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A narrative analysis of the experiences of living with HIV for heterosexual men

Tanya Millard
Edith Cowan University

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**A narrative analysis of the experiences of living
with HIV for heterosexual men**

&

**The experience of living with HIV for heterosexual men in Western
Australia**

Tanya Millard

A report submitted in partial fulfilment of the requirements for the award of
Bachelor of Science (Occupational Therapy) (Honours).
Faculty of Computing Health and Science,
Edith Cowan University

Submitted September, 2009

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Tanya Millard

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Abstract

The number of heterosexual men presenting with Human Immunodeficiency Virus (HIV) is steadily increasing in Australia. A paucity of literature currently exists surrounding the experience of living with HIV for heterosexual men, with most information targeted towards gay men, injecting drug users (IDUs) and women. This narrative literature review examines the body of knowledge concerning the experiences of heterosexual men living with HIV. The findings of this review indicate that for heterosexual men, HIV significantly impacts on their physical, psychological and social well being. In particular, they struggle with social and intimate relationships, negotiating disclosure, managing their stigmatised identity, and accessing both medical and non-medical services. A lack of understanding of the experience of heterosexual men living with HIV has undoubtedly constrained the development of appropriate interventions for this group. As HIV has developed into a chronic condition, it is crucial to identify the type of support services required by different populations presenting with HIV and target these services accordingly. Knowledge gained through this review will further guide decisions for service providers, policy makers, and health professionals concerned with meeting the needs of heterosexual men living with HIV. It will also assist heterosexual men themselves in understanding how to live with HIV.

Tanya Millard
Dr Sonya Girdler
September, 2009

A narrative analysis of the experiences of living with HIV for heterosexual men

T.N. MILLARD & S.J. GIRDLER

Department of Occupational Therapy, School of Exercise, Biomedical and Health Sciences, Edith Cowan University, Perth, Australia

The number of heterosexual men presenting with Human Immunodeficiency Virus (HIV) is steadily increasing in Australia. A paucity of literature currently exists surrounding the experience of living with HIV for heterosexual men, with most information targeted towards gay men, injecting drug users (IDUs) and women. This narrative literature review examines the body of knowledge concerning the experiences of heterosexual men living with HIV. The findings of this review indicate that for heterosexual men, HIV significantly impacts on their physical, psychological and social well being. In particular, they struggle with social and intimate relationships, negotiating disclosure, managing their stigmatised identity, and accessing both medical and non-medical services. A lack of understanding of the experience of heterosexual men living with HIV has undoubtedly constrained the development of appropriate interventions for this group. As HIV has developed into a chronic condition, it is crucial to identify the type of support services required by different populations presenting with HIV and target these services accordingly. Knowledge gained through this review will further guide decisions for service providers, policy makers, and health professionals concerned with meeting the needs of heterosexual men living with HIV. It will also assist heterosexual men themselves in understanding how to live with HIV.

Keywords: HIV; Heterosexual; men, diagnosis experience; disclosure; stigma; physical impact; psychological impact; relationships; service access

Introduction

Over the past decade in Australia, there has been a progressive increase in the number of new Human Immunodeficiency Virus (HIV) diagnoses (ABS, 2008; NCHECR, 2008). Although the most common mode of HIV transmission in Australia continues to be through men who have sex with men (MSM), heterosexually acquired cases are increasing (ABS, 2008; Guy et al., 2007). Since the introduction of antiretroviral medications (ARVMs) in 1996, HIV has transitioned from a relative death sentence to a chronic, however disabling condition (Corless et al., 2005; WHO, 2004). As a result, understanding the way individuals with HIV negotiate their daily lives has become an important concern for researchers, health care providers and the community. A considerable body of research has examined the experiences and service needs of gay men, injecting drug users (IDUs) and women, however there is a paucity of research which examines the experiences of heterosexual men who are HIV positive. In order to better plan and develop effective services, an understanding of what it is like to live with

HIV for these men is first needed. The objective of this narrative review was to describe the experience of living with HIV for heterosexual men.

Methods

Literature Search

The following questions guided this review: What research has been conducted evaluating the experience of heterosexual men living with HIV in Australia; What is the impact of HIV on the lives of heterosexual men and how do they manage their positive status; and, What are the barriers and facilitators to well being and service access for heterosexual men living with HIV. In order to identify relevant literature, comprehensive searches were conducted of the following data bases: CINAHL; MEDLINE; PsycInfo; ISI Web of Science; ProQuest 5000 International; MEDITEXT; Health and Medical Complete; and, Family and Society Plus. The main search terms were: HIV, AIDS, heterosexual, men, Australia, disclosure, stigma, health, medication, relationships, social support, service access, depression, physical impact, symptoms, employment and fatherhood. With librarian assistance, all terms were truncated, exploded and adjusted to match the specific database being searched. Reference lists of all relevant articles were manually searched. Abstracts of identified articles were examined for relevance to the guiding questions. The review included literature dated from the early 1990's through to the year 2009, with a focus on literature from 1996 onwards (since the development of ARVMs). Studies were restricted to those conducted in Western countries. Due to the paucity of research in this field, it was impossible to exclude research of lower methodological quality.

HIV Prevalence in Australia

Review of the literature revealed that there is concern regarding changes in the epidemiology of new HIV diagnoses in Australia, with the annual incidence steadily increasing since 1999

after a decade of decline (ABS, 2008; NCHECR, 2008). While the number of new HIV diagnoses due to MSM has decreased, there has been a parallel increase in the number of new diagnoses attributed to heterosexual contact (Guy et al., 2007). The Australian Bureau of Statistics (2008) reported that in 2006, 24.8% of new HIV positive diagnoses were attributed to heterosexual contact, and of these, 85.4% were men. A large proportion of these heterosexually acquired cases have been linked with overseas travel to high prevalence continents such as Asia and Africa (Guy et al., 2008; Combs & Giele, 2009).

Nationally, the most dramatic increase in heterosexually acquired HIV has been reported in Western Australia (WA) and the Northern Territory, where a high proportion of new diagnoses has been linked to mining workers typically holidaying in Asia (de Tarczynski, 2008; Guy et al., 2008). In WA between 2002 and 2006, 76% of new HIV cases attributed to heterosexual contact were acquired overseas, with the majority of infections being acquired in Thailand and Indonesia (Combs & Giele, 2009). This finding is a cause for concern given that research which evaluated the planned sexual behaviours of Australians travelling to Thailand revealed that a substantial number of travellers intended to have casual sex while abroad (Mulhall et al., 1993). Further, males were more likely than females to report willingness to have casual sex with a Thai national, thereby, placing themselves at a high risk of exposure to HIV (Mulhall et al.). Alarming, of the high proportion of Australian travellers participating in casual sex while abroad, only half reported consistently using condoms (Hamlyn & Dayan, 2003). The consequences of these high risk behaviours are evident in the increasing prevalence of heterosexually acquired HIV (de Tarczynski, 2008; Guy et al., 2007).

