraw from the study at any given time and were assured that their participation in the study would not impact the services accessed at the clinic. They were also advised of the availability of psycho-social support within the clinic, if needed. A consent form was signed by all the men interviewed in person whilst verbal consent was given by those who facilitated the interview via telephone

4.9.2 Demographic profile of participants

A demographic data form was completed for all the men at the point of recruitment. This provided background information surrounding age, area of residence, educational level, year of diagnosis and year of commencing treatment (Appendix D, p. 342). The ages of the participants ranged between 20 and 56 years, with majority of the men being 40 years and older. Only four participants were between the ages 20 – 24 years. Most of the participants resided in the urban parishes Kingston, St. Andrew and St. Catherine, with a few residing in rural parishes. Sixteen men were employed, though this ranged across part-time, full-time and self-employment. The educational levels of the men varied with majority having attained secondary level of education. Table 4 (p. 134) presents a summary profile of the participants included in the study.

Though the study did not explicitly query the sexual orientation of the participants, this information was willingly provided during the interviews with the men. One participant, Marcus, identified himself as transgender during his follow-up interview. The decision was taken to include Marcus nonetheless given his narrative referred to maintaining dual identities where he often publicly performed the socially expected masculine roles and retained his feminine characteristics until within the safe confines of his home (see pages 217-218 for a more detailed discussion and analysis). This was felt to further enhance an understanding of the complexity surrounding masculine identities within the Jamaican context. In addition, the Participant Information Sheet which was reviewed with each

participant prior to the commencement of interviews, explicitly indicated that being a Jamaican male was a requirement for inclusion in the study. Marcus did not object to being identified as a Jamaican male and willingly participated in the study.

Table 4: Demographic Profile of Participants

Participant	Age	Sexuality	Area of residence	Education	Employment Status
Bird	45	Heterosexual	St. Catherine	Secondary	Part-time
Bones	44	Heterosexual	St. Andrew	Skills training	Unemployed
Brenton	47	Heterosexual	St. Andrew	Secondary	Self-employed
Dante	37	Heterosexual	Kingston	Secondary	Unemployed
Dan	36	MSM	St. Thomas	Tertiary	Part-time
Eric	24	MSM	Kingston	Secondary	Part-time
Jay	43	Heterosexual	St. Andrew	Skills training	Self-employed
John I	43	Heterosexual	Kingston	Secondary	Full-time
John II	43	Heterosexual	St. Thomas	Secondary	Part-time
John III	45	Heterosexual	St. Andrew	Secondary	Full-time
Kevin	33	Heterosexual	St. Catherine	Primary	Unemployed
Marcus	24	Transgender	Kingston	Tertiary	Self-employed
Mark	41	Heterosexual	Kingston	Secondary	Self-employed
Mario	20	MSM	St. Catherine	Secondary (incomplete)	Unemployed
Paul	35	Heterosexual	Kingston	Secondary	Full-time
Que	44	Heterosexual	St. Catherine	Secondary	Unemployed
Richard	27	Heterosexual	St. Catherine	Secondary	Full-time
Richie	40	MSM	Kingston	Secondary	Full-time
Steve	47	Heterosexual	Clarendon	Secondary	Self-employed
Tallist	27	Heterosexual	Kingston	Secondary (incomplete)	Full-time
Trevor	56	Heterosexual	St. Catherine	Tertiary	Self-employed
Troy	29	MSM	St. Andrew	Secondary	Unemployed ²
Vincent	51	Heterosexual	Manchester	Primary	Unemployed
Whitey	37	MSM	St. Catherine	Secondary	Unemployed

² The employment status for this participant changed to full-time at the point of the follow-up interview.

4.9.3 Period of HIV Diagnosis

There was noted variation in the year of diagnosis for the men, spanning as early as 1995 to six months before the researcher commenced data collection mid-2013. Most men were diagnosed in the last four years leading into the data collection phase of the study. The year of diagnosis was not indicative of the commencement of treatment as not all the men commenced treatment the year of diagnosis. Table 5 shows the time of diagnosis and commencement of treatment for the participants. Majority of the participants initiated treatment the same year or a few months post their diagnosis. This may be indicative of the extent of ill-health at the time of presenting for diagnosis, which warranted an almost immediate linkage to treatment. Seven participants started their ARV treatment post the year of diagnosis. The time period for the commencement of treatment for all the participants ranged from four months to 14 years. The reasons for the delay in starting treatment included difficulty accepting HIV diagnosis which eliminated the relevance of starting treatment, CD4 count being outside the range for commencing treatment and time period allotted for medication preparation.

Table 5: Period of HIV diagnosis and treatment initiation for participants

Participant	HIV Diagnosis	Treatment Initiation	Participant	HIV Diagnosis	Treatment Initiation
Bird	2011	2011	Mario	2010	2010
Bones	2009	2009	Mark	2006	2006
Brenton	2006	2006	Paul	1999	2006
Dante	1998	1998	Que	2011	2011
Dan	2010	2011	Richard	2006	2006
Eric	2012	2013	Richie	2003	2003
Jay	2010	2010	Steve	2004	2005
John I	2003	2003	Tallist	2013	2013
John II	2008	2008	Trevor	2003	2007
John III	2001	2010	Troy	2008	2012
Kevin	2012	2012	Vincent	2008	2009
Marcus	2005	2005	Whitey	1995	2009

4.9.4 Commencement of ARV Treatment

Not all the men were able to readily identify their prescribed ARV medications. Some described their tablets as either the ‘white pill’ or ‘yellow pill’ which made it difficult for the researcher to note their medication. A few men travelled with their prescriptions and were thus able to provide the researcher with the document to allow her to note the information. Of those men who were able to indicate their current medications, most were prescribed Truvada and Efavirenz. Figure 17 indicates the distribution of prescribed medication for the participants. Some men were also prescribed Bactrim, a combination antibiotic that is used to treat infections caused by bacteria. It is also used to treat pneumonia, respiratory infections and diarrhoea. A few men were prescribed topical creams such as Bactroban which is used to treat dermatologic or skin conditions.

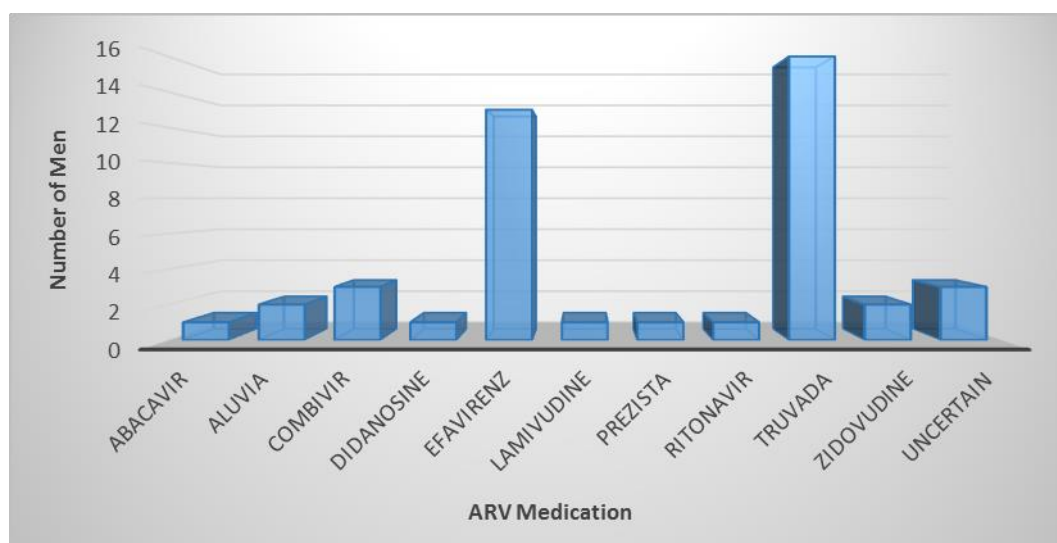


Figure 17: Distribution of ARV medication prescribed for participants

Only two men were noted to be on second line treatment having failed first line treatment. Such failure primarily occurs when patients do not optimally adhere to their treatment regimen, resulting in a developed resistance to the medication. Medication was also altered for some men who experienced intolerable side effects to their initial treatment. One male shared his difficulty adhering to a regimen involving three medications that had to be taken

multiple times each day. Upon discussing this challenge with his doctor, he was switched to alternate ARVS. His subsequent negative response to those medications resulted in a third alteration of prescribed medication.

4.10 DATA COLLECTION PROCEDURES

Data for the study was obtained from three sources: the men who willingly shared their experiences, key staff members (comprising the social workers, adherence counsellor and clinical director) and the researcher's memos. Semi-structured interviews were conducted with the men and formed the core data for the study. Semi-structured interviews were also conducted with the identified members of staff in an effort to capture insight to some of the issues uncovered by the men, especially those existing at the institutional level. Researcher memos were generated throughout the data collection and analysis phases. Memo writing proved crucial in capturing the researcher's reflexivity of the issues being shared by the men and the possible role she might play as the interviewer in the output of information shared. The semi-structured interview processes are further discussed below.

All interviews were audio recorded using a digital tape recorder with the participants' consent. The audio recordings were saved on the researcher's laptop and transferred to a USB flash drive for transcribing purposes. Five transcribers were recruited in total throughout the data collection period due to challenges encountered in either time commitment or the quality of transcription service being offered. The latter was important in ensuring that the transcripts accurately reflected the narratives of the men before data analysis commenced. All transcribers were required to complete a confidentiality agreement (See Appendix E, p. 344). The researcher listened to all audio recordings to ensure the credibility of the transcripts, as well as to familiarize herself with the men's narratives and capture any distinct emotions that may have been omitted in the transcript. This process also provided another basis for further reflexivity as it pertained emerging themes or insights.

Personal diaries were initially incorporated as data collection tools in the study. Participants were asked to keep a diary of their process of following their treatment regimen for two weeks post the initial interview. The use of the diaries was intended to help the participants identify, document and reflect on their treatment behaviours and their interpretations of adherence that may be influenced by others and the environment. Only one male agreed to maintain an audio diary which was done on ad hoc days for one week. Though the diary method was intended to capture rich, in-depth reflections from the men, this approach only garnered a brief report of the participant's activities prior to taking his ARV medication on the days in which he made a recording. The general unwillingness of the participants to engage with the diary method resulted in the decision to forego its use. It was subsequently decided that the researcher would focus on the interview process to capture the men's experiences and reflections of their treatment journey.

4.10.1 In-depth interviews

Data was collected using in-depth semi-structured interviews which have been noted to be useful in interpretive inquiry to elicit the participants' experiences (Charmaz, 2006). This technique has also been acknowledged as one of the principal data collection methods in intersectionality research (Cuadraz & Uttal, 1999). Participants were asked a series of questions surrounding their experiences being diagnosed as HIV positive and prescribed lifelong ARV treatment. The questions asked included: "Tell me about your HIV diagnosis", "What are your perceptions of or feelings towards your prescribed treatment?", "What has been your process of following your treatment since your HIV diagnosis?" (See Appendix F, p. 345, for the interview schedule).

Twenty-one interviews were conducted face-to-face in a meeting room or office space provided by the clinic. This setting was chosen as it was perceived to minimize possible risks to the participants and also lessen anxieties and discomfort that may be presented by an unfamiliar environment. It was also convenient as the interviews were conducted primarily on days when the men had scheduled doctor appointments. In most instances, the

researcher was provided with an office space which allowed the interviews to be conducted privately. In a few instances the interviews had to be conducted in the clinic's conference room which was also being used as an office space for a member of staff. This reduced the privacy of the setting and the men were asked if they preferred to reschedule the interview. In all instances they opted to continue. Participants were provided with refreshments and were reimbursed their travel expenses based on their parish of residence.

Three participants opted to do telephone interviews primarily as it was more convenient than travelling to the clinic. Telephone interviews have been celebrated as being beneficial in qualitative research, particularly those surrounding sensitive topics (Sturges & Hanrahan, 2004; Trier-Bieniek, 2012). Despite some authors' concern that telephone interviews result in the censoring of information (Holbrook, Green, & Krosnick, 2003), it is believed that the telephone interview provided the added benefit of protecting the identities of the participants who preferred to be interviewed via the telephone. This created a safe space for these men to openly share their experiences without the concern of being identified. Further, the notion of the telephone interview affording greater anonymity is reinforced in the literature (Greenfield, Midanik, & Rogers, 2000; Sturges & Hanrahan, 2004). The assurance of the safe-keeping measures used to ensure anonymity and confidentiality was particularly important for all participants.

An overview of the research was discussed with all the participants prior to being interviewed. They were also advised of their right to withdraw from the study at any given point. Two participants who agreed to do the study opted to withdraw before completing the interview. This was due to the time of the interview coinciding with their medical screening. All participants were required to complete and sign a consent form (See Appendix G, p. 346) indicating their willingness to participate in the study, have the interview audio-recorded and be contacted for a follow-up interview if deemed necessary. Verbal consent was obtained in the instances where telephone interviews were conducted.

Interview times varied between 20 and 90 minutes. Where interviews exceeded 60 minutes, participants were invited to schedule a follow-up interview. Some participants indicated a preference to complete the interview at which time a short break of approximately 10 minutes was allowed before the interview resumed. The researcher also made notes during the various interviews, ensuring to highlight what appeared to be main points, physical gestures or issues that required further investigation during the interviews. An effort was made to minimize notetaking however, as it was seen to potentially distract the participants, as well as hinder the researcher's focused attention on the men whilst they shared their stories.

4.10.2 Follow-up interviews

Follow-up interviews were conducted with six men. This was done to further explore and develop emerging themes arising from interviews. It also afforded an opportunity for the researcher to clarify particular issues arising from the discussions with the participants. Only one follow-up interview was held at the clinic, whilst two were conducted via telephone. The remaining three interviews were held outside the clinic setting, two of which were conducted in public parks and the third was done at the football field adjacent to the participant's place of employment. Both the telephone interviews and interviews outside the clinic setting offered greater convenience to the men, as it eliminated the cost of travelling to the clinic. One male shared experiencing some discomfort with being interviewed at the clinic and thus indicated his preference to meet at a park.

The choice to use public spaces introduced the issue of privacy and safety for both the researcher and the participants. The researcher ensured that the place chosen for the interview was public to allow visibility by others, with sufficient privacy to ensure the discussion with the men was not overheard. The interview style was altered to reflect a more conversational format that eliminated the use of the printed interview schedule and note taking. The interviews were audio recorded by disguising the tape recorder which was kept in an open handbag between the researcher and the men. This approach required the

researcher to remain cognizant of the environment at all times, to ensure that the privacy of the men was maintained. This interview style did not detract from the quality of the interview, as the men were not deterred by the approach, and the conversational style used did not attract the curiosity of onlookers. The absence of notetaking throughout the interview meant the researcher had to write her memos directly after the interview was finished, to ensure she effectively and accurately captured her observations and reflections. The main limitation of this interview approach was the inability to document certain gestures that may have held some significance. Audio recording the interviews however, still allowed the emotions of the men to be captured. For example, one male's anger could be clearly heard in the recording and helped to signal the emotions underpinning his narrative.

4.10.3 Staff Interviews

Whilst in the field, the decision was taken to conduct staff interviews with key members of staff directly involved in the treatment process of the men. Information from these individuals was considered important in supplementing information provided by the participants. Four staff members were identified comprising the clinical director, social workers and adherence counsellor. Interview guides were generated for each staff member (See Appendix H, p. 347) and included questions such as "Tell me about your role as the clinic's director/ social worker/ adherence counsellor" and "What are some of the issues that impact patients' treatment adherence?"

All staff interviews were conducted at the clinic at a time deemed convenient to each member of staff, and were audio recorded with the permission of the interviewees. The interviews were conducted within a range of 20 to 60 minutes. These interviews were transcribed and reference made to the content at varying intervals in the data analysis process. Some reference is made to the narratives of staff members, though significant effort was made to maintain their anonymity given the small staff complement and thus ease of identification.

4.11 RESEARCH ETHICS

A range of ethical considerations emerged in the design and implementation of the study. These surrounded: 1) obtaining ethical approval from both AUT and the local ethics board with responsibility for the clinic from which the participants were selected, 2) the assurance of anonymity and confidentiality, 3) the ethical considerations in determining appropriate interview venues, and 4) the measures taken to safe-guard the participants in addressing the transcribing of interview data, access and storage of the data.

4.11.1 Ethical approval

Ethical approval was obtained from two ethics committees: AUT's Ethics Committee (AUTEC) and the University Hospital of the West Indies/ University of the West Indies/ Faculty of Medical Sciences (UHWI/ UWI/ FMS) Ethics Committee. Ethical approval from the latter was required given the role of CHARES as the access point for the participants and its organizational linkage to the UHWI. Ethical approval was initially obtained from AUTEC on January 16, 2013 (See Appendix I, p. 349). This approval was included in the submission to the UHWI/ UWI/ FMS Ethics Committee and final ethical approval was given on April 17, 2013 (See Appendix J, p. 351).

4.11.2 Protection of research participants

Measures were taken to ensure the anonymity and confidentiality of participants' identities and the information provided. Anonymity was achieved by inviting each male to choose a pseudonym to identify himself throughout the data collection process. Some men expressed a preference to use their actual names; where this was felt to make the men easily identifiable random pseudonyms were applied by the researcher to the transcripts. A telephone interview was conducted with one male as an added measure to protect his identity, given his discomfort with participating in a face-to-face interview. It was recognized that the criteria for participating in the study required the men to be willing to openly acknowledge their HIV status with a researcher with whom they had not established a pre-existing sense of trust. Thus it proved necessary for the researcher to make herself

accountable by advising the men that if they sensed a breach of their privacy that the researcher could be held accountable by contacting the UHWI/ UWI/ FMS Ethics Committee.

Most interviews were conducted at the clinic which provided both a familiar and safe environment for the men to discuss their experiences surrounding their HIV diagnosis and treatment. There were instances where the men, due to convenience or comfort, indicated a preference to be interviewed outside the clinic space. This was done for three participants and in these instances a public space was chosen that was conducive to both the researcher and the men interviewed. Given these were public spaces, the researcher had to employ a more conversational style of interviewing, without the use of the typical notetaking implements (See section 4.10.2 for a more detailed description).

Access to the data was limited to the researcher, supervisors and transcribers. All transcribers were required to sign a confidentiality form prior to being employed by the researcher. Transcribers were advised to destroy all records of the interviews post completion of the transcription process. All contact information and hard copies of the men's narratives were destroyed prior to departing Jamaica. Electronic copies were maintained to facilitate the subsequent phases of the study.

4.12 DATA CODING AND ANALYSIS

Winker and Degel's (2011) intersectionality multi-level framework of analysis was the main model used to inform the study's data analysis. This framework provided a stepwise process for conducting data coding and analysis within an intersectionality focused study. As discussed earlier, the model was valuable for presenting a mechanism for analysis and facilitating a focus across both micro and macro levels. Winker and Degele's model broadly covers the coding of individual transcripts, a comparative analysis of interviews and a final synopsis that examines the intersectional interrelations across all levels. In this study the framework was adapted to include six steps as illustrated in Figure 18 (p. 145).

All coding was done using the NVivo software, a computer-assisted qualitative data analysis software developed by QSR International (Wong, 2008). As a data management tool, NVivo allowed for greater ease in the data sorting and coding process. Additional features also proved beneficial, such as the matrix coding query which was used in generating data for comparative analysis (Bazeley & Jackson, 2013). The following sections details the steps taken for the data coding and analysis.

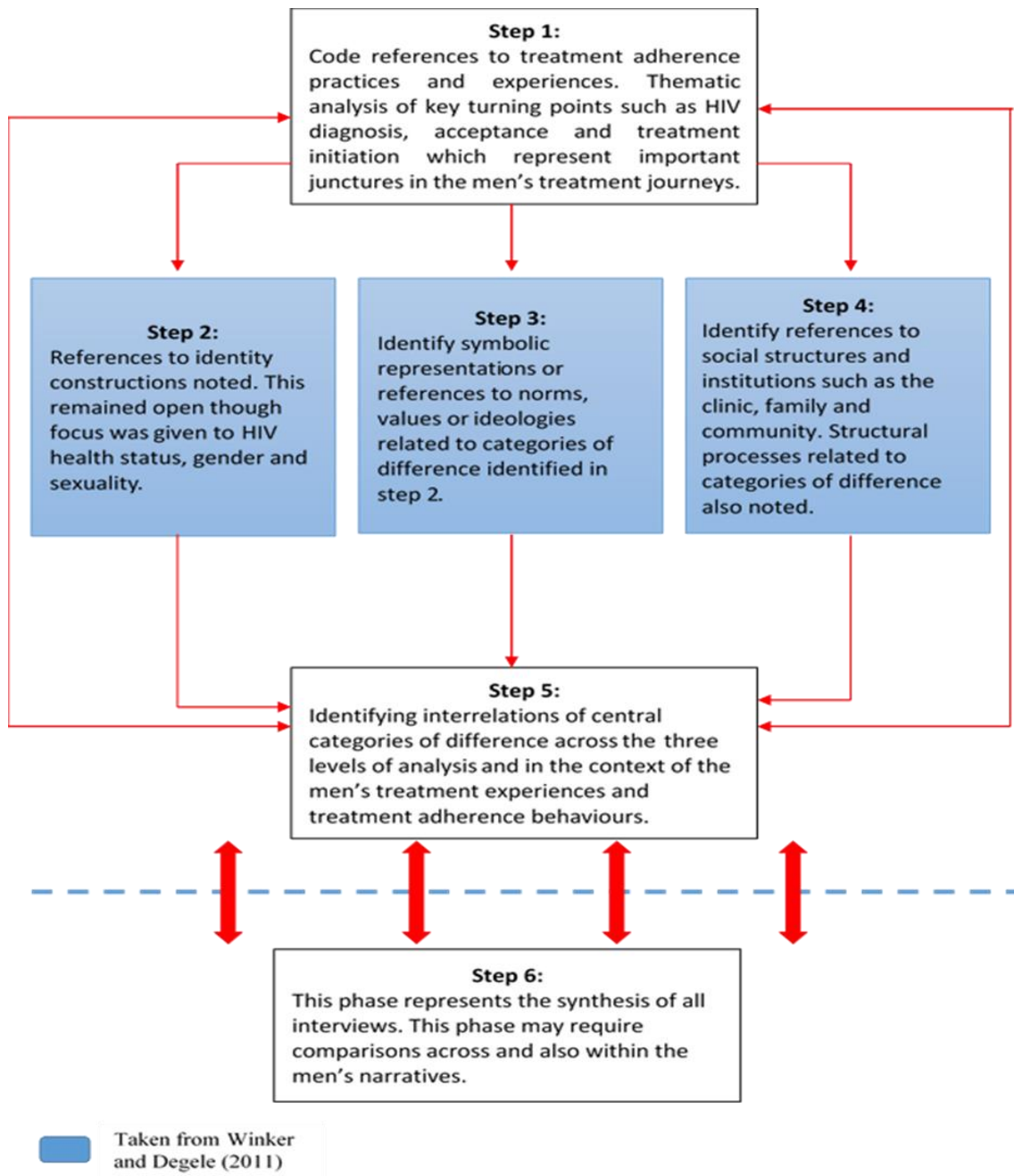


Figure 18: Data analysis stages

4.12.1 Outline of steps used in data coding and analysis

Step 1: Charting the men's experience surrounding their ARV treatment experience and practices.

Winker and Degele (2011) acknowledged that “the starting point and subject for analysis should be social practices that are accessible through empirical research” (p. 56). This, paired with the recommendations of Bowleg (2008) and Cuadraz and Uttal (1999), informed the decision to first evaluate the men's narratives to identify emerging themes and patterns about the participants' treatment experiences. The process of conducting a thematic analysis was adopted to guide coding and analysis at this stage. Thematic analysis is described as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). Thus the decision was taken to first answer the questions: What are the men's individual experiences surrounding their treatment journey? What are the patterns or stages in this treatment journey for the men interviewed? These questions helped to move from the individual experiences suggested by Cuadraz and Uttal to patterned themes on which an analysis of the interrelationship between social categories and across the levels of identity, symbolic representation and social structure could be applied. All references to ARV treatment were coded according to emergent themes. Of key importance were data related to how the men defined or perceived their ARV treatment, clear turning points in their treatment journey, medication management and coping.

Step 2: Identify references to identity or processes of identity constructions

This stage focused on how the men identified themselves in reference to categories of difference. Particular attention was given to gender, sexuality and HIV status; however, the researcher remained open to move beyond the theoretical definition of these categories which Winker and Degele (2011) identified as a useful starting point. As such, all references to the men's identities in relation to the three social categories chosen, and others, were coded in NVivo. Each of these categories was evaluated against the backdrop

of the Jamaican culture which was felt to prescribe certain peculiarities that were unique to Jamaica. Examples of patterned references to identity included HIV as either a defining or hidden part of self, and distinctions between MSM and heterosexual identities. It was also noted that these identities could emerge in delineation from or alignment to others. This is the process of identity construction that can shape the men's inclusion or exclusion from certain groups. Thus an awareness of these 'others' was also maintained as a signal to the men's identity constructions.

Step 3: Code symbolic representations: norms, values and ideologies

This stage aimed to make "all norms, values and ideologies to which persons refer, explicit" (Winker & Degele, 2011, p. 59). These norms, values and ideologies are perceived to be a bridge between the social/ structural forces around the men and their identities. Thus it reflects interpretations of particular beliefs or notions which are likely to shape the identities and behaviours of the men. This does not require the men to adhere or accept these identified norms, values and ideologies as their identities can be constructed in opposition to these symbolisms. Thus the men may identify themselves as rejecting the labels that have been imposed through these historical norms and ideologies of which they are cognizant. It was important to note whether the men accepted or rejected these prevailing norms and ideologies. It was also necessary to code those symbolic references to ARV treatment, given the focus of the research. Those symbolic representations that were the most prevalent across participants were included in the final analysis. Examples of prevailing norms and beliefs identified by participants included: men are expected to fulfil certain social roles such as father, leader and partner; HIV is no longer a death sentence because of the efficacy of ARV medications; HIV remains a stigmatized illness that can affect men's sense of belonging and well-being.

Step 4: Code references to social structures and processes

For Winker and Degele (2011), social structures referred to both social structures and institutions that are likely to impact the social practices and identity constructions of individuals. The family and clinic were identified as two social structures referred to in the

men's narratives. Though Winker and Degele acknowledged that social structures included laws, organizations and institutions, it was felt that it also extended to the social processes that could be attached to any of these social structures. To illustrate, HIV-related stigma, MSM-related stigma and social support were significant social processes that helped shaped the identities and choices of the men. Central to this phase of coding was the acknowledgement of the power dynamics surrounding how the men's identities were shaped and/or negotiated. Thus it was important to identify where these references existed in the men's narratives, and whether the men agreed, challenged or were indifferent towards the influence of such structures and processes in terms of their identity and treatment behaviours.

Step 5: Identify interrelations of categories across steps 1-4

This phase of the data coding and analysis process focused on identifying clear intersections across identity, symbolic representations, social structure and processes, and ARV treatment. According to Winker and Degele (2011), "it is crucial to uncover the most important subject constructions (that can also cut across levels) and their interwoven-ness and conflicts" (p. 59). Thus it was necessary to identify for each individual, instances where there was an interplay between the men's identities, the social structures or processes they encountered and their perceptions and choices regarding their ARV treatment. In doing this, it was again important to identify the tensions that resulted in the men challenging, adhering, or negotiating their social identities across the three categories examined in this study.

Step 6: Synthesis

As steps 1 – 5 occurred on an individual basis, this final step in the analytical process reflects a synthesis of all the transcripts. It drew on Winker and Degele's (2011) suggestion of a "strategy of fluctuation and comparison" (p. 57) and thus involved working both within and across the men's transcripts. More specifically, this was done by comparing each person's data at different time periods, comparing the perspectives and experiences of different participants, and comparing incidents/categories identified in the narratives of

different men. This process allowed for both a comprehensive and detailed understanding of the views and experiences of the men.

4.13 PRESENTATION OF FINDINGS

Winker and Degele (2011) did not provide insight to how the data could then be presented post their final stage of synopsis which is akin to the synthesis stage used in this study. It was clear that the men's identity constructions were impacted by key turning points in their treatment journey, commencing with their HIV diagnosis. As the men often narrated their experiences in reference to these key turning points, it became apparent that their treatment continuum was the core element that helped to shape the interplay between their identities, treatment experiences and adherence outcomes. Thus instead of charting the findings along the levels of analysis posited by Winker and Degele (2011), it was decided that a more constructive approach would be to maintain the central focus of men's treatment journey and the key junctures that showed the interrelationship between categories of inequality that further intersected with the three levels of analysis. Further, this was believed to maintain the focus on men's ARV treatment adherence as the core issue being examined in the study.

Following this, it was decided that the findings would be presented across four chapters that captured the main turning points in the men's treatment continuum, that further shaped their treatment experiences and adherence outcomes. The first chapter, *"Discovering I'm positive": HIV testing and diagnosis* captures the starting point of the men's treatment journey that forced the men to redefine themselves in the context of their HIV illness, in reference to 'others' and in relation to existing norms and values related to their social categories. The second chapter, *Transition: Moving from diagnosis to treatment initiation*, examines how men progress from learning of their HIV diagnosis into initiating their ARV treatment. The third chapter, *Re-negotiating self and identity*, gives space to understanding how a positive HIV diagnosis cause some men to redefine their personal identities as well as their social representations of self. This takes into account the interplay between personal notions of self and identity and socio-cultural norms, such as those that influence gender role expectations. The fourth findings chapter, *Navigating treatment in clinical and social*

spaces: Issues of power, identity and stigma, extends the analysis presented in the previous findings chapters to show how men manage their treatment in various contexts. Particular attention is given to clinical and personal spaces as they emerged as significant in determining the treatment experiences of the men.

The findings within each chapter are supported by rich contextual quotes, a critical step in showing the credibility of the study. There are also instances where the interpretive leap was made to unveil hidden or subtle meanings. These interpretations were evaluated against existing literature, through dialogue with other participants or with the input of supervisors. As noted in Chapter 1, critical realism supports a bridge between the real existence of a social world and multiple social constructions or interpretations of this world (Maxwell, 2012). This justifies the movement between the descriptive and interpretive, with the latter enabling the researcher to go further to identify and elaborate in-depth understandings of the men's experiences surrounding their ARV treatment adherence.

Chapter 5 FINDINGS I

“Discovering I’m positive”: HIV testing and diagnosis

5.1 INTRODUCTION

This chapter focuses on the period of HIV diagnosis for the participants, recognizing that this period played a key role in shaping the men’s treatment experiences and subsequent adherence outcomes. The chapter commences with an examination of the circumstances surrounding HIV diagnosis for the men. The men learnt of their HIV status either by actively seeking an HIV test or as an outcome of an unassuming activity, such as donating blood. The chapter then examines the men’s experiences of learning of their positive HIV diagnosis which, for most, was surprising and traumatic. These experiences are further analysed in relation to the intersections between the men’s identities, personal biographies and socio-cultural contexts; thus determining the impact of a positive HIV diagnosis on the men’s perception of themselves and their lives. Some men experienced a sense of disruption and loss, whilst others confessed considering suicide as an escape. The trauma of learning of a positive diagnosis was lessened for those men who were aware of the value and role of ARV in treating the illness, and who received the support and acceptance of family members, partners or peers. Overall, the men’s personal and social experiences at the phase of their HIV diagnosis were found to impact on how they progressed into accepting their HIV diagnosis and initiating treatment, which were identified as subsequent phases in the men’s treatment journey.

Figure 19 (p. 152) presents an overview of the key milestones encountered by the men in their treatment journey. It further demonstrates how these junctures are influenced by the men’s identities, related norms, values and ideologies, and a range of social structural processes. Each of these factors are deeply embedded in the socio-cultural, political and historical contexts of the Jamaican society, and are thus inextricably linked. The complex nature of men’s identities, the related norms and values to which they ascribe, and

structural processes, were found to shape the treatment experiences and adherence outcomes for the men in this study.

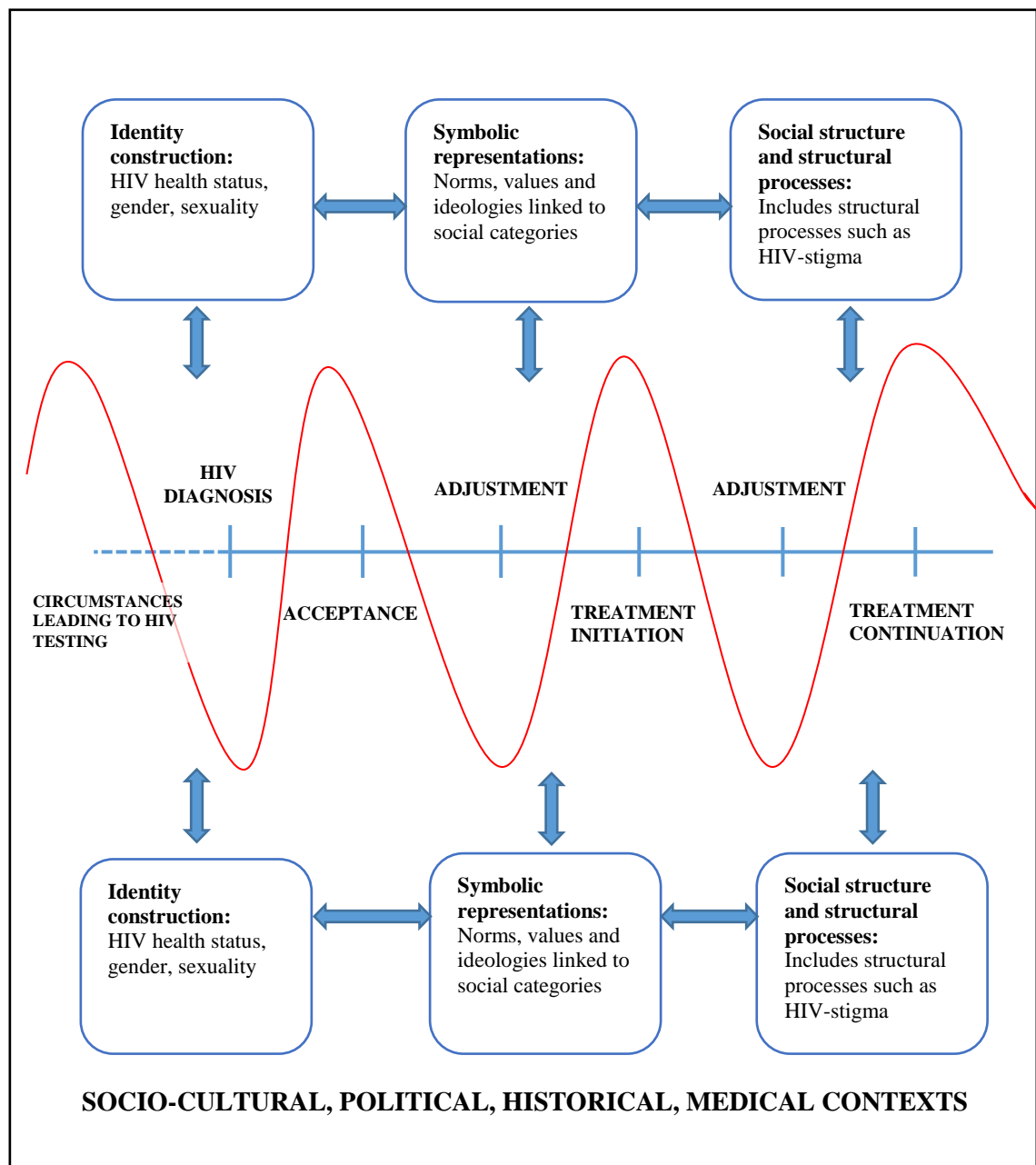


Figure 19: The treatment trajectory

5.2 CIRCUMSTANCES AROUND HIV TESTING: ACTIVELY SEEKING TESTING OR JUST BY CHANCE

The circumstances leading to HIV testing varied for the men in the study and included 1) actively soliciting diagnostic tests, which included HIV testing, given the recognized risk of exposure, 2) HIV testing being done as a routine, 3) becoming unwell and seeking medical attention which subsequently resulted in testing, and 4) HIV testing being unsolicited but linked to other events such as blood donation or preliminary tests for life insurance. Thus not all the men actively sought to do an HIV test, and those who did were propelled to do so for varying reasons, including becoming symptomatic or an acknowledgement of their risk of becoming HIV infected.

5.2.1 Needing to check: Recognising risk and routine testing

In some instances, the decision to get tested was triggered by learning that either a past or current sexual partner was diagnosed with HIV. Eric noted, *“My partner tested and tested positive, so I thought that’s the other thing to do cause if your partner is positive then you need to check yourself”*. Tallist recognized his risk of infection when a previous sexual partner advised his current partner of her HIV-positive status.

My first baby mom told my last baby mom that she’s positive, so I don’t know if she tell her that just to make us aware or whatever. Or saying that she’s positive so both of us must take a check to make sure. (Tallist)

Both Eric and Tallist garnered a heightened awareness of their risk of contracting HIV due to having had unprotected sex with the diagnosed individual. This awareness then propelled the men to actively seek HIV testing.

Some men indicated that they periodically participate in routine HIV testing. Dan stated, *“I just did a routine run of the mill. Summer I have nothing to do so I went to do a HIV test”*. This “routine run of the mill” testing was perceived to be linked to Dan’s awareness of the risks associated with having unprotected anal sex despite being in a stable relationship, to which he later alluded. Dan’s awareness of potential risks that informed his routine testing was also associated with his role as an HIV advocate. Thus routine testing became a

professional and personal habit rather than a response to a perceived likelihood of being HIV infected.

Similarly, Dante indicated that he discovered his HIV status through routine testing: *“I just decide to get tested one day. Just felt like to go and do a test and then me go find say me have it”*. Like Dan, Dante did not actively seek to do an HIV test because of a perceived risk of infection, as noted for Eric and Tallist earlier. Instead, HIV testing appeared to be either routine screening or a spontaneous act that was not hinged on the perception of being HIV positive. This spontaneous act was also noted for Troy who participated in free HIV testing that was being offered as a part of a public health campaign when he learnt of his positive HIV diagnosis: *“you see where they do the free HIV testing? So you go and you get tested. I remember the first time was when they did it in HWT and I got tested”*. Overall, men who actively sought to do an HIV test, did not do so because of a perceived likelihood of HIV exposure, with the exception of those men who had already learnt of a current or past sexual partner testing positive.