Invisibility of HIV within Heterosexual Society

HIV in mainstream Australian society is both highly stigmatised and socially obscure. Although globally HIV is considered to be a heterosexual epidemic, in the Australian context, HIV is largely depicted as a 'gay man's disease' (Kippax & Race, 2003; Persson, Barton &

Richards, 2006). This attitude is reflected in education and prevention strategies which have predominantly targeted MSM and IDUs (Kippax & Race, 2003; Persson & Richards, 2008; WHO, 2004). People who are heterosexual and HIV positive are stereotyped as having participated in illegal or deviant activities such as promiscuity, injecting drug use and bisexuality (Persson & Richards, 2008; Kartikenyan, Bharmal, Tiwari & Bisen, 2007). As a result, HIV has receded in the consciousness of heterosexual Australians who consider HIV to be an issue only affecting 'others' who engage in 'risky' behaviours (Persson & Richards, 2008).

The invisibility of HIV in Australia has resulted in misinformation and fear regarding its transmission, and stereotypes and stigmatising attitudes towards those who have contracted HIV (Persson & Richards, 2008; Persson et al., 2006). Australian heterosexual men do not perceive themselves at high risk for contracting HIV and rarely consider the possibility of HIV infection as an outcome of sexual encounters (Craft & Serovich, 2008). Risk of infection is only considered relevant to people involved with a gay man, IDU or sex worker (Peart, Rosenthal & Moore, 1996). Interestingly, many heterosexual men believe they are able to choose 'clean,' 'safe' women and therefore, do not need to use a condom when participating in casual sex (Moore & Halford, 1997; Peart et al., 1996). Collectively, these findings highlight that among Australian heterosexual men there is widespread complacency about HIV.

The Experience and Impact of HIV

Diagnosis Experience

Receiving a HIV positive diagnosis is a devastating experience. It is frequently described as a 'pivotal' and 'life changing' event which many see as a death sentence (Katz, 1996; Kremer, Ironson & Kaplan, 2009). Due to the relative invisibility of HIV within Australia's heterosexual community, routine HIV testing is uncommon and rarely the way heterosexuals

receive a positive diagnosis (Persson et al., 2006). Amongst heterosexual men, illness is the most common reason for testing for HIV, and a positive diagnosis is often experienced as a shock (Grierson, Thorpe & Pitts, 2006; Persson et al). They find the diagnosis difficult to accept and report being angry, depressed, participating in self destructive behaviours, and contemplating or attempting suicide (Persson et al). Their shock at receiving a positive diagnosis is compounded by their limited knowledge of HIV, pre-existing stigmas of HIV as a 'gay disease' and limited understanding about the implications of a HIV diagnosis (Persson et al). At the time of diagnosis, many heterosexual men are asked unnecessary questions from health care workers regarding how they acquired HIV, and receive inadequate information and support (Persson et al). Clearly, negligent attitudes towards the risk of acquiring HIV amongst heterosexual men contributes to the difficulties they face dealing with a positive diagnosis.

Physical Impact

The physical impact of HIV is considerable. For people living with HIV, coping with a range of symptoms becomes a prominent aspect of daily life, and often presents barriers to participating in valued activities, occupations and roles (Tate et al., 2003). HIV related symptoms restrict social functioning, mental well being and physical health, negatively impacting on overall quality of life (Tate et al.; Jai et al., 2004; Mosack et al., 2009). Many individuals living with HIV experience additional health related problems, with a large scale Australian study finding that 55% of positive heterosexual male participants have a co-existing health condition, with hepatitis C and B, and haemophilia the most commonly occurring (Grierson & Misson, 2002; Persson, Richards, Barton & Reakes, 2009). The profound physical and psychological impact of HIV infection results in individuals experiencing a higher risk for depression and substance misuse (De Santis, 2008; Aranda-Naranjo, 2004). Australian research indicates that a substantially larger percentage of HIV

positive heterosexual men use most recreational drugs compared to the general population (Grierson & Misson, 2002).

Research evaluating the association between health and sexual identity for HIV positive individuals is inconsistent. Coleman (2003) reported that HIV positive heterosexuals experience poorer functional health status than HIV positive gay individuals. However, Mosack and colleagues (2009) found that heterosexual men report experiencing fewer symptoms than gay and bisexual men, and less symptom intrusiveness than women. They are also more likely than any other positive group to report regular fluctuations in their CD4 cell count (Grierson & Misson, 2002). Many heterosexual men feel that the change to their body as a result of having HIV has made them sexually unattractive (Grierson & Misson, 2002). Overall, findings from the literature suggest that the physical impact of HIV adds to the personal, social and emotional burden of HIV for heterosexual men.

Psychological Impact

A HIV positive diagnosis has a devastating impact on psychological well being. Depression is the most frequent neuropsychological disorder associated with HIV, experienced by approximately 50% of people diagnosed HIV positive (Tate et al., 2003; Judd et al., 2005). The fluctuating nature of HIV causes considerable stress and anxiety (Chidwick & Borrill, 1996; Fleishman et al., 2000). Heterosexual men living with HIV experience particularly high levels of distress (Coleman, 2003; Pakenham, Dass & Terry, 1996). For these men, fear, loneliness, uncertainty, suicidal ideations and anger are common and frequently result in problems with social and physical functioning, general health and overall well being (Pakenham et al., 1996; Kartikenyan et al., 2007; Benton, 1999; Judd et al., 2005). A survey of HIV positive Australians, the HIV Futures II study, found that 21% of heterosexual male participants reported taking medications for anxiety, and 27% for depression (Grierson & Misson, 2002).