5.2.2 Becoming symptomatic with everyday illnesses and seeking healthcare

The majority of the men reported having particular symptoms or illnesses that led them to seek medical attention. These symptoms included skin rashes, itching, constant diarrhoea, fainting, noticeable weight loss, sleeplessness and thrush. Examples of these can be seen in the excerpts below:

Well, about a month before, I noticed some rash on my skin. So I went to this dermatologist by Spanish Town, and it was by the Spanish Town Health Centre. I went there and they gave me a cream and she examined me one day and they said I need to do an HIV test. (Bird)

I find that I was just getting sick for a while (long time). I was getting sick while I was on the work and I don't know what's the reason why you know. So I end up going to the doctor on Windward Road and took the test, and when I took the test the doctor told me that is what happened to me. (Jay)

How did I found out is that I went to clinic...I had some complications where I saw a few spots on my skin and I went there and they told me to do a HIV test, which I did and that's how I found out. (Whitey)

The physical manifestations of being unwell resulted in a distinction between an earlier healthy state and a sick status that emerged once the men became symptomatic. This awareness of becoming visibly sick then propelled the men to seek medical attention. Of the 24 men interviewed, 15 consulted with a physician due to the onset of symptoms which were later associated with their HIV diagnosis.

Some men were urged to see a doctor by either a close family member or friend who recognized the seriousness of their ailments. It was Richard's employer, whose own brother had died from the illness, who identified the likelihood of him being HIV positive.

My employer saw me acting strangely, seeing a lot of weight loss and thing and not being the person that I was before. And typically then, whenever time I've taken anything, like consume anything, whereby I have eaten anything I would feel that way and have loose bowel and thing. And having the loose bowel and constantly having loose bowel and pain and they decided unto themselves they were not going to take it lightly, whereby my boss took me to a medical company, same place downtown. (Richard)

By stating he was *"not being the person I was before"*, Richard established a distinction between his earlier healthy status and the emergence of an illness status due to the onset of symptoms that became recognizable by others. The physical manifestations of HIV are obvious warning signs to persons who are knowledgeable of HIV/AIDS, as found with Richard's employer. This makes it difficult to hide being unwell, which could expose some men to the perceptions and judgements of others.

Despite the emergence of symptoms, some men delayed seeking medical attention as they believed their symptoms were due to minor, everyday illnesses that could be self-remedied. As John I noted, *"I didn't know what I had. I thought it was because I wasn't eating on time...take too long to eat and so all these other things were happening"*. Similarly, Bird

associated the early signs of his ill-health to a familiar and easily remedied illness: *“I started losing weight. I remember having a cold that wasn’t getting better. Got wet one day and then I took sick”*. It was not until his self-treatment failed that he sought medical attention. The initial responses of both John I and Bird showed how some men are more likely to associate their ill health with a commonly known illness emerging in the general discourses of individuals in Jamaica, which are often times easily treated using home remedies.

Some men did not seek medical attention until their health had significantly deteriorated. For them, seeking medical care was the final step in responding to their ill-health. At this point the doctor is seen as a medical expert who is able to decipher what the men have not been able to address themselves. However, seeking medical attention was not always helpful for the men; two participants reflected on how their initial symptoms were misdiagnosed by doctors. This initial misdiagnosis subsequently contributed to further delays around their HIV testing and diagnosis. Ritchie shared his expectation that his doctor should have been aware of the symptoms of being HIV infected:

I say that I’m really feeling weak. He didn’t even check my pressure and things like that... I’m saying he should have picked it up with all the symptoms I was telling him about... he should have picked it up. (Ritchie)

Similarly, Bird sought medical attention for his persistent flu-like symptoms and weight loss after failed attempts to self-treat his perceived illness. He was, however, advised that his symptoms were stress-related:

I went to the doctor, tell him that a not feeling well, I'm not eating and I'm losing a little weight and I have this problem. So him say probably you need some vitamins, your body is stressed. So, he gave me some vitamin tablets and him say take some iron, and then after that, about a week later, I wasn’t feeling well but I didn’t go back to that doctor, I went back to another doctor. (Bird)

Both Bird and Ritchie recognized the importance of seeking medical care after becoming unwell. However, their expectations of their doctors were not met upon realizing that they were initially misdiagnosed. Patient misdiagnosis can result in an early mistrust in physicians that could subsequently affect how the men further address their health issues. For Bird, his persistent symptoms forced him to question the expertise of the initial doctor and consequently seek an alternative medical opinion. It was at this juncture that he was advised to do an HIV test that led to his positive HIV diagnosis.

In some instances, the men presented with opportunistic infections which resulted in their hospitalization. This is indicative of the late stage at which men tend to present for testing and diagnosis. A total of eight men indicated they were hospitalized at the point of initial diagnosis. The opportunistic infections presented included what one male perceived was a prolonged cold and persistent asthma attacks, which was subsequently diagnosed as pneumonia. Another male was also hospitalized due to a chest infection that was later diagnosed as pneumonia. Not all illness resulting in hospitalization were directly linked to the men being HIV infected. Three participants were hospitalized for unrelated conditions, namely a stroke, dog bite injuries and impaired mobility, during which time their HIV diagnosis was discovered as a part of general diagnostic procedures.

5.2.3 I didn't request an HIV test but I was told that I am positive

Three men discovered their HIV status without actively seeking to be tested. In two instances, the men were advised of their positive HIV diagnosis after donating blood. Mandatory HIV testing is conducted on samples of all donated blood in Jamaica. Thus these men were subsequently contacted and advised to visit a public health clinic closest to their area of residence, at which point they were advised of their HIV status. This meant that up to the point of being advised of their HIV diagnosis, these men were unaware of their HIV exposure and were oblivious to the possibility of being advised that they are HIV positive. As Paul shared:

It's like one of my friends get shot so I go up to UHWI (University Hospital of the West Indies) to give some blood. Then couple months after I think, I get a letter from a clinic say I'm to come out by Windward Road. But you done know, I wasn't pree-ing (paying attention to) it because that was the furthest thing from my mind. (Paul)

Trevor unintentionally learnt that he was HIV positive after engaging in a broader range of medical tests associated with obtaining a life insurance policy. As with Paul and John III, Trevor did not participate in the procedural requirement for his insurance with an awareness or expectation of being potentially HIV infected.

Overall, the men in this study discovered their positive HIV diagnosis through varying channels. This highlights the multiple avenues through which men could potentially be tested and diagnosed. Only two men intentionally sought to be tested in light of a recognized risk of infection. Of the remaining men, the majority became ill and subsequently sought medical attention, whilst the others discovered via routine or random testing, or by default of other medical procedures that included HIV testing. Though counselling is integrated within the formal guidelines for voluntary HIV testing, it was found that none of the men referred to this counselling process in discussing their HIV diagnosis. This questions the effectiveness of this process especially in mitigating the trauma which most of the men reported upon learning of their positive HIV diagnosis.

5.3 HIV DIAGNOSIS: FEELING SHOCKED OR UNSUPRISED

The circumstances around HIV testing did not differentiate between the general response of shock, surprise or disbelief for most men. As Dante, who spontaneously sought to be tested, emphasized, *"I was so shocked. I was so shocked"*. This response of shock was similar for Jay who was tested as a result of becoming ill and seeking medical attention: *"When I heard that I was diagnosed I was shocked"*. However, there were noted variations for some men, particularly the men who discovered their HIV status after donating blood. There were also some men who indicated an absence of surprise which suggested an awareness of the likelihood of risk of HIV transmission. This section looks at why some men were shocked whilst others were more accepting upon learning of their positive HIV diagnosis.

5.3.1 It can't happen to me

Some men experienced shock or disbelief upon learning of their HIV results, as they did not perceive themselves as engaging in behaviours that placed them at risk of becoming HIV infected. In particular, there was a delineation of self from someone who is promiscuous and thus deemed more likely to contract the virus. Thus the notion of being non-promiscuous resulted in these men believing they were not at risk of becoming HIV infected. For Jay, the promiscuous behaviour of having multiple concurrent sexual partners was labelled “*running up and down*”, which he deemed he was not doing at the time of his diagnosis; hence he struggled to believe his HIV positive results. As he stated, “*No I didn't take it serious because you know you not really running up and down and so forth*” (Jay). In contrast, Jay presented himself as: “*Every now and then [I] would go out and [I] meet someone and you might like them and they would like you, you and them make love and so forth, but you're not running up and down*” (Jay). This established a benchmark of comparison between promiscuous men who *run up and down* with multiple sexual partners, and other men, like Jay, who will occasionally meet someone to whom they are attracted and subsequently engage in unprotected sex. The distinction appeared to be based on the transitory nature of, and emotional investment in, the relationships. This distinction also showed a delineation between certain social categories of masculinity, where those men who display a sense of hyper-sexuality (*running up and down*) are expected to be more susceptible to contracting HIV, as against more sexually conservative categories of men.

In some instances, the men's immediate response to learning of their diagnosis was to reflect on their past in an effort to identify the specific point which exposed them to the virus. This act of introspection was seen to mirror the men's belief that they were not at risk of contracting HIV despite their sexual history. For instance, Bird shared: “*I've been questioning myself, saying I didn't have sex in the past 2 to 3 years*”. John II also experienced a sense of shock that propelled him to reflect on his past sexual history. As with Bird, this reflection shows a pre-existing belief that John II had not engaged in any sexual behaviour that would place him at risk. As he reflected, “*I started to check back*

from me born till them time deh. It's like me a search myself but me can't just point and say... Me can't pin point and say bwoy a Sophie or Sharon or whosoever" (John II). This introspection placed John II in a victimized position as he tried to identify which sexual partner was likely to have transmitted the virus. This overlooked his own role in potentially transmitting the virus, and minimized a conscious acknowledgement of habits or practices that could have placed him at risk.

5.3.2 But I always practice safe sex

Some men's response of shock or surprise was based on their belief that they generally practised safe sex and were thus not at risk of contracting HIV. As such, these men did not anticipate becoming exposed to the virus the few instances that safe sex was not practised. This was expressed by Bones who, given his general tendency to use a condom, never perceived himself at risk of contracting HIV. Further, he did not expect that the odd occurrence of condom breakage would be the point at which he contracted the virus. As he stated, *"I always use a condom yes but it burst on me and me get trapped....me get catch. Me never expect that cause me always use a condom"* (Bones). Being trapped suggested a sense of being deceived, snared and perhaps victimized by the positive HIV diagnosis. It also highlighted the belief that the general (as against consistent) practice of safe sex was sufficient in protecting against contracting HIV, which further explained the shock and trauma experienced by some men upon learning of their HIV positive diagnosis.

Que also grappled with the knowledge of his HIV diagnosis as he perceived himself to *"always practice safe sex. I always try to have sex with a condom"*. For him, the outcome of a positive HIV diagnosis also conflicted with his identity as a Christian male who does not have multiple sexual partners. As he shared:

I was going to church for I was baptized and so, and never was dealing with nuff woman at that time and that [becoming HIV infected] happened to me... if I was going up and down and catch it, I wouldn't feel so bad, for I was saying it would be my fault knowing that me run up and down and mess up myself... (Que)

Que delineated his identity and sexual behaviour from men who are “*going up and down*” and “*run up and down*”. This reinforced the belief that only men who engage in multiple sexual partnerships are at risk of contracting HIV. Further, his identity as a Christian and someone who generally (though not consistently) practices safe sex reinforced the perceived absence of risk. This underscores the notion that only men who exude hypersexual qualities akin to the hegemonic portrayal of Jamaican masculinity are at risk of contracting HIV. Thus men who consistently fail to use condoms, maintain multiple sexual partners, and are promiscuous and non-Christians were considered by some participants to be at greater risk of becoming HIV infected.

It was apparent that some men’s identities informed their perceived health risks and expected (or unexpected) health outcomes. So Que and Bones’ reactions of shock to their diagnosis were due to the disjoint between their perceptions of who is at risk and their self-perceptions. By distinguishing themselves from these hegemonic representations, neither Que nor Bones perceived themselves to be at risk, especially given their general though inconsistent use of condoms.

5.3.3 But I’m in a committed relationship

Another factor that contributed to the absence of perceived risk of infection, for some men, was their involvement in monogamous partnerships which they deemed stable, trustworthy and thus safe. In retrospect, Marcus recognized his vulnerability to becoming HIV infected was due to his commitment to his relationship with his partner, which did not warrant the use of condoms. Thus his notion of love, commitment and fidelity resulted in him neglecting the potential risk involved in having unprotected anal sex with one partner, who may not have been faithful.

I was looking for thing that was love of one partner, and unfortunately I was careless of what happened around me. That’s what made me so vulnerable by neglecting of the other things that was surrounded, umm me not being protective of myself. (Marcus)

Likewise, Dan did not perceive himself at risk of contracting HIV given he was in a serious relationship:

I was having a serious relationship. I have serious relationships. When I am talking about relationships I'm not talking every three months, I'm talking long term, years. But I was with a partner that cheated, a lot, and I knew that he had cheated and I got a STD, and HIV was the last thing on my mind, and I forgave him and he said it won't happen again. Stupid me.
(Dan)

Like Marcus, being in a monogamous relationship generated a sense of trust and safety for Dan which further nullified the need to engage in protected sex. However, this was further compounded by Dan's role as an HIV advocate which meant he was quite knowledgeable of the risks surrounding having unprotected anal sex. This knowledge was seen to contradict some of the prevailing social norms pertaining stable partnerships, trust and fidelity in Jamaica. Thus there is the notion that negotiating safe sex in a stable partnership is indicative of mistrust which can further affect the relationship. It therefore becomes difficult for some men involved in stable partnerships to negotiate safe sex even where the heightened risk of exposure is known. This raises the question of how safe sex can be negotiated in stable partnerships that equate trust and perceived fidelity with an absence of HIV risk.

Dan also indicated that his unlikely risk of exposure was reinforced by his approach to relationships that defied the typical stereotype of MSM. As he suggested, the stereotypical expectation of an HIV positive MSM is that he "*must have been bad out there*" and "*must have been picking up all the boys*". This suggests another type of promiscuity attached specifically to MSM whereby becoming HIV infected is an expected outcome. By declaring "*I wasn't doing any of those*", Dan indicated an awareness of, and perhaps personal ascription to, the social labelling of MSM, whilst explicitly demarcating himself. Thus by avoiding casual sex with multiple male partners, Dan did not anticipate an HIV positive diagnosis.

Dan's response of shock upon learning of his diagnosis was further shaped by his knowledge of HIV and the associated risks. He pointed out the dilemma of some men who are aware of the risks of having unprotected sex but are in stable partnerships where the absence of condom use symbolizes trust and fidelity. He argued that certain sexual health promotion messages such as the ABC approach that encourages persons to abstain, be faithful or use a condom, are not relevant to some men's lifestyles thereby placing these men at an increased disadvantage. As he explained:

I have been aware of what HIV is. I was aware of everything, practically everything about HIV. But like I have told one of my colleagues who does advocacy, that thing, that ABC thing, there is something lacking in that ABC approach. Because what happens to persons who are in a relationship and they trust? They say 'abstain' and you can't abstain, be faithful and you are faithful and here I am being faithful and I'm still screwed over.
(Dan)

So health messages suggesting abstinence and condom use prove irrelevant for men involved in stable partnerships where unprotected sex signifies the sentiment of trust and fidelity. In addition, as Dan noted, one partner's choice to be faithful does not warrant reciprocity. Thus some men who are knowledgeable of HIV experience the quandary of sentiments of distrust as an outcome of negotiating safe sex, or trust that their faithfulness and investment in a monogamous sexual relationship will minimize the risk of infection.

5.3.4 This should not have happened because I know about this thing

Prior experience with or knowledge of HIV made it difficult for some men to believe their HIV diagnosis. Such knowledge or experience was garnered through their work in the HIV community, personal affiliation with someone who works in the health field or personal affiliation with someone who is living with HIV or died as a result of being HIV infected. It was expected that this knowledge of HIV infection and awareness of its associated risks would have informed the men's sexual practices. Thus there was a sense of disbelief and disappointment in self for these men upon learning of their positive HIV diagnosis. This

was evidenced for John II who expressed surprise and shame upon learning of his HIV diagnosis given his mother is a nurse:

Me have to take the blame because I was supposed to be more careful cause me know about this thing... me learn about it. I know so much about this thing that me can't believe this happen to me. (John II)

Arising from this state of shock, shame and self-blame is the question: how could this happen, in the context of knowing about HIV and the necessary steps to protect against becoming infected? Here, the construction of self as being knowledgeable did not translate into informing John II's sexual practices, resulting in him feeling blame-worthy.

Paul expressed not anticipating being diagnosed with HIV as the same illness caused his mother's death when he was 13 years old. He believed the knowledge garnered from experiencing his mother's death should have guided his sexual practices to ensure he did not contract the virus. As he shared:

Instant me drop in a hole - bleeps. Yeah. The thing is because I have the experience with it, this never ever supposed to happen to me because me supposed to be on top of my game because, just through my mother died from it and me get the whole of the counselling already. (Paul)

Again, there is the perception that having sufficient knowledge of, and experience with, HIV safeguards against contracting HIV. However, though Paul was aware of HIV/AIDS and the associated risks, this did not inform his sexual practices as he admitted to having a history of *run[ing] around* and having *a whole heap of women*. This presents a challenge in ensuring that behaviour change occurs in tandem with increased HIV knowledge which is often used as a predictor of sexual practices in Jamaica. Paul's history of *running around* aligned him to an earlier categorization of Jamaican men who are hyper-sexual given they maintain multiple sexual partners. Paul's experience showed a likely trade-off between his knowledge about HIV risks and the prevailing norms surrounding this type of masculinity, especially where the former imposes constraints on the performance of this hyper-sexual masculinity.

5.3.5 Not surprised because I knew the risks

Contrary to the general response of shock or surprise upon men learning of their positive HIV diagnosis, those men who identified as MSM or gay indicated that they were not perturbed by their positive HIV test results. The absence of shock or surprise was due to an awareness that their sexual practices placed them at risk of contracting HIV, and thus they had accepted that becoming HIV infected was a plausible, though undesirable outcome. For these men, their sexual practices that placed them at risk of contracting HIV were explicitly linked to their sexual identities as MSM. As Whitey expressed,

it wasn't terrifying; but I can kinda know [could surmise] because through the behaviour that I was portraying... I'm not like a frantic person who is going to go out there and kill themselves because I know my lifestyle, I know what I did, but I have to accept it. (Whitey)

Whitey further explained that the behaviour and lifestyle he referred to was associated with his identity as an MSM: *"My lifestyle is a MSM lifestyle, in terms of men having sex with men"*.

Ritchie also indicated that he was aware of the risk of becoming HIV infected prior to his diagnosis. As with Whitey, he stated this was due to his MSM identity and the related sexual practices. As he shared, *"Based on my sexual activities and stuff, I say I could be HIV positive"* (Ritchie). This underscored an awareness of the heightened risk of HIV transmission for men who engage in unprotected anal sex. The desensitization to such risk presents becoming HIV infected as an imminent occurrence that cannot be escaped by MSM. Instead of employing strategies to protect against contracting HIV, these men accepted being HIV infected as likely, and thus an aspect of their identities before they were diagnosed as HIV positive. Thus the likelihood of becoming HIV infected was associated with these men's sexual identity rather than their choice to have unprotected sex. This reveals an important area for policy in relation to managing incidences of HIV amongst the MSM population.

The perception that becoming HIV infected was inevitable, did not propel MSM to get tested early and be linked to treatment and care. Ritchie's failure to test early, despite an awareness of his heightened risk to exposure, was based on the perceived stigma surrounding both HIV/AIDS and MSM behaviours in Jamaica. He indicated that the only clinic he was aware of at the time that did HIV counselling and testing was traditionally stereotyped as an HIV support organization for MSM, thus generally attracting social stigma and labelling of anyone who accessed the organization's services. As he shared:

Back then there was just more discrimination and stigma out there than now. And the only thing that come to mind about HIV was JASL and I didn't really want to associate myself with it. (Ritchie)

The notion of this particular clinic being largely associated with MSM was echoed in the narratives of other men interviewed. In each instance, the clinic was presented as a stereotyped or labelled environment that must be avoided to ensure the label of being gay or MSM was not inherited. Though some of these men identified themselves as MSM, the awareness of the stigma and discrimination surrounding this group meant they had to do what is necessary to protect their identities, and thus avoided utilizing the services of that clinic. This behaviour shows how men's access to health services can be impacted by their fear of HIV-related stigma or MSM stigma.

5.3.6 Not an issue because I'm HIV literate and I understand the role of treatment

A pre-existing knowledge or awareness of HIV and the role of ARV medication averted some men's fears and anxieties around being HIV positive. Trevor indicated that he was not traumatized by the test outcome given his HIV literacy and awareness of the availability and advancement of treatment:

I was always involved. My interest was not as a result of it being diagnosed. As a person who needs to be informed, I had to be HIV literate. So with or without I have an idea of what the illness was about. (Trevor)

Mark indicated that his response to learning of his diagnosis was less disruptive because his brother died earlier from the illness. According to Mark, *“Me neva tek it that much... [because] I had a brother that was sick...only fi find out say is really HIV him have or AIDS”*. He expressed that he was more impacted by his brother’s death than the knowledge of his own HIV status. Instead, his brother’s HIV-related death was used to fuel his determination to commence treatment. Thus his awareness of his HIV illness and the possible outcomes if left untreated appeared to influence him and cushion the shock or trauma of learning of his own HIV status, propelling him towards initiating and maintaining treatment.

The information provided by Trevor and Mark reinforced the significance of knowledge or experience in impacting the experience of learning about a positive HIV diagnosis. Both men showed that an existing knowledge of the illness or the experience of having a family member die from the illness, paired with an understanding of the value of ARV medication, can mitigate the adverse effects of being advised of a positive HIV diagnosis.

5.3.7 Having support and knowing life goes on

The stress of learning of one’s HIV status was also alleviated where effective social support was provided. This was noted for Kevin who indicated, *“it never really stressful, because as I said I had friends and family who really stand up with me and all a that, so when I go and do the second test, it was like nothing”*. This was similar for Marcus who shared that his experience was not perturbing as he attained the support of his partner at the time of his diagnosis:

At the time I didn’t worry cause I got a lot of support from him. Because I didn’t know anybody who was like that, I was in a position where the counsellor told me that life goes on, and I had support. I did have the support from him so I didn’t worry much too much. (Marcus)

5.4 THE IMPACT OF HIV DIAGNOSIS

Learning of a positive HIV diagnosis was found to negatively impact the lives of a number of men. Most of the men expressed having a myriad of emotions that captured the extent of the trauma or devastation experienced. Amongst these experiences was the perception that their lives became a nightmare or were disrupted by the onset of the illness. Some men indicated having thoughts of ending their life shortly after being advised of their HIV positive status. The negative impact of being diagnosed with HIV was found to relate to the men's struggle to accept the idea and reality of living with an illness that was incurable, stigmatized and likely to affect their relationships or interactions with others.

5.4.1 It became a nightmare. My life was shattered.

Most of the men interviewed described the point of learning that they are HIV positive as being traumatic, filled with a range of emotions including shock, grief, depression and devastation. As Troy expressed, *"I got tested and then the guy said to me, 'You know your test came back and it's positive'. And I was like, 'What!' And you know I was devastated"*. According to Richard, *"it was like my whole life came shattered in front of me when I found out"*. Bird also shared experiencing a range of emotions when he learnt of his HIV diagnosis:

I wanted to run out of the room cause when she said I had HIV and I was even confused and weak, and I don't know what I have and I don't know what she talking about. Tell you the truth, I wasn't crying but I was so depressed and thing. (Bird)

This sense of devastation was also experienced by John III who likened the period of learning of his HIV status to *"a nightmare"* where *"it was like I was out of my mind. I become so thin. I lose a lot of weight, just by fretting about it. Yeah man it was so devastating. I couldn't sleep, I couldn't eat nor nothing"* (John III). John III's experience demonstrated how the despair surrounding becoming HIV infected can further impact the physiological and psychological well-being of men. This was reinforced by Bird who

recalled, *“I remember one morning I couldn’t come out of bed, I was so weak, tired and depressed”*.

The devastation experienced by some men was found to be largely attributed to their perception of the social implications of being HIV positive. This perception forced some men to isolate themselves from others, as illustrated by Ritchie:

The doctor said to me, “You know you going to have to start go out and meet people. Cause if you don’t and lock up into that house, it going to drive you crazy. You understand?” So that is how the depression came down on me, cause I wasn’t going out anymore and I didn’t want to associate myself with anybody anymore. I lock myself away from the public... (Ritchie)

This self-isolation was seen as a response to the fear of being rejected, socially ostracized, or isolated by family and friends. As such, it reflects the subconscious or conscious acknowledgement of the stigma associated with being HIV infected that may in turn affect how others would now perceive these men given their acquired HIV infection. The resort to self-isolation was also evidenced for Troy who opted to become homeless because of his sense of *“giv[ing] up all hope”* and having *“nowhere to turn”*. Troy further explained, *“I was homeless because at that point I guess I had reached an extreme level of depression, now looking back at it. You know when you give up all hope... I left home and I was on the street”*. When asked what he thought caused the depression, Troy responded:

As I tell you - nowhere to turn. Worst of all my family, I couldn’t see how I could explain and tell them about it, if I don’t myself know [understand] about it. You understand? (Troy)

Troy’s response showed how some men’s response to their HIV diagnosis incorporates assessing the implications of living with the illness in their respective social contexts, comprising their family, peers and community. He alluded to the fear of the repercussions of his family and friends learning of his HIV status. This fear of disclosure is often associated with the fear of rejection and the loss of social support. This became evident

when Troy reflected on his family's response upon learning he was HIV positive: "*my family was more sympathetic. I never believed they would have been*".

Troy also alluded to a state of confusion due to the absence of appropriate knowledge that would generate a better understanding of the illness. This sense of not knowing potentially contributes to the trauma that some men experience upon being diagnosed with HIV. Like Troy, Mario ran away from home upon learning of his HIV positive diagnosis. His response was largely fuelled by the circumstances under which he was tested and subsequently diagnosed, and the resulting confusion regarding how he contracted HIV given he was not sexually active at the time of his diagnosis. As he shared:

I never had sex before I got tested and when I got tested it came back that I was positive. I was like, "what is this?" So I turn to the lady and say "I'm running away from home. I don't care what you want to say. No, I'm running away from home" ... I couldn't take it, my whole generation is going to know, the whole community and thing. So I run away from home and I stayed on the road. (Mario)

Mario may have contracted the virus vertically as he indicated his mother had died from the HIV illness. Despite the uncertainty of the source of HIV transmission, Mario was cognizant of the potential implications of his "*whole generation*" and "*the whole community*" knowing about his HIV status. Thus, there is an acknowledgement of a negative connotation attached to being HIV positive that could affect these men's lives negatively. This perception propels some men to isolate themselves or leave the environment that has now been redefined as unsafe on the premise of their acquired HIV infection. Men's choice to isolate themselves or leave home showed how socially imposed labels or evaluations associated with being HIV infected, can negatively impact psychosocial well-being and redefine how they function and are perceived in their various socio-cultural contexts.

5.4.2 Losing the will to live

Some men indicated having suicidal ideations shortly after learning of their HIV diagnosis. Though the specific point of the onset of these suicidal ideations varied, they were largely associated with the trauma of being diagnosed with a stigmatized and incurable illness. The idea of living with HIV was unfathomable for these men, resulting in them losing the will to live where ending their lives emerged as a viable option. This was noted in Bird's reflection on the night he was advised that he is HIV positive:

In the late hours of night, me alone in there. I just started praying and I say, 'Lord, I don't know what I got myself in but I don't know what to do seriously. During my prayer I said let me just go down the road and see if a car will lick me down and ting. (Bird)

John III also acknowledged that thoughts of suicide were linked to the devastation of learning of being diagnosed with a stigmatized illness:

for the person who really diagnosed and get to understand about their status, it can be a really devastating thing and I think it can also lead to suicide. If you are not strong, if you don't have that faith, if you don't have an inner being inside of you, I think it can be very devastating. (John III)

Here John III alluded to an awareness that a positive HIV diagnosis introduces an added dimension of complexity to men's lives which some grapple to accept. Perhaps it is the preconceived challenges surrounding difference, inequality and discrimination that propels some men to consider committing suicide as an alternative to living with HIV. As John III suggested, it requires a persona of strength, faith and courage to inspire the will to live and overcome the challenges and trauma of becoming HIV positive.

HIV/AIDS, being an incurable illness, was seen to equate with a permanent sick identity that could push men into an infinite state of dependency on others for care and support. The permanency of this sick identity and the resulting dependency on others forced some men to consider suicide, not as a method of escape but as an act of altruism. Here some men expressed the reluctance of becoming a burden of care to others, particularly family

members or loved ones who were likely to be negatively impacted by the men's HIV status.

This was noted for John I:

Well I remember once I feel like I would take my life. I remember that much...To put my family through it - I didn't want to bother. I just wanted a quick process to get it over and done with because there is no cure and all these things. (John I)

The idea of committing suicide to alleviate the likely burden of responsibility on family members drew on notions of a masculinity identity for some men. This occurred in two parts: firstly, male as hero, engaging in a risky and selfless act for the benefit of others and secondly, the intentional avoidance of a lifelong illness that is likely to threaten the man's identity as healthy, independent and strong.

The reinforcement of a masculine self that was hinged on the integral role John I played in his family, subsequently shifted his focus from dying to living:

I have my son to live for. My mother would not deal with me being dead right now. There would be a double funeral... (John I)

My son says he loves me. My son is always asking me if I'm ok. My mother just wants me to be ok. My girlfriend on the other hand says "Honey I need you. You mean so much to me and without you I am nothing". (John I)

Thus John I's determination to live, despite becoming HIV infected, hinged on his roles as son, father, and partner; the latter two roles being notably distinct qualities attributed to Jamaican masculinity. As such, this reinforced sense of fulfilling ideal masculine roles contributed to the diminished sense of loss and drive to commit suicide.

Dan admitted to struggling with repeated thoughts of committing suicide. Despite suicide being seen as an escape from the inevitable challenges of living with HIV, Dan perceived it as a cowardly act that likely conflicted with his masculine identity. As he shared:

I have thought of suicide, several times. But I don't like pity courage you see. If I go into that morose, I keep that internally, and then I get over it. I don't like to lose; I am very competitive. I like sports. I like sports and competition, that kind of stuff. The whole idea of losing for me, I think is the most offensive thing for me... losing, just feeling... So I just see this as another challenge. (Dan)

Dan's reference to himself as being competitive and sports-inclined, along with his disdain for losing are characteristic of the Jamaican hegemonic masculine identity. These qualities are incongruent with his thoughts of suicide, given suicide is seen as a cowardly act that garners '*pity courage*'. This revealed how some men's identities are evaluated, re-constructed or re-affirmed in response to becoming HIV infected. The idea of 'male as masculine' is considered at varying interludes, including those challenging points where suicide presents as an alternative to living with HIV. The retained value of the competitive male or the male as father or partner reaffirmed the social identities of these men, as their choice to live takes into consideration the perceptions and responses of others around them.

The role of others in influencing how men responded to their HIV diagnosis was also evidenced for Mario who admitted he attempted suicide in response to the overwhelming pressure imposed by his family in respect to his HIV illness.

My family was just so annoy[ing] against [for] me. They were like, "you take your medication? You know you going to die if you don't take it" ...Right okay, I want to die I don't business about nobody. So I over-dosed with them many times... (Mario)

It appeared that Mario's family became consumed by his HIV illness, which implied the need for constant care especially in light of imminent death if he failed to take his medication. As a result, Mario said his life "*was just too stressful*" which further propelled him to attempt suicide. Mario's experience with his family later became compounded by their knowledge of his MSM identity and the psychosocial impact of being with other MSM who were abusive. As he explained:

Staying around guys who would want to beat me up, my family they say “okay this is your fault. You don’t come here”. I have a bed and I can’t sleep in my bed. I have to sleep in cellars, that wasn’t me when I found out [being HIV positive], before they knew I was gay. That wasn’t me, I was living a happy life. (Mario)

Mario illustrated a distinction in men’s lives before and after becoming HIV infected. Yet, for Mario, his experiences were shaped by his identity as an MSM who is HIV positive and whose identity became known to his family. Thus becoming ostracized and isolated was in response to Mario’s learnt sexual identity and the perception that his abuse from other MSM contributed to his HIV infection, which further isolated him from his family. This illustrates the cumulative effect of intersecting dimensions of men’s identities and how their experiences are interwoven with structural processes such as stigma and discrimination.

Suicidal thoughts and tendencies also emerged in the absence of social support and due to the fear of being ostracized. This was seen for Richard who chose not to disclose his status to anyone as he feared this would expose him to the social antagonism or judgement often meted towards persons living with HIV.

I remember like twice I made an attempt on my life as in 2009, 2010 and 2000; no 2009, 2011 and 2013. I made an attempt twice to take my own life... Because sometimes like you sit down and you know you like want to say to somebody and you know at the end of the day you might say it to someone and at the end of the day you don’t know what him or her might do... (Richard)

Similarly, Troy identified an early sense of abandonment and isolation in the absence of social support. This sense of despair also fuelled his thoughts of committing suicide.

I fell into a life of despair because I remember one of the first, one of the six times when I was tested somebody had given me a card, saying here, this is somebody if you ever need any assistance; if you need somebody to talk to about it you just call this number. And it was a lady and I remember one day I just sat home and I was there and you thinking about it and you know when you have so many questions? And I called her and then she’s like “who’s this?” and I’m like “I’m the person you met”. And I’m trying

to figure out how to tell her where we met without disclosing too much you know. And then she recognized who I was and then she said “oh oh oh yes”, she said “well you have to call me back now I’m busy”. And I called her back about four times and she was always busy so you know I felt like... I’m like okay it’s a dead end road...(Troy)

The experiences of both Troy and Richard underscored the importance of the role of psycho-social support and social acceptance in the psychological and emotional well-being of persons diagnosed and living with HIV. In both instances, the absence of appropriate family or peer support contributed to the men’s feelings of despair, depression and isolation which spiralled into their suicidal thoughts or attempts. The sense of isolation and despair was also echoed by Bird who lacked the social support of a friend he supported during the difficult period of learning of his HIV diagnosis.

I’m not patting my back but during that time I was really being a friend to him. Which at my time, when the table was turned on me, I wish that somebody had done that for me. Because I had to go through it alone. (Bird)

5.4.3 I can’t have a perfect life anymore: Lifestyle disruptions and loss

A positive HIV status was perceived to be a disruption or termination of the normal lifestyles of some men. As Bones declared, “*You know when you have that [HIV] a done you done [suggesting life is finished]*”. For some men, this disruption or sense of loss was based on a sick identity which the men attributed to becoming HIV infected. This sick identity surrounded the men’s beliefs that becoming HIV infected meant they would: 1) become visibly unwell, 2) be required to take life-long treatment, and 3) be reduced to a state of dependence on others for their care and well-being, including health practitioners. This was evidenced by Troy who asserted:

I’m not a person who can take [pills] even when I’m sick and then my family is going to see the bag of pills and my brothers love to search up my place (laughs). I was so like [saying to myself] - ‘my skin a go bump up all over; you going to look like leprosy and then you a go meagre’... So those were the things that I was so afraid of. (Troy)

Troy's perception of the symptoms and treatment of his illness highlighted the emergence of a sick identity which he felt would alter his regular lifestyle and how he interacted with others, including his family. Becoming HIV infected, therefore, results in a sense of loss of a normal life that existed outside becoming symptomatic, and being required to take medications and depend on others for care and support. Thus the onset of these issues signalled the end of a 'normal' life for Troy and the start of another phase of life. As he reflected, *"I guess this is the way I'm gonna have to live. I can't have a perfect life anymore"* (Troy).

Dan also shared that becoming HIV infected resulted in a disruption of his *"multi-faceted"* life, particularly as it concerned his academic performance.

My GPA fell from a three point something to the cellar. I mean, I didn't know the GPA could get that low and still pass. I mean, a bunch of Ds, I had that little kennel of dogs on my report card. And I am slowly trying to get my life back together. (Dan)

Dan's academic pursuits are indicative of his personal ambitions that were likely linked to a desired career path. Thus becoming HIV infected, not only affected his academic progress but likely his futuristic aspirations such as those pertaining to his intended career. Dan gave an account of his struggle to regain stability in this aspect of his life:

I am trying to stay. I am still trying to salvage that, and it seems like an uphill battle, like I am just pushing around. I can't concentrate, I can't think. It would be so easy for me to give up on my education [but] I have come so far; I've spent so much money. I've done a lot. (Dan)

Becoming HIV infected also affected some men's identities as it pertained to certain stereotypical masculine qualities such as being financially stable, independent, employed and respected. For instance, Bones reported a distinction in his economic independence before being diagnosed and his subsequent financial constraints. He further highlighted a shift in his status from being a significant member of his community, to someone of little

significance likened to be “*just a trash*” that is “*not remembered*” once others in his community learnt of his HIV status. As he shared:

I used to be a little sub-contractor, get a lot of work sometimes [and] employ a lot of youth. But from that [HIV illness], [I’m] not remembered... just a trash... breeze can blow me anywhere it want to blow me. (Bones)

Bones’ experience indicates that being HIV positive is also a social identity that imposes certain stereotypes that can result in men being socially ostracized and excluded from their social settings. This was noted for Bones when the knowledge of his HIV identity within his community led to his loss of respect, purpose, employment and subsequently financial independence.

This shift in men’s status due to being HIV positive was also noted for Que who lost his job after becoming ill:

The situation that I find myself in, I never dream that I would find myself in because I was in a good job. Just start, you know, get better in my job and that just happen. Really, really hurt and I really, really feel bad about it. (Que)

As with Bones, Que’s job symbolized a sense of independence and financial stability. However, his job also provided an opportunity for further professional development which was destroyed subsequent to becoming ill. Thus there is a mixture of hurt, a sense of loss of future aspirations, as well as a reconstruction of a masculine self that is no longer employed, financially stable or independent. These disruptions in Que’s sense of manhood were further reinforced when he shared:

Sometimes I home and know that I use to a do road, use to work, have my vehicle, use to drive where you know I want to go and just be my own man. And I realize that me come live to see that I sit down and somebody come hurt me and me have to be depending on somebody to give me something. That really hurt me... and is not an easy road to go through. (Que)

Becoming HIV infected shifted Que from a state of independence, characteristic of being his *own man*, to dependence, where he indicated “*depending on somebody to give me something*”. Again this illustrates the dynamics surrounding the emergence of an HIV identity and how it interrelates with existing dimensions of men’s identities and their related social habits.