Research regarding the impact of sexuality on the mental health of HIV positive men is conflicting. Coleman (2003) reported that heterosexual men with HIV experience poorer mental health than gay men. However, Orr and colleagues (2004) found that gay men were more likely to be given a diagnosis of a depressive or psychiatric disorder than heterosexual men. Research has indicated that heterosexual men are considerably less likely to be referred for mental health care or seek help and accept treatment than gay men, and are more likely to present with a substance misuse problem (Orr, Catalan & Longstaff, 2004; Newman et al., 2008). They also experience more complications with bereavement than gay men (Orr et al., 2004). General practitioners who work with HIV positive individuals describe heterosexual men as being less 'in tune' with their emotions compared to gay men (Newman et al.). It has been proposed that where gay men may be better able to express their psychological concerns, heterosexual men may not willingly disclose their mental distress, and subsequently, are not offered much needed mental health services (Orr et al.). Collectively, research has highlighted the pervasiveness of depression among heterosexual men living with HIV and the overall inadequacies of services to meet this need.

Disclosure

Disclosure of HIV status is complex and often referred to as a 'double edged sword' (Fesko, 2001). Individuals with HIV are required to conduct a 'cost benefit analysis' and negotiate choices such as to whom to disclose, how to disclose and when the right time to disclose is (Smith, Rosetto & Peterson, 2008; Persson & Richards, 2008; Cusick & Rhodes, 1999). Decisions relating to disclosure are a recurrent stressor, where disclosure may result in negative experiences such as stress (Persson & Richards, 2008), rejection (Smith et al., 2008), stigma and prejudice (Emlet, 2006; Smith et al.; Mayfield-Arnold et al., 2008), breaches of confidentiality (Persson et al., 2006) and feelings of shame and guilt (Emlet, 2006; Persson & Richards, 2008; Smith et al.; Holt et al., 1998). However, benefits from disclosing HIV

positive status include increased social and emotional support and the development of stronger bonds of intimacy (Cusick & Rhodes, 1999; Smith, et al.; Mayfield-Arnold et al.; Persson & Richards, 2008). Disclosure has also been linked to safer sex practices and increased adherence to antiretroviral medications (Mayfield-Arnold et al.; Crepaz & Marks, 2003). Collectively, research indicates that disclosure of HIV positive status has important health and social implications, and is therefore an important area for future research with heterosexual men.

Individuals may keep their positive status secret from friends, family and colleagues due to fear of anticipated stigma and the risk of losing their friends, jobs and partners (Kartikenyan et al., 2007; Mayfield-Arnold et al., 2008). The choice not to disclose positive status is particularly common amongst heterosexual men, where reluctance and fear of disclosing HIV positive status is compounded by the obscurity of HIV in heterosexual society (Persson & Richards, 2008). In fact, research has indicated that heterosexuals are more likely to conceal their positive status than any other group (Emlet, 2006), and one in ten Australian heterosexual men have not disclosed their positive status to anyone (Grierson & Misson, 2002). Further, males are considerably less likely to disclose positive status to new intimate partners than females (Cranson & Caron, 1998).

The choice not to disclose requires individuals to censor themselves out of fear of exposure. In a process referred to as 'passing', positive individuals present themselves as being as 'normal as everyone else' whilst concealing their status from all but a select few (Persson, Barton & Richards, 2008). Positive heterosexual men frequently develop rules surrounding disclosure and strategies for 'passing' including blaming periods of ill health on pre-existing conditions (Persson & Richards, 2008). Through restricting the number of people they disclose to, the individual protects themselves against stigma and discrimination, however the burden of carrying this secret may manifest into psychological and physical consequences (Mayfield-Arnold, et al., 2008; Persson et al., 2006; Greene, Frey & Derlega,

2002; Emlert, 2006). For heterosexual men with HIV, disclosure is clearly linked to the anticipation and experience of stigma. It is evident that they require further assistance and support to negotiate issues pertaining to disclosing their status.

Relationships

The prominent impact of HIV on social relationships has been widely described (Brashers, Neidig & Goldsmith, 2004; Smith et al., 2008). As HIV has developed into a chronic condition, personal and social relationships have become increasingly important for positive individuals (Greene et al., 2002). Health issues, secrecy, issues of disclosure, depression, and most importantly, stigma, present profound barriers to the maintenance of valued relationships and social support (Persson et al., 2006; Smith et al., 2008; Brashers et al., 2004). Many positive individuals withdraw from familial and social relationships, resulting in social isolation (Brashers et al., 2003). Conversely, some people living with HIV report improvements in relationships as a result of the challenges of living with HIV (Benton, 1999). However this was rarely reported in research involving heterosexual men.

The detrimental impact of HIV on the social relationships of heterosexual men is a theme repeated throughout the literature. Heterosexual men frequently feel isolated, lonely and overwhelmed by their positive status (Missildine, Parsons & Knight, 2006; Brashers et al., 2003; Persson et al., 2006). In addition, many perceive that they have lost their 'masculine' identity and report losing male friends (Missildine et al., 2006; Persson & Barton, 2007). For heterosexual men, the desire to conceal HIV positive status, avoid confronting questions, fears of rejection and the anticipation of stigma results in withdrawal from social and familial relationships (Missildine et al.; Persson & Barton, 2007). In fact, heterosexual men report receiving significantly less support from close friends and are also less likely to spend time with other HIV positive people than any other positive group (Grierson & Misson, 2002; Mosack et al., 2009; Grierson, Thorpe, Saunders & Pitts, 2004; Bartos & McDonald,

2000). These findings are of concern considering that amongst HIV positive individuals, avoidance coping and social isolation are associated with increased psychological distress (Fleishman et al., 2000). Collectively, research has highlighted the profound impact of HIV on the social relationships of heterosexual men.

Intimate Relationships

Seeking Relationships

Heterosexual men experience considerable stress and anxiety over their intimate relationships (Persson et al., 2006; Grierson & Misson, 2002; Brashers et al., 2004). They are required to negotiate anxiety over having HIV and guilt at the possibility of transmitting the virus to partners (Missildine et al., 2006). Recent Australian research has indicated that positive heterosexual men are more likely to be single than either positive women or gay men, and are more likely to report being sexually inactive than any other positive group (Grierson & Misson, 2002; Persson et al., 2006; Grierson et al., 2004). For single heterosexual men, many consider meeting a woman with whom to have an intimate relationship an 'impossible dream' (Persson et al., 2006). This finding is important considering that for HIV positive heterosexual men, partners are a primary source of emotional support (Grierson & Misson, 2002). Heterosexual men who are in relationships at the time of diagnosis are frequently concerned that their partner will leave them after disclosing their status, and many consider terminating relationships (Cranson & Caron, 1998). They are also less likely to remain in their existing relationships after receiving a positive diagnosis than females (Cranson & Caron, 1998).

Relationship Barriers

Heterosexual men with HIV face numerous and profound barriers to the establishment and maintenance of intimate relationships (Pakenham et al., 1996). For heterosexual men, having HIV results in feelings of being compromised as a man and a sexual being (Persson & Barton,

2007; Cranson & Caron, 1998). They report feeling as though they no longer have anything to offer in an intimate relationship and are therefore, undesirable (Missildine et al., 2006). Research indicates that heterosexual men are more likely to be concerned about relationship losses and strains than gay men (Jenkins & Guarnaccia, 2003). Due to their HIV positive status, heterosexual men confront psychosexual problems, questions surrounding sexuality, compromised ability to reproduce, and stigma which deters them from forming and maintaining intimate relationships (Missildine et al.; Brashers et al., 2003; Cranson & Caron, 1998; Persson et al., 2006; Persson & Richards, 2008). Further, they may not want to burden their partner and wish to avoid the issues pertaining to disclosure (Missildine et al.; Cranson & Caron, 1998; Persson et al.; Persson & Richards, 2008). Withdrawing from intimate relationships removes the risk of infecting partners, and protects partners from experiencing the emotional distress associated with being intimately involved with a person who has HIV (Missildine et al.; Brashers et al.). For these reasons, many positive heterosexual men experience reduced interest in seeking and maintaining intimate relationships and may resign never to have sex again (van der Straten, Vernon, Knight, Gomez & Padian, 1998; Persson & Barton, 2007).

Sex

Physical intimacy is clearly one of the domains most devastated by HIV for heterosexual men. With unprotected sex being the primary means through which HIV is transmitted between heterosexual partners, the ways HIV positive heterosexual men negotiate their intimate relationships and sexual needs is of primary concern (Persson et al., 2006; Grierson & Misson, 2002). For positive heterosexual men, the absence of a safe sex culture within heterosexual society compounds the stress associated with physical intimacy (Persson & Barton, 2008). In order to avoid transmitting HIV to sexual partners, they are required to examine and adjust both personal and sexual behaviours (Benton, 1999). Coping strategies

such as the avoidance of emotionally intimate relationships may be utilised to evade potential rejection (Missildine et al., 2006). For heterosexual men, the fear of infecting partners coupled with the desire for intimacy creates a high degree of tension, making sex a source of stress and confusion (Missildine et al; Persson & Barton, 2007).

Research indicates that many heterosexual men who enter relationships post HIV diagnosis are able to maintain a healthy, active sex life (Persson et al., 2006). However for those in serodiscordant relationships (positive male negative female) where positive diagnosis was received within existing relationships, many struggle to change established sexual practices (van der Straten et al., 1998; Skurnick et al., 1998; Persson et al.). Couples are required to employ behaviour modifications such as the use of barrier methods, withdrawal or undetectable viral load and also, to negotiate acceptable risk (van der Straten et al.). Research has indicated that between 25% (Skurnick et al.) and 53% (Semple, Patterson & Grant, 2002) of serodiscordant heterosexuals participate in unprotected sex. Clearly, heterosexual men require more support and information to manage the barriers, risks and desires associated with maintaining a safe and active sex life.

Stigma

For individuals living with HIV, stigma and discrimination are a common experience. Positive heterosexual men encounter stigma and discrimination on a frequent basis (Persson et al., 2006; Herek, Widaman & Capitano, 2005). In fact, it has been suggested that they experience higher levels of HIV related stigma than gay men (Coleman, 2004). Unlike gay men, for the majority of heterosexual men, stigma is a new concept which they are required to manage (Persson & Barton, 2007). For heterosexual men with HIV, the experience of stigma is linked with problems negotiating disclosure and as negatively impacting on social, familial and intimate relationships (van der Straten et al., 1998; Sobo, 1995). Society's attitudes that HIV is a 'gay disease' results in feelings of loss of identity and as though they no longer

belong in the heterosexual community (Persson & Barton, 2007). As a result, many positive heterosexual men withdraw socially (Persson & Richards, 2008).

Stigma further contributes to underutilisation of health services, avoidance of pursuing and maintaining employment and restrictions in community participation (Aranda-Naranjo, 2004; Herek et al., 2005; Benton, 1999). One in three Australian heterosexual men report being discriminated against at work as a result of their positive status (Grierson & Misson, 2002). Further, a high proportion of heterosexual men report experiencing less favourable treatment than other people when attending medical services (Grierson & Misson, 2002). Clearly, societal attitudes compound the difficulties of living with HIV for heterosexual men.

Impact on occupational roles and participation

As HIV progresses, an individual's ability to participate in valued occupations and roles is often restricted. HIV infection challenges men's ability to fulfil typical gender roles such as worker and provider (Persson & Barton, 2007). In order to focus on their health needs, men frequently withdraw from work and relationships (Sowell, Phillips & Grier, 1998). HIV positive individuals are more likely to be unemployed than their peers (Gibbie, Hay, Hutchison & Mijch, 2007). Over 50% of individuals living with HIV have stopped work at some time for HIV related reasons and of those who leave work, only a small percentage return (Grierson et al., 2004; Ezzy et al., 1999). For many positive heterosexual men, HIV has negatively affected their career plans (Grierson & Misson, 2002). Amongst Australian heterosexual men, reasons for ceasing work include stress and depression, fatigue and poor health (Grierson & Misson, 2002). Interestingly, heterosexual men are less likely to return to work following improved psychological health than heterosexual women (Grierson & Misson, 2002). For those who do maintain workforce participation, fatigue, difficulties concentrating and having to work fewer hours impacts their working capacity (Grierson & Misson, 2002).

Unstable workforce participation has numerous social and economic consequences (Pakenham et al., 1996; Grierson et al., 2006). Australian research has demonstrated that a considerable percentage of positive heterosexual men receive an income below the poverty line with many reporting difficulties paying for life's basics including clothing, food, housing, and utilities (Grierson & Misson, 2002). Further, research indicates that heterosexual men experience significantly greater difficulty meeting the costs of HIV/AIDS medications and other medications than gay and bisexual men (Grierson & Misson, 2002).