The outcome of an HIV infection as a lifestyle disruption also pertained to the loss of futuristic ideas or dreams such as getting married and having children. Importantly, this was irrespective of the men’s sexual identity, as both MSM and heterosexual men indicated the lost opportunity to have their own families. Troy explained his loss of “*a perfect life*” surrounded his inability to get married and have children given his HIV status. These aspirations were labelled “*life visions*” for Troy. He further explained the sense of loss regarding his “*life visions*” as follows:

I would like to get married but then... I don’t know how to find someone. Are they living with HIV?... Yeah I’m alive, I would like to have a family. No, I can’t say that out loud. I use to like to have a family... My niece asked me the other day she say “Troy so can you like have a child?” I said “no because I’d infect the person you understand and then the baby would now be born with it and then the wife would even worse because of the medication that I take”. Then that would be a more devastating effect. (Troy)

Bird similarly expressed the loss of the futuristic dream of getting married and having a family:

I always said I’d want to get married and have a family one day Now I have to put that on hold, or just forget it completely... It’s not easy for me to meet you and like you; it’s not easy to talk to you and say, “you know say I’m HIV positive” or something. I might turn you off and you might not talk to me after that. (Bird)

Being a husband/partner and father are identified as intrinsic values for Jamaican men as they reinforce the sexual and paternalistic roles that emerge as aspects of Jamaican hegemonic masculinity. These values help to shape men’s social identities and aspirations

which become challenged in the context of a sexually transmitted infection that is stigmatized and regarded as a barrier to sex and childbearing. These internalized representations of masculinity were reflected for both MSM and heterosexual men underscoring the power of these hegemonic values. Thus Troy, who identified himself as MSM, projected the desire to have a wife and children. This suggests that norms surrounding fatherhood intertwine with sexual identity and the cultural undercurrent that prescribes heterosexual contexts for reproduction and childrearing in Jamaica.

For Paul, his life disruption commenced when his wife, whom he married after they both learnt of their positive HIV status, died from the illness. Getting married post learning of their HIV infections appeared to create a sense of stability for Paul and his wife. As he indicated, *“we got married and we just keep we self to we self. So you know we don’t have a reason to stray”*. This alluded to a sense of being socially responsible which continued even after his wife had passed.

We [Paul and his then wife] have a self-consciousness that this is a sexually transmitted disease so we not going to be wicked and go around and spread to any and everybody; that nuh right. And it stopped right there. And she died even though I’m still here. Even though I have somebody, I protect myself and when time I see that the relationship going to get too serious and they want to have intercourse without a condom and a talk about baby, I sit them down and say this is it. I done know say self-preservation is a hell of a thing. Who can stay, stay and who can’t stay - leave. (Paul)

Therefore, it was evident that the awareness of the risk of HIV transmission was the key consideration in the decision to not intentionally expose others to the illness despite personal aspirations for a long-term partnership and/or children. Thus being socially responsible emerged in tandem with the acquired HIV identity for some men, and resulted in men prioritizing the well-being of others over the hegemonic ideals of husband/partner and father. This sense of social responsibility was evidenced for both Troy and Bird. As Bird declared, *“I’m not gonna try and put nobody through all that”*.

Importantly, HIV illness was not always seen or experienced as a long-term or permanent lifestyle disruption. As Jay expressed, “*my life was shattered for a time, but I know it’s not forever*”. The sense of the temporary nature of the disruption was also shared by other men as they progressed from the period of HIV diagnosis into adjustment to living with the illness, which is discussed in the following chapter.

5.5 SUMMARY

The period of HIV diagnosis was identified as a pivotal stage in men’s treatment trajectory, as it was at this stage that men were introduced to the reality of living with a chronic illness that required lifelong treatment. Majority of the men did not actively solicit an HIV test, which contributed to the predominant responses of shock, disbelief and trauma. Men generally waited until they were symptomatic to seek healthcare and were often hospitalized due to the extent of their ill-health. This reinforced the literature that indicates that men tend to delay in seeking healthcare. Some men were surprised at the outcome of their HIV tests given they did not perceive themselves to engage in behaviours that placed them at risk of contracting HIV. Here men delineated themselves from a preconceived notion of who is at risk, which they generally classified as men who are hypersexual, promiscuous and unfaithful. There was also the belief that the general, though inconsistent, practice of safe sex was sufficient to protect men from contracting the virus. Those men who anticipated the likely risk of exposure, given their sexual practices and sexual identity, were not shocked at the outcome of their HIV positive diagnosis.

Learning of a positive HIV diagnosis was particularly difficult for men. Some perceived that their life dreams and aspirations were destroyed, whilst others lost the will to live. In each instance, men contemplated the implications of living with HIV as a stigmatized and incurable illness that would alter their social identities and relationships with others. The realization of HIV being an incurable illness meant the introduction of a permanent sick identity that required continuous treatment and interactions with the health professional. As a stigmatized illness, men feared the repercussions of others discovering this aspect of their selves, which contributed to the devastation and sense of loss that some men experienced.

Some men reported shifts in their masculine identities, from being independent, financially stable and respected, to becoming unemployed, dependent on others for care and subjected to social ridicule. This highlighted how men's experiences of being diagnosed with HIV were shaped by intersections of their identities, socio-cultural norms and social structural processes such as HIV- related stigma. The personal and social experiences around learning of an HIV positive diagnosis determined men's ease of accepting their HIV diagnosis, which was a crucial step for men to progress into initiating their ARV treatment.

Chapter 6 FINDINGS II

Transition: Moving from diagnosis to treatment initiation

6.1 INTRODUCTION

This chapter focuses on understanding the transition period between HIV diagnosis and treatment initiation for the men in this study. It was found that acceptance of a positive HIV diagnosis and adjustment to living with HIV as a lifelong condition were milestones in the men's treatment trajectory (see Figure 19, p. 152), that characterized their journey from diagnosis to treatment. These turning points were important for all the men, though the timing around each varied pending their unique circumstances, such as their self-perceptions in the context of their HIV diagnosis, the extent of their symptoms and whether they required immediate ARV treatment.

6.2 ACCEPTANCE OF HIV DIAGNOSIS

Acceptance of their positive HIV diagnosis emerged as an important step to be taken by the men prior to progressing into their treatment. It necessitated their belief that the HIV results given were accurate and entailed the men to acknowledging and reconciling that they are living with a chronic illness that requires lifelong treatment. The significance of this transition was aptly expressed by Bird when he said, *"I've come to peace with it"*. Failure to accept the positive HIV diagnosis often resulted in a dismissal of the presence of the illness and acted as a barrier to follow-up care and treatment initiation. This was illustrated by Steve who shared, *"I take long to believe when the doctor told me and that's why I take so long to go on medication"*. Thus disbelief and subsequently non-acceptance of an HIV diagnosis are likely to become barriers to men's linkage to care and treatment.

The challenge of accepting a positive HIV diagnosis was noted for most participants, except for those men who were not surprised or negatively impacted by their diagnosis. Thus self-acceptance of the acquired HIV identity occurred more readily for those men who recognized an early risk of infection being associated with their sexual practices and sexual identity, and those men who felt their pre-existing knowledge and experience with HIV

already prepared them for the reality of living with HIV (Chapter 5, section 5.3 examines this in detail). For others, the transition from a positive HIV diagnosis to accepting HIV as a part of self was not a smooth process, and revealed complexities surrounding men's pre-existing self-perceptions and their altered perceptions of self and quality of life due to being HIV infected.

6.2.1 Acceptance hinged on becoming symptomatic

Some men were not able to accept their HIV diagnosis until they became symptomatic, displaying physical manifestations of being unwell such as rashes, pneumonia, or significant weight loss. This was particularly noted for those men who refuted their initial positive HIV diagnosis and repeated HIV testing later in the progression of their illness. For these men, it was not until they became symptomatic or seriously ill, that they were able to accept their repeated HIV diagnosis. Thus their ill health or onset of symptoms became the evidence that proved the accuracy of the HIV test results, as Jay noted:

when I took the test the doctor told me that is that happened to me. I didn't really take it serious until I end up getting sick again and come down UC here and admit for a good while until I end up coming out the clinic here and from that I started taking the medication.

Jay did not accept his diagnosis until he became symptomatic and his health deteriorated to the point of warranting hospitalization and an almost immediate transition into commencing ARV treatment. The latter is indicative of the extent of his poor health, given the clinic adopts the recommendation of initiating ARV treatment at CD4 counts ≤ 350 per mm³, which is the general marker for persons who have progressed to the advanced stage of HIV infection (WHO, 2007).

Similarly, Dante stated that he was better prepared to accept the confirmation of his HIV status and progress to commencing treatment after he became symptomatic. As he stated, *"when I go back again now I take it serious. First me start lose weight. Went back to the hospital now and they start to give me medication"* (Dante). Like Jay, it was not until he

became visibly ill and his deteriorated health warranted hospitalization, that he was able to accept the results of his second HIV test.

The importance of becoming symptomatic before progressing into treatment was further reinforced by Troy who described the five years surrounding his initial diagnosis and yearly re-testing as *“Good - as I told you there was no symptoms, no signs or anything like that”*. This meant that Troy consistently denied or questioned his repeated HIV diagnosis over a five-year period because he did not display any signs or symptoms perceived to be related to being HIV positive. As he further explained:

I got tested and then the guy said to me, ‘Umm, you know your test came back and it’s positive’. And I was like, ‘What!’ and you know I was devastated. But then somehow me just, somehow you say that’s a mistake and then you go somewhere else and you know, you do it again and you get back the same result and its positive and you like don’t accept it. They’re telling you but you don’t accept it. Is like someone say, ‘oh you’re fat’ and you go mm, no I’m not. (Troy)

This period of denial for Troy did not change until he became symptomatic and his deteriorated health required urgent medical attention. He described the period leading to his acceptance of his diagnosis as follows:

I started noticing that I started to tremble and started getting high, high, feeling like high fever and then extremely cold temperature. My body just changing temperatures like rapidly and then I’m blanking out... and then I came to the doctor and when I came to the doctor the doctor said ‘You know, you’re HIV positive? We need to tell you, you were tested and it seems you are HIV positive’. I said ‘I know I’m HIV positive’ (laughs). Well at that point I finally accepted it, ‘wow I am HIV positive’. (Troy)

For Troy, Dante and Jay, it was evident that their self-perceptions as being non-HIV positive was based on the absence of visible symptoms associated with being HIV infected, rather than the outcome of their HIV diagnostic tests. This reinforces the symbolism of the physical manifestations of an illness being characteristic of a sick identity, but more so an HIV positive identity. Such a perception was further underpinned by Troy’s description of

his fear of becoming visibly HIV positive (see page 175 for quote). Therefore, the absence of these symptoms can result in men challenging the accuracy of an HIV test.

The absence of visible signs of an HIV infection can also act as a barrier to how quickly men progress between their initial HIV diagnosis and accessing care and treatment. The role of becoming symptomatic being a predecessor to acceptance of diagnosis and the subsequent linkage to care and treatment was noted for the majority of participants who were symptomatic at the point of diagnosis. A total of 15 men initiated treatment shortly after being diagnosed with HIV, which suggested the extent to which their health had deteriorated before seeking medical care, being tested, accepting their HIV diagnosis and subsequently commencing ARV treatment. Waiting until symptoms appear can result in men presenting late for treatment, at which point their HIV infection may progress to its advanced stage, thus requiring a more complex system of care.

6.2.2 I had so many questions: Becoming HIV literate as a pathway to acceptance

For some men, receiving accurate information about HIV and their ARV treatment was instrumental in enabling them to accept their HIV diagnosis. Troy's struggle to accept his positive HIV diagnosis resulted in him being tested six times over a five-year period, thus causing an extended delay between his diagnosis and progression into treatment. Much of this period of denial for Troy was characterized by his uncertainties regarding the implications of living with HIV. As he shared:

Emotionally I was dying. If every time you go back and you get the same results you're like okay wow and then you personally want to know how long, not knowing that there is something [that] is called a CD4, you wanted to know how long you have to live. You understand? So that was the main thing. I wonder how long I was gonna live... (Troy)

The question of "How long am I going to live for?" showed the fear of living with an illness that is historically presented as a death sentence. This fear, along with other doubts or unanswered questions pertaining to the illness, were recognized as barriers to men's ability to accept their HIV diagnosis, reconcile and adjust to the reality of living with HIV,

and subsequently progress into their treatment initiation. As Troy further expressed, *“You kinda want to just have a one away conversation with somebody who knows something to find out more”*.

The desire for knowledge was not always informed through appropriate means, resulting in misinformation and misconceptions of HIV/AIDS and ARV treatment. This was noted for Troy who indicated that his assumptions of his HIV illness and the prescribed ARV treatment were shaped by wider social (mis)constructions within his social contexts. He provided an illustration of overhearing a conversation that led to the belief that ARV medications contributed more to his demise rather than improving his health. This belief prevented him from initiating treatment.

I was like okay, I’m gonna die one day so pssh. Why should I worry about getting the pills? Yeah. If I am going to die, with or without the pill why worry about getting the pills? I probably will die more reasonably without the pills than with the pills (laughs). (Troy)

Troy’s experience showed the power of social constructions of health, illness and associated treatment in shaping how HIV positive men choose to approach their health. The absence of appropriate and accurate information can result in delays in men accepting their diagnosis and progressing to the appropriate care and treatment. Given Troy indicated that this experience occurred shortly after his fourth repeated HIV test, it raises the question of the occurrence and validity of HIV counselling as an intricate aspect of HIV testing and diagnosis in Jamaica. The absence of appropriate counselling occurring in tandem with HIV testing can affect men’s preparedness to accept their test outcomes and transition into care and treatment if necessary (David & McGuire, 2007).

John II found that he was able to change his outlook of HIV as a death sentence and *“carry on with my life and my plans”* after he became HIV literate. Prior to this point he shared, *“It was like anything is anything, yuh nuh. Me not even a tek any medication or nothing because maybe I was never educated properly about this thing you know”* (John II). For

John II, it was not until he garnered an awareness of the importance and efficacy of ARV medication, that his perception changed. As he noted,

most people say from you have AIDS you a go dead. Well after coming to CHARES they tell me about taking the medications and you can live a normal life and things like that. Well me kinda look on it from a different side and say well me can carry on with my life and my plans. My plans for my life can still come through. (John II)

Initially, the sense of loss and perception of HIV being a death sentence meant Jay gave up on living – *“anything is anything”*. Becoming informed of the illness allowed him to experience a *“normal life”* wherein he regained his sense of hope and life aspirations.

The importance of becoming HIV literate as an important step in accepting an HIV diagnosis and progressing to treatment initiation was also noted for Troy when he transitioned into a sense of readiness to initiate ARVs. He spoke of an encounter he had with a nurse who willingly responded to his questions on HIV/AIDS and the treatment process. He described this opportunity as giving him a *“huge kick”* to commence his treatment process at CHARES. As he explained:

I remember when I was in the hospital the night. I was surprised how concerned the nurse was... I remember I asked her so many questions. I felt so embarrassed. And I say ‘Miss sorry to bother you with my questions’. And I keep asking 101 questions and she’s like, “no no no. that’s okay” ...

She answered all your questions?

Yeah. I had so many questions. She’s like: “No, bumps don’t have to come. Bumps are like this and that”. She got me excited and I’m like okay and I need to come over by CHARES and find out more then. So that I think, that was the only thing who gave me a huge kick. (Troy)

Both Troy and John illustrated the importance of obtaining accurate HIV information in helping men to transition from their HIV diagnosis into acceptance and subsequently treatment. These men referred to their initial knowledge being shaped by the social misconstructions of HIV/AIDS and ARV treatment, which in turn affected how they

progressed in their treatment journey. Altering this effect involved the men becoming informed by health representatives who were equipped with the accurate knowledge to better empower the men in how they perceived and approached their HIV illness. The role of health professionals in facilitating this process of awareness and transition highlights an area of need, where this information should be provided at an early stage in men's treatment journey to better shape their treatment experiences and inform their treatment decisions.

6.2.3 Changing perception: From death row to lifelong illness

The struggle to accept a positive HIV diagnosis was often premised on the perception of HIV as a death sentence. The notion of HIV being a death sentence was associated with HIV/AIDS being a lifelong, incurable disease that, in the past, has accounted for numerous deaths. The transition towards acceptance occurred when men developed an altered perception of the illness no longer being terminal, thus allowing a sense of hope in living with a lifelong illness. John I showed this changed perception from HIV as a death sentence to a liveable condition when he said:

I'm living on death row. So if I should think I'm living on death row, I'm gonna be a dead person. But if I think I can live through it, I'm alive now.

Why do you say you are living on death row?

Because it's an incurable disease, for now. But I will remain alive for a very long time. (John I)

John I's shifted outlook of his HIV infection was found to be based on an awareness of the role of ARVS and the continuous advances in treating HIV. Thus he was able to acknowledge being able to live for an extended period, despite the absence of a cure for HIV/AIDS.

Self-determination was identified as an important step that helped some men progress from perceiving HIV as a death sentence to the recognition that they can live with an incurable

illness that can be treated and controlled. This meant a conscious shift from the previous assumptions around being diagnosed with HIV to embracing an outlook that supported the notion of being able to live a fulfilling life. This was vividly outlined by Richard in an allegory surrounding the ‘vehicle of death’ and ‘vehicle of life’:

When I found out of my ‘caption’, it’s like I saw death driving in a car coming right [at me] ... I didn’t know who was the driver... but I know in myself that yea I am the passenger. But how am I gonna just hop on to that vehicle right and I know in myself say listen, I can choose whether to take that vehicle, the vehicle of death or the vehicle of life. So I stand up and I said listen, I’m not going to go there. So I decided on to myself say listen, I’m gonna let it pass. If you should have to do it, if you should step to it and thing, is like you throw in your own towel and life itself. So I decided onto myself I’m not gonna go any further with this. I’m gonna at least try to find ways in which to treat it until something has happened.

This allegory captured Richard’s deliberations and subsequent choice to change his outlook of his HIV infection (which he consistently refers to as either ‘caption’ or A-illness) as a death sentence to an opportunity to live. Self-determination occurs when men make the conscious choice to move beyond their pre-existing beliefs and social myths of HIV being terminal, to embrace the promise of having a future with the aid of treatment. The ability to opt not to “*throw in your own towel*” and choose “*life itself*” indicates men’s willingness to accept their HIV diagnosis and progress into commencing treatment.

For some, this choice was not solely based on the alternatives of life versus death, but also focused on the opportunities presented by being able to live longer. Dan perceived his HIV infection to be a “*restart button*” which offered him the opportunity to live a better and, more likely, purposeful life. As he explained:

I don’t see HIV as a death sentence. I honestly see it as a restart button. It may sound weird but it is really a reset button for me and because I cannot deny that I am HIV positive. I can’t say, why? I just have to move on. It really is reset. And it is a now is your chance. Cause there is no cure right now so what options do you have? You either get worse or get way better, and way better sounds good. (Dan)

Acceptance of HIV as a lifelong though treatable condition engendered a sense of awareness where some men consciously chose to live and experience a good quality of life despite their HIV infection. The choice and perceived opportunity to live and progress beyond an HIV diagnosis were found to be directly associated with the role of ARV medication. As Kevin expressed, *“taking the medication now it kinda make me have a hope that I can live”*.

The assumptions of HIV being synonymous with death have not changed over time, despite the advances made in addressing the epidemic in Jamaica. Thus for most men, it was someone who is knowledgeable of HIV and the positive benefits of ARV who became the catalyst in engendering a more positive view of the future despite being HIV infected. The following excerpts illustrate this further:

In the eighties, I will tell you straight up, when it was just coming on stream if you were diagnosed then it means death. So many people died because technological and medical advances were just coming on stream. The testing for it wasn't like anything else. Knowledge of these things was now available. As one doctor would say, you have it, you can live as long as though you never had it. You don't have to be afraid just make sure you taking your medication. (Trevor)

Every night that she come in she would counsel me, talk to me, say 'It's not a death sentence. You can live up to how much years if you just live on your medication and take your medication'. (Kevin)

He said 'listen, it's not a death sentence, if you work with it, all it means you might have to take tablets for the rest of your life'. (Bird)

It does not mean death. It only means death when you are not prepared to deal with it effectively. Specifically taking your medication if you want to live, taking your medication is promoting life and if you want it around, you have no choice. (Trevor)

It is evident that the changed perception of living with HIV can be impacted by the health professional message that living with HIV is not a death sentence given the benefits of ARV medication. Though these messages link living with HIV as conditional to men taking

their ARV treatment, they still offer a sense of hope for the future that enable men to accept their diagnosis and move into their treatment phase.

6.2.4 Acceptance by others

The importance of acceptance of an HIV diagnosis in defining the experiences of the men did not rest solely with their self-acceptance of their diagnosis but extended to their acceptance by others, whether family, close friends or intimate partners. Being accepted by others was intrinsically linked to overcoming the fear of stigma that is often attached to HIV. An awareness of this stigma imprints a social identity that can result in some men fearing ridicule, prejudice or abandonment, which further impacts how they engage their treatment. This was noted by Dan who shared:

Your family is so important. It is crucial. I can't tell you how light I feel that I was able to tell my mom and my sister. It was as if an entire weight has come off my shoulders. Because here I was trying to do school, trying to come to grips, trying to take my medications, meet my doctor's appointments, dealing with the loathing and the fear and dealing with the self-doubt and beating up myself... I [would] just stand in my room – so [a sense of positioning] my room doesn't have any of that experience, bearing weight that is heavier than mine.

For Dan, the acceptance and support of his family was crucial in helping him to cope with the many challenges surrounding his HIV infection, including his personal struggles with self-acceptance, and maintaining his treatment regimen and follow-up care. This reinforced the important role of social acceptance in strengthening men's sense of belonging and in ascertaining the social support that some men deemed as paramount in their treatment journey.

Being accepted by others made it easier for some men to transition into accepting their HIV status. Troy acknowledged that his life improved, despite the challenges of being unemployed, because he obtained his family's acceptance and social support. As he stated *"life has been better [since disclosing his HIV status and gaining acceptance]. I might be jobless but I have my family"*. Troy further explained:

It's much better because... that I have help... Dad is there now... cause you know living in a world where you don't have anyone is hard; I think that it is [hard]. But now that your family accept you and they're here for you and they will give you the support if they need to. And then dad he give me a gift when I accomplished what I wanted... He gives me goals and they were like remember you can live as long as you can.

Troy's experience showed how acceptance by family members can lead to psycho-social support that revives a hope for the future and personal aspirations which for some men were lost upon being diagnosed with HIV. Troy was motivated to live as long as he wanted and move on to achieve his goals. Thus acceptance by others can give men the momentum to accept their HIV status and transition into living a productive life.

HIV remains a largely stigmatized and misunderstood illness in Jamaica, hence the need for the acceptance of others was often juxtaposed against the backdrop of the men's fear of the negative repercussions associated with being HIV infected. As Dan stated, *"you are trained that it is chronic but everyone else thinks it's life ending. It is a very stigmatized illness. People think that you are a walking dead"*. The fear of being socially ostracised forced Troy to conceal his HIV identity by attributing his HIV symptoms to another illness which he felt was more readily accepted by his peers. In doing this, Troy maintained a sense of belonging with his peers, which otherwise may have been threatened by disclosure of his HIV status. Being labelled as "HIV infected" is thus seen to hold the potential of shifting men from the position of 'insider' who is accepted and embraced by his peers and family, to 'outsider' who is rejected and scorned. Troy shared this dialogue that depicted the conversation with his friends who questioned the appearance of bumps on his skin:

'Wait what happen to your skin, how you a scratch so? Where them bump them from?' And constant your [my] constant reply - ptomaine poison. 'Ptomaine poison? Wow you get ptomaine poison like three months now' (chuckles).

Troy's declaration of the appearance of bumps being a result of ptomaine poison was noted as a key aspect of his process of self-acceptance. When pointedly asked if he was moving

into that space of accepting his HIV diagnosis at this point, Troy replied: *“Yes I did. But at this point now I didn’t know how to confront anybody and how to explain HIV. How I feel and I didn’t know [or] want to answer any questions. I just wanted to die in a corner”*. It is uncertain whether he had commenced treatment at this point but it is apparent that an integral aspect of the process of acceptance was the safe navigation of a stigmatized illness in the presence of others. So given it was not safe to admit being HIV positive, Troy offered an alternate explanation of ptomaine poison, which despite being challenged, he maintained during the period of having rashes on his skin. The absence of a safe space to freely share his HIV status also encouraged a sense of isolation where he preferred *“to die in a corner”*.

At times, the need for the acceptance of others was directly linked to intimate relationships, whereby the men desired a relationship in which they could comfortably disclose their HIV status and feel accepted. The uncertainty of that acceptance made Whitey reserved about engaging in a relationship. As he indicated,

although I still want to be in one I haven’t found the right person who will say okay... you know I am HIV positive and this is who I am and they probably say okay, I can accept you for who you are. (Whitey)

Bird expressed a similar sentiment, *“It’s not easy for me to meet you and like you; it’s not easy to talk to you and say, “you know say I’m HIV positive” or something. I might turn you off and you might not talk to me after that”*. By stating *“I am HIV positive”* both Bird and Whitey showed that they had already progressed into accepting their HIV status as an aspect of their identities. However, they acknowledged the challenge that this aspect of their identities may pose in gaining acceptance by others which shows their awareness of the negative connotation attached to being HIV infected as a social label. This sentiment is perhaps more exacerbated in the context of intimate relationships due to the fear of the risk of HIV transmission.

The significance of garnering the acceptance and support of close family members or partners was noted for Marcus who readily transitioned between his diagnosis and acceptance of his HIV status. He indicated that this was due to the support he received from his partner at the time of his diagnosis. As he shared,

at the time I didn't worry cause I got a lot of support from him... I was in a position where the counsellor told me that life goes on and I had support. I did have the support from him so I didn't worry much too much until after he died...you know things started to be pressure on me. (Marcus)

The acceptance and support obtained from Marcus' partner became a vehicle for Marcus to move beyond his diagnosis. This reinforces the linkage between acceptance and ascertaining the support of others in men's transition into care and treatment, as well as resumption of their personal goals. Marcus' experience further showed that changes in access to psycho-social support can have adverse effects on men's ability to cope with living with HIV and continue their pursuit of goals despite being HIV infected.

Failure to receive the acceptance and support of intimate partners can be traumatic and result in a disruption of how the men perceive and approach their treatment journey. The absence of both family and partner acceptance and support propelled Whitey to consider committing suicide.

I have this virus and my family start whispering behind my back and the friend that I had wasn't there anymore, umm and basically he was my lover and he abandoned me. Then basically is like going through it alone but there is no support. And I said to myself that I just can't take it anymore. That's when I thought, I thought of having a suicidal thing. (Whitey)

Whitey's experience illustrated the extent to which negative social labels can impact the well-being of some men. In particular, his experience demonstrated how a shift from being accepted to rejected by those considered to be close to the men, can result in feelings of abandonment and isolation. The absence of acceptance or being rejected by others on the premise of an acquired HIV identity can have adverse outcomes, which for Whitey led to

suicidal ideations. Though Whitey was not traumatized upon learning of his HIV diagnosis, he maintained the importance of retaining a social support network in “*going through*” the journey of being ill.

Social acceptance is largely premised on the portrayal of identities that are validated as reflecting the socio-historical constructed rules of appropriate identities for Jamaican men. The process of garnering social acceptance becomes more complicated when men present with multiple dimensions of their identities that are not readily accepted within society. An example of this is noted for Troy who indicated struggling with others accepting him being both MSM and HIV positive: “*I remember that was the biggest obstacle I had in my life – which was acceptance*”. Being accepted by others meant Troy was no longer required to conceal his identity as an MSM who is HIV infected. This removed the burden of pretence that characterized his interactions with his family and peers prior to disclosing his HIV status. It was in disclosing his HIV status that Troy was also able to reveal his MSM identity to his family. He stated that his family was “*now accept[ing] that I am also that way [MSM who is also HIV positive]*”. This alluded to the complex and intersecting nature of some men’s identities, where some dimensions become hidden due to the social disapproval of such identities. Both MSM and HIV identities attract social stigma and disapproval in Jamaica, which likely forced Troy to conceal these aspects of his identity for fear of ridicule, scorn or rejection. By doing this, he prioritized the need for a sense of belonging amongst both his family and peers. Having the opportunity to reveal and gain acceptance of being HIV positive as one aspect of his identity made it easier to subsequently disclose and garner acceptance of his sexuality.

Importantly, social acceptance was clarified as not requiring others to approve or embrace the particular behaviours akin to men’s identities. Instead it was portrayed as persons providing an open and trusting environment in which the personal choices and representations of men’s identities could be understood and respected. As Troy explained,

It might not be the opinion that you want to hear but I’m more like a person to discuss things. So I know how [to address] the boundaries and

the do's and the don'ts. And that I guess that's how when I got out, my sisters, to know when I say I'm going to the doctor, I know I can I don't have to make up any excuse and go anywhere else I'm going. (Troy)

Having a sense of an open and trusting environment allowed Troy the liberty of being open with his family whilst establishing boundaries. It also enabled him to "*feel free*" in visiting the clinic without the fear of accidental disclosure.

Not all men felt it necessary to attain social acceptance to progress in their treatment journey. Instead, these men opted to maintain their HIV identity as a private aspect of their self that was not subjected to the scrutiny, evaluation or judgement of others. Marcus was very pointed in negating the need for social acceptance in progressing through his treatment journey. He maintained that his health and the value of "*living his life*" superseded the stigma and rumours related to his illness.

I'm going to enjoy my moment until my day comes. My health is very important to me... And even though I hear those ridiculous stigma, that doesn't matter to me and so what, I'm living my life comfortable. (Marcus)

Bird felt that it was better to not disclose his HIV status to anyone given the perceived social repercussions of disclosure. This, however, did not hinder his progression from acceptance into engaging in his treatment. As he expressed:

I just say to myself say nobody can't know because, even the church, no matter which church you go, you find discrimination so I try and live my life and thing, and say nobody no have to know and just try and do what I have to do and that's it. (Bird)

Bird's concealment of his HIV identity required the use of strategies to prevent accidental disclosure to his family, especially as it pertained to his ARV medication. Bird achieved this by attributing his ailments and medications to pneumonia, which was deemed more socially acceptable, whilst taking his ARV medication in private.

They gave me some medication for the pneumonia and thing and then I start taking the tablets and you know when I went home my family said,

“what kind a tablet them give you?” I show them the pneumonia antibiotic medicine but I hide the others. I take them in private so they don’t know.
(Bird)

Despite accepting being HIV positive as an aspect of his self, Bird remained cognizant of the social perceptions of an HIV identity that could affect his interactions with his family members. His choice to disguise his HIV identity as a more acceptable illness, and take his ARV medication in private, emerged as safe ways for Bird, and potentially other men, to manage his HIV identity amongst family and other social groups.

Paul was also reserved about disclosing his HIV status despite acknowledging the importance of having social support. Rather than disclosing his status to his family members, he opted to only advise a close friend who he described as his “*biggest confidante*”. The decision to not disclose his status to his family was linked to his “*self-preservation*” which was understood to be the need to protect himself from the prevailing stigma and discrimination associated with the illness.

Some of my family can’t keep their mouth. They may say it to the wrong person and it spread and have a stigma in the community. It’s not everybody... as I said self-preservation is a helluva thing. It’s not everybody can deal with this thing. The society on a whole, regardless of all the corruption and whatever, not acceptable fully to this thing here. I don’t care what anyone want to say, they are not acceptable to it yet. (Paul)

The stigma attached to being HIV positive forced Paul, Marcus and Bird to hide this aspect of their identities. This choice meant the men opted to engage their treatment journey without the support and acceptance of others. As Paul aptly stated, this choice reflected an act of self-preservation, which ensured the men avoided the negative repercussions often associated with an HIV positive identity. Thus by keeping their HIV identities hidden, men were able to protect themselves and safely navigate their healthcare, whilst also avoiding potential stigma, prejudice or unsolicited attention which could impact their relationship with family members and peers, and further impede their treatment journey.

The importance of men treating their HIV status as a hidden aspect of their self, was reinforced in some men being negatively labelled and ostracized because of others learning of their HIV diagnosis. This act of labelling meant the men were demarcated by their HIV status and subsequently reproached, isolated or scorned. Bones was branded by his community as having AIDS when his brother, upon learning of his HIV illness, decided to “*walk and scandal me all over the place*”. Bones further explained:

Him all come out on the road and say ‘You see me brother Bones, him have AIDS you know!’ When people hear bout AIDS dem get [gesticulates a sense of avoidance or distancing]. Maybe if him did say HIV it wouldn’t sound so harsh but when him go say AIDS now, it come in like...a hell, real hell.

Being branded with negative labels of being HIV infected or living with AIDS, imposes stereotypical assumptions and discriminatory behaviours that can impact men’s well-being in spaces once deemed safe and habitable. Though Bones made a distinction between being branded as having AIDS instead of HIV, where the latter was perceived to attract less social ostracizing, it is recognized that both labels imprint particular social identities on men that can affect their quality of life, especially where these stereotypical assumptions are maintained.

6.3 ADJUSTMENT TO LIVING WITH HIV

Once men transitioned into accepting or believing their HIV status, they did not return to a state of disbelief but instead engaged in other processes that helped them to adjust to living with the illness and prepared them to initiate treatment. Thus adjusting to living with HIV emerged as another important process for the men. The reality of HIV being a chronic and stigmatized illness meant that the men had to make conscious changes in how they approached their daily existence post diagnosis and acceptance. This adjustment process was found to be ongoing and involved the men consistently attuning to the realities and implications of being HIV positive, both in the context of their personal lives and their environment. A key landmark of this adjustment process was the men’s determination to live with the reality of being HIV infected. To illustrate, Richard’s adjustment process was

indicated by his determination to “*try my best to live with it*”. Adjusting to living with HIV also involved men changing their perceptions of HIV, envisioning a life beyond their HIV diagnosis and renegotiating or re-constructing their identities. These sub-processes did not occur in isolation of each other, nor was the process linear or predictable for the men (See Figure 19, p. 152). Nonetheless, the cumulative impact was found to be important in how these men continuously adjusted to implications of living with HIV, which included adhering to a daily treatment regimen.

6.3.1 Just like another disease: Reconstructing HIV as a chronic illness

Reconstructing HIV as a chronic rather than terminal illness was found to be an important step taken by some men as they adjusted to living with HIV. This entailed men perceiving their HIV infection and associated treatment as comparable to any other disease that required long term treatment. Marcus likened his experience of living with HIV to his grandmother’s experience as a diabetic, “*It reminds me of my grandmother who have diabetes. She has to take her medication... so put it as I have sugar or diabetes and just work with it*”. Similarly, Dan stated “*if you take your meds it becomes almost like a person living with diabetes taking their pills every day*”. Overall, this was seen as the men engaging in a process that normalized their HIV status, dismissing the social stigma that delineated them on the basis of their HIV identity, and instead reinforced their similarity to any individual having to treat a chronic illness with daily dosages of medication.

For some men the ability to readily accept and move into adjusting to living with HIV was hinged on their early perception of HIV as a chronic illness. This included the belief that HIV is not a death sentence or a disease that results in a sick identity characterized by extreme sickness that requires dependency on others for care and support. Richard made this distinction from having a sick identity by delineating between HIV as a disease and HIV as an illness. According to Richard:

I’m not gonna say I have a disease. I use illness because when a person have a disease or something like that, they are bedridden. In my own

aspect they are bedridden, they can't move or they can't do or say anything right. They are like skinny, meagre, anaemic, understand?

Richard opted to identify his HIV infection as an illness rather than disease as the latter was more representative of a sick identity which he rejected. As noted with other participants, having a sick identity warranted men to display extreme features of being unwell, such as being bedridden or meagre. In each instance the sick identity requires a visible representation of being unwell. The presence or absence of these manifestations of sickness become the benchmark by which men determine the gravity of their HIV infection.

Men who were already diagnosed with a chronic illness that involved taking medication daily appeared to more readily transition into adjusting to living with HIV. This was done by likening their HIV infection to their pre-existing chronic illnesses, which for most of the men was either diabetes or hypertension. When advised by his doctor that being HIV positive meant engaging with lifelong treatment, Bird stated *"I said to myself say if I have to take the blood pressure tablets for the rest of my life, might as well"*. Thus no distinction was made between living with hypertension and living with HIV as both required him to follow a long-term treatment regimen.

In some instances, normalizing HIV occurred where the men presented HIV as less consequential than other chronic illnesses, particularly cancer. All the men who compared being HIV infected to someone diagnosed with cancer, noted that being diagnosed with cancer was more likened to being a death sentence than living with HIV. The following excerpts illustrate this:

Cancer and those stuff is worse than this sickness here you know. (Jay)

I think cancer is much more deadly. I've seen it and I know. I have seen people living with HIV who is not on medication and live. I've seen people with cancer and on medication and they still pass on. (Brenton)

I [Brenton's doctor] have so many HIV patients and not one have died. And he has about seven cancer patient; only one is living. So you see, it's not what you might think. (Brenton)

What about the persons who have cancer? I think their life is shorter than mine. (Eric)

A more profound illustration emerged in a story shared by Troy of his uncle who was diagnosed with cancer and expressed his preference to have instead been diagnosed with HIV/AIDS.

And he said, he has done so many chemo and he doesn't see where and how it's making him better. He was spending so much money scraping and you scraping and you doing this and at the end of the day it doesn't make any difference. And he's like "I pray to God every day, if he could perform some miracle to give me AIDS (laughs)". I'm like "Uncle Charles why would you want AIDS?" I was like, "Does AIDS just kill you like in three years?" ... He's like "No, don't let anyone tell you people can't have AIDS and you live all 40, 50 years. It doesn't even show but cancer, no, that one is an instant killer. (Troy)

Troy, Brenton and Eric each demonstrated how being HIV infected is re-constructed in comparison to other illnesses. Though cancer does not attract the social stigma often associated with HIV, it appeared the men perceived having cancer to be more indicative of qualities of a sick identity which they endeavoured to avoid. Thus the notions of 'cancer resulting in the appearance of being sick' or 'cancer being a death sentence' illustrated the beliefs and perceptions of men that became the benchmark by which to determine that living with HIV was not as challenging.

6.3.2 Reinforcing a sense of self in the lives of others

The gendered roles performed by the men proved to be significant in charting how they perceived themselves post their HIV diagnosis and, for many, also influenced how they approached their ARV treatment process. Men often identified their social roles as father, husband, partner, son or caregiver, as significant drivers in their determination to pursue a healthy lifestyle post their HIV diagnosis. For John I, this emerged in his roles as a father,

partner and a son, as discussed in Chapter 5, section 5.4.2. As John I further added, *“I play a vital role in each person’s life. Even persons I don’t know, I play a vital role in their life as well, by encouraging them or motivating them and stuff like that”*. John I’s acknowledgement of the *“vital role”* he plays in the lives of these individuals underscored the significance of his masculine identity which incorporates being a father-figure, provider and partner. Thus, he was able to shift the focus from being HIV positive to the need to live given the vital role he played in the lives of those who cared, loved and depended on him. The reinforced importance of his identity and role in the lives of others allowed John I to re-construct his sense of self. Here HIV remained a part of him that required continued treatment, but was no longer perceived as a definitive aspect of his identity or the social roles he performed.

Being a father instilled a sense of responsibility to care for self in order to effectively maintain the role expectations of father as provider and nurturer. In particular, there was a noted desire for some men to see their children mature and complete school. When asked why he maintained his ARV treatment despite his expressed frustrations with the process, Bones responded: *“Mi have a likkle 6 year old baby me can’t leave. Me keep think bout her you know”*. Thus for Bones, his daughter became his primary motivation to continue living each day and maintain his treatment regimen. His outlook of not being able to ‘leave’ or die, showed a prioritization of the traditional masculine role of father as provider, which could only be fulfilled if he maintained his ARV treatment in an effort to prolong his life.

Dante also highlighted the significance of his social role as a father in inspiring him to overcome the desire to default his ARV treatment. As he explained, *“I can’t take pills but I get used to it. I have to take it. Me did give up one of the time but my little son motivate me and talk to me”*. Dante identified his son saying to him, *“Daddy you gotta take your medication”* as the pivotal point at which he started adhering to his treatment regimen. When asked to explain the impact this had, Dante responded, *“You know he’s my little son, so I gotta be here for him. So me get on top of my game and do what me have to do”*. Dante’s response reiterated the significance of his role as father being an intrinsic aspect of

his identity. Thus by reinforcing the value of his identity as a father, Dante acquired the determination to “*get on top of my game*” whereby he took control of his health by taking his ARV medication, which ensured he could “*be here*” for his son. Though Dante has 11 children, he emphasized his role in this son’s life because “*a grow up with him*”, meaning he had the responsibility of raising him and thus played a more direct fatherly role. Nonetheless, Dante asserted that being a father to all his children was a significant driver of his determination to live beyond his HIV diagnosis. As he said, “*A dem me a live for right now*”.

There was some overlap between gendered roles and age for Dan who alluded that his role in his family was particularly important given he is the eldest son: “*I must say my role in the family is important. I am the eldest. Also have a very good, very respectful relationship with my family*”. This suggested Dan’s role held a sense of responsibility to himself and to his family members. This sense of responsibility drove his initial fear of disappointing his family if they learnt of his HIV status: “*I was fearful to tell them because, for some reason I thought they were going to blame me. Not blame me for doing anything bad, blaming me for letting my guard down*”. Receiving the opposite response echoed the significance he played in the life of his family which in turn helped him to improve his approach to living with HIV. As he stated:

I am a fighter in the sense of fighter against injustice, and so for them it’s just a continuation of that. Now they are fighting for me and they want me to do well. Which makes me feel really good to see now they are fighting for me and care more about my health than I was because I wasn’t really following on my regimen of vitamins. I was just doing my ARVS. I was barely coming to the doctor in terms of doing follow up tests and all that kind of stuff. (Dan)

Men’s self-perception and revival of a positive meaning or purpose for their lives are inadvertently shaped by the perceptions of others. John I, Bones, Dante and Dan were able to regain a positive outlook of their lives and develop a determination to move beyond their diagnosis and engage living with HIV. This showed how the reinforced value of some

men's identities are rooted in the roles they play in the lives of others. Thus the perception and appraisal of others holds the potential to re-construct men's self-identities and transform their approach to living with HIV.

6.3.3 Shifting focus: Moving HIV from the foreground to the background

Another important step taken by some men in adjusting to living with HIV was shifting their illness from the foreground to the background of their identities, where their HIV status was acknowledged but not treated as central to their identity or their life aspirations. Where this occurred, HIV was no longer perceived to bear much (if any) power in shaping how the men perceived themselves or how they engaged in their daily activities. Paul's portrayal of living beyond HIV initially appeared to be a denial of his HIV status when he stated *"It's only on a piece of paper that I'm HIV positive but my personal view is that I am not positive"*. This was clarified, when prodded by the researcher, in his subsequent statement that indicated the intentional shifting of the awareness of his HIV status where he remains cognizant of his responsibilities surrounding his HIV infection, but does not allow it to define his identity.

Why do you say that?

Because I developed a mental thing about it. I'm conscious that it is there you know. But there is a thing that says it's not there. That doesn't mean that you nuh have it so you going to go and get yourself into problem. You just have a mind-set say - nothing nuh do me. On the paper it says this and this is what I'm to do because it says this on the paper but me good. I'm going what - 17 years, I swear to God, 17 years. (Paul)

Paul's response indicates that a positive HIV diagnosis does not warrant it becoming a salient aspect of his identity. Whereas having a positive HIV diagnosis required him to be conscientious of his responsibility in treating his illness, he chose not to internalize his HIV diagnosis as a fixed imprint on his identity. This reinforced the notion that 'being HIV infected' is a fluid identity that can be shifted pending men's choices on how to approach living with HIV.

At times, shifting the emphasis given an HIV status required men to submerge themselves in other areas that were aligned to other aspects of their identities. This was noted for Kevin who increased his church attendance and participation in an effort to escape the focus on his HIV identity:

I just take it [HIV diagnosis] off my mind because most of the time when I put it on my mind, it kinda stress me. So I just really block it out. So most time I will go to church meeting, [be] more active in things for the church that my mind can be steady.

The shift of Kevin's HIV identity from foreground to background required an increased focus on his spiritual identity. This suggests that some men will give greater saliency to dimensions of their identities perceived to be more conducive to their personal experiences, ideals and goals. So attaching less significance to their HIV illness, in their daily lives, became a useful strategy for men as they adjust to living with HIV and transition into other phases of their treatment trajectory.

The shift of an HIV diagnosis into the background of men's identities became pivotal for some men to move forward in the pursuit of their personal dreams and ambitions. As John III expressed, *"Right now me no really a focus on the sick part. Focus on my goals and my dreams... me more a think on my goal and where me want to reach in life like that"*. John I also alluded to treating HIV as peripheral rather than central to his life as an effective step in moving forward.

you have to first convince your mind its ok, there is nothing. That's how the healing process comes in. If you sit down and think about it, all it does is stress you out and make you worse. You know what stress is? Everything start to break down. Your body system starts to break down; every different part. You get all diagnosed with things that you never have before because you stressed. So your mind controls your body. If you control your mind, you control your body... If you tell your mind you don't have it, you'll be fine. You don't have to worry about it. (John I)

John I suggested that shifting the significance of a positive HIV status from the forefront to the background of men's identities could help to minimize the negative effects that being HIV positive has on their personal experiences. This shift would then allow men to engage in a process of healing of the hurt, disappointment and anguish that are often experienced upon initially learning of a positive HIV diagnosis. The healing process equips men with the assurance that "[they] will be fine" which results in an easier transition of moving forward with their lives.

For Eric, the ability to minimize the significance of being HIV positive was due to his awareness of the benefit of his ARV medication. As he explained:

you don't deal with it on a daily basis either you know. You make yourself deal with it on a daily basis... It makes no sense you get up and wonder about it. If I'm not on meds and I get up and wonder every day: I wonder if- I wonder if- I wonder if. Okay you are on meds, it simply means that you are getting help. Just as how the bill that's supposed to pay, yes you not getting a million dollars, but you get a stipend to put towards it. That's how I see it so I don't get up and deal with it every day because I'm getting help. (Eric)

The role of ARVs in treating and controlling HIV was seen to facilitate Eric's ability to move on with his life. Thus his knowledge of the efficacy of his treatment engendered his confidence in the efficacy of his medication in improving his health once his treatment regimen was maintained. This confidence minimized the need to focus on being HIV infected at the forefront of his daily experiences.

The time lapse since diagnosis also appeared to make a difference. Those men who were aware of their HIV diagnosis for over 8 years showed a greater level of adjustment to living with HIV by shifting the salience of their HIV illness to the background of their lives. Paul's indication that it has been 17 years since he was diagnosed (quote given on p. 204) alluded to sufficient time having passed for him to accept, adjust and move beyond his HIV diagnosis being a forefront determinant of his self-perception or life experiences. This outlook was similar for John I who noted that his HIV infection was forgotten due to the

passing of time. For him, the awareness of his HIV status was only significant *“in the first half”* of his journey since diagnosis. As he further added, *“It’s over 10 years now so it wouldn’t have an impact on me now. Like I said, I don’t remember that I have it”* (John I). Like Paul, John I suggested an HIV identity being transitory, where its significance in shaping men’s identities and experiences changes over the course of men’s lives. Perhaps it is the adjustment to the efficacy of treatment that enables men to gain confidence in re-defining their identities and lives outside the context of their HIV infection, whilst maintaining their prescribed treatment regimen.

6.3.4 Moving on: Life beyond HIV

Adjustment to living with HIV encompassed the idea of *“mov[ing] on with your life”* (Tallist) where men made an intentional decision to alter their outlook of life as more than their HIV infection. In doing this some men minimized the significance placed on being HIV positive in engaging with their daily routines. For Dan, the ability to move on and pursue a life beyond HIV incorporated *“your will to live... It is the thing that will determine whether you stay healthy and try to live healthy”*. Again, this reinforced the shift in men’s perspective from HIV as a death sentence to foreseeing a future despite being HIV positive. As Dan later postulated:

when you first became positive you thought, “oh my Lord I’m going to die. I don’t believe this is happening to me.” But it is so easy to then say I am not going to die and I will take good care of myself if that motivation is strong.

Moving on involved the outlook that being HIV infected did not alter the identity or abilities of the men. As Brenton asserted, *“I’m smiling because I’m alive and okay... I do every and anything. I can do everything”*. The emphasis placed on his ability to do *“every and anything”* countered the perception that being chronically ill significantly impairs an individual’s life by forcing him to be dependent on others for care and survival. The minimized significance of being HIV infected was also adopted by John I who maintained

that his life is “*pretty normal*” because he is able to engage in the activities he did prior to becoming infected. The following shows the dialogue with the researcher:

My life is pretty normal and I am pretty happy with it.

Describe what makes life normal.

I have sex, I exercise, I stay up late, I don’t have to worry about going to the doctor, the regular routine before I got sick. I am living like a regular person who don’t have it. (John I)

The continuation of activities as maintained prior to being diagnosed with HIV allowed men to reinforce a sense of normality that symbolized moving beyond their diagnosis. Some of these routine activities were likely linked to the men’s identities and affected their interaction with others. Thus being able to maintain the ability and choice to have sex, exercise and stay up late allowed John I to maintain a sense of normalcy that was comparable to his life prior to being diagnosed and the life of “*a regular person who don’t have [HIV]*”.

6.3.5 A positive turnaround because of HIV diagnosis

The decision to move on with life at times incorporated men renewing their vision of a positive future or becoming inspired by their HIV infection to make a positive turnaround in their lives. Some men changed their outlook from HIV being a negative experience to one that is purpose-driven. As Bird expressed, “*everything just work out for a purpose*”, suggesting that becoming HIV infected played a transformative role in men’s lives. Paul believed that becoming HIV infected was “*the best thing that ever happen to some people*”. He suggested that an HIV status created a sense of social responsibility that compelled persons to be more mindful of their lifestyles and behaviours that could jeopardize both their health and the health of others.

This changed outlook fuelled men’s drive and determination to live beyond their HIV illness. They were no longer consumed by the challenges and negative responses towards becoming HIV infected but rather saw it as a platform to pursue their ambitions. Brenton

expressed that he “*achieve[d] much more since I’ve been diagnosed than before I was diagnosed*”. This suggested that being diagnosed with HIV resulted in a positive turnaround in his life where he was driven to achieve more whilst living with HIV. Similarly, Marcus indicated that becoming HIV infected and commencing ARV treatment were pivotal in transforming his life positively. As he stated:

I will always say, maybe if I wasn’t on treatment maybe I wouldn’t be thinking about myself and how I do now, in terms of where I want to go, where I want to see myself, and what do I want to achieve. So maybe it put me in a position for me to really want something out of life. (Marcus)

Bird was inspired by a friend who treated his HIV illness as a motivation to renew his vision for his future. As Bird explained, “*I remember after he found out about it, he went back to university, he got his apartment and thing*”. Thus the ability to acquire material assets and achieve whether professionally or academically established a sense of hope for the future and countered some of the existing sense of loss and hopelessness that was initially discussed by Bird. Though the loss in terms of the hope for a wife and children remained, he indicated being motivated and having a renewed hope for his future.

Paul described his HIV illness as “*a tool of social engineering*”, recognizing the role it played in engendering a sense of social responsibility regarding his sexual health and the health and well-being of others. He further explained the role of an HIV identity in engendering a sense of social responsibility as follows:

if you are a person who is conscious and thinking about people's life and safety, you'll behave yourself, eat right, don't drink, don't smoke, do exercise... When you have this you have to monitor the thing... you have to make sure you take care of yourself because you have this thing monitoring. (Paul)

Maintaining this sense of social responsibility caused a shift in Paul’s sexual behaviours from previously “*run[ning] around*” to now being mindful to not expose others to the virus. As Paul declared: “*It mek you monitor your behaviour. Now I see it as a tool to*

model your behaviour". Similarly, this acquired sense of social responsibility forced Bird to stop engaging in sexual behaviours despite his desire to get married and have his own family. As he stated: *"I don't want anyone catching this thing on my regards, so I just stick to myself"* (Bird). Much of the behavioural changes adopted by men included the consistent use of condoms and engaging in monogamous relationships. As Marcus indicated, *"I've been more cautious in what I do in terms of always ensuring that I have condoms on me. So I practice safer sex and I also educate my peers as well"*.

The positive turnaround for men at times involved adopting transformational roles, where they endeavoured to use their experiences to educate others on HIV/AIDS. Thus moving on with their lives engendered as sense of activism that allowed them to positively impact the lives of others. For example, Marcus shared:

It's the diagnosis that has changed me to be able to want to do so much, to help and to make a change or a difference amongst young people, the youths... and myself too cause as I said before if it wasn't because of it, maybe I wouldn't smell the coffee that was so close to my nose, I would've probably still going on like wild or searching.

In choosing to move forward Marcus developed both a personal aspiration and social conscience that thereafter guided his decisions to transform his life and *"make a change or difference amongst youth"*. This social responsibility reflects in some men taking on identities as advocates or ambassadors for change in fighting the HIV epidemic.

Richard was inspired by his illness to write a book which documented his journey of living with HIV. This book is intended to be an educational tool aimed at informing and empowering persons living with and without HIV. As he shared:

I have a baton and I'm gonna pass on the baton and that baton is the book that I'm writing right - "fighting through it". Right, that baton, how you're gonna cope with it, how you're gonna coping with your caption [HIV status] right. So we just have to try our own best, and I'm trying to urge others up here; it don't worth the wait. It don't worth it. So we have to take a stand against it [HIV/AIDS]. (Richard)

Like Marcus, Richard was propelled by his diagnosis to lobby for increased HIV awareness. In doing so, these men moved from positions of being victimized by their HIV infection to becoming advocates for change. This shows the extent to which men's identities are reconstructed in the face of their HIV infection and their evolving experiences. Moving on with their lives entailed personal endeavours such as educational, professional or material pursuits, as well as engaging in social activism where the men willingly used their experiences or knowledge to encourage others to take the necessary steps to avoid HIV transmission.

6.4 SUMMARY

This chapter examined how men transitioned from their HIV diagnosis to readiness to initiate and maintain their ARV treatment. For the men in this study, the transition entailed two distinct processes: 1) accepting their HIV diagnosis as factual and subsequently making the choice to move on, and 2) adjusting to the realities and implications of living with a chronic illness.

By accepting their HIV diagnosis, men acknowledged that their HIV test results were accurate and that HIV was now an aspect of their selves. For some men, acceptance of their HIV test results was hinged on becoming symptomatic. In these instances, men engaged in repeated HIV tests and failed to progress to their treatment until the onset of symptoms validated their test results. These symptoms produced a visible sick identity which was recognizable by others, thereby forcing men to seek healthcare. Acceptance of a positive HIV diagnosis was facilitated by men becoming better informed on the implications of living with HIV, which included surpassing the myth that HIV is a death sentence. Men generally feared the negative repercussions of others learning of their HIV status due to the stigma associated with being HIV positive. Thus social acceptance, despite a known HIV status, was important in enabling some men to accept their diagnosis and progress into their treatment phase, especially where they obtained the support of family members and peers. However, not all men felt it necessary to attain social acceptance in their progression to

initiate treatment. These men prioritized the need to protect their HIV identities that could subject them to social scrutiny, stigma and reproach.

Once men accepted being HIV infected as an aspect of their selves, they did not appear to return to a state of disbelief. Adjustment, however, was found to be a continuous process that occurred along men's treatment trajectory as they encountered varying issues pertaining to their illness, identities, and social contexts. Adjustment to living with HIV involved men reconstructing their perception of HIV as a chronic and thus liveable condition. In some instances, it involved men reinforcing the value of living in the social roles they played, such as father, son and partner. Adjustment also entailed men shifting the focus on their HIV status from the foreground to the background of their identities whereby instead of treating their HIV status as central to their identity, being HIV infected became less salient to these men's self-perceptions and identities. This approach was important in empowering men to move on and regain a sense of normality in the pursuit of their goals and aspirations.

Chapter 7 FINDINGS III

Renegotiating self and identity

7.1 INTRODUCTION

This chapter explores how men viewed their HIV status in relation to their self and identities. It was found that being diagnosed with HIV resulted in changes in how men perceived themselves and interacted with others. In some instances, there was a re-negotiation and alteration to the presentation of the men's sense of self and identity within the context of the social environment in which they existed. This entailed some men re-constructing their existing sense of self to accommodate their HIV identity. It also involved men performing expected representations of their selves to show some semblance of prescribing to social norms that would ensure men's continued acceptance, social safety and retained social positions. Thus men were seen to re-negotiate, navigate and perform their gender, sexual and health identities in varying social contexts. This renegotiation, navigation and performance of self and identity emerged as key strategies adopted by most men in protecting their identities and ensuring their traditional social positions were not threatened.

7.2 MISTAKEN AND HIDDEN IDENTITIES

Men were at times labelled or assumed to be MSM because of their HIV identity. This revealed a prevailing social misconception that HIV/AIDS is a gay disease that is only contracted by MSM. Bird shared his experience of participating in an HIV support group after which he received a text message from another male participant which he found offensive as it suggested that he was an MSM given his HIV status:

So I called him and asked him 'what this text for?' 'It was being suggestive of what you need to do to me' (voice of other male). I say 'I'm not gay'. Him say, so how me HIV positive and a not gay?... I tell him that is not everybody who have HIV is gay. There are heterosexual people. 'Me nuh think so'. That was his response, so I just say 'listen, don't call me anymore'. (Bird)

Trevor also refuted the perception that being HIV positive was indicative of his sexuality. When asked his opinion on the belief that a male who is HIV positive is also an MSM, Trevor responded:

That's not true... I don't buy it, because I'm not and I can tell from all the people that are here. There are many guys out there, there are women coming up here too, some excellent ladies so they would have to be hetero[sexual].

Both Bird and Trevor's need to clarify their sexual identities on the premise of their recognized HIV status, revealed the tendency to associate both identities. Though this was not a common occurrence, it still highlighted the survival of certain social misconceptions that can shape how men are perceived and treated by others. The men's response also revealed the importance of men reinforcing their sense of self, despite being HIV positive. As such, men moved into a space where other dimensions of their identities were not defined by social perceptions of the implications of being HIV infected.

The stigma associated with having HIV forced some men to hide their HIV identity. This was noted for Bird, Paul and Marcus in the previous chapter, where these men preferred to not disclose their HIV status to their peers or family members for fear of social reproach. As Bird shared,

Why I decide not to tell people is because with the prejudice. A lot of people have different ideas about this thing and I wouldn't want to know that alright, you know that I have it and I come beside you and you drawing away, you not eating. You know that if I'm near you, you not going to use the bathroom or so, I don't like that...

At times, the decision to treat being HIV positive as a hidden part of self was further compounded by other dimensions of men's identities that are also meted with social disapproval. Being an HIV positive MSM introduced heightened social antagonisms and stigma that forced men to hide their true selves. This was noted for Whitey who was

challenged by the social perceptions of his identity as an MSM who is HIV positive. As he asserted:

I am the problem because I'm positive and I'm MSM and I have to go out there in the public and if somebody sees me now they are gonna say, 'a batty boy [derogatory term for MSM], him positive' and then things going to take a toll and I have to live with it... (Whitey)

Identifying himself as the problem showed an internalization of social standards that depict right or wrong, appropriate or problematic identities. Varying social institutions help to transmit and reinforce these social standards and ideals which shape the construction of masculine identities in Jamaica. Being an HIV positive MSM is perhaps more challenging due to the stigma that is attached to each dimension of the men's identities, which reinforce the old-age correlation between HIV/AIDS and same-sex relationships.

Awareness of these social rules imposes boundaries on men's behaviours in particular social contexts, especially those that can result in negative repercussions. Rather than displaying overt signs of his true identity, Whitey opted instead to conceal his identity as an HIV positive MSM in those social environs that were likely to resent him. As he shared:

I tend not to be that obvious to say I'm a MSM. I know I'm a MSM, I know I'm positive but I'm not going to fling it in your faces saying this is who I am... they said Jamaica is a homophobic country which I don't believe so... Although I can be some bad, some of the time, when I'm around friends but not too much and if I am going out or coming I have to act a certain way so I won't be too, too much of one person versus the other. (Whitey)

Representations of social identities are important in determining men's access, acceptance, safety and acquiring a sense of belonging in particular social groups. Some social groups may be more accepting and tolerant of social identities that are denounced at the societal level. As a result, men are required to strategically navigate their varying social terrains to determine spaces that are safe to reveal their true identities, and spaces that require performances of a socially appropriate self.

7.3 I ADJUST TO SURVIVE AND COPE: THE ROLE OF PERFORMED MASCULINITIES

The changes occurring with men's identities did not solely pertain to the incorporation of an HIV identity, but extended to other dimensions of their pre-existing identities such as their masculinity and sexuality. There were instances where the men reinforced, navigated or challenged the prevailing notions of manhood in light of their HIV illness and treatment process. At other points, this negotiation process did not relate specifically to men's HIV status, but was compounded by their sexual identities. Men were compelled to protect any aspect of their identities that did not conform with a socially defined standard of masculinity. For example, Dan resided in one of the university halls which he described as "*one of the butchest blocks*". This meant the hall, being an all-male dormitory, was riddled with sentiments of exaggerated masculinity which was intrinsically linked to heterosexuality. As he added, these were "*the mighty veterans of who have the hard wine [hard core sex], all that stuff*". This space forced Dan to constantly navigate strongly reinforced masculinity norms despite being an MSM living with HIV, two intricate aspects of his identity that countered the 'status quo'. Despite accepting his MSM identity and proclaiming his political stance regarding homosexuality in Jamaica, Dan indicated a sense of controlled behaviour whereby his MSM identity was never overtly expressed.

I am a little effem myself, I believe so. I think I walk effem, but I don't... it's not something that I adopt because that's not who I am... when I am with ultra hetero guys I could but I choose not to. I won't be waving a rainbow flag but at the same time I don't believe in bashing. (Dan)

Despite perceiving himself as a slightly effeminate MSM man, Dan made a conscious decision to stifle the representation of his MSM identity in the presence of his peers who he classified as "*ultra hetero*". His decision showed a careful navigation of self in the presence of those who explicitly reject and abhor masculinities that do not replicate the ideal standard of maleness in Jamaica. In doing this, Dan acknowledged the existence of socio-cultural norms that shape gender and sexuality expectations of men. These norms that celebrate a portrayal of ultra-heterosexual masculinity underscore the expectation of

Jamaican men to be heterosexual and display other traditional qualities such as aggression and hypersexuality. Such norms establish a benchmark by which men are evaluated and deemed acceptable by society. Residing in an all-male dormitory, considered to be the epitome of ultra-heterosexual norms, forced Dan to hide his HIV positive MSM identity which would distinguish him from the established social benchmark. This highlighted the role of social norms and gender role expectations in shaping how some men navigate their identities in the context of others who are perceived to be social enforcers of prevailing socio-cultural norms. To avoid being demarcated as different, some men engage in behaviours that better reflect the qualities that are expected of the typical Jamaican male.

Like Dan, Troy alluded to navigating the socio-cultural terrains of masculinity and sexuality within his environment to ensure his safety and social acceptance. Troy distinguished between public and private spaces which provided either a safe or unsafe environment in which to reflect his true identity as an MSM. *“I always [perform masculinity] ... even in those environments, I do still perform like, worse being around here [his place of employment], at a place like this you have to be very masculine”* (Troy). The significance of *“a place like this”* was due to Troy’s place of employment being largely a male domain. Such work environments often contain greater exhibitions of hyper-masculinity, therefore mandating Troy’s performance of the hegemonic masculine ideal to prevent disclosure of his HIV and MSM identity.

Marcus, who identifies as transgender, also indicated that it was necessary for him to perform masculinity as a survival tool given the hostility often targeted at men who identify as anything but a heterosexual male. This sense of hostility is fuelled by the social reinforcement of gender normative behaviours that prescribes appropriate gender identities (either male or female) and corresponding gender appropriate behaviours. Though Marcus accepted his identity as a transgender, he was forced to transition into a masculine presentation of self, given this was socially expected and acceptable. As he expressed:

You accept yourself but then how do you matriculate [behave] when you’re in an environment where you feel that you’re not safe? So you have

to come up with a strategy. You either adjust the femininity to cope or you don't go there.

Have you ever had to adjust?

Many times, cause living in this new area I'm now currently in, I have to adjust because it's a bad area. As people may say, and you don't want them to come and kill you. I want my life; I love my life. And you not born and grow up in that area make it worst. So I have to adjust. (Marcus)

The term 'matriculate' used by Marcus referred to his behaviour or overt representation of himself that would ensure his acceptance within his residential community. Portraying socially defined inappropriate gendered behaviours could result in his community becoming unsafe, further alluding to the strict social norms regarding non-heterosexual identities. Marcus feared that the social reproach of others in response to his gender identity could have adversely affected his well-being. Being cognizant of this, he opted to negotiate his identity by "*adjust[ing] the femininity to cope*". When asked how he adjusted, Marcus explained the following:

I adjust in the fact that I change my features in walking. So instead of walking like I'm in a nine inch heels and strutting the run-way I walk like I'm bouncing like a man, and when I go in I just shake it off cause that's not me; [it's done] in order to survive and cope.

Here it is evident that the strategies employed were quite pragmatic and related to the outward behaviours that performed or evidence his adjusted masculinity. The action of "*bouncing like a man*" is a noted feature of the heterosexual male, whose overall posture and demeanour should echo manliness. Marcus's effort to perform this role was a clear coping strategy that ensured his survival. He added, "*I reduce and the fact that I reduce, it's less attention on me*". This approach allowed him to integrate more effectively with his community and others around him. As he expressed, "*[I] reduce in terms of instead of being so feminine "out there". I hide it from people who I'm not too familiar with. You reduce to fit in, to look more masculine, look macho, which I try to*". The use of the term 'reduce' suggested a minimizing of self in an effort to fit in. Thus, rather than portraying

his true femininity, Marcus opted to hide his true identity in the presence of those he was not familiar with and thus did not consider safe. The minimizing of his femininity allowed him to effectively “*fit in*” by being more masculine and macho.

The need to consciously navigate the presentation of identity due to the social norms surrounding masculinity and sexuality was further shared by Mario:

Because I know I’m gay, certain places I go I have to just act in a manner that the people can see that I’m not gay. So that’s why I hide my behaviour or my speaking so forth so, because I speak to you right now if I go to the place they’ll say “oh this man yah a batty man”. So I can’t talk certain way I have to just say “Yow wah gwan” which I hate, I don’t like speaking like that.

Mario acknowledged that the portrayal of his true sexual identity was constrained by the prevailing Jamaican norms regarding heterosexuality. This awareness warranted Mario performing the expected roles of masculinity so that “*the people can see that I’m not gay*”. Thus the performance of gender or sexual identities emerge in the way men dress, speak, walk or conduct themselves in the presence of others, as noted for Dan, Troy, Marcus and Mario. These performance traits underscore an established system of normative behaviours that categorize and delineate men, as exemplified by Mario who said, “*because of how you behave they say “oh a batty boy that”. So at the end of the day behaviour all covers everything around the gay life*”. Thus the outward presentation of self through particular behaviours, are used to determine men’s social identity and judge whether the portrayed identities are socially acceptable. As such, socially prescribed and enforced normative behaviours become the baseline by which men are evaluated and granted social acceptance. Performing masculinity becomes an essential tool in ensuring men who do not naturally fit the hegemonic masculine model, meet the standard to become socially accepted. This coping strategy ensures safety in a potentially gay-hostile environment and is reflective of the transient nature of the men’s identities which can shift to suit the needs of their environment or personal circumstances.

7.4 “THAT’S THE THING WITH MEN”: REINFORCING THE MASCULINE SELF

The pressure to conform to the prescribed norms of Jamaican hegemonic masculinity were at times seen to conflict with the lifestyle changes engaged by some men in adjusting to living with HIV. For example, Jamaican men are often required to continuously exude strength and resilience irrespective of their personal circumstances. This may prove challenging for the male who is traumatized by the outcome of his HIV diagnosis and who is forced to suffer in silence due to the absence of appropriate or permitted social outlets. Such conflict between gendered norms and the reality of living with HIV was demonstrated by Dan who shared:

As a man that is supposed to be strong out there in society, if you have to be strong out there in society, who do you talk about your weaknesses and fears to? And I can’t afford to go to a psychologist or a psychiatrist.

For Dan, the expectation that men should be strong and resilient countered his need to ascertain a social outlet where he could be open about his fears regarding being HIV infected. These contra identities resulted in Dan initially suffering in silence, which impacted his emotional well-being, and consequently his treatment journey:

here I was trying to do school, trying to come to grips, trying to take my medications, meet my doctor’s appointments, dealing with the loathing and the fear and dealing with the self-doubt and beating up myself... I just stand in my room – so [demonstrating a sense of positioning] my room doesn’t have any of that experience, bearing weight that is heavier than mine. (Dan)

Dan’s notion that his room that does not have the experience “*of bearing weight heavier than mine*”, underscored the isolation experienced because of the need to protect his masculine identity. He perceived his masculinity could be questioned by revealing his HIV identity, or seeking emotional support which could be interpreted as a sign of weakness and frailty. Some men are forced to choose retaining a performance of their masculine self at the expense of addressing their personal and emotional needs as they struggle to adjust to the realities of living with HIV. This choice revealed the tendency to prioritize a portrayal

of an identity that is socially acceptable, rather than introduce a re-constructed persona that challenges men's pre-existing masculine identities and subsequently remove them from positions of social stature in contexts that celebrate their manliness.

There were instances where the traditional notions of masculinity conflicted with optimal health outcomes for men. Dan's experience provided an example of how such norms at times force men to take on roles such as hero, leader or headship that require men to sacrifice their health and well-being for the benefit of others. Dan revealed that much of his choices pertaining to his health were shaped by the social driven desire to be in charge and to be recognized as a hero. These roles are captured in the following excerpts:

That's the thing with men - we see the responsibility. Sometimes we take up this hero role and really in this case, I really feel like I'm doing something more for my population; and when I say population I mean my population of persons who are living with HIV. (Dan)

Yeah, what a man desire is to just be in charge and you know men have to be, you know head of [something whether home or group]; it's a bad thing... society puts that on men sometimes...where you are given responsibility, don't drop down, don't be weak-kneed, so us man have to be in charge. It's like, our response to [being a] man is how to be head... it would be a shame that I should die being an advocate. (Dan)

According to Dan, men are expected to be "*in charge*" and be the "*head*" whereby they are assigned clear gender-orientated responsibilities. The mandate to "*don't drop down*" or "*don't be weak-kneed*" further indicated the punitive measures that can be meted for failure to comply with these requisite norms. As a result, some men are forced to trade-off between their personal health and well-being to ensure social conformity. This holds implications for men's treatment processes, as noted for Dan who sacrificed a prescribed test for his socially recognizable role as a hero.

The saliency given to Dan's masculine identity as a hero was further captured when he stated:

I know that my health should be the most important thing. My health is my ocean, really. My health is my ocean and I should try to deal with it and look after it. It really, it's really a priority; but when people look at the measure of my life, and I'm being... this is going to be my selfishness, my vanity whatever you call it, they don't want to look at my health, they are gonna see what did Dan do as a [HIV] positive person to impact the lives of other persons in his community.

Thus some health choices and outcomes were hinged on the general characteristics aligned to the representations of the hegemonic Jamaican male: heroism, strength, tolerance and endurance. In this instance, Dan identified the importance of being responsible for others at the expense of his own health. Further, the need to be remembered as a hero reinforced the masculinity ego which he referred to as 'vanity'. Being socially recognized as a hero offered greater personal and social value than pursuing personal health needs which does not add value to the representation of the masculine self.

7.5 A NEW DIMENSION: INTRODUCING A MASCULINE AND FEMININE MSM IDENTITY

Some participants delineated between feminine MSM and masculine MSM as a new dimension for describing the gendered sexual identities of MSM. According to Mario, being "*masculine or feminine just tell who you are [and] the role that you play*". Dan further explained that this distinction is based on "*who is at bottom and at top*"; alluding to the sexual roles played by MSM. A feminine MSM was portrayed to mimic the female sexual role by being "*at [the] bottom*" whilst a masculine MSM is deemed to perform the more dominant sexual role by being "*at [the] top*".

The distinction extended beyond the men's sexual roles to capture personality and behavioural traits that were aligned to traditional gender norms of masculine and feminine behaviours. A feminine MSM is expected to display more effeminate behaviours whilst a masculine MSM is identifiable by his portrayal of macho masculine behaviours that were comparable to representations of the hegemonic heterosexual male. Yet this comparability is socially refuted once a male is suspected to reflect alternate types of masculinities, such

as MSM, that are not readily accommodated within Jamaica's cultural context. As Dan posited:

Masculinity in Jamaica has to take a cultural definition... masculinity here is so cultural. It's based on sexuality and also based on who is at bottom and at top [referring to the sexual roles of MSM]; a lot of who take cock and who gets fucked... and if you're gay, if you even have a tups [slight indication] of gayness, there goes masculinity (laughs)... Your question, is it because you're gay or is it because of masculinity? Yes. They don't see my masculinity because I'm gay. And if they even suspect [it would not change outcome], I could be the roughest of man, rrrr rrrr rrrr [simulating growling as a sign of aggression akin to masculinity].

Dan captured the complexity around how Jamaican men's identities are deeply interwoven with socio-cultural definitions of masculinity and sexuality. These definitions outline particular behaviours that become indicative of the binary male – female gender roles. Any identity perceived to be non-conforming is deemed deviant and subsequently abhorred. Social tolerance of blurred lines is minimal, hence Dan's statement *"They don't see my masculinity because I'm gay"*. The blurred line of comparability between a heterosexual male and masculine MSM is not socially tolerated within Jamaica. As such Dan acknowledged that his true identity as a masculine MSM would be met with social disapproval if it was revealed. This would occur despite his testament of representing the hegemonic masculine ideal through his social acceptance and membership in an environment he described as a strong replica and reinforcement of masculine ideals.

Perhaps the main criterion for social representation of the hegemonic Jamaican masculinity is a heterosexual identity. Contra-heterosexual identities are received by society with great reproach, which can result in men being excluded, ostracized and labelled with derogatory terms such as "batty man", as Mario was classified. As a result, men possessing subordinate identities were seen to be at greater risk, especially where their HIV status further aggravated the negative sentiment attributed to these men. Mario perceived that being an MSM, whether feminine or masculine, held implications for how some men are able to access their ARV treatment and care. He stated that *"if that's how you behave to collect*

your medication, take your medication, if persons see you with it, they gonna have something to say about it” (Mario). Mario’s experience underscored the finding that men are constantly evaluated by the behaviours they depict in their various social contexts. Thus extra precaution had to be taken in ensuring that the portrayal of femininity or MSM perceived behaviours were minimized or eliminated in particular social contexts that could threaten the well-being of these men. Mario further shared how his general behaviours were moderated by existing social norms:

Many places, supermarkets, pharmacies, downtown, the wholesales and so forth, to me the whole Jamaica. Places where I go I have to know how I talk cause they say “you speak with a little feistiness, a little accent, a little something, you’re from Jamaica so, it’s only batty man talk that way” (Mario)

The awareness of these social guidelines on gendered behaviours impact how men choose to publicly display their identities. At times the social identity portrayed is not a representation of the true identities of men, but rather reflect a performance of expected gendered and sexual roles. Performed masculinity, therefore, becomes an important tool in ensuring men survive within their socio-cultural contexts in Jamaica.

7.6 BECOMING A MORE SPIRITUAL PERSON

A number of men reported the adoption or reinforcement of a spiritual identity post learning of their HIV diagnosis. The men showed a greater sense of spirituality or spiritual conversion, specifically based on Christianity which is the main religion in Jamaica. When asked about the impact of being HIV infected, Jay responded “*it make me more stronger in the Lord*”. Similarly, Kevin indicated “*I get serious more in the gospel and worship even more*”. Mario stated that shortly after his diagnosis “*I started going to church more*”.

Richard’s HIV diagnosis affirmed his spiritual identity as he declared, “*I’m like a very strong spiritual person*”. The characteristics of this heightened or new spiritual self was also noted in the adoption of spiritual practices such as increased church attendance, deeper

reliance on prayer and a greater sense of faith. An example of this was presented in the daily habits of John III:

I pray to the Lord and I do that every day. If I am alive I have to do that, every morning, every evening I have to pray and have my worship with my family so that is what helps to keep me. (John III)

The move towards this new spiritual identity for some men was triggered by their initial fear of dying because of their HIV infection. As Jay said, *“From that I just turn around, I have to reconsider my life. If I die I prefer die in the church, so I just change my whole entire life from there”*. Thus being diagnosed with HIV became a turning point that caused a dramatic spiritual transformation. Here, the adopted or reinforced spiritual identity offered men a sense of hope, renewal and redemption. The latter was captured by Troy who expressed, *“I even taken up back the church now, seeing if I can get back on the straight and narrow”*. This *“straight and narrow”* was classified as a path of correction that would lead to a more fulfilling life post diagnosis. Troy further shared:

I want to live so I can repent properly and see if I could get back on umm, so called, the right path.