HIV also challenges men's reproductive ability. For heterosexual men, receiving a positive diagnosis impacts their views of becoming a father (Sherr & Barry, 2004). Research suggests that many heterosexual men with HIV still want children with fatherhood viewed as an important part of life which would provide them with a sense of 'normality', 'meaning' and 'something to live for' (Sherr & Barry, 2004; Paiva et al., 2003; Sunderam et al., 2008; Persson et al., 2006). However few HIV positive men receive any information regarding reproductive options (Paiva et al., 2003; Sunderam, et al.; Sherr & Barry, 2004). For these men, having children is complicated by the possibility of maternal infection and although 'sperm washing' has been developed, it is expensive, not readily available, and not entirely 'risk free' (Sunderam et al.; Paiva et al.; Persson et al.). Reproductive issues are further compounded by the difficulties men face finding a partner and anticipation of disapproval from others including their general practitioner (Paiva et al.). Very few men report having discussed reproduction with a health care provider and as a result, feel uninformed of their options (Sherr & Barry, 2004). This frequently results in heterosexual men feeling a sense of loss at not being able to fulfil the role of a father (Persson & Barton, 2007). Collectively, research indicates that heterosexual men's desires for fatherhood are relatively ignored in present health and family planning services. Men clearly require more support and information in order to make informed decisions regarding their options to have children and how to negotiate this safely.

Management of HIV Positive Status

Non-medical HIV Services

Support services are particularly beneficial for people living with HIV. Support services assist in relieving feelings of depression, physiological distress, anxiety, isolation and loneliness (Basta, Shacham & Reece, 2008; Kalichman, Sikkema & Somlai, 1996). However, heterosexual men are reluctant to utilise non medical HIV services (Kartikenyan et al., 2007; Persson et al., 2006; Beedham & Wilson-Barnett, 1995; Grierson & Misson, 2002). In fact heterosexual men are less likely to seek any type of social emotional support or support from the HIV community than any other group (Jenkins & Guarnaccia, 2003; Bartos & McDonald, 2000). They perceive that the services do not meet their needs as they are targeted towards, and predominantly used by gay men (Persson et al.; Beedham & Wilson-Barnett, 1995). Factors including a high number of gay clients, clinic appearance and a focus on gay men's health deter heterosexual men from using these services (Thorpe, Grierson & Pitts, 2008; Beedham & Wilson-Barnett, 1995). They feel that they do not 'fit in,' and are 'like outsiders' (Persson et al.; Beedham & Wilson-Barnett, 1995). The anticipation of stigma or rejection is also a significant barrier to seeking social support for individuals living with HIV (Brashers et al., 2004). As a result, heterosexual men generally obtain the majority of support through their general practitioner, receiving little or no support at the community level (Coleman, 2003; Grierson & Misson, 2002). Clearly, issues with the applicability of non-medical services for HIV positive heterosexual men require urgent attention.

Medical Services

HIV testing and treatment is readily and freely available throughout Australia (Department of Health and Aged Care, 2000). Early detection of HIV is important in preventing transmission and preserving immune function (Manavi, McMillan, Ogilvie & Scott, 2004; Hocking, Rodger, Rhodes & Crofts, 2000). Despite this, trends in late presentation of Acquired Immune

Deficiency Syndrome (AIDS) have demonstrated that Australian heterosexual males have the highest percentage of late presentation compared to all other groups (McDonald et al., 2003; Hocking et al., 2000; Lemoh et al., 2009; Guy et al., 2008). Late presentation is defined as receiving an AIDS diagnosis within three months of being diagnosed as HIV positive or, presenting with a CD4 cell count of less than 200 at the time of HIV positive diagnosis (Lemoh et al.). Late presentation amongst heterosexual males has also been reported in other countries including Scotland (Manavi et al., 2004), Italy (Borghetti et al., 2008), France (Delpierre et al., 2006), and Sweden (Brannstrom et al., 2005). This indicates that many heterosexual men who have engaged in high risk behaviours are failing to test for HIV infection in the early stages of disease progression. For these men, a late diagnosis of HIV may contribute to psychological distress, and result in difficulties coping (Kartikenyan et al., 2007). Further, a late diagnosis means that risk behaviours have not been adjusted in order to avoid transmission to sexual partners (Hocking et al., 2000). Clearly, fear of stigma and the attitudes held by Australian heterosexual men are resulting in underutilisation of HIV testing services. More systematic screening programmes are clearly needed in order to include populations perceived as low risk such as heterosexual men.

Medications

For the majority of people living with HIV, taking medications is a crucial part of daily life. The development of ARVMs has provided the opportunity for positive individuals to live longer with a higher quality of life, however they are required to adhere to rigorous medication regimes which are often challenging to maintain (Sowell et al., 1998). Non-adherence to ARVMs significantly reduces the benefits of treatment, and can result in the individual developing resistance, thereby reducing the efficiency of other treatments (Gibbie et al., 2007; Catz et al., 2000). Heterosexual individuals demonstrate a lower adherence to medications when compared to gay and bisexual men (Power et al., 2003; Wagner, 2002). A

high percentage of heterosexual men report difficulties taking ARVMs including remembering to take their medications, dosage timing, managing the side effects of the medications, organising meals, carrying medications and taking a large number of medications (Grierson & Misson, 2002; Wagner, 2002). Collectively, research indicates that for heterosexual men, difficulties managing ARVMs can detrimentally impact their health and well being.

Limitations

Although considerable research has focused on the experience of living with HIV, there is a paucity of research specifically examining the experiences of heterosexual men. As literature on the experience of living heterosexually with HIV for men in Australia is largely insufficient, much of the reviewed literature was based on anecdotal evidence. The majority of information pertaining to heterosexual men was located in studies which described and/or compared the experiences of different populations with HIV as opposed to specifically the experiences of heterosexual men. Research which focused on heterosexual men predominantly concerned ethnic minorities and other marginalised groups including IDUs.

Conclusion

As the prevalence of heterosexually acquired cases of HIV increases in Western countries, the risk that epidemics which have thus far remained relatively localised, will spread to mainstream population is becoming very real (WHO, 2004). For Australian men who acquire HIV overseas, there is the risk that they will return home and engage in sexual contact with casual or regular partners before HIV symptoms become apparent (Hamlyn & Dayan, 2003). In this way, the already increasing numbers of heterosexually acquired cases of HIV has the potential to escalate, bringing with it enormous health and economic costs. A lack of understanding of the experience of heterosexual men living with HIV has undoubtedly impacted negatively on attempts to develop appropriate interventions for this group. It is

crucial to identify the type of support services required by different populations presenting with HIV/AIDS and target these services accordingly. With the increasing number of new HIV diagnoses attributed to heterosexual men in Australia, it is critical that we consider the experience of living with HIV for this population. The findings from this literature review will assist service providers, policy makers, and health professionals concerned with meeting the needs of heterosexual men living with HIV. It will also assist heterosexual men themselves in understanding how to live with HIV.