What’s the right path?

To see if I can get something more meaningful out of that... so I can live...

So you can live?

Truly live happy. (Troy)

The spiritual identity presented by some men also appeared to be a coping mechanism that aided men in the continuous process of adjusting to living with HIV. John III asserted that his faith in God was pivotal to his ability to live with HIV:

If my faith in the Lord and my belief in the Lord was dead, trust me, maybe I would have passed out long time. But when I remember that He is always here, in spite of what, I just trust him. So this is one of my main source of strength.

Renewed faith contributed to some men developing a sense of endurance as well as hope that their illness can be healed. Vincent indicated that he prayed daily to be healed and granted the endurance for each day: *“Like me beg the Father to heal me, bless me and guide me through the long course of the day”*. For Jay, this was evidenced when he said, *“I make sure I have a comfortable devotion with the Father, with the Creator, because there is no sickness that He cannot cure”*. The belief in the power of God to heal HIV was shared by Richard who stated,

God is the only physician, He is the healer, right, and He said in His word, He has been wound or wounded, and by His stripes we are healed but only if we have faith we can overcome our own mountain and ride out our storms.

The terms ‘mountain’ and ‘storms’ referred to the experiences and challenges surrounding living with HIV. By maintaining this sense of faith in God, Richard was able to harness the determination to surpass the challenges of living with HIV. This progression, with the help of his faith, was aptly captured in what Richard described as a spiritual encounter with God:

my God answered say “listen, there is nothing that they can do on their own without my help. I’m gonna pull you through, your storm, I’m gonna take you over your mountain, I’m gonna take you across your Jericho”, and I’ve seen where I’m crawling, I’m stepping, I’m climbing, I’m swimming, I’m crossing my walls, my mountains, my Jerichos, and thanks be to God, I’m passing it and I’m passing it with something that someone and not just someone, worldwide is gonna see. Worldwide is gonna be educated.

Richard’s progression through his diagnosis and treatment journey were captured in his use of continuous verbs: *“I’m crawling, I’m stepping, I’m climbing, I’m swimming, I’m crossing my walls... I’m passing it”*. These actions showed Richard’s transition through varying stages of his HIV and treatment journey that comprised a range of challenges which he classified as *“my walls”, “my mountains”, “my Jerichos”*.

The belief in God as the Healer was also noted for John I who declared that his ability to live with the illness for the past 10 years was primarily due to God, who he described as being *“the Healer of my being alive”*. John I shared:

I’m alive. I’m 43. I’ve been living with this for 10 years so I don’t do this on my own. It has to be God. So apart from the people who play whatever role, God plays a vital role in my life. He’s pretty much the healer of my being alive now. I shouldn’t be alive; I should be a dead person.

John I likened his early experiences after being diagnosed with HIV to Job, a Biblical character who is recognized to have experienced a series of afflictions that left him destitute, ostracized and isolated. This comparison was felt to be very symbolic as it suggested a parallel between living with HIV and the series of afflictions endured by Job. John I perceived that Job *“went through a lot and I could compare it with mine”*. Job’s sense of endurance and resilience emerged as key qualities that John I adopted in his personal experience of living with HIV. Despite likening himself to Job, John I determined that he was unable to mirror the level of endurance which the Bible character is known for. As he said, *“I turn to God and say ‘God I can’t do what Job do... I’m not Job. I’m not as strong so I need you to help me through this one’”* (John I). This sense of personal limitations did not diminish the significance of John I’s spiritual identity in his ongoing adjustment to living with HIV.

The strong sense of spirituality was at times portrayed to be crucial in defining men’s treatment experiences. When asked what was important in his treatment journey, John III responded:

Faith in God and your medication, because guess what? When you in the situation, for the person who really diagnosed and get to understand about their status, it can be a really devastating thing and I think it can also lead to suicide. If you are not strong, if you don’t have that faith. If you don’t have an inner being inside of you, I think it can be very devastating. As I say faith then your medication.

Similarly, Jay alluded to his faith being intrinsic to his treatment process, especially as he perceived the role of the doctor alone to be inadequate. As he shared, *“Once you can have a prayer life, God can change anything. If you have to take the medication and if you believe in God, He will help you”* (Jay).

7.7 “FROM BLACK TO MUDDY”: THE DILEMMA OF CONFLICTING SELVES

There were instances where aspects of men’s identities, existing and emerging, conflicted with each other. This was noted in particular for Dan who grappled with his heightened spiritual identity post his HIV diagnosis and existing sexual identity. As he asked: *“Can you be spiritual and be a MSM?... live a Christian life, have a Christian mind-set such as having tolerance, patience and kindness and be able to have a relationship [with another male] to have a love?”* This question was primarily reflective of Dan’s awareness of the traditional principles of Christianity which present same-sex relationships as immoral and thus unacceptable. Thus being an HIV positive MSM who is also a Christian were perceived to be incompatible dimensions of Dan’s identity. This incompatibility was further reinforced by Dan’s friends: *“I have friends here who are, they’re not positive and they are not MSM and they are trying to have me pray my gay away by introducing me to the Bible”*. It was important to note that Dan’s reference to his friends being neither HIV positive nor MSM, positioned them as being outsiders in relation to his seemingly conflicting, multidimensional and complex identity. The shared spiritual identity established a sense of belonging or attachment to his peers, whilst other dimensions of his identity (being an HIV positive MSM), were used to distinguish and evaluate the appropriateness of Dan’s sense of self. Such conflict reinforces the role of others in evaluating, reinforcing and correcting men’s social identities.

The conflict between the multiple dimensions of Dan’s identity, and the role of others in imposing notions of appropriate and acceptable identities was seen in the following excerpt:

I am loving reading the Bible, I really love reading about Jesus and my interpretation of what Jesus was saying and their interpretation of what

God is saying are two different things. Because if, now this is going from black to muddy, but for them there is no way I can find peace as a MSM man and a human being. They don't think... so they are saying that once you're MSM, you're deficient, that you're, yeah that you will never be saved. (Dan)

The notion of “*going from black [and white] to muddy*” was seen to depict a shift from the explicit demarcation between traditional binary identities (masculine vs feminine, heterosexual vs MSM, Christian vs non-Christian) that help to define socially appropriate behaviours. Moving from this clear demarcation of black and white to muddy, indicated Dan's position that his identity is not, and should not be, relegated to oppositional dimensions. Though his friends believed it was not possible to find peace and garner self-acceptance as an MSM Christian, Dan felt otherwise.

However, being aware of prevailing social norms presented a dilemma whereby Dan was forced to either re-define or reconcile his notion of self in the context of his sexuality and his spiritual identity. Yet there was, and likely remains, no easy resolve. At times the process of re-negotiating self, did not have a certain end as the intersections between the dimensions of self, within the contexts of the perception of others and social norms, were oftentimes contradictory and “muddy”. This was aptly captured by Dan:

That is kind of rough for me. I will be honest, it is a dilemma I am going through because I like the relationship [with God] I have knowing that I am reading [the Bible] and getting to know that spiritual side of me but I don't want to lose, I don't want to tell myself that I am no good because I am a good person. That is something I need to learn, that I need to come to grips with.

Dan's “*need to learn*” and “*come to grips*” highlighted the ongoing journey of addressing the compatibility and incompatibility of existent and emerging dimensions of men's identities. As noted in Figure 19 (p. 152), this process of learning and adjusting is continuously shaped by the norms and ideologies pertaining to the dimensions of men's identities, and are enforced by a range of social structural processes such as gender socialization, HIV stigma and MSM stigma. The interrelation of these varying levels holds

implications for the construction and representation of men's identities and their approach to their health, particularly in the context of their HIV infection and ARV treatment.

7.8 SUMMARY

Learning of, and adjusting to, an HIV positive diagnosis affected men's self-perceptions and their social identities. A number of men reported developing or strengthening a spiritual identity, which became a useful tool in their adjustment to living with HIV and moving on to attain their dreams. Being HIV positive also forced some men to contend with the social connotations attached to the illness which had implications for how they were perceived and treated by others. Some men endured mistaken identities as being HIV positive was assumed to also depict an MSM identity. This mistaken identity reflected the belief that HIV/AIDS remains a "gay disease", a concept that emerged in the early years of the epidemic. The awareness of the stigma and stereotypes attached to an HIV identity forced some men to hide their HIV identity due to the fear of social reproach. The decision to treat HIV as a hidden part of men's sense of self was at times compounded by other dimensions of their social identity that invited further social disapproval. Thus being an HIV positive MSM was seen to attract intensified social antagonism and stigma that could aggravate the social dissent towards men whose identities comprised both dimensions.

Men were at times required to navigate or reinforce a representation of hegemonic masculinity in an effort to protect their true identities and maintain a sense of belonging within their social groups. The performance of masculinity emerged as a useful strategy adopted by some men, in an effort to protect their MSM or transgender identities and ensure their well-being within selective social spaces. The emphasis placed on social norms that prescribe the social identities of Jamaican men were found to impact on how men chose to identify themselves personally and within the context of others. The pressure to conform held implications for men who felt the need to prioritize their socially determined roles as heroes and leaders, at the expense of their pursuit of optimal health.

The findings also revealed a new dimension of masculine identities which has not been previously documented in the Jamaican health literature. A few men introduced the delineation between a masculine and feminine MSM identity that adopts a gender-role divide for MSM, comparable to the traditional gender-role behaviours of men and women. These introduced dimensions highlight the multidimensional nature of men's identities and the confluence that can lead to blurred lines of distinction. This can lead to the dilemma of conflicting selves, where dimensions of a man's identity prove incongruent given the emphasis on conformity to social norms and expectations of others.

Overall, this chapter identified the role of social norms in establishing benchmarks by which men's representation of their selves are constantly evaluated. As a result, men are pressured to comply with the need to present a masculine self that fits the norms of the ideal Jamaican male. The pressure to conform to this social ideal influences men's treatment experiences and adherence outcomes. Some men are forced to conform at the expense of their health, whilst others navigate these social benchmarks to ensure their continued access to their treatment and care which they deem important in maintaining their health.

Chapter 8 FINDINGS IV

Navigating treatment in clinical and social spaces:

Issues of power, identity and stigma

8.1 INTRODUCTION

This chapter examines the treatment experiences of the study participants, which encapsulated the previously examined sub-processes of accepting, adjusting and moving forward, whilst extending into other everyday experiences surrounding ARV treatment. It was recognized that men's experiences with their ARV treatment journey was not defined solely by their individual circumstances or self-perceptions, but rather extended to incorporate the perceptions and expectations of others within their families, peer groups, communities and the healthcare system. This chapter gives particular attention to the role of the clinic in empowering or disempowering men in their efforts to manage their treatment regimen. The chapter also examines men's experiences of navigating their treatment in personal spaces such as their homes and communities. Both clinical and personal spaces emerged as significant in defining men's treatment experiences, particularly as it pertained to men's notions of self and identity. Thus the intersections of men's identities, issues of power and stigma, and men's treatment experiences are examined within both the clinical and personal space. Particular attention is given to how men's identities are maintained, challenged or re-negotiated in relation to their ARV treatment journey, and the intersecting points with their personal and clinical spaces. Intrinsic to this analysis is assessing how domains of power and influence from both health and socio-cultural perspectives are interwoven and influence how the men perceive themselves, as well as influence their approach to their health. This is seen to have direct implications for their health outcomes, as how the men experienced these intersecting points shaped how well they adjusted, complied or engaged with their daily treatment regimen.

8.2 THE CLINIC AS CENTRAL TO TREATMENT AND CARE

The healthcare system was positioned as being central to men's experiences of initiating and adhering to their treatment regimen. The healthcare system provides avenues for HIV diagnostic testing and determines when an individual commences treatment, the medication that comprise his specific treatment plan and the standards of optimal adherence against which he is constantly evaluated. Thus the clinic emerged as a main determinant of men's understanding of and approaches to their treatment, and subsequently their treatment outcomes. The clinic also played a role in defining men's perception of themselves in relation to their ARV treatment. For instance, as captured in the previous findings chapters, the clinic was responsible for transforming men's outlook of HIV as a death sentence, instead giving men a sense of hope to move beyond their HIV diagnosis with the aid of ARVs.

8.2.1 Determining the point of treatment initiation

Historical changes surrounding the availability and accessibility of ARVs proved relevant in determining the point of treatment initiation for the participants. Men diagnosed during the early years of the epidemic in Jamaica reported that ARV treatment was initially not affordable and thus impacted their ability to initiate and sustain treatment. The early costs of ARV medication and provision through the private sector acted as barriers for many persons in need of ARV treatment, contributing to the number of AIDS-related deaths reported in the early years. Paul stated that he did not commence ARV treatment until seven years post being diagnosed due the cost of ARVs at the time of his diagnosis and his obliviousness to cheaper or alternate sources; factors that also contributed his wife's death. As he shared:

It [ARV medication] was expensive. At the time it was in the \$2000 bracket. The cheapest place that had it was Lasco Pharmaceuticals, half price, \$2500. Full price was \$5000 for one. That is \$10,000 for two. At the time \$10,000 a nuff money to find. It was sticky. As I said my wife was dead so you know right there so alone I just said... just fuck it, whatever happen happens...The thing is, I didn't know about CHARES and these places. It was the doctor who told me about CHARES. When I went up

there the medication was for \$1000, cover everything, cover the two. I didn't know this. (Paul)

It could be argued that the unaffordability of treatment further reinforced the position of power for the healthcare system in determining whether an individual is able to commence ARV treatment. This position is further underscored when health sectors are required to consider the trade-off of investing further in the treatment of one population at the expense of another. The devastating outcomes of such choices are exemplified by the death of Paul's wife which was linked to the unaffordability and thus inaccessibility of HIV treatment and care.

The seven years gap between Paul's diagnosis and treatment initiation also highlighted the failure of the health system in ensuring a wider dissemination of information that would allow for greater awareness of revised health policies that made ARV treatment more affordable. It is perceived that this sense of responsibility was greater for those diagnosed in an era when the cost of ARVs resulted in higher incidences of AIDS-related deaths. Thus issues of affordability and accessibility must be continuous considerations in ensuring the equitable treatment of all impacted and thus, optimal health outcomes.

Where men's CD4 counts were not at the prescribed levels to initiate ARV medication, their CD4 count and viral load levels were constantly monitored to allow for the appropriate timing for initiation. This required men to commit to maintaining their clinic appointments, which provided both the CD4 and viral load tests as a part of their service provision, further reinforcing the clinic as pivotal to the men's health journey. Such positioning was evidenced for Trevor who did not commence his ARV treatment until four years post his diagnosis.

You said that you didn't start; when you were diagnosed in 2003 you didn't start treatment until 2007

Right because treatment was related to CD4 count. Though you are diagnosed, you're constantly being monitored and once the CD level falls, then they say pause, and now you are to go on the ARV. (Trevor)

Trevor's experience revealed a system of control where the clinic determined when, what and how men initiated, accessed and engaged their treatment. The power dynamics involved in this process did not appear to be evident to the men as none acknowledged being driven by the obvious bio-medical perspectives but rather accepted their doctors being experts in making the best decisions on their behalf. One male referred to his doctor as "*The Great Dr. D!*"

8.2.2 The unquestioned authority of the experts

Many of the men expressed sentiments of great trust in the decisions of their doctors, who they perceived were knowledgeable of the epidemic and thus conversant with best practices regarding treatment and care. Trevor's sense of confidence in the expertise of the health professionals within the clinic was associated with the clinic's role in HIV/AIDS research and its linkage to a university and training hospital. He stated: "*I think the university and being the CHARES is the Centre for HIV administrative, we have the experts here*". Trevor believed that this expertise translated to the doctors always acting in the best interest of the patients.

The deep trust and reliance on the knowledge and expertise of health practitioners resulted in some men adopting a passive approach to their treatment process, where they accepted and complied with their doctor's recommendations without engaging in dialogue to ensure a full understanding of their treatment regimen. According to Trevor, "*if he [Dr. D.] tells you that he's putting you on this medication because of 'stone and steel' you go with it... No matter what your condition is... You can put your trust in that guy*". This passivity where men merely accept the recommendations given by their doctors reveals a top-down approach to men's treatment process that underscores the perceived authority of the physician. Passivity was also noted where men failed to share information that may prove pertinent in designing appropriate treatment plans to suit their unique circumstances. The

confidence vested in the perceived expertise and authority of the doctor contributed to some men's limited understanding of their treatment process, as seen for Tallist in the following dialogue:

What do you know about the ARV medication? The tablets that you're taking, what you know about it?

Mi nuh know much about it

So why do you take them?

Because the doctor told me that I better start to take it. (Tallist)

The relationship between these men and their physicians revealed power dynamics where the physician provided the voice of medical authority, being the expert, whilst the men were passive though compliant patients. Inadvertently this engenders a system that continuously disempowers and silences men in the presence of those who have been traditionally esteemed as owners of bio-medical knowledge. It also counters the recent shift to actively engaging patients in their healthcare and treatment decisions.

Instances of mistrust were also noted where some men struggled to develop a relationship with their physicians due to the frequency of staff turnover in the clinic that offered "*no space for dialogue, none. It's just, as me say - business as usual*" (Paul). This view was shared by John III: "*when I normally go there you tend to see different-different doctors... Sometimes it is coincidence you buck up back [re-encounter] the same doctor who saw you the last time*". As with earlier findings, limited and rotating personnel were indicative of the resource-limited nature that characterized the clinic and resulted in strict time limits in attending to patients.

The space for dialogue is important in allowing a patient the opportunity to fully express himself and where possible have his questions answered. Denial of this space can result in the silencing of men, further contributing to the estrangement of some men from their

treatment process. This was aptly noted for Paul who shared the experience of feeling silenced after attempting to ask his doctor a question.

There was something me want to see on my file and me say [to the doctor], “Tell me ‘bout this no doc”. And he was like, “you have to wait until I look through the file first”. Me say “but no not about this”. [The doctor interjected] “You hear what I said? You have to wait”. Now me did a get up and come out you know because me did a get upset... and me say you know what happen, easy [relax]. You want your prescription, you want your medication, [you have to] grin and bear [endure]. And me just sit there and [then] me just come out; me just take my things and come out. That was the worse I ever felt from a doctor. (Paul)

Paul’s experience also highlighted the perceived need to endure and tolerate sub-optimal service in an effort to retain access to healthcare.

8.2.3 Assessing the clinic’s role in ensuring treatment preparation

The healthcare system proved integral in preparing men to commence their treatment. Treatment preparation was seen to entail ensuring an understanding of the likely side effects of ARV medication, equipping men with appropriate time management and scheduling skills, and psychosocial preparation to commit to lifelong treatment. Failure to ensure men’s full understanding of these areas were found to impact men’s readiness to commit to lifelong treatment, thereby affecting their adherence outcomes. For instance, John III indicated that he was not properly prepared to initiate treatment as the doctor did not “*really spend much time with me*” and offered “*no preparing about it*”. Though this was not his experience at CHARES, it remains indicative of health system-related barriers that impact men’s access to appropriate health care. John III perceived that the absence of treatment preparation contributed to his default in treatment and further deterioration of health: “*I start to break down and so on and then my CD4 start to fall... I think that was basically it, cause I didn’t really get no pre- nothing, no counselling really*”.

The process of preparing men to initiate their ARV treatment predominantly focused on advising the men to “*always take the medication and on time*” (Dante). This has emerged

to be largely prescriptive and aligned to the earlier definitions of adherence that required patients to follow rigid medical instructions (WHO, 2003). As Brenton and Jay shared:

They tell me to take my medication, because first they say to me “Take your medications, see to it that you take your medications same time every single day. So if you’re taking your medication at eight o’clock in the morning, you take your medication eight o’clock and if you’re taking the other one at ten or eleven o’clock you take it.” (Brenton)

they keep telling you that...when I go to the pharmacy they say – “make sure you take your medication”. I said sure. (Jay)

The health message to “*always take your medication and on time*”, largely focused on the efficacy of the ARV medication which ideally requires consistency in both dosage and timing. It also communicates an image of the ideal patient who is both compliant and adherent of this message. However, this message fails to capture and address the unique and complex situations of patients. It is questionable whether a space for the patient’s voice was provided in negotiating the best treatment approach to be engaged by the men, outside the requirement of consistently and committedly taking ARVs. It was felt that this type of dialogue was absent given the earlier noted reports of limited consultation time with some doctors and the high staff turnover. It was also questionable whether or not the practical implications of this health message were considered or addressed by medical practitioners. For instance, how feasible was it for men to take their medications at the same time each day in the context of their work or home environment, work schedule, and personal beliefs regarding dietary requirements? The emphasis on advising men to take their medication and on time was seen to be a blanket statement that ignored the unique circumstances of the men’s lives, especially where their HIV identity was hidden. Whitey opted to protect his HIV identity by taking his ARVs at home, rather than travelling with them and taking them in public spaces. As a result, he noted: “*The reason why I missed out is because some of the time when I don’t come in or I come in very late, I miss that dose*”. Thus the need to protect his HIV identity resulted in Whitey’s inconsistency in taking his tablets. Perhaps open dialogue with his physician would have identified an alternate approach that would respect

Whitey's need to protect his HIV identity, whilst ensuring he maintained the schedule and timing of his ARV medication. As another participant alluded, *"me understand that there is a lot of people them seeing right. But try to even schedule 5 or 6 minutes to have a discussion with the person. You know the difference that little discussion could make?"* (Paul).

The night dosage proved particularly difficult for most men to maintain due to the general requirement of taking the night dosage on an empty stomach. This competed with the men's timing around their evening meals after which some would fall asleep and subsequently miss their night dosage. An example of this is noted for John III:

Well the night one yeah, sometime I sleep off. I sleep off the night one especially... I go home and me drop asleep... If I have to take it at 10 and wake up at 12, that will be two hours past my time and so on. So sometimes I still take it then, or if I sleep and don't wake up until early in the morning, I just don't bother take it for that night. (John III)

John III's inconsistency in taking his ARV medication may hold implications for the efficacy of his treatment regimen which underscores the importance of ensuring men are effectively prepared and educated on the implications of both optimal and sub-optimal adherence.

Most reported being advised of the possible side effects of the medications they were prescribed; however, the experience of initiating treatment still proved stressful for many. Reported side effects included vomiting, drowsiness, diarrhoea, fatigue, agitation, hallucinations, vivid fantasies, nightmares and dizziness. For Kevin, the experience was *"stressful because, when I started medication is like it started to give me weird dreams, scary dreams"*. Similarly, John II expressed:

It's terrible man; I didn't know I could really go through it. It did have me a way. It's like I was in a different world. Even when mi go to my bed and a sleep, is like I am not in my bed; it's like I am floating.

The extent to which Kevin and John II were prepared to endure the side effects of their medication is uncertain. Nonetheless, there remains an opportunity to ensure abstract expectations become more specific in ensuring men's preparedness to initiate and maintain their treatment. This point is bracketed with the acknowledgement that the extent to which a side effect is experienced can be amplified by other factors which may prove difficult to clinically predict, thus limiting the extent to which a physician could prepare a patient for such outcomes.

The extent to which some men were poorly prepared to commence ARV treatment emerged in reports of overdosing or men not taking the medication as advised. Ritchie shared the experience of being poorly prepared to manage his treatment which resulted in the incorrect management and intake of his medication. As he stated:

You see the first part, when I just went on medication, the doctor just give me the medication. At the time I was weak cause I got a stroke. It was my friends that was helping me. I couldn't even walk on my own and the doctor gave me the medication, and said 'these are the medication; take them on a daily basis.' Now, my friend now, who don't go no support group meeting and no get involved, ...they don't have the experience about the medication, and I was too weak to understand what was gonna happen when they were giving me the medication wrong. I was taking the efavirinz in the morning, when I should be taking them at night. So I was finding I was sleeping all day, when I should be up, you know. When night time come now, and I can't sleep cause when the efavirinz soak in my system and put me to sleep and I wake up, I have this enormous energy, I can't sleep. (Ritchie)

Ritchie's experience revealed the failure of his attending health provider in ensuring he was effectively prepared and received adequate support in his treatment journey. Ideally, this approach would have taken into consideration the broader contexts of Ritchie's life which could impact his ability to independently manage his treatment upon being discharged from the hospital. Thus it would have proven useful to consider Ritchie's limited acuity and the absence of an informed support system in determining his ability to independently manage his treatment. Ritchie's experience highlights a gap in patient education and preparation,

which could impact how effectively men manage their ARV treatment and their adherence outcomes.

Reported instances of overdosing revealed a potential gap in effective treatment preparation. Troy and Que reported instances of overdosing during the early stages of their treatment. In both instances it was perceived that inappropriate information was provided by either the doctor or pharmacist, which led to the men consuming more than the prescribed dosage. As Que shared:

One of time when I take the medication, because I was taking so much pills, one of the time I feel them lick me out... I feel like is dead me dead... But what I realize, I did overdose, according to what the doctor said. So when I go back to the doctor he say “No, you not supposed to take so much”. (Que)

Que reported taking a daily regimen of 18 tablets before learning that he was taking the incorrect dosage. This dosage exceeded his prescribed regimen which comprised six tablets daily. The extent of Que’s mismanagement of his prescribed dosage could potentially have had adverse effects on his health and well-being. As with Ritchie, Que showed a limited understanding of his treatment management which further indicated an absence of effective treatment preparation. This was further reinforced when Que explained that he was “*eager to take the medication at the time because I was saying if the medication going to make me better I will just take it*”. This eagerness to take the medication portrayed Que’s effort to construct his identity as a good patient within the framework of the clinic’s key health message: always take your medication and on time. Ascribing to this notion of a good patient, with the outcome of getting well, resulted in Que bypassing the importance of understanding the rationale of his prescribed medication regimen. Que’s initial approach to his treatment also revealed a sense of passivity whereby he failed to ensure he understood his prescribed regimen that would enable him to independently and effectively manage his health and treatment. This sense of passivity concurred with the earlier finding of an over-reliance or trust in the physician to make decisions that are in the best interests of the patient. It also exposes gaps in the quality of healthcare provision as there is a recognized

need to assess patients' readiness to engage treatment independently, which ought to include ensuring sufficient understanding of their treatment dosage and timing.

The gaps in patient preparation and support were also noted for Troy who expressed some confusion around taking his medications. When asked the number of tablets currently being taken Troy responded: *"It's one but it's two... It is one pill but I'm taking two"*. Further investigation revealed that he was referring to the combination ARV drug which was replaced by two medications, given the pharmacy no longer had the combination ARV in stock. Troy noted that when the switch occurred he noticed that the instructions for the medications were different. Whereas his initial prescription required taking the medication on an empty stomach, the replacement drugs indicated the opposite. This was confusing as he could not grasp why the instructions were different if the medications were the same. As a result, he opted to maintain the previous instructions to which he had become accustomed. As he explained:

Even though on the bottle it says one should be taken, on the bottle one says take it before meal and one says take it on an empty stomach and one says take it with meals but then the original one that we had first just had a general rule of taking it on an empty stomach before you go to bed so you [I] just maintain that rule.

So you just take it on an empty stomach?

Yeah, even though they are two different instructions. Cause I had asked the pharmacist. I remember the first time I received it I saw the two different prescriptions and I said wait a minute, how come this is saying with meal and saying without meal? What about my times that I had? It's gonna mess up my time because I had it just at night now this would mean I would be taking one like three four in the day which is when I'll be eating and then one at that time in the night which is like 9:30 during that time. But she said "No no no, remember the three in one tablets you just take it either with the meal or without the meal".

It was clear that the recommendations provided by the pharmacist did not offer much clarity for Troy. He struggled with the implications of the new prescription given he had

already established a set routine around taking his previous combination ARV. As a result, Troy reported maintaining the instructions of his previous medication which he felt were easier to follow. This choice is seen to have implications for the efficacy of his treatment and thus his health outcome. Troy's confusion and choice to follow a previously prescribed regimen, revealed the issue of a lack of concordance between patient and the varying health professionals involved in ensuring his access to treatment. Who ensures that the information communicated by the doctor and the pharmacist are consistent to avoid patient confusion? Has the patient been sufficiently empowered to gauge the information provided by the pharmacist and the doctor to ensure the most effective decision regarding treatment is made? Troy's experiences, in response to these questions, exposed further gaps in health service provision that could jeopardize men's treatment experiences and health outcomes.

8.2.4 The clinic as a system of control in determining men's treatment experiences

Men's lives became deeply interwoven with the clinic once they committed to their treatment process. The clinic determined when men were scheduled for their doctor appointments, the point at which viral load and CD4 tests were conducted, and the timing for prescription renewal. This meant the clinic was pivotal in monitoring and regulating men's treatment process and experiences, producing a system of control and a forced state of dependency. Men did not have the liberty of accessing health services outside the strict confines of the regulatory system dictated by the clinic. The forced routine around the clinic was noted for Dante who shared: *"When a come to see the doctor every three month, I get a prescription... When it [ARVs] finish a come back here and get it over the pharmacy"*. Prescription renewals and access to ARV medication was hinged on the men maintaining their clinic visits on a strict schedule provided by the clinic. This system of control and forced dependency proved problematic for some men who were not able to maintain the given clinic appointments. The confines of a rigid schedule and the requirement to maintain clinic appointments to obtain prescription renewals forced Whitey to ration his ARV medication until he obtained a new clinic appointment. As he stated:

when it comes on to the stage where my medication is running out, I have to go back to the doctor and I have to get a prescription before it ends. Because if it ends before the date of the clinic date, I basically have to skip my medication... If my medication is running out, what I do is I skip one like a day or something. (Whitey)

The clinic is seen to enforce a system of control that forces men to maintain their clinic appointments. Though these rules underscore the importance of continuous medical evaluations to determine men's health progression, they potentially threaten the well-being of men when they fail to adhere to such rules. Thus Whitey's choice to ration his medication was done in an attempt to manage the strict schedule imposed by the clinic, which did not coincide with timing of his prescription refill. Whitey's experience also revealed the transactional relationship between the clinic and patients, as the men were forced to maintain their clinic appointments in order to receive the benefit of their prescriptions, ARV medication and periodic viral load and CD4 tests. Thus men's access to their treatment is held at ransom to them being compliant with the rules of the clinic.

Whitey's experience was shared by other men who expressed challenges of rescheduling their appointments due to unforeseen factors such as the inability to afford the cost of travel to the clinic or work schedules. Dante acknowledged missing his doctor appointments because he forgot or was unable to afford the transportation costs to travel to the clinic. As he shared:

How comes you end up missing it [clinic appointments]?

Is either I have something to do that day; sometimes I don't remember and come the wrong day, yuh nuh? Sometimes I am coming all the way from downtown and have money problem. Sometimes the money don't come in the right time and all a dat. (Dante)

Though men are able to request appointments outside the prescribed schedule, this proved problematic and resulted in lengthy waiting periods before the new appointment. According

to Dante when he calls to make a new appointment to see the doctor, “*most time all two months before me get a next appointment*”.

Dan claimed that the clinic’s system of control was more rigid for MSM or gay men, as “*they consider gay guys to be trouble makers for some reason*”. According to Dan, this perception of gay men impacted the flexibility meted in rescheduling their appointments as may be deemed necessary. He reflected on the following experience he had with the administrator responsible for scheduling appointments:

I just simply want[ed] to reschedule my appointment. She went through all the stuff that the doctor, the clinic only makes appointments for 8 persons, and I stressed, 8 *persons* cause now I can’t understand how any clinic anywhere with HIV, could see 8 persons a day. And she insisted, 8 persons in a day and she couldn’t find a time for me right away, blah blah blah... [continues to report on conversation with receptionist] ‘Should I speak to my social worker?’ [Receptionist:] ‘She’s in a meeting’. [Dan:] ‘Oh, should I speak to my adherence counsellor?’ [Receptionist:] ‘She is also in a meeting’... so I said ‘May I speak to the administrator?’ [Receptionist:] ‘She’s in a meeting as well’. So in other words I couldn’t speak to anybody. I was literally screwed; I’m screwed. You can quote this, she said “go fuck”; she didn’t say it, but obviously that’s the message: go fuck yourself. Do what you have to do. (Chuckles) (Dan)

Dan’s experiences reinforced the challenges experienced by Dante and Whitey that forced them to circumvent the clinic’s rules, and which held implications for their access to treatment and health outcomes. Dan highlighted the rigidity of rescheduling appointments, as well as perceived MSM stigma that emerged as barriers to his access to the clinic’s health services. The outcome is a sense of powerlessness and defeat where he noted “*I was literally screwed*” (Dan).

Other barriers arising from the regulatory system maintained by the clinic included the lengthy waiting period men experienced both in waiting to see their doctors and subsequently to have their prescriptions filled at the pharmacy. The challenge surrounding the waiting time was aptly expressed by Dante:

Basically I have to be in the area waiting, waiting for them to find my docket and umm once they do, it's like I've been there from 7 so by 12, 1 o'clock I am still in the waiting room, waiting for my docket to be found. And it was bad. It is bad. Since now, it's bad because it's like I've been here from morning and I'm getting upset sometimes when I do get upset and by the time I reach the doctor and she test my pressure, my pressure high... Once I leave the waiting area to go down to the other section I have to wait again another hour or so before they call me and that's another big problem. I can't deal with it. I can't deal with it.

This extensive waiting period to access services continued into accessing the medication from the clinic's pharmacy.

The pharmacy now... once I'm there I have to wait another time again. [It's not] 'til basically 9 o'clock before my name can be called to hand in my prescription, then after than I have to wait another two or three hours before I get my medication. And it, it's basically stressing, its stressful there trust me... if I can limit myself from going there I'll do so... (Dante)

John III perceived the requirement to wait for lengthy periods for the medication was due to the medication being "*free, you know them little punishment a go on*". This notion of men being punished or treated adversely underscored the mechanistic, centralized system of control embedded in the clinic. Not only are men's health routines developed around the clinic's schedule, but they are forced to adhere to the recommendations of the clinic or risk penalties. Such penalties may include lengthy waiting periods for rescheduled appointments or lengthy waiting periods at pharmacies, both of which affect men's ability to maintain and thus adhere to their prescribed treatment regimen.

The challenges around lengthy waiting periods at the pharmacy forced some men to identify strategies to access their medication without the wait. For Brenton, this meant leaving his prescription to be filled at the pharmacy days in advance:

If I know my medication is going to run out this week, I'll bring it like on Monday, drop it off at the pharmacy, leave it, pick it up when I can. When I can I just come back another day and pick it up. I just don't wait until it's run out and then I have to sit down and wait.

Strategies such as that adopted by Brenton highlighted the hurdles that some men are required to overcome or navigate in order to access their medication. It therefore becomes necessary for men to identify ingenious, though potentially harmful ways, of ensuring their continued access to their ARV medication. The clinic's role in men's treatment processes is two-fold: enabling as the determinant of when and what medications are needed by men to control their viral load, and disabling where its regulatory system of control imposes barriers to men's access to their treatment and care.

8.3 COMPETING APPROACHES TO CARE: THE HEALTH PROFESSIONAL VERSUS PATIENT PERSPECTIVE

There were noted instances where men opted not to conform to the prescribes of the traditional bio-medical approach upheld by the clinic. Here, men were seen to be more active in their health decisions, redefining treatment and modifying their treatment approaches. These actions showed men's ownership of their HIV health status, as well as the decisions aimed at improving their health.

8.3.1 Nutrition, exercise and adherence walk together: Extending the biomedical understanding of treatment

Some men appeared to challenge or question the traditional approach to defining treatment, as well as the treatment regimen prescribed by their doctors. The need to challenge or question the physician's perspective was identified in some men's disbelief in the efficacy of their ARV treatment. This disbelief was partly fuelled by the perception that ARVs function *"to keep you but it cannot cure"* (Jay). As Jay further explained, *"this medication that they give you don't really help you more than so. It just help you to just go through and just try fight life"*. For Jay, ARV medication did not provide a significant change to either his sick or HIV identity, as for him this required being cured of the illness. This outlook reflected the general expectation that medications should cure and not simply manage diseases; a perspective shared by Troy's friends who he acknowledged failed to initiate treatment because *"they don't believe in the medication"*. The inability of ARV medications to cure HIV challenged the value men placed on taking their ARV medication.

A few men contemplated the existence of a cure for the illness which was not made available to them. Jay, who was persistent in his belief that a cure existed for HIV, argued that the interim provision of ARVs was a political move by the government to sabotage its people. As he further stated, *“if they should get the right procedure and medication, they are not gonna make any money from it. So cure is there”* (Jay). Jay’s outlook impacted his treatment approach. Though he maintained his ARV treatment, this was supplemented with alternative medicines he believed provided a cure for HIV. This is further explored in section 8.3.3.

Majority of the men extended their definition of treatment beyond the bio-medical focus on their ARV medication, to include diet and exercise. According to Dan, *“treatment is not only the medication, but treatment is the food you eat, your lifestyle changes”*. This was captured by Richard who stated: *“I think that medication alone does not heal people; it’s how you treat your body”*. He further explained:

Three of them [medication, diet and exercise] play a pivotal role... Put it on a pie chart, you would put the medication at the very top because without the medication your body will just drop down, right... I think the medication itself fight the virus that is in the body so when you take the medication it helps to reduce the amount of virus in the body... I am not a medical practitioner but I believe in myself that eating as much poultry food doesn’t help the body because I think eating as much starch, vegetable and legumes help to build the blood count in the body... [and] put vitamins in the body so once your body have as much vitamin, it help to fight the bacteria that is supposed to come in the body... the exercise itself now... It’s like a very pivotal, because exercises help to rejuvenate the mind and stimulate the body... You have to exercise. (Richard)

None of the men indicated their doctors advised them of the importance of diet and exercise in ensuring their overall health and well-being. One doctor indicated that it was not important for patients to eat before taking the ARV medication, which countered the significance of a healthy diet and exercise maintained by some men. The divergence between the patients’ and doctors’ perspectives created gaps in men’s knowledge that

affected their adherence outcomes. The perception of the efficacy of ARV treatment being contingent on a suitable diet was echoed by a number of men:

When I take the medication, I have to have food to eat. (Kevin)

I never use to eat and I use to take it [ARVs] and I feel to say it do me more bad than good. Knowing that I never use to eat and I use to take these strong medication, so I feel say it do me more, it do me some harm. So I say I don't want it to go back to the days when I am not eating and me a take the medication so I try my best to always a eat something now. So when I take it I know say with the medication you have to have something to feed on so umm, I don't really want to go back to the days when true me not eating I don't take it. (Que)

Nutrition and adherence walk together. So you can't separate the two of them you understand, and if persons go out there and cannot find food to eat them not going to take the medication. (Ritchie)

When a man is ill, he needs more calories, therefore a balanced meal is crucial. You have to know what to eat to make sure that the fighting of the infection is successful... Yeah, making sure that your diet is right, so you can effectively deal with your ailments. The more the nutrition is okay you take care of the body's defence system so it can fight along with your ARV. Although you are on ARV and your nutrition is faulty, you could be in trouble. Both are complimentary. (Trevor)

Central to these men's perspectives was the belief that the efficacy of their ARV medication was contingent on them maintaining their nutrition. Thus for the men, their treatment responses to their HIV illness surpassed the biomedical message that focused solely on the role of ARVS. There is a need to improve the dialogue and partnership between men and their physicians to ensure the ideas around treatment contingencies are fully explored and addressed. Such dialogue would allow the physician to understand and appreciate men's perspectives regarding the significance of their nutrition alongside their ARV medication. It would also provide an opportunity to equip men with a better understanding of the role of their nutrition and empower them on ways to maintain a baseline and cost-effective diet.

Men's focus on both exercise and nutrition, alongside their ARV medication, filtered into the symbolism of the body image of the male which was primarily based on an external or physical representation of self, but also hinged on the internal or physiological state of wellness. The significance of men's body image is juxtaposed against earlier identified conceptualizations of the sick or HIV infected identity, which most men presented as largely encapsulating the outward appearance of being unwell (rashes, weight loss, being incapacitated). As Dan stated, *"I have found that people who take their meds and take good care of themselves they tend to look fitter than before they even became positive"*. Similarly, Mario shared *"Well if you don't eat I mean you're gonna really look bad because I see some gay guys in New Kingston [how they] look [when] they eat, and when they don't [eat] they look like some animals"*. Thus the triple combination of ARVs, healthy diet and exercise, enabled men to attain a restoration of the outward appearance of the healthy self, which was key to some men's masculine identities. The significance of this triple combination was further reinforced by other men's perceptions that ARV medication alone was not sufficient in restoring them to a healthy state.

8.3.2 Affordability as a barrier to treatment

There were noted instances where men alluded to the role of their low socio-economic status in influencing their adherence to their prescribed treatment regimen. For example, Marcus indicated that his adherence to his treatment regimen was impacted by his inability to consistently afford a proper meal.

It wasn't easy the fact that, yes they say adhere, I don't know what they mean by adhere. They said to take your medication on time but then I wasn't in a position at that time to manipulate that, [to] eat something to take it. I had to come up with my own strategy. One of my problem was to find ways of how do I get something to eat... so I have to find ways of how do I manage it, taking my 'vitamins' [ARVs] and being able to cope.
(Marcus)

Marcus established a divergence between the biomedical message: "take your medication on time" and the personal realities of some men that prevented them from affording a diet

that was perceived to be essential in supporting the continuous intake of their ARV medication. As Ritchie further illustrated,

It's not just about medication alone and I lose group members because of nutrition. They not working, they can't afford to buy the food so they don't take the medication... Why you take it with meals, is to help your body to cope with the medication at all times. How long can you take the medication without meals?

The issue of men's financial challenges did not solely impact their nutrition, but also directly affected their ability to afford transportation costs to maintain clinic visits. Troy indicated that his inability to afford his bus fare had prevented him from obtaining his medication refills repeatedly: *"That has happened to me like four times where I couldn't get them because I simply never had bus fare to go for them, as simple as bus fare is to get"*. The cost of travel was greater for those men who travelled from parishes outside of where the clinic is located, especially for men travelling from rural parishes.

Though first-line ARV medications are provided free of cost, some men indicated being unable to afford the cost of prescribed medication or procedures related to other related illnesses such as a yeast infection or dermatitis. This was aptly illustrated by Dan who shared: *"I have a prescription for an ultra sound in my bag right here. I've had it for weeks now [but] it cost a good amount of money"*. Stories of missed appointments, unfilled prescriptions or outstanding tests were consistently shared by men who were unemployed, irrespective of their educational background. In contrast, one employed male expressed that he was not challenged by the cost of supplemental medications given he has health insurance. Usually such health insurance policies are obtained as a part of employment benefits offered by some workplaces. For Troy, becoming unemployed post initiating treatment resulted in an intentional shift from an outpatient clinic where he paid for his health services to CHARES. As he explained, *"I had to pay up top [outpatient clinic] but then I was working so that wasn't a problem"*. This reinforces the linkage between men's employment status and their financial stability which further affects their health behaviours.

Varying strategies were used by the men to cope with their financial constraints, including staggering their prescription refills or as Que explained “*when I cannot afford it, well I just have to wait until I can afford it*”. Another noted strategy was borrowing money from friends or relatives which Troy indicated placed him at risk of being interrogated about his health.

You know some people say “yes I’ll lend you this” but you don’t necessarily tell them what exactly it’s for...[then] you ask them for it and [they ask] “what you going up to UHWI for?” That’s a question I tend to shy away from when they ask me. (Troy)

Overall, the men’s unemployment status proved significant in determining their ability to afford the varying costs associated with maintaining their treatment and care. This reinforces the role of structural forces in influencing men’s health choices, and subsequently their health outcomes. It also reveals gaps in the health system design that has not accounted for such costs. Whereby the provision of free ARV medication and access to publicly funded healthcare is of noteworthy benefit to the health of these men, they remain challenged by their lower socio-economic status.

8.3.3 Treatment is clinical, and also social and psychological

Some men redefined the contours of their treatment to include their psychological and social well-being. For example, Dan described his treatment as being “*clinical, social and also psychological*”. Dan’s broadened outlook of his treatment process reinforced the significance of a holistic approach to men’s health and highlighted the importance of psychosocial support throughout men’s treatment trajectory, within both their personal and clinical contexts. For example, Ritchie highlighted the importance of his support group in helping him to overcome the initial challenges of adjusting to his medication.

Make me tell you man, I get frustrated. I say I can’t deal with this thing, so much medication, so much time for the day. What kept me going... if I didn’t have the experience that I had with the support group knowing when and what is best for me or I would have stop... [I] use to call and say, ‘I

going through this and I feel to give up' and they say 'No, Ritchie man, a no you that'. They talk, they talk me out of it. (Ritchie)

The participants revealed that the clinic no longer facilitated support groups. Those men who were initially involved in these support groups reminisced on the value it offered, and their interest in their revival. The changes to the facilitation of these support groups may be reflective of the limited capacity of the clinic. Nonetheless, it highlights a gap in the treatment response to men's health issues as focusing on the clinical proves insufficient. As Dan lobbied, the treatment response to men's health should adopt a holistic approach that takes into account the social, psychological and spiritual domains of men's health. A shift towards a more patient integrated approach could alter the design of healthcare delivery to better encapsulate these functions which could enhance the treatment experiences and health outcomes of HIV positive men.

8.3.4 “Backing up ARVs”: The case for alternative medicines

The limited confidence in the efficacy of treatment propelled some men to re-define their treatment regimen to include the intake of supplements such as vitamins and experimentation with alternative medicines. As Trevor stated, *“Medication is there but it needs back up”*. Whereas vitamins are often prescribed by doctors to encourage healthy support of the immune system, there are ongoing debates on the suitability of alternative medicines. Two men indicated taking varying herbal remedies such as bissi, cerasee and moringa which were each recommended by their peers as a form of detox to purge the men's bodies of their HIV-related illnesses. Both men acknowledged pausing their intake of their ARV medication during the period of detoxing. Neither perceived the potential negative effect this could have on the efficacy of their treatment regimen.

For the men who indicated taking alternative medications, such as herbal medicines, when asked if the suitability of these treatments were discussed with their doctors they all indicated no. There was resounding reservation to explore such remedies with doctors due to the fear of negative repercussions that could result in the men being denied access to the

clinic's health services. This outlook reinforced earlier perceptions of the authority of the clinic, especially where health professionals within the clinic were seen to possess the power to punish patients who fail to comply with medical directives. Jay indicated sourcing alternative treatment from Kenya due to his belief that his prescribed ARVs were ineffective in treating his illness: *"I just decide that it [ARVs] can't work, so I just source some different medication and it [alternative medication] really help me"*. In exploring the implications of combining both medications, Jay was asked if he discussed the use of alternative treatment with his doctor. He responded:

I can't talk [to them]. I can't do that (*sounds emphatic*)

You can't talk to them about it - why?

Because of... they will let you know that they don't have to do it [don't have to assist] because the medication is very expensive.

So you think if you tell them, they will not help you any more in terms of medication?

Yeah... so you cannot do that. (Jay)

Jay exemplified how the perceived threat to their access to treatment forced some men to comply with a regimen which they neither understand nor fully embrace. As a result, a sense of duality is created where men acknowledge the authority of health professionals and thus endeavour to comply with their directives, whilst discreetly being subversive in manipulating their treatment process. These subversive acts showed men's attempts to take control of decisions pertaining to their health, especially where they questioned the effectiveness of the treatment approaches proposed by their doctors.

The fear of being punished also acted as a hindrance to some men soliciting care and treatment. Mario, the only male in the study who discontinued treatment, expressed a desire to resume his clinic appointments but was discouraged by the fear of rejection and being judged for his non-compliance by the doctor. As he shared:

I wanted to go back; I wanted to come to CHARES cause uhm to me they're safe and I'm wondering if I have another STI or something you know. I kinda ponder about the risks of that but I just never had the push to come here I was just so afraid to come back here.

Why were you afraid?

... How the doctor look at me [as though] “okay this guy is just playing. He only take the medication for just a few months or one year and then we don't see him back again”; so that's how I think. That's how I think that's what they would say to me... (Mario)

Whereas the clinic should ideally represent a safe space for all PLWHIV, it appeared that it also represented a symbol of judgement, evaluation and perhaps sentencing whereby some persons are granted or denied access to services. Thus Mario's perception of the doctor's 'look' or glare and subsequent thoughts possessed enough power to cripple his desire to resume treatment and care, especially given the recognition of his vulnerability. The outcome of Mario's continued default in treatment, amidst his additional health concerns emphasized the power of the clinic in enabling or disabling men's engagement with their treatment process.

8.4 THE POWER OF THE CLINIC IN SHAPING MEN'S IDENTITIES AND TREATMENT EXPERIENCES

Men's treatment experiences were found to be shaped by an interplay between their personal and/or social identities and the healthcare system. Central to this was the intersection of men's pre-existing identities and their acquired HIV identity that introduced the interdependence of the healthcare system. As a result, men were required to engage their personal representations of self and their perceived social identities within the clinic domain. The clinic was seen to operate as an extension of other social institutions that policed socio-cultural norms around men's identities. Thus the clinic was identified as playing a role in influencing the (re)constructions of men's identities, which further impacted their adherence outcomes. As such, the role of the clinic, at times, contradicted

with the expectation of it being a neutral and safe space for all men, irrespective of their personal identities.

8.4.1 ARV medication as a symbol of a new identity

Unlike the HIV identity which for many portrayed illness, ARV medication was presented as a symbol of hope in re-attaining a healthy identity. The benefits of taking the ARV medication were primarily evidenced in the outward appearances such as weight gain, disappearance of rashes or other skin conditions, disappearance of lumps or reduction in the swelling of lymph nodes. Bird indicated that a friend struggled to believe he was HIV positive because *“I had put on back the weight and so I never look bad, cause even the rash did clear up off my skin”*. Though this new identity was not aligned to gender or sexuality, it represented a counter identity to being HIV infected. This was further illustrated in following excerpts from Vincent and Jay:

If it never work me would a look meagre... Every time me go a doctor, some weight go on, none no cut off. (Vincent)

everybody keep on telling me that “you look good. You look different”. But I know in myself cause I can feel it in my body [that] I feel different; I feel free-er. (Jay)

Bird, Vincent and Jay highlighted the importance of a healthy identity as a part of men’s constructions of their masculine. This image of the healthy self, allowed men to reclaim a sense of their identities prior to becoming HIV infected. As Bird asserted, *“I’m back to my old self”*.

Whereas Bird presented his ARV medication as restoring his *“old self”*, Richard portrayed it as providing a sense of newness: *“the medication itself plays a pivotal role where life from death may dwell because the medication itself help to uplift your body in the most positive way of your life”*. This reiterated the symbolism of the medication in shaping a new identity that reflected a healthy semblance of self despite being HIV infected. It also

presented a shift in men's perspectives that allowed them to move beyond dwelling on their HIV diagnosis and instead engage in a positive transformation of their lives.

The affirmation of the importance of ARV medication in restoring an "*old self*" or development of non-HIV semblance encouraged men to maintain their treatment regimen, which included their routines around the clinic. This was noted for Que who expressed:

I see some people that really have it compared to me, it just give me more hope to take my medication. I come in here [clinic] and see people who, if you see them on the street, you can't know that you point them out and say they are sick.

Seeing others who have been living with HIV for a longer period, and noting that they did not appear sick, reinforced the importance and efficacy of ARV treatment for Que. His response reiterated the importance of men perceiving their treatment as integral in restoring a healthy identity, as a preliminary step into their decision to adhere to their prescribed regimen.

8.4.2 "Named and shamed": Becoming visible due to clinic attendance

The use of the acronym CHARES and the inconspicuous location of the clinic were deemed to be useful strategies that helped to minimize the visibility of the clinic and thus protect the identities of its service population. The usefulness of this strategy was reinforced by one participant who considered the clinic's design and location quite suited to maintaining the privacy of his HIV identity:

coming here to CHARES is like coming around a little secret corner. You just sit in a little cave and you talk, you know kinda cool, like a hanging spot. I think the main reason I was able to progress and be more open about my status and so forth is because of privacy, the privacy I got when I came here. (Troy)

Troy asserted that the privacy afforded by the clinic's location enabled him to progress across his treatment trajectory.

Despite efforts to minimize the visibility of the clinic and its patients, some men still reported experiences where their HIV identities were exposed because they were seen entering the clinic. So the clinic was presented as a space that provided for the health needs of PLWHIV whilst branding them with a stereotyped HIV identity. For Mario the label of being HIV positive was imposed with a mere '*step*' into the clinic.

So in terms of CHARES, you're afraid of persons seeing you and knowing that you're HIV positive?

Yeah, cause I feel it. If I come here, once you step in here, [the response is] "come on that's a HIV positive person". There's no question to ask, just the step. (Mario)

Some men revealed their fear of being noticed attending the clinic as this could potentially expose their HIV identity. Bird expressed: "*You don't know who you will see or who might see you. You there hoping nobody don't see you coming in this building or find out what it's for*". Later in the interview, Bird shared his experience of being labelled as being HIV positive due to being seen at the clinic:

I remember I was here, I think it was the second time I was here, and this patient was here that know me. And you know he went and say to somebody "You know I see Bird at CHARES" and the person come back and tell me... So the same person who told me say, 'what you a worry yourself for? [why are you worrying?] If them never have it, them wouldn't know say you have it.' [That person would not have known you are HIV positive unless they were also HIV positive.]

Bird's presence at the clinic was used to validate the claim that he is HIV positive, an identity he preferred to keep hidden. The suggestion that "*If them never have it, them wouldn't know say you have it*" further reinforced the imposition and confirmation of an HIV identity on the basis of being seen entering the clinic. The potential risk of exposure shifted the value of the clinic from being a safe and supportive environment to one which threatened the anonymity of the men's HIV health status and safety within their communities and social groups. In an effort to avoid the risk of exposure, some men go

through great lengths to protect their privacy, the most extreme choice being the intentional avoidance of the clinic which surrenders their access to care and potentially treatment.

Though most public health centres in Jamaica provide comprehensive services for a range of illnesses some men still described experiences of being named and shamed as being HIV positive as a result of being seen attending a particular health facility. These experiences reinforced the symbolism of the clinic in imposing socially reinforced identities and stereotypes on men, which ultimately impacted their comfort and willingness to continue accessing care. This was noted for Troy who found his attempt at accessing HIV health care at a comprehensive health clinic exposed his hidden HIV identity, unlike his experience attending CHARES. He reported:

For me, at the point, I think one of the main reasons I didn't want to go by Comprehensive [the Comprehensive Clinic] is because of the crowd and the amount of person that most time I go down by Comprehensive I see that know me. At that point in my life I was more a secretive person, a secretly HIV positive person. I wouldn't, I didn't want anyone to see me. You know down at Comprehensive you have the 'third section'. One of the main reasons I never went back I went there one day and then a lady came in and she was saying that. "Hey, where you from?" Like she was arguing with somebody that time, "the boy deh gwan like say we no know wah a gwaan with him". Because once you sit down at that part everybody know what wrong with you... I was like okay, oh, this is like a mark." (Troy)

The 'third section' was presented as a specialized area that readily identified persons seated in this section as being HIV positive. Thus for Troy, being required to sit in this 'third section' stripped him of the veil that protected his "*secretly HIV positive*" identity and instead imposed "*a mark*" that subjected him to the social evaluations of others. The experience of having his HIV identity publicized not only shamed Troy, but propelled him to shift to CHARES which he perceived to be a safer space.

The fear of unintentional HIV status disclosure prevented some men from accessing their care and treatment. One male shared his experience of encountering someone he knew at the hospital where the clinic is located, after which he left without maintaining his medical

appointment and his prescription for ARV medication. Two participants were noted to travel from rural parishes to attend the clinic used for the research. Both explained their choices were precautionary measures to ensure that persons within their community would not encounter them whilst attending a health facility and thus readily surmise their HIV identity. As Steve expressed, *“I never want anyone in my parish to see and know”*. It was also observed that some men endeavoured to disguise themselves and thus protect their HIV identities by wearing caps that hung low in their faces and large sunglasses. The use of such strategies to prevent the exposure of men’s HIV identities were important steps taken by men to ensure their continued access to their care and treatment in a space that could name and shame the men on the basis of their HIV status.

8.4.3 The clinic as a symbol of men’s sexuality

Some health centres were also presented as a symbol of men’s sexuality given the continued belief that HIV infection in men is acquired through same-sex relationships. This assumption created a binary identity for men as being HIV infected and thus MSM. Both identities attract significant antagonism within the Jamaican cultural context, thus engendering a sense of intensified ostracism for HIV positive MSM. The awareness of these social antagonisms forced some men to seek services from clinics perceived to be gender and sexuality neutral. For example, Trevor explicitly indicated avoiding a clinic given *“it attracts some undesirables”*. These ‘undesirables’ referred to MSM who were perceived to be the main clientele of the clinic. The name of the clinic has historically become synonymous with the HIV infected MSM community, where accessing its services implied that men were both HIV infected and gay. As a result, there was a recognized stereotype attached to this particular clinic that forced some men to circumvent it in an effort to protect their HIV identities and avoid the inherited stigma of an MSM identity. The following excerpts exemplified the stereotyping of the clinic and the resulting avoidance to prevent being labelled as an MSM.

I think the h-o-m-o-s [spells word] are very much at [that clinic] and they are daring with it and it annoys you when you see it. No one really wants to know, keep it to yourself. I'm not gay. (Trevor)

You have some guys down there because they know that it is a place for [MSM] they are not afraid; they are not afraid to tell their status. There are many of us who say be what you want to be, no problem but you don't throw it in the face of others who don't usually have such a practice. (Trevor)

And the only thing that come to mind about HIV was JASL and I didn't really want to associate myself with it; but I didn't know about all these different places that was offering the same service, so I just shy away from it. (Ritchie)

The symbolism of the clinic as a “*h-o-m-o-s*” domain was noted to influence men's decision to access its health services. This intentional avoidance existed for both heterosexual men and men who identify as gay or MSM, as illustrated by Trevor and Ritchie respectively. For Ritchie, the need to avoid this clinic in an effort to protect his sexual identity resulted in a delay in being tested and linked to requisite care and treatment earlier in his disease progression. This behaviour shows how men's access to health services can be impacted by their fear of MSM stigma. It also shows how barriers to men's health access can exist at both the institutional (clinic) and wider societal levels.

8.4.4 Partners versus combaters: Delineating care on the premise of gender and sexual identities

The clinic was also identified as a barrier to some men accessing their care and treatment. This was particularly noted for MSM who felt they were stigmatized and discriminated due to their sexual identity. Dan shared an experience with a staff member of the clinic which he perceived as blatant discrimination given his known MSM identity:

Now there has been complaints that this lady and this particular clinic has a problem with MSM people, people who they know to be MSM and people who they know to be very active in MSM advocacy and also HIV

advocacy. They honestly, they are not sensitive, and they do not see us as partners but see us as combaters, as people to be squashed as nuances.

Dan's reference to the clinic's perception of MSM as combaters and nuances exposed a perception of MSM as a gradation of masculinity that defies traditional hegemonic norms of a preferred social identity. This perception supported the social hierarchy of masculine identities, where heterosexual men were ranked closer to the hegemonic ideal, whilst MSM were perceived to be deviations of the social norm. Enforcing these social norms within the clinic setting created barriers where some men are treated with greater sensitivity, compassion and empathy, whilst others face barriers to accessing their care and treatment. The outcome is a production of health inequalities that are akin to the social disadvantages these men experience outside the walls of the clinic.

Whitey indicated that the experience of stigma within the clinic also exposed the sexual identities of MSM, which heightened their vulnerability outside the clinic space. As he explained:

if you're like going to the health centre, umm you know you have some of those nurses who are bitchy and once your MSM, and you go in there they tend to talk, and you will be pointed out. Once you're pointed out basically there is gonna be problems and they are not the ones who gonna be the problem. Because I am the problem because I'm positive and I'm MSM and I have to go out there in the public. (Whitey)

Whitey's experience highlighted the bridge between the clinical and social/personal contexts of men's lives. It also showed how the clinic, as with other social institutions, becomes a representation and enforcer of general socio-cultural norms and ideologies pertaining to men's self-identities. Thus being "pointed out" in the clinic revealed the stereotype attached to MSM identities that result in the men being treated with social disdain or scorn. The clinic, therefore, reinforces the social stigma and discrimination often meted towards MSM, irrespective of the men's HIV identities that warrant them accessing the clinic's services. Additionally, the negative responses of the clinic's staff expose men's sexual identities and bring into the public an identity that is primarily kept secret. This

threatens men's well-being in the clinic space and other social environments, such as men's residential communities, which could further subject men to becoming doubly marginalized by their discovered HIV positive and MSM identities. This risk was aptly captured by Dan's experience with the adherence counsellor:

the way she did everything out in the open, it makes you uncomfortable. You don't do those kind of things in the open you should have privacy. Questions on your sexuality and all those stuff, you don't ask those questions, especially given our environment, where you have 2 or 3 other clients who you don't even know sitting in the same room because those persons could arrange to get you killed, or go out into the community and talk. Your confidentiality and privacy and your life is very important. And also for you to develop a relationship with your medical provider you should be able to be comfortable. You should have privacy, the ability to speak openly...

This risk of exposure forced some men to not disclose their sexuality when engaging with their doctors as explained by Ritchie:

I'm talking about my sexuality... is not any and anybody you want to tell your business...these doctors I don't tell certain things, so I just say, most of it I just hide from him...

The clinic was portrayed to have inverted values: as a safe space for addressing HIV-related health concerns, and as an unsafe space that upheld social values pertaining to contra-hegemonic Jamaican masculine ideals. As a result, some men were forced to carefully navigate their representations of self within the clinic space to ensure an avoidance of MSM stigma that could hinder their access to optimal care. Men's protection of their MSM identity within the clinic space can negatively affect their treatment plans or information shared by health practitioners.

The experiences of Ritchie, Whitey and Dan underscored the hierarchy of masculine identities that was seen to delineate between HIV positive MSM and heterosexual men. This hierarchy was further evidenced in the disparity in the quality of care and expressions of empathy received by varying categories of men. Dan proposed a third stratum in

delineating the social identities that determined the quality of care received by patients. In addition to HIV positive MSM and HIV positive heterosexual men he proposed the inclusion of HIV infected women, where women were deemed to be the most privileged in accessing optimal care and treatment. Dan further explained:

you know that women could trace off people on the street and get away with it so when they are offended at the clinic or they are offended anywhere, they could just let that person know. A man can't do that, and if you do that you're accused of being less than masculine... What kinda man does that? Either you are ghetto or trashy. Women, any woman can fight back immediately; I've seen it... Men can't do that right away. Our only way to do it is it has to be house coached, or couched in either you lash out or you make a comment but it can't be sustained, it can't be for long and you certainly can't be too violent. Because its either you are MSM, you come off as either being too feminine or just too quarrelsome or too whatever. That has been a challenge because it means that when I go to the clinic for instance, the people who are shouted at are men. Honestly. Like somehow they feel like they have to bark at us guys. But we can't respond in kind you see. It's just so, it different. We have a different expectation you know umm, there is a different expectation of us...

The approach that I've seen that men use is that we have to go in a very... we can't go in there rambunctious and all of that stuff, we have to go in there like gentlemen. Literally, like gentlemen... Because the guys that are considered to be trouble makers, they consider gay guys to be trouble makers for some reason. Some reason we are supposed to be trouble makers... (Dan)

Dan perceived that women were more privileged in their access to the clinic's health services, and had greater freedom to demand respect within the clinic's space. Men however were restricted by the social evaluations of masculine behaviour, which could potentially label them as MSM, feminine or trouble makers. Being labelled as trouble makers could subject men to social antagonisms, further affecting their access to health services. Thus men, irrespective of their sexual identity, are forced to regard the social norms pertaining to appropriate masculine behaviours in varied social settings, including the clinic space. As noted before, the hegemonic masculine ideal is reinforced as a

benchmark or guideline for appropriate masculine behaviours that can impact how well men are able to navigate their clinic space to ensure their continued access to treatment and care.

8.4.5 The clinic as a woman's domain

The clinic was described as a woman's domain that largely catered to the health needs of HIV positive women. This belief reinforced the earlier proposed hierarchy of identities that privileged women in their access to the clinic's services. According to Dan:

I've also observed that at the clinic, there are many more women there than guys umm than men. On any given day I've gone to the clinic, if there are 20 people in the room, I'm not exaggerating, if there are 20 people in the room, only 3 to 4 of them, a quarter, maybe less are guys, honestly. And I'm thinking every time I've been to the clinic and the room is just full with [women]... if it is full it would be more women. And every clinic I've been to and even at the workshop [HIV workshops], there are more women. At the pharmacy there are more women...

The over-representation of women in these clinical spaces suggested that women are more willing to seek healthcare and health information than their male counterparts. Earlier discussions regarding the hierarchy of gender and sexual identities may also point to these clinical spaces being better designed to meet the health needs of women than men.

8.5 A GENDERED APPROACH TO TREATMENT AND CARE

Gendered norms were recognized to be integral in shaping how some men managed their treatment. Traditionally gender roles were seen by some men to filter into the treatment responses of men in comparison to women. According to Paul:

Woman on a whole, them tend to more to the 'T' [more focused on details] where them health is concerned you know. When a man you know... alright say for instance, we feel a pain in a we belly, we say we a go watch it. A woman in a pain, you know say she run gone a doctor same time. So we tend to make it play out. I would a more say the woman... she take more care and interest more than the man.

Paul's perception of Jamaican men's approach to their health underscored the literature that showed men delaying seeking healthcare until they are seriously ill. This approach was seen to be a macho response that recognized men's strength and resilience. Ritchie perceived that this gendered approach to health is attributed to gender socialization, where females are taught to *"take care of themselves better than the males"*. As he added:

Males tend to depend a lot on females to do things for them: to cook for them, to wash for them, to do everything for them so when it comes down to things where they have to do things for themselves, is like them is a big ship out in the sea. (Ritchie)

Gender socialization reinforces traditional gender roles of the female being the caregiver, nurturer and homemaker, whilst the male is required to be authoritarian, breadwinner and strong head of the home. Becoming ill makes it difficult for men to maintain their traditional roles, especially where their delay in seeking healthcare results in an advance of the ill-health that warrants dependence on others for care and support.

8.5.1 Intersecting lines: gender, sexuality and health

Gendered norms surrounding healthcare were not relegated to the binary divide between males and females but instead extended to other notions of identity such as the masculine MSM and feminine MSM divide introduced by some participants. This gendered layer of sexuality resulted in a mirrored gendered approach to health for masculine MSM and feminine MSM. Thus masculine MSM were described as reflecting the health behavioural responses of the typical male, thereby fitting into a mould of social expectations. Similarly, feminine MSM portrayed general health behaviours akin to women. According to Ritchie:

the guys who are more feminine do better on medication than the ones who are more masculine, and the masculine ones do not come out for medications. They don't even come and get themselves tested. They shy away. Even if them get tested and them know them status, them shy away from coming to clinic. Don't even think them come.

When asked why this is the case he explained:

Because them feel say them straight. And is only gay man contract HIV, because that was a might in the earlier part, and it is still going on to, it no gone. It no gone. The straight, the one them that act masculine who come a clinic, you cannot tell them that them gay, you cannot tell them that them bisexual. Them 'straight', you understand and them cannot make them friend know that them HIV positive and them on medication cause the first thing that going to come out a the friend mouth, 'so how you catch it?' you understand so them have to a live in a the private. You understand me so it comes back, it tie in to your adherence with medication. The friend them that they have around them, is the hardcore male them so they don't want them know see them on ARV medication. And the way them was brought up to they don't how to take care of themselves. (Ritchie)

At the backdrop of MSM identity is a consciousness of the social constraints surrounding masculinity and sexuality. Masculine MSM who are HIV infected appear to struggle with these social ideals and the potential repercussions of being exposed as being counter the norm. Thus some present themselves as being 'straight' and in doing this "*act masculine*" and reject any suggestions of being gay or bisexual. This reinforces the process of 'fitting-in' in re-constructing self to ensure safety and social acceptance.

Despite the clear parallels in the gendered approach for both masculine and feminine MSM, there were some MSM who moved beyond their gendered expectations to take ownership of their health; further reinforcing the complexity of men's identities in light of their health. In doing this, men prioritized their health identity that countered the overt representation of being HIV positive. Troy, in recognizing the importance of his ARV medication, was motivated to adhere to his treatment and "*to be strong and healthy and fit to run and fight and do all the energetic stuff*". Troy's emphasis on his strength, health, fitness and energy reinforced the value many of the men placed on the restoration of a healthy identity that helped them to protect and move beyond their HIV identity.

8.5.2 Challenging gendered norms

Some men found it necessary to navigate or challenge existing socio-cultural norms on masculinity and sexuality in their responses to their HIV treatment. These men acknowledge the status attached to the representation of the hegemonic ideal, which some men perceived they could not maintain in the context of their HIV infection. For instance, some men indicated refraining from the hyper-sexual mandate as they were now conscious of the risks involved in having unprotected sex with multiple partners. A few men also opted to abstain from having sex as a means of protecting self and others. This shift towards a social consciousness therefore redefined men's ability to represent the hypersexual masculine ideal.

Men also challenged the socially constructed gendered approach to health whereby males are often portrayed and expected to be complacent in addressing their ill-health. For instance, Paul opted to prioritize his health which he deemed was comparable to the traditionally perceived female approach to their health:

Well in this case now, me can talk say me don't play with my state [being HIV positive] none-at-all [an absolute expression of not doing something under any condition]. If the clock strike nine, 9 o'clock me take it [ARVs]. You done know you go over like 5 or 10 minutes, but me no miss it because me know say if you miss it, it give the virus a time to start counteract the medication. Build up a, what you call it, immunity to the medication so you can't even make a day slip. If a that case now, me and her a run for par and par [in tandem to each other] in that [treatment approach] cause me no play that way. (Paul)

The significance and implications of being HIV positive forced men to redefine their treatment approaches outside the gendered norms that prescribe distinct male and female health behaviours. Paul, in acknowledging these norms, identified that his shift in his health behaviours positioned him as “*run[ning] for par and par*” with the socially constructed feminine approach to health. The choice to move beyond gender binaries becomes a crucial step for some men to pursue their optimal health, especially where they recognize the risks of defaulting in their treatment.

The influence of social constructions of masculinity in the context of men's health was still evidenced for health conditions perceived to be minor or self-remedied. Though Paul created the space to prioritize the management of his HIV illness, he otherwise refused to seek medical attention for "*the everyday sickness*". As he shared:

...me no go doctor man. All when me lie down and a dead me no go doctor man. Never a go and even now, even now me don't go doctor if me feel, like me start have diarrhoea or me feel a pain, me don't go doctor. But me know say my medication [ARVs] me don't miss it... When it come on to the everyday sickness, you mad, me no go a doctor; [I'm] not going. Me never find myself a doctor yet unless a something that me know say me cannot control; like chicken pox, you have to go doctor. But for a little flu or little something, me no go doctor, me a go ride it out or take a little home remedy. (Paul)

Paul's distinction between "*the everyday sickness*" and "*something that me know say me cannot control*" presented a delineation between perceived self-remedied conditions and more serious illnesses, which underscored some men's initial responses to becoming symptomatic that mimicked everyday sicknesses such as the common cold. The first response to self-treat before seeking medical care, even with the knowledge and acceptance of being HIV positive, showed the extended influence of masculine ideals. Thus Paul's health choices, outside his HIV infection, reflected the need to prove strength, resilience and independence. The continued influence of gendered norms outside the context of an HIV infection was further evidenced when Paul explained: "*it's just a man thing. It not a fear of anything, it's just a man thing...man have to **macho** [participant emphasis] ...You have to be the man. Is like [being] an Alpha*".

8.6 THE BALANCE OF TWO WORLDS: THE SOCIAL AND THE CLINICAL

The prescribed medical response to treating men's HIV illnesses was found at times to conflict with men's social/recreational lives, resulting in them deciphering the best way to balance both worlds. This often entailed a trade between men's commitments to their treatment conditions and their desire to live a normal life. The need to balance both their social and clinical contexts required men to navigate safe space in which to engage their

treatment. Though the clinic was generally perceived as a safe space, men were required to continue their treatment in their social contexts. This proved particularly challenging for those men who refrained from disclosing their HIV status.

8.6.1 Managing the clinical to incorporate the recreational

Some men reported being challenged by the timing or conditions of taking their medication each day, as this required them to alter important routines in their daily lives. For example, men reported being restricted by the conditions of non-consumption of alcohol whilst taking their ARVs. This condition required men to either alter their social habits or modify their treatment patterns to accommodate these social habits. This was noted for Vincent who confessed modifying his prescribed treatment regimen to accommodate his habitual drinking. Despite being advised by his doctor to quit smoking and drinking, Vincent shared his own approach to managing his medication whilst maintaining his drinking habits:

So when I drink in the night, I go in 10 o'clock, I don't take the pill then. I take one hour sleep and me jump and take my pill because a rum me drink so me nah take the rum and medication. (Vincent)

The timing around treatment doses also proved problematic for some men. As a result, some men opted to modify their treatment regimen to balance the demands of both their clinical and social contexts. Some men were forced to alter their treatment regimen to prevent the discovery of their HIV illness which would make them less socially accepted by their peers. Whitey confessed opting to not take his medication when he was partying with his friends as he perceived this could risk accidental exposure of his HIV identity. As he shared:

it's not a habit of me missing my medication but if I do go out for a party I probably miss my medication because I'm at a party. So it's gonna look obvious for me taking out my bag and medication and putting it my mouth. It would be scary and so forth so basically I kinda missed it out. (Whitey)

Similarly, Eric opted to take all his medication in the morning to ensure his medication routine did not conflict with his recreational activities. This was primarily due to the desire

to lead a normal life without the fear of risking disclosure of his HIV status. As he explained:

Okay you see if I know that I'm going to take it for a year, then I don't care what my friends want to say, I'm not going out, I'm not going to drink. You see because it's something that I'm going to have to live with, not that I cannot tell them but the fact that I don't want to tell them, me nuh want fi haffi a explain [I don't want to have to be explaining] myself to nobody. So if I knew that it's not going to hurt me if I take it in the day, then I can take it in the day because it's not that I don't go out every night, I work on the weekends, I'm not a heavy drinker, I don't smoke. So it's not really making a negative impact but I just don't want to explain myself to anybody. (Eric)

Whitey, Eric and Vincent exemplify how some men challenge the rigid biomedical messages to 'take the medication on time, all the time'. Instead they each modified their treatment approaches to suit their unique circumstances. This showed the men's attempt to reassert themselves and presented their efforts to eliminate the divisive life that was created by managing a strict medical regimen outside the context of their everyday lives.

8.6.2 Navigating safe spaces for treatment: the public versus private space

Maintaining HIV as a hidden identity required men to identify safe spaces that allowed them to take their medication without inviting the curiosity or interrogation of others who may not be accepting of their HIV illness. Thus many of the men made a conscious effort to either disguise their medication or take it in hiding to protect their identity. Ritchie was forced to create a safe space at his workplace given he was required to take dosages of his medication whilst at work:

When I go to work in the morning and I eat, I have to find way, hide out go in the bathroom or somewhere private cause it was so much medication and I had a pill container, I just put them in there so I go to work now I just go somewhere private and take them. (Ritchie)

The notion of safety primarily surrounded men's HIV identities, and extended to associated assumptions regarding their sexuality and gender that needed to be either avoided or

protected. Dan, who lived in student accommodation, found it particularly difficult to navigate his treatment around his peers. This space was described as “*always [having] an invasion, [and thus] you have no privacy*”. The continuous activity characteristic of student accommodations required Dan to be selective of the timing of his medication to prevent accidental disclosure of his HIV status. Thus he often did not follow the prescribed schedule for taking his medication, as he was forced to take them when his flatmates were asleep. This need for precaution was further compounded by his MSM identity which he was forced to keep secret due to fear of negative repercussions. This reinforces the quandary men who identify as HIV positive MSM often experience, as they may be subjected to heightened levels of discrimination. Acknowledging this risk, Dan employed strategies that allowed him to maintain his treatment, though not on schedule, whilst protecting his HIV positive MSM identity. This is presented in the following dialogue:

How do manage your medication while living on hall and having close friends who are homophobic? How do you manage that with your medication?

Oh my gosh. Firstly, hide my meds. I put it in a very discreet spot. I can't even jiggle it as much when I take it... I take my meds late at night, when I believe people are sleeping or I don't take [them] in front of other people
(Dan)

The need to alter timing of ARV medications to protect men's identities and safety holds potential implications for the efficacy of their treatment and thus health outcomes. Though the generic health message mandates men taking their medication on time each day, it is evident that the social realities for some men become hindrances to this process. Men are forced to manage their ARV treatment within particular social spaces that could potentially threaten their presented masculine identities or protected HIV and/or MSM identities. By modifying particular doses men achieve what could be classified as the 'best of two worlds' where they maintain their commitment to their daily regimen whilst ensuring appropriate representations of their social selves.