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**The experience of living with HIV for heterosexual men in Western
Australia**

Tanya Millard

The experience of living with HIV for heterosexual men in Western Australia

Abstract

Over the past decade, Australia has witnessed a progressive increase in the number of new Human Immunodeficiency Virus (HIV) diagnoses, particularly amongst heterosexual men. While a considerable body of research has examined the experiences and service needs of HIV positive gay men, injecting drug users and women, there is a paucity of research examining the experiences of heterosexual men who are HIV positive. This paper presents the results of a phenomenological study which aimed to explore the experience of living with HIV for heterosexual men. In-depth interviews were conducted with five self-identifying heterosexual men who were HIV positive. Thematic analysis of interview data revealed three main themes in participants' experiences: shock at receiving a positive diagnosis, struggling to accept and deal with positive diagnosis, and learning to live with HIV. The findings highlight the uniqueness of the experience of living with HIV for heterosexual men and support the need for more targeted services to be developed for these men. Knowledge gained from this study will further guide decisions for service providers, policy makers, and health professionals concerned with meeting the needs of heterosexual men living with HIV. It will also assist heterosexual men themselves in understanding how to live with HIV.

Tanya Millard
Dr Sonya Girdler
September, 2009

The experience of living with HIV for heterosexual men in Western Australia

T.N. Millard, S. L. Girdler & S. Rowell

Department of Occupational Therapy, School of Exercise, Biomedical and Health Sciences, Edith Cowan University, Perth, Australia.

Over the past decade, Australia has witnessed a progressive increase in the number of new Human Immunodeficiency Virus (HIV) diagnoses, particularly amongst heterosexual men (ABS, 2008; NCHECR, 2008; Guy et al., 2007). While a considerable body of research has examined the experiences and service needs of HIV positive gay men, injecting drug users and women, there is a paucity of research examining the experiences of heterosexual men who are HIV positive. This paper presents the results of a phenomenological study which aimed to explore the experience of living with HIV for heterosexual men. In-depth interviews were conducted with five self-identifying heterosexual men who were HIV positive. Thematic analysis of interview data revealed three main themes in participants' experiences: shock at receiving a positive diagnosis, struggling to accept and deal with positive diagnosis, and learning to live with HIV. The findings highlight the uniqueness of the experience of living with HIV for heterosexual men and support the need for more targeted services to be developed for these men. Knowledge gained from this study will further guide decisions for service providers, policy makers, and health professionals concerned with meeting the needs of heterosexual men living with HIV. It will also assist heterosexual men themselves in understanding how to live with HIV.

Keywords: HIV; heterosexual; men; experience; service access

Introduction

Concern has been raised over changes in the epidemiology of new HIV diagnoses in Australia, with the annual incidence steadily increasing since 1999 after a decade of decline (ABS, 2008, NCHECR, 2008). Globally, HIV is considered a heterosexual epidemic, however in the Australian context, transmission occurs mainly through men who have sex with men (MSM) (ABS, 2008). Research has indicated that while the number of new HIV diagnoses attributed to MSM in Australia has been decreasing, there has been a parallel increase in the number of new diagnoses attributed to heterosexual contact (Guy et al., 2007). In 2006, 24.8% of new HIV positive diagnoses were attributed to heterosexual contact, and of these, 85.4% were men (ABS, 2008). Many of these cases of heterosexually acquired HIV have been linked with travel to high prevalence countries including Asia, Africa and India (Guy et al., 2008; Combs & Giele, 2009).

In Australia, HIV is largely considered a 'gay man's disease,' and is both highly stigmatised and socially obscure (Persson et al., 2006). Education and prevention campaigns

have reflected this attitude, predominantly targeting MSM and injecting drug users (IDUs) (Kippax & Race, 2003; Persson & Richards, 2008; WHO, 2004). Consequently, HIV has receded in the minds of heterosexual Australians who consider HIV to be an issue only affecting 'others' who engage in 'risky' behaviours (Persson & Richards, 2008).

Australian heterosexual men do not perceive themselves at high risk for contracting HIV and rarely consider the possibility of HIV infection as an outcome of sexual encounters (Craft & Serovich, 2008). They believe they are able to choose 'clean' 'safe' women and therefore, do not need to wear condoms while engaging in casual sex (Moore & Halford, 1997; Peart, Rosenthal & Moore, 1996). HIV positive heterosexual men are typically stereotyped as concealing a gay or bisexual identity, being promiscuous or an IDU (Persson & Richards, 2008; Kartikenyan, Bharmal, Tiwari & Bisen, 2007).

Research with positive heterosexual men has indicated that they experience problems with the psychological aspects of HIV. In particular, they have significant difficulties with emotional distress (Coleman, 2003; Pakenham, Dass & Terry, 1996; Kartikenyan et al., 2007; Benton, 1999; Judd et al., 2005), depression and anxiety (Grierson & Misson, 2002), bereavement (Orr, Catalan & Longstaff, 2004), and substance abuse (Grierson & Misson, 2002). Positive heterosexual men are less likely to disclose their mental distress and seek support than any other HIV positive group (Orr et al., 2004; Newman et al., 2008).

The social aspects of living with HIV are also problematic for heterosexual men. They have particular difficulties with disclosure, stigma and negotiating HIV within intimate relationships (Persson et al., 2006). Heterosexual men are more likely to be single and sexually inactive, and to conceal their positive status than any other positive group (Grierson, Thorpe, Saunders & Pitts, 2004; Emler, 2006). It has also been suggested that HIV positive heterosexual men experience higher levels of HIV related stigma than gay men (Coleman, 2004).

Positive heterosexual men experience difficulties managing HIV medications, side effects and symptoms (Grierson & Misson, 2002; Wagner, Remien, Carballo-Diequez & Dolezal, 2002), and are the least likely positive group to seek HIV related services and support (Jenkins & Guarnaccia, 2003; Bartos & McDonald, 2000). They perceive that HIV services do not meet their needs as they are targeted towards, and predominantly used by gay men (Persson et al., 2006; Beedham & Wilson-Barnett, 1995). As a result, many HIV positive heterosexual men struggle with their complex needs with little or no support.

For positive individuals in Western Australia (WA), HIV services are limited to Fremantle Hospital, Royal Perth Hospital and the Western Australian AIDS Council (WAAC). Unlike PozHet in Sydney and Straight Arrows in Melbourne, there are presently no heterosexually targeted services in WA. The specific aims of this study were to explore and describe the meanings associated with the experience of living with HIV for heterosexual men in WA, and the perceived support and service needs of these men.