The challenge of finding a safe space in which to take the medication propels men to discontinue their ARV treatment. This reflects a trade-off between the protection of a social identity that is accepted by others or the risk of accidental disclosure in adhering to a prescribed treatment regimen. Mario confessed that his approach to his ARV treatment was initially inconsistent due to the fear of his HIV status being discovered his partner. This inconsistent pattern eventually led into his discontinuation of his ARV treatment and access to care. According to Mario:

I was actually hiding it from the guy I was talking to [dating]... I use to tell him because I did the surgery and the doctor gave me these pills to take. He couldn't really read them so he didn't know what was in the bottles. I tried to hide it, I didn't want nobody to see me taking the pills, like on the road everybody just use to watch everything. I use to take it on and off and then I just stopped. (Mario)

Mario's attempt to shift his treatment space from home to "*the road*" also proved problematic as "*everybody just use to watch*". This reinforced the dilemma of the public versus private space in threatening the safety and well-being of HIV positive men, especially as it concerns their treatment. Though an individual's home is often characterized as a private and thus safe space, Mario positioned "*the road*" as a safer alternative given the need to protect his HIV identity. There is a recognized need for men to be consistently vigilant of others who could potentially appraise their social worth on the premise of their represented social identities. Accidental discovery of a hidden HIV identity could subject men to stigma, discrimination or other prejudicial attitudes that could affect the general well-being of men. As a result, men are constantly deliberating when, where and how they should take their medication. This revealed men's hyper-sensitivity to the socio-cultural norms and ideologies that are defined and enforced within their social, personal and clinical contexts. It also exposes the inherent power embedded within these spaces and the role of their occupants in determining the health choices and outcomes of HIV positive Jamaican men.

8.7 SUMMARY

This chapter examined the treatment experiences of HIV positive men in clinical and social contexts. It was found that the clinic plays a pivotal role in determining when and how HIV positive men access their treatment. This introduces a system of control that positions the clinic as central to men's treatment approaches and extended care. Rather than providing a space for men's input in their treatment design, men are provided with the generic message to take their ARV medication on time each day. This message produced a mould of the ideal compliant patient, to which some men ascribed. However, some men were subversive, challenging the clinic's system of control by modifying their treatment regimen to suit their personal, social and professional circumstances. In some instances, men re-defined their treatment to extend beyond their ARV medication to ensure a more holistic approach to their health. The absence of dialogue between the physician and patient reflected both a top-down authoritative process, as well as men's fear of being judged or punished if their doctors learned of their modified treatment approaches.

The clinic, as with other social institutions, acted as an enforcer of socio-cultural rules that assess men's social identities, and subsequently impact men's health outcomes. As a result, some men were named and shamed as being HIV positive by default of attending the clinic, treated as combaters rather than partners in the fight against HIV, or experienced intensified stigma due to the linkage between men's HIV status and assumed (or actual) MSM identities. The imposition of social norms creates barriers to men's access to treatment, and their adherence and retention in care. Some men opted to challenge or circumvent these social barriers in an effort to prioritize their health. At times, the strategies adopted by men aimed to balance the demands of both their social and clinical contexts. These strategies reinforced the need for improved dialogue between men and their doctors, to ensure the chosen treatment plan is suitable for men's personal and social realities.

Chapter 9 DISCUSSION

9.1 INTRODUCTION

This chapter provides a synthesis of the main findings in response to the research questions used to guide the study. These findings are discussed against the backdrop of existing literature with the aim of identifying areas in which the study's findings confirm, extend or challenge the existing body of knowledge. New insights emerging from the study are highlighted, and limitations identified. The chapter outlines the study's contributions to the methodological and theoretical contributions to the use of intersectionality in studying men's health. Recommendations for HIV policy, programme and practice, as well as avenues for future research, are also presented.

9.2 OVERVIEW OF THE STUDY AND RESEARCH QUESTIONS

This study adopted an intersectionality-informed qualitative design to understand the ARV treatment experiences and adherence outcomes of HIV positive Jamaican men, and to examine how their treatment experiences and adherence outcomes are influenced by intersections of their gender, sexuality and HIV health status. The main research question was:

“How do the social identities of HIV positive Jamaican men intersect to influence their ARV treatment experiences and adherence outcomes?”

The four sub-research questions were:

1. How do HIV positive Jamaican men perceive their ARV treatment and define their ARV treatment adherence process?
2. How do Jamaican men on ARV treatment self-identify against the backdrop of dominant discourses surrounding gender, sexuality and men's health status?
3. What are the social structures and processes that influence Jamaican men's identities and choices regarding their ARV treatment?

4. How might a better understanding of the ARV treatment experiences and adherence outcomes of HIV positive men inform HIV policy and program development in Jamaica?

One of the significant contributions of this study is its use of an intersectionality-informed approach that sought to address the limitations of intersectionality as a methodology, whilst providing an example of its application as a research design. Intersectionality theory was chosen to guide the design and analysis of the study given its recognized value in examining the multidimensional, complex and interdependent nature of HIV-positive Jamaican men's identities, which could subsequently impact their health choices and outcomes. The use of an intersectionality-informed framework enabled the researcher to shift from the additive approach traditionally used in understanding public health issues (Bowleg, 2012), as well as adopt a micro-macro level analysis (Bowleg, 2008; Winker & Degele, 2011). This allowed an examination of how fluid, interrelated and mutually constituted dimensions of men's identities shape their treatment experiences at the micro level, and further interlocked with systems of oppression, inequality and privilege at the macro structural level. Winker and Degele's (2011) multi-level framework was adapted for the study as it provided a useful stepwise process to guide data analysis, taking into account the relationship between men's social identities, social norms, values and ideologies, and social structural processes. The study also drew on intersectionality research guidelines provided by Bowleg (2008) and Cuadraz and Uttal (1999), as these authors identified the importance of understanding participants' experiences of their HIV diagnosis and treatment process before examining how these are shaped by the interplay of men's complex identities.

This study makes an original contribution to understanding a population and issue that remains integral in effectively addressing the HIV epidemic in Jamaica. Though a growing body of literature exists on men's health in Jamaica, little attention has been given to understanding the health of HIV positive Jamaican men in general and none focuses on the treatment experiences and adherence outcomes of Jamaican men. The study provides an in-

depth understanding of the key turning points experienced by HIV positive Jamaican men in their treatment trajectory, which comprised HIV diagnosis, acceptance, adjustment, treatment initiation and treatment continuation. The treatment trajectory was not linear or prescriptive, as it was largely shaped by the unique personal and social circumstances of the men, such as their pre-existing HIV knowledge and access to social support networks. The study revealed varying changes in men's emotional state, health, and outlook of life across their treatment trajectory, highlighting that for men, living with HIV is often a challenging journey. The findings chapters in this thesis charted how the participants progressed along their treatment continuums, and how their treatment experiences were shaped by the health system, clinic and personal contexts in which they were required to continue their treatment.

Men's treatment experiences and approaches were found to be defined their identity constructions which exist against the backdrop of socio-cultural norms and processes. The study demonstrated that men engaged in a continuous process of reconstructing, negotiating or navigating their social identities in response to the emergence of a stigmatized HIV identity, which men had to decipher how to incorporate in their existing sense of self. Men were faced with the constant need to consider their personal and social identities, and how this related to their HIV status and treatment journey. As a result, some men strategically manipulated their social identities to ensure they retained a sense of belonging, social acceptance, and safety, whilst minimizing potential barriers to their treatment process and thus optimal health.

The findings revealed a number of symbolic representations that shaped how men perceived themselves and approached their treatment process. These norms, values and ideologies reflected some of the prevailing socio-cultural and historical norms surrounding gender, Jamaican masculinity, sexuality, HIV/AIDS and ARV treatment. Men were forced to contend with these norms, choosing to accept, challenge or navigate them as they determined the best approach to living with and treating their HIV infection. Some key norms related to the delineation between masculine and feminine roles, which affected how

some men behaved, perceived the clinic and approached their health. Another pertained to the shifting perception of HIV as a death sentence and the view that ARVs were like vitamins that ensured good health.

The research showed that men's treatment experiences and adherence outcomes were further impacted by social structural processes and social institutions that often enforce socio-cultural norms that define men's identities. HIV and MSM stigma were key social processes that affected how men perceived themselves, were treated by others and, consequently, how they managed living with HIV. Gender socialization was also found to be a strong determinant of men's understanding and enactment of prescribed gender roles, which were found to extend to their health seeking behaviours. A number of social institutions affected how men in this study engaged their treatment. The clinic was arguably the most central in this process, given it was seen as pivotal to men's diagnosis, determination of treatment regimen, timing for treatment initiation and further linkage with follow-up care and support. Outside the medical context, men were further affected by their memberships within their family, peer groups and communities.

Overall, the findings of the study evidenced an interplay between men's identities, prevailing socio-cultural norms and social structural processes in shaping HIV positive men's treatment experiences and adherence outcomes in Jamaica. As noted in Figure 19 (p. 152), the non-linear nature of men's treatment trajectory is determined by these intersecting facets of men's lives. Thus men's experiences are not solely determined by their personal responses to becoming HIV infected. Rather, they are shaped by the social constructions of their complex identities, which may privilege or stereotype men on the basis of their HIV status, gender and/or sexuality.

9.3 DISCUSSION OF MAIN FINDINGS

The findings of this study corresponded with much of the literature reviewed in Chapter Three. There are noted areas where the findings make a unique contribution to the existing body of knowledge, particularly as it pertains to the focus on HIV positive men in Jamaica. The study further extended some of the earlier findings of international literature.

9.3.1 The treatment trajectory of HIV positive Jamaican men

In the study, men's experiences showed that their treatment trajectories are non-linear, being impacted by a range of factors including their identity constructions, the imposition of related socio-cultural norms, and social structural processes. As men's personal identities and response to socio-cultural norms and processes varied, so too did their progression along their treatment trajectory. These differences highlight the heterogeneity of men, where despite the common exposure to certain social and structural processes, institutions and norms, the specific impact on the personal lives and treatment experiences of the men will vary. In this study, the treatment trajectory for HIV positive men comprised five distinct phases: HIV diagnosis, acceptance, adjustment, treatment initiation, and treatment continuation. Each of these phases were identified as turning or decision points that acted as a precursor for the subsequent phase. Though Vrijens (2011) theorized that the treatment adherence process commences with treatment initiation, this study found that it was at the point of being diagnosed with HIV that men had to contemplate the realities of living with HIV, which included lifelong treatment.

Only a few men actively solicited an HIV test, whether as a routine test or because they learnt of a current or previous sexual partner testing positive for HIV. Other men became ill and consequently sought medical attention, and a few learnt of their HIV status by default testing done for insurance purposes and on all blood donations. The majority of the men waited until they became symptomatic before seeking medical attention. This finding concurs with other studies that reveal a pattern of men delaying in seeking healthcare (Courtenay, 2009; Galdas et al., 2005; Jarrett et al., 2007). The extent to which some men's health deteriorated before seeking medical attention, underscored national surveillance data

that shows Jamaican men generally presenting late for HIV testing and diagnosis, and a significant number of men presenting with advanced HIV at the time of diagnosis (Ministry of Health National HIV/STI Programme, 2013). Studies suggest that men's tendency to delay in seeking healthcare is partly attributed to socio-cultural factors such as gender norms and social constructions of masculinity (Addis & Mahalik, 2003; Jarrett et al., 2007; Tyler & Williams, 2014). These conclusions proved relevant to this study; however, it was recognized that participants' delay in seeking healthcare was also due to an absence of perceived risk of contracting HIV, as well as men perceiving their symptoms were due to minor, self-remedied illnesses.

Some participants delineated themselves from men they deemed more likely to contract HIV. These men were described as being promiscuous, hypersexual or not in a committed relationship, traits which were found to be characteristic of Jamaican hegemonic masculinity (Chevannes, 2001; Hope, 2010; Lewis, 2003b). Though these men perceived themselves to not be at risk, their sexual behaviours were reflective of the masculine identities from which they delineated themselves. This disjoint suggests that men can be aware of risky practices, yet engage in such behaviours because they deem themselves to be different from a typology of male more likely to contract HIV, a finding that has been shared in other studies (Dowson, Kober, Perry, Fisher, & Richardson, 2012).

Some men also perceived that their general (though inconsistent) tendency to engage in protected sex was sufficient to prevent the likelihood of contracting HIV the few times condom usage was not maintained. The pattern of inconsistent condom usage has been noted in earlier studies involving Jamaican men (National HIV/STD Control Programme & UNAIDS, 2012; Norman & Uche, 2002), and is reflected in other areas of health protection and prevention. This study also highlighted the challenge some MSM experienced of negotiating condom use in long-term partnerships, due to its symbolism of a lack of trust or speculated unfaithfulness. This finding is consistent with studies that identify condoms being perceived as a barrier in marriages or steady partnerships (Anglewicz & Clark, 2013; J.P. Figueroa, 2014).

A few men reported being diagnosed with other conditions after initially visiting physicians with symptoms that were later associated with their HIV infection. These experiences revealed missed opportunities for earlier HIV testing and potentially earlier diagnosis of these men. Researchers suggest that these missed opportunities are indicative of physicians' failure to provide HIV testing, especially to persons identified as having a higher risk of contracting HIV (Helleberg et al., 2012). Earlier testing and diagnosis within primary and secondary care settings have been found to result in an earlier linkage to treatment and care (Burns et al., 2008; Sudarshi et al., 2008), which would prove beneficial in enhancing the health and well-being of men.

This study concurred that learning of a positive HIV diagnosis is often a tumultuous period filled with a range of emotions such as shock, anger, denial, fear and depression (Hult et al., 2009; Leyva-Moral et al., 2015; Roth & Nelson, 1997; Stevens & Doerr, 1997). These emotional responses have been shown to be similar for other chronic illnesses such as cancer, hypertension or an acquired disability (Charmaz, 1995; Kvigne et al., 2014). The extent of emotional challenges, upon learning of an HIV diagnosis, led some men to experience suicidal ideations. As found in other studies, these men grappled with the medical reality of a long-term and devastating chronic illness, and with the possible symbolized death of a physical and social self that rendered men to be incompatible with society's normative system (M. Anderson et al., 2010). HIV remains largely stigmatized in Jamaica (R. Carr, 2002; J.P. Figueroa, 2014), thus contributing to the emotional trauma and devastation experienced by many men. White and Carr (2005) reported that HIV-related stigma in Jamaica often propels men to become suicidal, due to the fear of being isolated or socially ostracized. Thus the acknowledgement of the stigma attached to being HIV positive impacts how men incorporate their HIV status as a defining aspect of their personal and social identities.

Men in the study also experienced a sense of loss of future aspirations (Leyva-Moral et al., 2015), including those pertaining to their socially defined roles such as becoming a husband or a father. Thus a positive HIV diagnosis resulted in biographical disruptions in men's

lives, disrupting their daily lifestyles (Bury, 1982) and challenging their socially constructed, yet personally embraced masculine identities (Charmaz, 1994). Men's response to their HIV diagnosis was, therefore, compounded by the need for lifelong treatment, the outcome of changes in their daily lifestyles and future aspirations, and the challenges of HIV being a stigmatized illness that would re-shape how men are perceived and treated by others.

Not all men reacted so adversely to their HIV positive diagnosis. As found in a study by Anderson et al. (2010), MSM were generally more resigned to their diagnosis from the outset. MSM participants in this study revealed that this was due to their association of their HIV risk with their sexual identity. This suggested that some MSM are aware of the risks associated with unprotected anal sex, despite MSM participants attributing HIV risk to their sexual identities rather than sexual behaviours.

The period in which men in this study were diagnosed with HIV proved important in determining their outlook of the illness and implications for their self-perceptions. Men diagnosed during the early years of the epidemic in Jamaica, referred to its symbolism as a death sentence. This was comparable to other men who were aware of the role and benefits of ARV medication upon their diagnosis. Thus the increased availability and subsidization of the costs of ARV medication created a reconstruction of an HIV diagnosis from a death sentence to a chronic illness, a finding that is echoed in other studies (Baumgartner & David, 2009; Kremer, Ironson, & Kaplan, 2009). The latter offered a more positive outlook for the future which allowed some men the opportunity to more positively and intentionally reconstruct their personal and social identities, as well as personal pursuits. For many, ARV symbolized a restoration or reconstruction of a healthy identity that afforded them a sense of hope for the future (Leyva-Moral et al., 2015).

The findings showed that acceptance of an HIV positive status was a critical step in men's progression to initiating ARV treatment. Similarly, Sikweyiya et al. (2014) identified acceptance of a positive diagnosis as a key turning point in men's experience with their

HIV illness. Once men accepted their HIV status they moved on to determine the best approach to *living* with HIV. Those men who effectively transitioned from their HIV diagnosis to treatment initiation reinforced the view that men's acceptance of their HIV status reflects ownership of their illness, thereby allowing them to regain control of their lives and determine the next steps to ensure their well-being (Tsarenko & Polosky, 2011). As with other studies, men's struggle to accept their HIV positive diagnosis was found to result in a protracted time span between testing and linkage to care and treatment initiation (Samet et al., 1998). Delay between a known HIV diagnosis and treatment initiation poses a public health concern given the missed opportunities to ensure viral suppression and minimize the risk of HIV transmission (WHO, 2013). This delay also has implications for the long-term health outcomes of men, as they fail to access the benefits of early treatment initiation (Sandfort, Knox, Collier, Lane, & Reddy, 2015).

In some cases, the extended periods of denial, despite the same outcome from repeated HIV tests, brings into question not only issues of men's fear of their test results and society's likely negative reaction, but also the occurrence and quality of pre- and post-test counselling which should ideally enhance men's testing experiences. Quality voluntary counselling and testing (VCT) services should ideally enable those who obtained a positive HIV test result to better accept their HIV status (UNAIDS, 2000), assist them in overcoming the trauma, and diffuse myths and fears associated with a positive HIV diagnosis (Meursing & Sibindi, 2000; Nyanzi-Wakholi et al., 2009; Richter, van Rooyen, Solomon, Griesel, & Durrheim, 2001). The WHO and UNAIDS emphasize the importance of pre- and post-test counselling irrespective of the test outcomes, as it has been identified as playing a pivotal role in HIV/AIDS prevention and support (WHO & UNAIDS, 2007).

This study demonstrated that the onset of visible symptoms of an HIV infection is an important trigger that propelled men, who initially denied their HIV test results, to consequently accept their repeated HIV positive diagnosis. It was not until these men became severely ill or symptomatic that they considered the accuracy of their initial HIV test results. Thus, being symptomatic was seen to provide the evidence of an HIV identity,

thereby validating initial test results. Symptoms included rashes, noticeable weight loss, and fainting spells, the visibility of which exposed men's sick identity and subjected them to the curiosity, speculation or judgement of others. Men's tendency to wait until they were symptomatic before accepting their HIV status was noted in other studies conducted globally (M. Anderson et al., 2010; Dowson et al., 2012; Nyanzi-Wakholi et al., 2009).

Acceptance was also hinged on men becoming more informed about HIV and the role of ARV treatment, which men reported was carried out by doctors or nurses rather than counsellors or social workers. This information helped men to shift their understanding of HIV as a death sentence to a chronic and thus liveable condition, with the aid of ARV treatment. Understanding the role and efficacy of ARV medication reignited a sense of hope and rekindling of future dreams and aspirations, and was thus seen as a turning point for some of the men, a finding that concurred with other research (Baumgartner & David, 2009). Receiving social acceptance and support from family members and peers proved essential in helping men transition into their self-acceptance (Baumgartner & David, 2009) and subsequent treatment initiation and retention (Alfonso, Geller, Bermbach, Drummond, & Montaner, 2006; Malcolm, Ng, Rosen, & Stone, 2003). Garnering social acceptance was not necessary for those men who kept their HIV illness hidden in an effort to avoid social stigma and reproach which could potentially act as barriers to their treatment process. HIV disclosure that resulted in men experiencing social reproach and HIV stigma was found to have both an indirect and direct impact on men's treatment process. There were some reports of loss of social stature, where men were mocked, scorned or ostracized due to their HIV status. This made requirements of travelling to the clinic for appointments difficult and eroded some family members' willingness to offer support.

Adjustment to living with HIV was found to be an ongoing process throughout treatment initiation and continuation. Men are required to adjust to varying changes that can occur along their treatment continuum, whether in the personal, social or health-specific dimensions of their lives. Within the literature, adjustment to living with HIV is likened to coming to terms with a chronic illness which involves reckoning with the transition from a

healthy to chronically ill identity (Baumgartner & David, 2009). Though this transition could relate mainly to the lifelong dependence on medication and care, in this study men's altered perception of their HIV infection as a chronic illness made it comparable to less stigmatized conditions such as diabetes and hypertension, for which some men were already being treated. The comparability of HIV to other chronic illnesses helped men to reconstruct their HIV illness as a treatable and thus liveable condition, despite the stigma generally associated with being HIV infected in Jamaica. Normalizing HIV as a chronic illness (Maliski et al., 2008) has been partly enabled by the role of ARV medication which has, in recent years, transformed HIV from a traditionally perceived death sentence to a treatable illness (Mattes, 2014). However, HIV is yet to be fully normalized in many societies, including Jamaica, because of its stigma as a sexually transmitted disease (Campbell & Cornish, 2010). Treatment adherence messages help to reinforce the value of ARV treatment in improving men's physical health and well-being, where they are encouraged to maintain their treatment regimen in order to live a relatively normal life (Mattes, 2014).

The study found that adjustment also involved men incorporating HIV as a part of their self-identity, which takes into consideration the perceptions and evaluations of others (Roth & Nelson, 1997). The adjustment process was eased when men acquired a reinforced sense of value in their social roles as father, partner or husband, which existed prior to being diagnosed with HIV. Here men garnered a determination to live because they identified their roles and responsibilities to either their spouses or children. As such, these men were able to reconstruct certain aspects of their masculine identities (father-figure, head of household, lover) that existed prior to contracting HIV, despite the changes that occurred as a result of their HIV infection. This finding concurs with other studies that indicate men being able to reconstruct their personal identities upon resumption of their regular social, recreational, relational and familial activities (Mattes, 2014).

Adjustment also involved some men shifting their HIV illness from the foreground to background of their personal identities over time. Whereas the HIV treatment regimen

became part of the daily routine for these men, being HIV positive was not accepted as a definitive aspect of their sense of self. Other studies have referred to a fluctuation from illness in the foreground to wellness in the foreground where for the former, “the burden of the illness weighs heavily on a person’s life, and people are consumed with the suffering and loss experienced” (Telford, Kralik, & Koch, 2006, p. 462). The changing impact of HIV on men’s identity constructions has been described as evolutionary (Tsarenko & Polosky, 2011), suggesting that over time, the salience attached to an HIV identity will change as men learn to cope with their new illness identity and endeavour to reconstruct a sense of self outside the domains of a sick identity. In some cases, the men in this study accepted their HIV status as an aspect of their selves and saw it as an opportunity to redefine their lives and adopt a sense of personal agency in influencing the lives of others, a finding shared by others (Barroso & Powell-Cope, 2000). Participation in HIV advocacy and education became important strategies that helped some men gain a new meaning or positive transformation of their lives, a finding noted in other studies (Tsarenko & Polosky, 2011). As noted by Baumgartner and David (2009), this sense of empowerment also showed men taking control of their HIV illness.

Treatment initiation is classified as encompassing the period of receiving a prescription and taking the first dose of ARV medication (Vrijens et al., 2012). In this study, treatment initiation occurred at varying points based on men’s CD4 counts, thus positioning the clinic as central to determining when and how men initiated treatment. As noted in the situational context presented in Chapter Two, Jamaica does not maintain WHO’s most recent guidelines that recommend initiating treatment for all persons irrespective of their CD4 counts (WHO, 2015b). Despite the challenges surrounding the promotion of early treatment initiation and the recognized limitations of the Jamaican health system to support this transition (such as the lack of financial resources, technical expertise and institutional capacity), there remains the question of the lost benefit to those who are prevented from starting treatment earlier. Lost benefits of not initiating treatment earlier are perceived to relate to an earlier response to controlling the progression of the virus with the ultimate aim

of reducing viral loads to an undetectable level and improving CD4 counts (Lima et al., 2015). Initiating treatment earlier is also justified as a preventative measure as lower viral loads minimize the risk of transmission to others (Vitoria et al., 2013). Therefore, the clinic's choice to not initiate treatment at the current WHO recommended level, even if those decisions are based on the rationale of limited resources, poses health implications for infected individuals and their partners.

The important role played by the clinic was presented throughout men's treatment journey, given their reliance on their physician for HIV monitoring tests, follow-up care and prescription refills. Though the findings capture men's continued engagement with their treatment, it did not identify whether optimal adherence was achieved and maintained. This was beyond the scope of the study and presents as an area for future research. Instead, findings showed that men adopted varying treatment approaches, which at times modified their physician's recommendations, to accommodate personal circumstances or preferences, such as the intake of herbal remedies or pausing medication to facilitate recreational activities.

This study showed variable patterns of adherence due to the men needing to consider the best approaches to managing and continuing their ARV medication in varying contexts and given their unique circumstances. As a result, men's treatment continuation patterns were found to be non-linear and at times disruptive, due to the conflicting demands of their personal and social lives, and the varying contexts in which they navigated their HIV illness and treatment regimen. To illustrate, some men's lower socio-economic status was found to influence their ability to procure medication for opportunistic infections, purchase food that was perceived to be essential to taking prescribed medication, or afford transportation costs to maintain clinic appointments or obtain ARV medication refills. This revealed the prevailing issues of poverty and unemployment that exist at the structural level but contribute to shaping the health behaviours and outcomes of HIV positive Jamaican men. The role of men's socio-economic status and thus financial capabilities acting as a

barrier to medication adherence is not new and is thus well charted in the literature (Bourne et al., 2011; Kalichman, Kalichman & Cherry, 2016; Tuller et al., 2010).

9.3.2 Re-constructing self and identity in response to an HIV diagnosis

Men's identities are seen to comprise multiple, layered and intersecting categories of difference (Bowleg, 2012; Crenshaw, 1991; Davis, 2008), which can be affected by the onset of a chronic illness (Charmaz, 1991). Studies have highlighted changes to men's masculine identities upon developing a chronic illness (Kvigne et al., 2014; Mesquita et al., 2011) such as acquiring HIV/AIDS (Baumgartner & Niemi, 2013; Sikweyiya et al., 2014; Siu et al., 2015). This study demonstrated that a positive HIV diagnosis signalled a change in Jamaican men's social identities as it imposed a socially denigrating label that affected how some men were perceived and treated by others. Baumgartner and Niemi (2013) noted that an HIV positive status could affect an individual's pre-existing identities and roles, such as pertained to his sexuality, relationships, employment, spirituality and sociability. The impact of an HIV infection on other aspects of men's selves was also found in the current study. This finding reinforces the intersectionality perspective that men's identities are complex, multidimensional and interdependent (Cuadraz & Uttal, 1999); thus the introduction of an HIV positive identity was seen to impact other aspects of men's selves.

Becoming HIV positive introduces a sick status that is both bio-medically and socially constructed (Tewksbury & McGaughey, 1998), thus showing an interplay with existing social norms that define Jamaican men's identities. Jarret, Bellamy and Adeyemi (2007) argued that men's perception and response to their illness is largely defined by socio-culturally defined gendered norms. For men in this study, the shift from a healthy to sick state was found to challenge many of their former self-images of being strong, healthy and resilient. The effects were more pronounced when men's HIV illness impacted their employment, relationships, independence, sexual virility and physical appearance, as noted in other studies (Maliski et al., 2008; McGonagle & Barnes-Farrell, 2014). These lifestyle

disruptions affected some men's social status and respect within their homes and communities, repositioning them to subordinate or marginalized positions.

Some qualities that depict a Jamaican masculinity ideal became the benchmark by which some men determined their self-worth in the context of their acquired HIV illness. The dominant form of masculinity within Jamaica is characterized by representations of heterosexuality, sexual virility (often evidenced in the number of children borne), financial stability and authority over his household (P. Anderson, 2012; Chevannes, 2001; Hope, 2010; Kempadoo, 2004; Lewis, 2003a). Those men who perceived their HIV illness affected their desire for long-term relationships and children struggled to progress in their treatment continuum in comparison to those men who were already married or maintained their long-term partnerships and had children. This finding was similar to other studies that recognized men's inability to produce and provide for a family, due to the onset of a chronic illness, stripped men of the opportunity to attain their masculinity ideal (Maliski et al., 2008).

There were reported instances of some men's HIV identities being assumed to be indicative of an MSM identity. As a result, some men were exposed to the social antagonisms and stigma attached to being HIV positive and MSM. This proved particularly difficult for a number of heterosexual men in the study, who intentionally delineated themselves from MSM to avoid the associated stigma. An earlier study conducted in Jamaica identified a similar finding of HIV positive men often being assumed to be MSM (R. White & Carr, 2005), which subjects them to intensified stigma that could further impact their treatment experiences.

Awareness of the stigma and discrimination attached to an HIV identity, forced a number of men to conceal their HIV status in settings that could prove potentially detrimental. The need to protect their personal identities was heightened for MSM who acknowledged the stigma attached to being both HIV infected and an MSM in Jamaica (R. Carr, 2002). Masculinity norms in Jamaica are enforced by a range of social institutions (Chevannes,

2001, 2003; Lewis, 2003b), including the men's family, peers and the clinics from which the men accessed their health services. The divergence between these gendered norms and men's reality of being diagnosed with and living with HIV, forced some men to isolate themselves and suffer in silence, an outcome that has been identified in other studies (Sikweyiya et al., 2014; R. White & Carr, 2005).

In order to protect their personal identities, as distinct from their socially represented selves, some men performed the requisite masculinity ideal by being macho in appearance, speech and conduct. Performing masculinity guaranteed men's sense of belonging in their respective social groups, as well as ensured their safety and well-being in a society that abhors alternate representations of masculinity such as presented by MSM or transgender identities. The required performance of Jamaican masculinity, as a coping strategy, underscored the perspective that manhood is a social status that requires public demonstration to ensure the status is maintained (Vandello & Bosson, 2013). This reinforces the perspective that Jamaican masculinity is largely an exteriorizing of gender-specific behaviours done to jointly obtain social approval and avoid social sanctions (Lewis, 2004). Thus alternate representations of masculinity, such as those noted for MSM and transgender participants, threatened these men's membership within their respective social groups and communities.

This study identified an HIV positive diagnosis as a turning point that led some men to develop or strengthen their spiritual identities. This finding is similar to other studies that identify spirituality as a coping mechanism for persons diagnosed with chronic illnesses (Rowe & Allen, 2004), and HIV infection (Kremer et al., 2009; Kremer, Ironson, de Deugd, & Mangr, 2014; Tuck & Thinganjana, 2007). Being part of their local Christian community offered men in this study a sense of hope in their future and provided them with the strength, confidence and determination to overcome the challenges of living with HIV (Peterson, 2011). Rekindling their faith and connection with the church was identified as a redemptive strategy that allowed men to feel forgiven and released from the sins associated with contracting HIV. This was important in some men's pursuit of a more fulfilling life

post their HIV diagnosis. Literature has pointed to spirituality improving the quality of life and health outcomes of PLWHIV over time (Kremer et al., 2009; Tuck & Thinganjana, 2007).

However, not all men were able to find solace and acceptance within their Christian communities, despite a similar experience of a stronger spiritual identity post HIV diagnosis. Formal church doctrines have been identified as barriers in the public health response to HIV in the Caribbean (Kang Dufour et al., 2013). Some MSM in this study reported experiences of being socially rejected or rebuked by church members who are aware of their sexual identity. A noteworthy example was one male's experience of being encouraged to change his sexual identity in order to receive redemption for his sins and acceptance within his church community. As noted in the study by Foster et al. (2011), the tensions between Christianity and homosexuality in Jamaica, forced some MSM to minimize or halt more overt spiritual practices, such as attending church, whilst remaining steadfast in their spiritual convictions. Whereas the church was reported to offer a sense of support and solace for heterosexual men, the opposite was noted for MSM. This may hold implications for the involvement of faith-based organizations in the continued response to the HIV epidemic in the Caribbean (Kang Dufour et al., 2013).

Initiating and adhering to ARV treatment proved beneficial in restoring a number of men to a healthy status as existed prior to becoming symptomatic and being diagnosed with HIV. This restoration of a physically healthy state enabled these men to reclaim their pre-existing masculine selves and identities (Nyanzi-Wakholi et al., 2009). In particular, some men highlighted the effectiveness of ARVs in removing the physical manifestations of their HIV infection such as rashes and weight loss, which helped them to shift their HIV infection from the foreground to the background of their identities. The recognized benefits of ARVs in sustaining a healthy, non-HIV infected appearing identity thus propelled a number of men to maintain their clinic visits and adhere to treatment. This finding is similar to a study by Siu et al. (2015) who noted that men were vigilant in maintaining their health as it helped them to regain their masculine identities, whilst protecting their HIV status.

9.3.3 The crossroads: Men's social identities, treatment experiences and adherence outcomes

This study demonstrated how men experienced and approached their treatment in varying environments, including the clinic, their residential communities, and amongst family and peers. The healthcare system was positioned as being central to men's treatment experiences, given the pivotal role it played in men's HIV diagnosis, defining the appropriate treatment response, and determining the point of treatment initiation and how men were linked to the health system for continued care. Thus living with HIV resulted in the men in this study having restricted lives that were largely structured around their treatment requirements or conditionality of their illness (Charmaz, 1995). Men's daily routines were reconstructed to fit within their HIV illness prescribes, as it pertained their medication schedule, medication contingencies and routine check-ups.

Men reported being challenged by strict procedures around clinic appointments and prescription renewals that impacted their access to ARVs. The need to rely on the clinic for prescription renewals within specific time periods, engendered a sense of dependency on the clinic, that was perceived to limit their freedom in managing and making decisions pertaining to their health. Other studies have found that this perceived system of control and loss of freedom discourages men from engaging with HIV services and maintaining their health appointments (Leyva-Moral et al., 2015; Skovdal et al., 2011). At times, these strict procedures resulted in some men moving beyond the physician's recommendations to incorporate alternate health practices that could potentially derail the treatment and control of their HIV illness. Such practices included medication rationing due to missed appointments to obtain prescription renewals, intentionally missed dosages to accommodate recreational activities such as partying and drinking alcohol, and the incorporation of alternative medicines, some of which were perceived to be a cure of HIV.

The power embedded in the biomedical knowledge and expertise of the health professional, was found to prevent some men from being more active in determining their treatment pathway. The current study showed that men who perceived their doctors as experts, were

generally passive in their communication with their physicians, and thus failed to question or discuss in-depth their treatment recommendations. Men's passivity contributed to their limited understanding of their treatment requirement, which led to some men deviating from their prescribed treatment regimen, without due consideration of the implication for their treatment process. Men's treatment process and outcomes should ideally be a product of the transactional relationship between patient and provider that takes into consideration men's personal circumstances (Gearing et al., 2011) such as work and family obligations, as well as their personal understanding of their treatment process. A number of men in the study indicated a preference for a more holistic response to their HIV illness, that takes into account their psycho-social, physiological and spiritual needs. This reinforces the WHO's (2003) standard that elucidates the importance of treatment plans being a negotiated and collaborative plan that gives space to, and considers, the opinion and realities of men.

The absence of a space for dialogue was further compounded by system-related issues such as high staff turnovers, lengthy waiting periods and strict time limits in attending to patients. These issues created barriers to the formation of patient-physician relationships thereby defying the opportunity for men to establish a sense of trust in their physician that would enable them to openly discuss their concerns. The absence of a space that promotes consistent dialogue with a physician can result in men being silenced and distanced from their treatment process.

The study found an interplay between men's identities and the health centres from which they accessed their HIV health services since their diagnosis. Some men reported that health centres known to provide HIV specialized services, represented a symbol of an HIV identity that labelled patients as being HIV infected upon entering the facilities. This labelling resulted in men fearing the accidental disclosure of their HIV status, that could result in experiences of stigma and discrimination. Similarly, Skovdal et al. (2011) found that the risk of being seen attending an HIV clinic was a noted barrier to men's commitment to their medical appointments.

Some clinics and health facilities emerged as enablers of predominant social norms and stigmas that prescribe socially acceptable masculine identities, and punished men who represented much of the prevailing social norms and stigmas pertaining to HIV/AIDS and men's gendered and sexual identities. Where men's perceived social identities deviated from the benchmark established within prevailing social norms, men were predisposed to social antagonism, isolation, stigma and discrimination. In this study, women were often perceived to be more privileged as they received greater empathy and support than men in accessing health services. Some MSM perceived that patients were further delineated and ranked on the basis of their gender and sexual identities, with greater status and respect being meted towards men who appeared distinctly heterosexual. MSM or transgender men reported issues of stigma and discrimination that impacted their access to treatment and care. The recognized risk of attracting undue tensions in accessing their healthcare forced some MSM to hide their sexual identities and perform the expected masculine roles that afford them privilege in both their clinical and social environments. This introduces a hierarchy, predicated on patients' gender and sexual identities, that determines patient access to health care services. This hierarchy draws on the notion of women being victims of the HIV epidemic, whilst men are largely villainized; more so MSM given the early assumptions of HIV/AIDS being a gay disease (R. Carr, 2002). The hierarchy of health care access premised on patients' gender and sexuality was further reinforced by the perception of the clinic being a woman's domain. Other studies have pointed to the view of the clinic or hospital setting as female spaces, which consequently acted as a barrier to men's uptake of HIV services (Dumbaugh et al., 2014; Skovdal et al., 2011).

The current study demonstrated that gendered norms are integral in shaping how some men manage their treatment. Such norms reinforce a masculine approach to health, where some men protected aspect of their masculine identities, such as the portrayal of strength or resilience, at the expense of attending to their health (Galdas et al., 2005). The men in this study perceived women to be more vigilant in ensuring their health and well-being. This gendered approach to health is supported by literature that highlighted the poorer health

seeking behaviours of Jamaican men (J.P. Figueroa et al., 2015; Morris et al., 2011; Walcott et al., 2014), and men in other societies (Addis & Mahalik, 2003; O'Brien et al., 2007; Siu et al., 2013). The pressure to conform to socially prescribed masculine roles, such as hero, leader or head of household, at times forced men to sacrifice their health outcomes for the sake of others. As a result, some men reported prioritizing representations of their masculine selves that would ensure their retained status quo, at the expense of effectively managing their HIV illness.

The study found that some men, though they ascribed to some notions of the Jamaican masculine ideal, challenged gendered norms in an effort to prioritize their management of their HIV illness. These men engaged in a process of reconstructing their masculine selves around the importance of maintaining their ARV treatment and other healthy lifestyle behaviours. Hence men consciously altered their sexual and health behaviours to reflect a sense of social responsibility where they refrained from the hyper-sexual mandate characteristic of the Jamaican masculine ideal, as well as ensuring they always practised safe sex. The need to protect others from the risk of HIV transmission forced some men into celibacy. Thus men took charge of their HIV illness and felt responsible for ensuring the disease was not transmitted to others. A study by Siu et al. (2014), however, found that changes in men's sexuality post HIV diagnosis were due to a waned interest associated with men perceiving themselves to be less sexually virile rather having a sense of moral responsibility in preventing the transmission of the virus.

Some men identified unique ways to prioritize treating their HIV illness, whilst protecting aspects of their masculine identity. This approach included ensuring treatment regimens pertaining to men's HIV illness were strictly adhered, whilst perceived common illness were treated with scant regard or self-remedied. In doing this, men reconstructed their self-identities in the context of their HIV illness and drew on aspects of masculinity norms which they deemed more relevant to their identity and approach to their health. The re-evaluation and selective prioritization of masculinity norms in response to the emergence of a chronic illness has been noted in the literature (Maliski et al., 2008; Mesquita et al.,

2011). Thus men were able to maintain a healthy and strong representation of their selves by adhering to their ARV treatment. Studies have shown that ARV treatment enables men to reconstruct or restore their masculine identities, enabling them to resume earlier masculine identities or roles, and regain the sense of status and respect that was lost due to their HIV illness (Siu et al., 2014).

The current study further demonstrated the importance men place on the physical appearance of health as an important feature of masculinity. A number of men acknowledged the role of ARV medication in restoring a healthy identity, which was comparable to the phase of being symptomatic and obviously unwell. Thus ARV medication is deemed intrinsic in restoring men's physical and social identities which were challenged by their HIV illness (Siu et al., 2014). Furthermore, most men adopted a healthy diet, supplements and exercise as additional steps in ensuring their physical appearance and health. This in turn helped men to resume traditional roles such as pertained to employment, family responsibility and sexual virility. A few men acknowledged becoming more health conscious post their HIV diagnosis and treatment initiation, recognizing the importance of a healthy lifestyle in enhancing their quality of life. In some instances, this adopted healthy lifestyle was deemed comparable to a female approach to her health, which showed men were often cognizant of gendered norms that delineated a masculine and feminine approach to health. Men's willingness to compare their adopted healthy lifestyles to that of women was also found in the study by Siu et al. (2014).

9.4 LIMITATIONS OF THE STUDY

Though this study yielded significant findings that contribute to knowledge production, it also has some limitations. All the participants in this study were recruited from one clinical setting located in the urban parish St. Andrew, potentially limiting the diversity of men who were recruited to participate in the study. There was some variation in the demographics of the men included in the study, for instance in terms of their parishes of residence, sexual orientation, employment status, age group and educational attainment (See Table 4, p. 134). However, it was noted that none of the men could be classified within upper-income levels,

and the majority were either unemployed, self-employed or working part-time, at the time of data collection. This could potentially limit the experiences captured to that of men who are within middle and low-income categories. An intentional move to include men within the high-income grouping would undoubtedly enhance the complexity surrounding men's social identities.

Another limitation pertained to the recruitment process, which was deemed to be subjective given the role of the clinic's social workers in identifying patients who met the study's inclusion criteria and who could potentially be included in the study. It is expected that there were certain subjectivities around the familiarity with some men who would be more willing to participate than other men who were more reserved or less known. There is also the possibility that some men felt compelled to participate given they were invited to participate by a clinic staff member. This was allayed by advising all participants at the point of recruitment that their participation in the study held no implications for their access to the clinic's services.

The men recruited to participate in this study were selected from a pool of existing patients. This meant that men lost to follow-up, and who no longer attended the clinic, were not included in the study. Given the focus of this study on ARV treatment experiences and adherence outcomes, it would have been useful to capture the voices of men who had opted to discontinue services at the clinic and who could in turn be defaulting their treatment. The staff members' attempts at recruiting some of these men proved futile as in most instances their contact information, as documented in the patient registry, was no longer valid. This absence of men who had defaulted in their treatment was supplemented by the inclusion of one male who defaulted but had resumed treatment prior to the study, and another who defaulted treatment but was recruited by a fellow participant as a part of an introduced subgroup of men.

Staff members who were identified as directly involved in the treatment journey of patients were interviewed at the outset of the study. Given the small staff complement and thus the

very distinct roles of these staff members, it became difficult to integrate their data without risking the anonymity of their identities. Only general information surrounding the type of medication, treatment regimen or the clinic's *modus operandi* were utilized in establishing the background information surrounding the clinic and its services.

My understanding of the intersectionality approach improved significantly after the data collection phase. As such, there are moments when I pondered whether I could have further interrogated the overlapping contours of the men's identities and how they reflected on power relations and issues of dominance. Though some issues became apparent or suggested during the data analysis, it was more important to remain true to the data, rather than superimpose my own thoughts, ideas and perhaps assumptions. It was then better to identify these issues as areas for future research.

9.5 METHODOLOGICAL IMPLICATIONS

As intersectionality has been primarily used in feminist research (Cho, Crenshaw, & McCall, 2013), this study showed the broader reach of an intersectionality lens beyond that of women's marginalization and disempowerment. Thus this study provided a useful example of the application of an intersectionality-informed framework in conducting health research on men, particularly as it pertains to HIV/AIDS which remains an important public health issue globally.

The main challenge of adopting an intersectionality-informed approach in this study was the recognized absence of a clear consensus on how to conduct intersectionality research (Bowleg, 2008). As a result, much of this study entailed "self-teach[ing] and learn[ing] through trial and error" (Bowleg, 2008, p. 313). Though Winker and Degele's multi-level stepwise process, in an adapted form, was useful for this study, the apparent limitations of this framework, paired with the need to match it to the scope of this study's research focus, required me to draw on insights from earlier theorists, particularly Bowleg (2008) and Cuadraz and Uttal (1999). The recommendations of these intersectionality scholars clarified the first step required in intersectionality research, which is an understanding of

participants' experiences of the particular social phenomenon of interest. For this study, particular attention was given to the ARV treatment experiences and adherence outcomes of HIV infected Jamaican men. Understanding the men's experiences around their treatment journey thus became the starting point of questioning and analysis. Reflecting on this study, commencing with an understanding of the experiences or practices that are influenced by varying power relations was identified as a pragmatic first step to establish in intersectionality health research. Doing this established a platform for a more critical interrogation of how men's HIV status, gender and sexuality intersected to affect these experiences.

This study also makes a methodological contribution by showing how some noted limitations, already identified in the literature, can be addressed and surpassed in doing intersectionality research. Intersectionality has been criticized for the ambiguity surrounding the principle of a simultaneous analysis of multiple, intersecting categories of difference (Carastathis, 2014). In responding to this challenge, some intersectionality theorists justify commencing with an understanding of individual categories before examining how their overlap with each other (Cuadraz & Uttal, 1999); which is quite distinct to the additive approach that intersectionality scholars refute (Hancock, 2007). This study supports this view, especially as it was found to make the process of doing intersectionality analysis less murky and thus more manageable. Thus data analysis commenced with identifying men's references to their HIV identity, gender and sexuality independently, after which the intersections were explored. Rather than treating social categories equally in the current study, some flexibility was maintained that allowed participants to identify which dimensions held greater importance at different stages of their illness, treatment trajectory or in varying contexts. This approach exists in tandem with identity literature that indicates shifting salience attached to the multiple dimensions of an individual's identity (Tweksbury & McGaughey, 1998). An example of this within the current study, is a man, who upon being diagnosed with HIV, responds by giving his HIV

health status greater salience than his masculine identity which superseded prior to becoming HIV infected.

The study also reinforced the value of intersectionality in crossing the boundaries of micro analysis to cover both meso and macro levels of analysis. This is not new, already being proposed and addressed by both Bowleg (2008) and Winker and Degele (2011) whose ideas helped to inform the study's research design. However, whereas Winker and Degele limited their macro level analysis to the examination of social structural processes such as stigma, this study included the role of social institutions, which are found to be enforcers of many of the norms driving these social structural processes. This explicit linkage to social institutions allowed an interrogation of the role of the Jamaican health system and varying personal contexts, such as men's families, communities and churches, in shaping men's treatment experiences. Though men experienced stigma in accessing their health service or in attempting to find refuge in their churches, the particular experiences of stigma were quite distinct and thus could be easily missed under the broad umbrella of social stigma.

The current study also reinforces the value of intersectionality research as a transformative tool, which draws on its feminist tradition that advocates for social justice and transformation for the population being researched (Bilge, 2013). This shows the pragmatic reach of intersectionality. In this study, transformation was attempted primarily at the micro and meso levels, with the participants and the research clinic respectively. By clarifying for the men in this study matters pertaining to their sexual and reproductive health, which were either unclear or inaccurate, the researcher was able to engender a greater sense of awareness that could inform how they proceeded with their personal sexual and reproductive health choices. Further, the policy and practice recommendations arising from the study draw on the "multiple forms of discrimination" (Hankivsky & Cormier, 2011, p. 228) experienced by the participants; therefore, providing a response that is "more true to people's actual lived experiences and therefore more effective and better able to target the actual location of oppressive forces at work in society" (Bedolla, 2007, p. 246).

9.6 KEY RECOMMENDATIONS FOR POLICY AND PRACTICE

The study identified gaps in existing service provision and areas for improving the treatment experiences and overall health outcomes of HIV positive Jamaican men. The identified recommendations span three categories: programme planning and service provision, policy and legal reform. Some attention is given to HIV prevention given its continued role in addressing the epidemic and the noted issues surrounding condom use, HIV knowledge, and risky sexual practices, which emerged in the study.

Programme and service provision

The UNAIDS (December 9, 2015) calls for “the development of comprehensive policies and programmes that promote men’s access... and address their specific needs”. An important aspect of policy and programme development is changing the language around men’s health issues, especially in the context of HIV/AIDS where men (particularly MSM) are often stigmatized for their role in the spread of HIV. Myths and stereotypes have only served as barriers to men’s willingness to get tested and access health services (Courtenay, 2000; Jarret et al., 2007; Walcott et al., 2014).

Men’s perception of the clinic as a woman’s domain, on the basis of larger proportions of women in attendance and the sense of greater empathy from health professionals towards women, warrants the recommendation for structural policies that engender gender equality in the delivery of health services. Such system-level changes should be informed by a rights-based approach, recognizing men’s right to an equal opportunity to access a high standard of healthcare (WHO, 2015c). This approach would encourage the development of gender-sensitive health interventions (Payne, 2009), and the promotion of safe and supportive health systems that acknowledge and respect the unique health needs of Jamaican men.

Ongoing research is needed to further understand the shifts in men’s (and women’s) health approaches and the factors that contribute to the prevailing disparity between male and female uptake of HIV services post diagnosis. Such research should utilize more relevant

approaches, such as those that simultaneously assess the determinants of Jamaican men's health, given the noted limitations of the traditional additive approach (Bowleg, 2008; Griffith, 2012; Hankivsky, 2012). The findings of these studies would then inform the design, evaluation and modification of health programmes and services tailored to improve the health outcomes of HIV positive men and women in Jamaica.

It is important that further attention be given to the training and sensitization of personnel on the different ways of working with HIV positive men, to ensure their involvement, partnership and empowerment. Health facilities that offer HIV services should be redesigned to provide a safe space for all persons living with HIV, irrespective of their personal identities, ensuring they have a high degree of choice and control over their health journey, in a supportive and non-judgemental manner. Thus gender, sexuality, age, class or religion should not emerge as barriers to men's access to a high standard of health care.

A number of participants raised concerns about the practicalities of services, for example, the rigid scheduling of appointments and lengthy delays in waiting to be attended to both at the clinic and the pharmacy. Each of these factors act as barriers to men's access to their treatment and care, and fails to regard men's personal circumstances such as employment commitments and inability to afford transportation costs. Greater flexibility is needed in ensuring men's ease of access to physicians outside the set schedules prepared for clinic appointments. Health accessibility ensures men's access to information, care and services at points deemed necessary by the men. This flexibility would address men's problematic approaches to their health such as medication rationing or following expired prescription regimen. The appointment system could be further improved by assigning patients specific time appointments that allow them to see the physician at the agreed time, rather than waiting for lengthy periods. This approach would allow men to better structure their other commitments, knowing that they will be able to complete their clinic visits and pharmacy refills within a set time period.

As most men in this study identified their treatment as needing to extend beyond the narrow biomedical response to treatment HIV, it is proposed that Jamaica's health system adopt a more holistic approach to addressing HIV/AIDS. A holistic approach would take into consideration the psychological, social, physical, and spiritual aspects of HIV positive men's health. Thus space should be given to men's interest in ensuring a balance between their medication regimen, nutritional intake, physical appearance and psychological well-being. This response exists in tandem with the WHO's recommendation to implement holistic and person-centred approach that is "grounded in principles of human rights and health equity" (WHO, 2015a, pp. 1-2).

Greater attention should be given to counselling as an intrinsic aspect of HIV testing and other aspects of services provided for HIV management. Though the findings of this study did not specifically capture an evaluation of the quality of VCT, its absence from men's narratives and their accounts of extended periods of misinformation, uncertainties and fears, suggested that there is a need for this issue to be researched and strengthened. The WHO and UNAIDS emphasize the incorporation of counselling in HIV testing as it provides an opportunity to provide patients with HIV information irrespective of their test outcomes, and offer appropriate support, referrals and other services that can help patients cope and adjust to an HIV positive outcome (UNAIDS, 2000; WHO & UNAIDS, 2007). Studies have supported the need for post-test counselling to be ongoing as it aids patients to gradually adjust and overcome their fears of living with HIV (Nyanzi-Wakholi et al., 2009).

Men's support groups, whether online or face-to-face, provides an opportunity for men to receive ongoing psycho-social support from trained counsellors or other men living with HIV. Though some NGOs are known to provide support groups for PLWHIV, the men in this study indicated that, at the time of the research, they were not involved in such groups. Beyond counselling provided within clinics, there is a need for more community-based counselling and guidance services, which are responsive to the needs of particular groups and provide reliable sources of information. Further, due to increasingly limited financial resources available to fund HIV programmes in Jamaica (D. Carr & McClure, 2014), it is

proposed that more ingenious ways of providing ongoing support be developed that minimize costs to both facilitators and members who would be required to travel to attend meetings. There is a growing body of research on the use of social media in HIV prevention, education and support of PLWHIV (Leyva-Moral et al., 2015; Taggart, Grewe, Conserve, Gliwa, & Roman Isler, 2015; UNAIDS, 2011c). Establishing online chat rooms, websites and mobile networks would allow HIV positive men to connect with each other and HIV peer educators in an online forum that is both anonymous and safe, which are important factors for persons recently diagnosed with HIV or have defaulted in their treatment and are fearful or uncertain of how to resume.

Policy response

Jamaica's policy response would be aptly supported with the development of a men's health policy, as exists in Australia, the UK and Ireland (J.A. Smith, White, Richardson, Robertson, & Ward, 2009). The rationale for such a policy is the recognized need to address men's unique health needs and in fostering an equitable health system that meets the needs of both men and women (Commonwealth of Australia: Department of Health and Ageing, 2010). Further, this policy would support the provision of appropriate health services that target men in general, ensuring that issues related to men's health-seeking behaviours, masculinity norms, and ideas pertaining to men's health are addressed (P. Baker, 2015). It is anticipated that the development and implementation of a national men's health policy will be spearheaded by the newly created National Family Planning Board – Sexual Health Agency (SHA), an independent statutory agency emerging from a merger between the National Family Planning Board and the National HIV Programme to create a single sexual and reproductive health agency (Planning Institute of Jamaica, 2014). This merger is outlined in the draft National Integrated Strategic Plan (NISP) for Sexual Health and HIV (2014–2019).

Further policy response could be aimed at promoting greater public education/ awareness that promote the rights of PLHIV. This would extend the existing efforts to end HIV

discrimination in various sectors within the society. Jamaica has made some progress in its policy reform, having developed and implemented its National Workplace Policy on HIV/AIDS in 2012, which endeavours to protect the employment rights of PLHIV and prevent incidences of stigma and discrimination. However, as noted in this study, men's health outcomes are intricately related to their varying social contexts, such as the community, workplace, home and health facilities. Thus policies should be multi-focused, using language and approaches that are tailored to the respective target audiences.

Legal reform

There is a recognized need for legislation that effectively protect the rights of PLHIV from issues of stigma and discrimination. Though some measures for redress were identified in the study, it is believed that established laws that protect against HIV discrimination will help to remove barriers to accessing an optimal standard of healthcare and other services throughout the country. This legislative change warrants the involvement of a wide cross-section of stakeholders, particularly political leadership, technocrats, policy makers and a diverse representation of PLHIV.

HIV prevention

A cross-cutting issue is that of the continued importance and challenge of HIV prevention messages. These need to continue to promote consistent condom usage, highlighting that the occasional instance of unprotected sex, which was a feature of some men's accounts in the current study, can result in HIV transmission. Those messages must be delivered in a non-judgemental, supportive and positive way for them to be effective, encouraging open debate and sharing of information (Bloch, Mulhall, Farthing, & Hillman, 2012; Rose et al., 2012). Special attention should be given to the MSM community given that this is a high risk and highly stigmatized group in Jamaican society (R. Carr, 2002; Charles, 2011). The culture and style of HIV prevention interventions should match those discussed above, reflecting men rights, choices, and access to a safe and supportive environment.

HIV financing

As a middle-income country with an excessively high debt burden, Jamaica remains challenged by its ability to finance idealistic HIV response strategies. The WHO (2016) recognizes the need to give particular attention to middle-income countries, given the changing requirements of donors which now target low-income countries. This warrants the development of innovative and sustainable approaches that minimize the dependence on external donor agencies for funding. This may include focusing inward to identify potential sustainable partnerships or funding opportunities within the private sector or other non-governmental options. Reference to best practices in other Caribbean or small island developing states may also provide useful lessons that can be patterned. For example, it is worthwhile assessing the strategies adopted by St. Lucia and Dominican Republic which resulted in their shift from a state of high to medium dependency on external funding since 2011 (Pan American Health Organization & WHO, 2013).

9.7 RECOMMENDATIONS FOR FUTURE RESEARCH

This study focused on exploring intersections of gender, sexuality and HIV health status. It would be useful for future research to explore further dimensions of complexity that could impact on the treatment experiences of HIV positive Jamaican men. This could take into consideration men's socio-economic status, educational levels, disability status, or any other dimension that would ensure the interrogation of how men's treatment experiences are affected by their identities.

Another emerging area for further research is assessing the role of VCT in facilitating a successful and rapid transition in men's treatment trajectory. As noted earlier, men in this study did not explicitly refer to VCT in sharing their experiences around testing, acceptance and adjustment. Though some men shared being advised that HIV is not a death sentence, counselling extends to provide information as well as support that should ideally enable men to better transition from their diagnosis into treatment initiation.

9.8 CONCLUDING REMARKS

This journey has been both rewarding and challenging. Perhaps the most enriching experience was having the opportunity to sit with 24 Jamaican men, courageous enough to expose their personal, and often judged, experiences of living with HIV. This experience gave me an opportunity to see HIV/AIDS through men's eyes, a totally different lens to my own as a female Jamaican researcher.

The findings of this study have offered insights to how HIV positive Jamaican men approach their health in varying contexts. Receiving a positive HIV diagnosis proved to be a traumatic experience for the men in this study. They were forced to contend with living with a stigmatized and incurable illness that affected their health and, personal and social identities. Men's experiences around their diagnosis and treatment reflected a continuous interplay between men's personal and social identities, the norms that help to shape men's socially acceptable identities, and the social and clinical institutions that act as enforcers of these social norms. The evidence shows that men were at times pressured to conform to social expectations at the expense of their health, whilst others surpassed these expectations, choosing instead to redefine their masculine selves to better accommodate their treatment needs.

Much of the findings support international research that looks at men's help-seeking behaviours, and contributes to the limited local body of knowledge on men's health in Jamaica, particularly as it relates to the focus on HIV positive men. Men have largely gone unrecognized or stereotyped in varying accounts of the epidemic, thus it is hoped that this study will contribute to an increased awareness of the need to address the health vulnerabilities of HIV positive Jamaican men. Furthermore, by adopting an intersectionality-informed approach, the study showed how men's treatment experiences and adherence outcomes remain largely defined by the intersections of their identity, and how these are measured against the societal benchmarks that determine socially appropriate representations of Jamaican masculinity.

The study identified a number of gaps and opportunities for improvement in the targeting and provision of HIV health services for Jamaican men. These span policy, programme and service provision, and encompass HIV prevention strategies in an effort to stem the spread of HIV. Jamaica is faced with significant financial constraints, characteristic of many low to middle-income countries, which is further aggravated by its continued funding of its excessive debt burden and commitment to the IMF. Despite these challenges, it is feasible and pragmatic to give greater focus to the health needs of HIV positive men in Jamaica. More focused HIV prevention strategies, earlier testing, improved counselling, earlier linkage to care and treatment and ongoing support along men's treatment trajectory hold the promise of ensuring men's health and continued participation in their respective social roles, as well as minimizing the risk of HIV transmission to bridged populations. Jamaica needs to identify innovative approaches to meet its obligation in the global efforts to end HIV/AIDS as a public health threat by 2030, with an interim goal of 90% of PLWHIV being tested and knowing their status, 90% being linked to treatment and 90% achieving viral suppression (WHO, 2015a).

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Appendices

APPENDIX A: PARTICIPANT INFORMATION SHEET

Participant Information Sheet



- Project Title

Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV

- An Invitation

My name is Shakeisha Wilson, and I am a doctoral student at the Auckland University of Technology, New Zealand. Prior to pursuing my studies in New Zealand I was a lecturer at the University of the West Indies, Mona. I also volunteered in various capacities that relate to the needs of vulnerable groups, including persons living with HIV/AIDS. My work with the HIV community led to my current research focus.

The Centre for HIV/AIDS Research, Education and Services (CHARES) has agreed to assist me by inviting its members to participate in the research. Thus, you are invited to participate in this study which seeks to understand the process of antiretroviral (ARV) treatment adherence for HIV positive men. It is recognized that taking medications everyday as prescribed may at times be difficult, thus it is important to understand how you manage your individual treatment.

Your participation in this research project is voluntary and you may withdraw from the study at any time prior to the commencement of data analysis. Please note that though I volunteer with some HIV organizations, I have no involvement with the services offered by CHARES. Therefore you will not be advantaged or disadvantaged in any way if you choose to participate or not.

- What is the purpose of this research?

The research is in partial fulfilment of my doctoral degree at AUT. However, I believe that the results can contribute to a better understanding of the treatment adherence needs of men and thus may help in a targeted approach in future programs surrounding ARV treatment

- How was I identified and why am I being invited to participate in this research?

I am seeking participants who meet the criteria of being a Jamaican male, 20 years or older, who have been diagnosed with HIV and been prescribed ARVs for at least 6 months before the initial contact. Dr. Geoffrey Barrow, Clinical Director of CHARES, agreed to assist in the identification of potential participants. Thus as an existing patient of CHARES, who meets the initial criteria for inclusion in the research, you have been invited to take part in the study.

As the research process unfolds, further criteria will be used to select potential participants. Thus not all persons initially identified will be included in the final study. However, all persons who were initially recruited will have the opportunity to receive a copy of the research findings if they so choose.

Persons to be included in the study must also sign a consent form. Anyone choosing not to sign the consent form will not be included in the research.

- **What will happen in this research?**

The project would require that you participate in an interview, maintain a diary log and participate in a theory checking exercise to occur at the end of the study. You may also be asked to participate in a follow-up interview.

1. Interview: The first interview will be approximately 60 minutes in length. In these interviews I will ask you a range of questions surrounding your experience of being diagnosed with HIV, prescribed life-long treatment, and following your treatment.
2. Follow-up interview: You may be asked to participate in a follow-up interview to clarify or explore a concept that was not discussed in our initial interview. This follow-up interview will be approximately 45 minutes in length. Contact for the follow-up interview will be done within 3 months of the initial interview.
3. Adherence diary log: You will be asked to keep an adherence diary/ log for 2 weeks after the initial interview. The diary log can either be written or voice recorded. The written diary log involves you writing your reflections at least once daily using a guided form to be provided. The voice recorded diary log involves you calling a toll free number at least once daily to record your reflections on your medication adherence. The choice of either the written or audio diary is based solely on your preference. You will be provided with pre-paid stamped envelopes to return the written entries and a box will also be provided at CHARES for you to also submit your entries.
4. Theory checking exercise: At the end of the data collection/ analysis process, I will ask to meet with you for approximately 30 minutes to discuss the outcome of my data analysis and the theory developed. This will be done within one year of our first interview and will present an opportunity to give your feedback on the theorized process of adherence.

Note that all interviews will be audio recorded. All audio/ voice recorded data will be transcribed and the transcripts returned to you to allow you to check for accuracy. You would be given 2 weeks to provide feedback on the transcripts, after which I would proceed with the analysis. Where preferred, I can arrange to meet with you to review the transcripts orally. **As well, you may choose to participate in the first interview but not do the diary log or participate in the follow-up interview and/or theory checking exercise.**

- **What are the discomforts and risks?**

It is not anticipated that you will experience any notable discomfort or risk. However, it is possible that you may experience slight emotional discomfort when talking about your experience of learning about your HIV diagnosis and the subsequent process of taking your prescribed medication.

- **How will these discomforts and risks be alleviated?**

You can request that the audio recorder be turned off at any time during the interview if you are experiencing discomfort. You can also choose to withdraw from the interview at any time deemed necessary.

CHARES has agreed to provide free counselling support to participants in the research if needed. If you would like a counselling session please 1) contact either the Administrator or Clinical Coordinator at CHARES at 927-1620 ext 2791 or 2686, 2) indicate that you are a research participant, and 3) note your desire to schedule a counselling appointment.

- **What are the benefits ?**

It is anticipated that by participating in the research you may benefit from sharing your experience of taking and managing your ARV medication. It is hoped that as the researcher, I will assist you in better understanding your process of adherence and the factors that help to shape your choices.

The research also contributes to the production of my doctoral thesis, along with conference papers and journal articles. It also has the benefit of offering me additional insight to an area of need that can further equip me in my role as an HIV advocate on my return to Jamaica.

- **How will my privacy be protected?**

If you agree to participate in the research, you will be asked to create a pseudonym which is a false name or an alias. This alias will be used to identify you in all the data collected (interviews, diaries etc) and thus your real identity will be protected. Where excerpts from transcripts are to be incorporated in the study's outputs (thesis, conference papers, journal articles and reports) the researcher will ensure that your identity remains unknown through the use of the alias given.

As the researcher, I will ensure that your information is treated with the utmost respect and will be kept confidential. My supervisors, Dr. Cath Conn and Dr. Shoba Nayar, are the only additional persons who will have complete access to the data. Where someone is employed to assist in the transcription of tapes, they will be asked to sign a confidentiality agreement, to protect the information shared by the participants.

All research material will be securely kept in a locked filing cabinet in my primary supervisor's office at AUT for 6 years. During this time only the study researchers (myself, Dr. Conn and Dr. Nayar) will have access to the information. After 6 years all the study material, transcripts and audio tapes will be destroyed.

- **What are the costs of participating in this research?**

There is no cost for you to participate in this research. Any transportation costs incurred in travelling to the interviews will be reimbursed. It is anticipated that you will need to commit approximately 1 hour for the interview. If you are asked to participate in a follow-up interview, you will be required to commit approximately 45 minutes for the interview. If you agree to maintain a diary log, this will be done for 2 weeks after the initial interview. As well, you are asked to commit 30 minutes towards the end of the study to participate in a theory checking exercise to review the outcome of the data analysis.

- **What opportunity do I have to consider this invitation?**

You have up to two weeks to consider taking part in the study. You can contact me directly at the number provided below if you have any questions or desire further clarification.

- **How do I agree to participate in this research?**

To participate in the research you must complete and sign a Consent Form which you can receive from me directly or from the receptionist desk at CHARES.

- **Will I receive feedback on the results of this research?**

If you desire, a summary report of the research findings will be given to you upon completion of the study.

- **What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Cath Conn, cath.conn@aut.ac.nz, (09) 921 9999 ext 7407.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz, (09)921 9999 ext 6902.

- **Whom do I contact for further information about this research?**

For independent advice on your rights as a research participant please contact Professor Horace Fletcher, Dean, Faculty of Medical Sciences, University of the West Indies, Mona, Kgn 7 (Tel: (876) 927-1297, e-mail: medsci@uwimona.edu.jm)

Researcher Contact Details:

Ms. Shakeisha Wilson, swilson.aut@gmail.com, (876) 437 6214

Dr Shoba Nayar, snayar@aut.ac.nz, (09) 921 9999 ext 7304

Project Supervisor Contact Details:

Dr Cath Conn, cath.conn@aut.ac.nz, (09) 921 9999 ext 7407

Field Supervisor Contact Details:

Dr Moji Anderson, moji.anderson@uwimona.edu.jm, (876) 970 6321

Approved by the Auckland University of Technology Ethics Committee on 16/01/2013, AUTEK Reference number 12/303.

APPENDIX B: LETTER OF INVITATION TO PARTICIPANTS

Letter of Invitation to Participants



April 26, 2013

Title of Study: Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV

Researcher: Shakeisha Wilson, Department of Community Health Development, Auckland University of Technology, New Zealand

Field Supervisor: Dr. Moji Anderson, Department of Sociology, Psychology and Social Work, University of the West Indies, Mona

My name is Shakeisha Wilson, a doctoral student at the Auckland University of Technology, New Zealand. I am conducting a study on the process of treatment adherence of Jamaican men who are HIV positive. The Centre for HIV/AIDS Research, Education and Services (CHARES) has agreed to assist me by inviting its members to participate in the research.

The research is in partial fulfilment of my doctoral degree at AUT. I believe that the findings can contribute to a better understanding of the treatment adherence needs of men and thus may help in a targeted approach in the future. A summary report of the findings of the research will be given to each participant and CHARES.

The research will be conducted primarily using interviews either at CHARES or a venue to be agreed on. The interviews should be approximately 1 hour in length and a participant may be asked to schedule time for another interview. Participants will also be asked to contribute to the study by maintaining an adherence diary for 2 weeks after the initial interview. These diaries can either be written or voice recorded using a toll free number.

Your participation in this research project is voluntary and you may withdraw from the study at any time prior to the commencement of data analysis. Please note that I have no

involvement with the services offered by CHARES, therefore you will not be advantaged or disadvantaged in any way if you choose to participate or not.

Details of the research project are outlined in the attached information sheet and further information can be given by calling 437-6214 or e-mail: swilson.aut@gmail.com.

Thank you.

Shakeisha Wilson (Researcher)

Approved by the Auckland University of Technology Ethics Committee on November 29, 2012, AUTEC Reference number 12/303.

APPENDIX C: CONTACT CONSENT FORM

Contact Consent Form



*Project title: **Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV***

*Project Supervisor: **Dr. Cath Conn***

*Researcher: **Shakeisha Wilson***

- ☐ I have been contacted by a representative of CHARES who discussed this research project and invited me to participate in the research.
- ☐ I have received a copy of the Information Sheet dated 29 October 2012 and have read its contents.
- ☐ I agree to have my contact details given to the researcher, Shakeisha Wilson, who will contact me to further discuss the research.
- ☐ In signing this document I understand that I have not consented for my details to be used other than for the purposes of establishing contact with to further discuss the research.

Participant's signature:.....

Participant's name:.....

Participant's Contact Details (if appropriate):

.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTEK Reference number *type the AUTEK reference number*

Note: The Participant should retain a copy of this form.

APPENDIX D: DEMOGRAPHIC DATA FORM

Participant Demographic Sheet



Project title: **Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV**

Project Supervisor: **Dr. Cath Conn**

Researcher: **Shakeisha Wilson**

Participant ID #: _____

Date: _____



1. Choose an alias (not your real name) that you would like to be identified by in the research: _____
2. How old are you? _____
3. What is your parish of residence? _____
4. In which parish do you work? _____
5. What is your highest level of education?
 - a. Primary ☐
 - b. Secondary ☐
 - c. Tertiary ☐
 - d. Skill ☐
 - e. None ☐
6. What is your employment status?
 - a. Full time ☐
 - b. Part time ☐
 - c. Self-employed ☐
 - d. Student ☐
 - e. Not employed ☐

7. Do you live (tick all that apply):
- a. Alone ☐
 - b. With a partner ☐
 - c. Children ☐
 - d. With other family members ☐
 - e. With friends ☐
 - f. With someone other than a family member or friend ☐
8. How many partners do you have currently?
- a. None ☐
 - b. 1 ☐
 - c. 2-3 ☐
 - d. 4-5 ☐
 - e. More than 5 ☐
9. In which year were you diagnosed with HIV? _____
10. Did you start ARV treatment in that year? Yes ☐ No ☐
11. List the different medications you have taken since being diagnosed with HIV:
-
-
-

Thank You

***Approved by the Auckland University of Technology Ethics Committee on November 29,
2012 AUTECH Reference number 12/303***

APPENDIX E: TRANSCRIBER CONFIDENTIALITY AGREEMENT

Confidentiality Agreement



For someone transcribing data, e.g. audio-tapes of interviews.

*Project title: **Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV***

*Project Supervisor: **Dr. Cath Conn***

*Researcher: **Shakeisha Wilson***

- ☐ I understand that all the material I will be asked to transcribe is confidential.
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature:.....

Transcriber's name:.....

Transcriber's Contact Details (if appropriate):

.....
.....

Date:

Project Supervisor's Contact Details (if appropriate):

.....
.....

Approved by the Auckland University of Technology Ethics Committee on November 29, 2012 AUTEK Reference number 12/303

Note: The Transcriber should retain a copy of this form.

APPENDIX F: PARTICIPANT INDICATIVE QUESTIONS

Indicative Questions



The following presents a range of questions to guide the interview sessions

Project title: ***Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV***

Project Supervisor: ***Dr. Cath Conn***

Researcher: ***Shakeisha Wilson***

1. Tell me about your HIV diagnosis.
2. Tell me what treatment adherence means to you.
3. Tell me about your experience starting ARV treatment.
4. Describe a typical day in taking your medication.
5. Is there anyone who has been important in your management of your ARV treatment? If yes, who are these persons and what role have they played?
6. If I were a new patient, being prescribed the same treatment as you are taking and came to you for advice, what would you tell me?

Approved by the Auckland University of Technology Ethics Committee on November 29, 2012 AUTEK Reference number 12/303

APPENDIX G: PARTICIPANT CONSENT FORM

Consent Form



Project title: *Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV*

Project Supervisor: *Dr. Cath Conn*

Researcher: *Shakeisha Wilson*

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 30 April 2013.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I agree to be contacted for a follow-up interview if necessary.
- ☐ I agree to participate in the theory checking exercise at the end of the research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature:.....

Participant's name:.....

Participant's Contact Details (if appropriate):

Date :

Signature of witness :

Name of witness :

Date:

Approved by the Auckland University of Technology Ethics Committee on November 29, 2012 AUTC
Reference number 12/ 303 Note: The Participant should retain a copy of this form.

APPENDIX H: STAFF INTERVIEW GUIDE

Staff Interview Guide

1. Explain your role as [specify staff role] for CHARES?
2. How long have you been working at CHARES?
3. Do more males than females present as HIV positive at the clinic?
4. How is treatment adherence defined or understood?
5. How are the patients prepared for adherence?
6. In your experience, what factors do you perceive play the greatest role in determining patients' treatment adherence?
7. Are these factors the same for all male patients?
8. What are some of the factors or issues (social, structural, treatment related) surrounding ARV adherence?
9. Is there an observed difference in adherence levels for males and females?
10. Explain the instruments used to assess each patient's adherence.
11. What level of adherence is considered optimal?
12. Define defaulted patients (Is it the same as poor adherence?) How are defaulted patients identified? How are they treated/ addressed?
13. What are some of the coping strategies utilized by patients on ARV?
14. Is the revised WHO guidelines 2010 regarding start point for prescribed ARV treatment maintained by CHARES?
15. If yes, what have been some of the noticeable differences before and after the implementation of the new guideline?
16. Is the general prescribed treatment for a patient based solely on medication or does it encompass other lifestyle practices such as diet and exercise?
17. Is it important for patients to eat before taking their medication?

18. Is there an open space for patients to discuss incorporating supplementary medication/ treatment such as vitamins, herbs etc?
19. What are the implications for someone missing one dose of medication?
20. What are implications for someone missing a daily dosage of medication?
21. What are implications for the person who responds to their missing a dose by doubling their subsequent dose of medication?

APPENDIX I: AUTECH ETHICS APPROVAL



16 January 2013

Cath Conn
Faculty of Health and Environmental Sciences

Dear Cath

Re Ethics Application: **12/303 Understanding the process of antiretroviral (ARV) treatment adherence amongst Jamaican men living with HIV.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTECH).

Your ethics application has been approved for three years until 11 January 2016.

As part of the ethics approval process, you are required to submit the following to AUTECH:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/research/research-ethics/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 11 January 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/research-ethics/ethics>. This report is to be submitted either when the approval expires on 11 January 2016 or on completion of the project.

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

A handwritten signature in dark ink, appearing to read 'Rosemary Godbold', with a stylized, flowing script.

Dr Rosemary Godbold
Executive Secretary
Auckland University of Technology Ethics Committee
Cc: Shakeisha Wilson shakeisha_w@yahoo.com

APPENDIX J: UHWI ETHICS APPROVAL



THE UNIVERSITY OF THE WEST INDIES

MONA CAMPUS
Faculty of Medical Sciences
Office of the Dean

Dean: Horace Fletcher, MB, BS, DM (O&G), FRCOG, FACOG
Professor of Obstetrics and Gynaecology

April 17, 2013

Dr. Moji Anderson
Department of Sociology, Psychology and Social Work
The University of the West Indies
Mona, Kingston 7

Dear Dr. Anderson,

Re: Ms. Shakeisha Wilson's research proposal entitled- Understanding the process of antiretroviral treatment adherence amongst Jamaican men living with HIV/ AIDS. ECP 165, 2012/ 13

Thank you for submitting the above mentioned proposal for review by the UHWI/UWI/FMS Ethics Committee.

The proposal was reviewed and approved, having met the required ethical standards.

Yours sincerely,

Professor Horace Fletcher
Chairman UHWI/UWI/FMS Ethics Committee

Mona, Kingston 7, Jamaica W.I.
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Fax: (876)977-2289, (876)977-3470