Methodology

In order to explore the experience of living with HIV for heterosexual men, a methodology which allowed the subjective experience to be described was needed. As such, the qualitative paradigm using phenomenology was selected as the method for this study. Phenomenological approaches are applicable when there is a lack of understanding surrounding an experience or phenomena central to individuals' lived experience (LeVasseur, 2003). It allows the researcher to reveal the meaning associated with the experience of a particular phenomenon through in-depth, structured analysis of individuals' subjective experience (Crotty, 1996; Finlay, 1999).

Sample

Purposive sampling was used to recruit participants' through the WAAC. The WAAC is a not-for-profit community organisation providing a range of services for people living with HIV/AIDS, including prevention, treatment and care services. To be eligible for inclusion in

this study, HIV positive men had to identify as heterosexual, live in metropolitan WA and be able to communicate in English. Participants were aged between 27 and 46 and came from a variety of different cultural and socioeconomic backgrounds. They had lived with a HIV positive diagnosis for between 10 months and 13 years, with an average of five and a half years. All were clients of the WAAC. It is acknowledged that while all of the men in this study identified as heterosexual, some may have acquired HIV through sexual contact with men. The research protocol was approved by the Edith Cowan University Ethics Committee and a letter of support was supplied by the manager of Positive Services at the WAAC.

Data collection

Within a phenomenological framework, in-depth face-to-face interviews were conducted by the researcher with five HIV positive men who identified as heterosexual. Four interviews were conducted in the counselling rooms at the WAAC, and one was conducted in a participants' home. An interview guide was loosely followed throughout each interview (See Appendix A). The interview guide explored the men's experiences surrounding the physical, psychological and social aspects of HIV, and accessing HIV related services.

Data analysis

All interviews were transcribed verbatim and analysed using Colaizzi's method of qualitative data analysis (Colaizzi, 1978). Data was initially analysed by the researcher who extracted significant statements from the data, and described the meanings elicited from the statements. Extracted meanings were then organised into clusters of themes. In order to validate these themes, the researcher then returned to the original data to ensure that they were directly derived from the data. The researcher met with an expert in qualitative analysis and together, they reviewed the data and negotiated each theme and theme cluster until consensus was met. This process resulted in the emergence of a framework which supported the description of the participants' experiences of living with HIV. The researcher then integrated the themes into an exhaustive description and validated the findings. Due to the small number of participants,

redundancy of descriptions was not reached. Trustworthiness of the data was achieved through member checks after each interview and with one participant following the completion of data analysis. An audit trail describing the processes utilised during data collection, analysis and interpretation was recorded by the researcher (Guba, 1981).

Reflexivity, journaling, bracketing, and cross checking the findings and data analysis methods with an expert in qualitative research were also employed to enhance the trustworthiness of the data (Guba, 1981).

Findings

The transitional nature of the experience of being a heterosexual man with HIV emerged from the interview data and provided a comprehensive framework which supported the description of this phenomenon. Three transitional phases emerged from the interview transcripts: *initial diagnosis; struggle to accept and adjust to a positive diagnosis; and, learning to live with HIV*. Each phase encompassed numerous sub-themes which are outlined in Table 1 (See Appendix B), and described in further detail below. In presented findings, pseudonyms are used.

Phase one: Initial diagnosis

Initial diagnosis refers to participants' experiences of receiving a positive diagnosis and encompasses their shock, perceptions of HIV as a 'gay man's disease' and a death sentence, and fear of disclosure. Many of the men described receiving limited information and support at the time of diagnosis. This time was marked by fear, anxiety and confusion.

Shock at receiving a HIV positive diagnosis

The overwhelming shock of receiving a HIV positive diagnosis dominated participants' descriptions of this phase. "You feel like everything has crumbled. I was shocked, devastated," Adam said. Of the five participants, three tested for HIV at the suggestion of a doctor, one tested as a result of routine testing, and one requested the test for reasons unknown. Only one participant described anticipating a positive diagnosis, however, he still

reported being shocked. Collectively the men reported feeling “numb” and struggling to process information given by health providers during this time:

Everything they said to me that day just flew over the top of my head. She spoke to me for half an hour afterwards and nothing soaked in (Matt).

Many of the men described feeling isolated and overwhelmed during this time.

Perceptions of HIV as a 'gay man's disease'

Shock at being diagnosed HIV positive was strongly related to the men's perceptions of HIV as a “gay man's disease”. The men recounted having limited knowledge about HIV and being ignorant of modes of transmission. They described having the mind set that HIV was mostly acquired by gay men. For example, Chris explained his confusion at receiving a positive diagnosis:

Once I heard about it I thought... Ok I'm not gay, how did I get it? Because it was in my head that if you're gay you get it, that's how you get it.

Some of the men identified that while they were aware of other ways of acquiring HIV such as injecting drug use and unprotected sex with prostitutes, they perceived MSM to be the most at risk. They appeared to believe their heterosexuality would protect them from HIV:

I thought it was all just gay people... well I knew it was from drug use too but I thought it was just more gay (Matt).

Overall, for the men in this study, their conceptualisation of HIV as a gay disease seemed to add to their shock at receiving a positive diagnosis.

Belief that HIV was a death sentence

The men discussed having inaccurate beliefs about the prognosis of being HIV positive. They unanimously described the initial perception of HIV as a death sentence, and as a result, recounted feeling “gutted” and “devastated”. As Joel explained: “I thought well that's it, you know, I've caught this hideous disease that's gonna kill me.” Similarly, when asked about his knowledge of HIV prior to diagnosis, Chris responded: “Absolutely nothing. I thought if you catch HIV you are going to die in six months' time.” During this initial diagnosis phase, the

overwhelming shock at being diagnosed HIV positive was compounded by the men's belief that they were going to die soon.

Fear of disclosure

During the initial phase following diagnosis, disclosure was typically avoided. Participants reported feeling so overwhelmed by the struggle to comprehend the implications of a HIV positive diagnosis, that disclosing to anyone was simply "too hard". Their reluctance to disclose was largely attributed to fear of rejection and discrimination. For many of the men, the perception of HIV as a gay man's disease was a significant barrier to disclosure, as highlighted by Chris:

Just because its sexual...It's just in peoples' heads, a lot of people like me have never heard about it, never had any experience with it, they don't know much about it... Alright I'll tell my family. They will ask, 'Well have you been sleeping with other men?' That's what they are going to think. How am I gonna sit down and explain to them, 'No, look this can happen different ways'... But who's gonna believe it?

Similarly, Ben reflected on societies stigmatising attitudes towards people who are HIV positive:

You don't want people to think less of you ... you're going to get put in some sort of category... you're either going to be a junkie or you're going to be gay or something.

Phase two: Struggle to accept and adjust to a positive diagnosis

This phase encompasses the men's experiences in the time immediately following their positive diagnoses, and includes participation in reckless and self destructive behaviours, struggling with emotions, disclosing to a select few, managing HIV within intimate relationships, struggling with a changed identity and experiencing difficulties with medications.

The time following initial diagnosis was ominous. The men described it as being "a really dark time" marked with depression, anxiety, confusion and loneliness. The unexpected nature of their diagnosis made it extremely difficult for them to accept and adjust to their

positive status. During this phase, men typically delayed seeking help. The limited information they had received at time of diagnosis and their difficulties processing this information, resulted in them continuing to believe that HIV was a death sentence. Their thoughts were consumed by HIV and their lives were dominated by the news of their illness:

It use to effect my whole life...it was definitely a long time when you know it was everything, everything was revolving around that (Ben).

During this phase, Chris described feeling as though he had nothing left to live for. Believing he had only “six months to live”, he left the country to “die in peace”.

Self destructive and reckless behaviours

During this phase the men commonly recounted participating in reckless behaviours such as increased drug and alcohol use, and placing themselves in high risk situations where death or serious injury was possible. Some of the men described using drugs and alcohol to escape the reality of being HIV positive:

It was painful, confusing and distressing and so the diagnosis and all that turmoil pushed or exacerbated my drug use, it really took off (Joel).

Ben described behaving recklessly in order to punish himself for acquiring HIV:

I was probably really pissed off with myself over it so [I was] out to hurt myself... I had several occasions when I woke up in hospital from drug overdoses around that time and I used to go fishing in the Northern Territory. When no one else would I would stand up to here [gestures to waist] fishing and wasn't too concerned about [the crocodiles] and what could happen.

Struggle with emotions

The men described struggling with the psychological impact of receiving a positive diagnosis. Negative emotions occurred primarily as a result of the fear and uncertainty surrounding their diagnoses and their sense of loneliness and isolation:

I felt quite isolated because it wasn't something I could discuss with parents or friends and so, very anxious as to what it meant to live with HIV and what the future held. It was a really dark time (Joel).

The men also discussed their anger and frustration at having acquired HIV. Adam for example, described his frustration at not knowing how he came to be HIV positive:

You look back into your life think harder and harder and see maybe where did I go wrong or something? And there's actually no answer to that.

During this phase, depression was experienced by all of the men and had a considerable impact on their ability to participate in valued occupations and roles:

Some days I get really depressed and I just sit at home all day and just do nothing when I could be out there doing things with my partner and my children or finding a job or something (Matt).

Chris also admitted that his emotional struggle resulted in him contemplating suicide:

I knew nothing, so I said, 'I want to kill myself'.

Despite knowing that they were depressed, the men were unanimously reluctant to seek help with their mental distress, wishing to simply "deal with it" themselves:

I just try and keep it to myself cause yeah I don't want to be diagnosed as depressed or anything like that (Matt).

Disclosing to a select few

Following the early period of non disclosure, the men's struggle to accept and adjust to their diagnoses commonly led them to disclose their HIV positive status to a select few whom they believed could "handle" the news and provide support. These people were typically family members or close friends. Disclosure during this phase was a coping mechanism for the men, with reasons for disclosure being "to have someone to talk to", "needing to tell someone," "for support", and "to be honest and open". Disclosure was also reported in situations where they felt they "couldn't withhold the information," such as within intimate relationships and to health care providers. The men described careful consideration of who to disclose to, the consequences this would have, and how they anticipated the person would react. Participants felt that it was this careful consideration that contributed to the generally positive reactions they received. Joel provided this justification for his positive experiences disclosing to others: "I guess that's because it's a carefully managed and moderated thing".

Several men described instances of discrimination from health professionals after receiving their positive diagnoses or disclosing their positive status. They gave examples of being treated differently to other patients and being treated last. Joel described the reaction of his dentist to his disclosed status:

The dentist came out with full gown, gloves, goggles, you know the whole bit, and I just felt humiliated... I have a new dentist now, but I haven't disclosed to him.

Similarly, Chris described the reaction from the doctor who diagnosed him with HIV:

I went to his office and sat and waited for an appointment because that was normally the way I did it. He came out and asked me, 'Why didn't you call before you came here, you should call the next time you come and make an appointment'. I was shocked because when he didn't know I was HIV positive, I could just sit there and wait for a visit.

The men who had experienced stigma or discrimination from health care professionals were reluctant to disclose their positive status in similar situations unless it was absolutely necessary. Their negative experiences resulted in them compartmentalising their health care needs into HIV related and non-HIV related issues, having different doctors for each.

Managing HIV within intimate relationships

The ways the men managed HIV within their intimate relationships was highly individualised and complex. Three of the men were in relationships at the time of diagnosis; two were single and actively seeking relationships. This variation in relationship status made it difficult to capture the essence of this sub-theme. Collectively however, the men described considerable stress and anxiety over their sexual relationships following a positive diagnosis. Joel provided this explanation: "[I questioned], would I ever have a partner again, you know? I felt unlovable and defective." During this phase, the men either chose to avoid sexual relations or were in denial and continued to engage in unprotected sex with their negative partners.

The men who were in established sexual relationships at the time of diagnosis described contrasting experiences. Adam, who received a positive diagnosis at the same time as his wife, described the detrimental impact of HIV on his marriage: "It really pushed us

apart.” He described having completely ceased sexual intercourse with his wife since receiving a positive diagnosis. Conversely Matt, whose negative de-factor partner was with him at the time of diagnosis explained the positive impact of HIV on his relationship: “It’s probably brought us together a bit communication wise”. However, he also reported continuing to have unprotected sex with his negative partner. Joel also continued engaging in unprotected sex with his negative partner:

I was seeing someone at the time, having unprotected sex. You get diagnosed and then all of a sudden you have to start wearing condoms. And she’s like ‘Well what’s that all about?’ I was so devastated and so upset and just couldn’t come to grips with disclosing to my partner at that time.

So it was hard, I tried to carry on, and thought well I’ll withdraw [but] she wouldn’t facilitate that.

Clearly, the men who were in sero-discordant relationships (positive male negative female) at the time of diagnosis struggled to modify established sexual practices, and as a result, placed their partners at risk of acquiring HIV.

For the men who were single at time of diagnosis, the prospect of finding a partner seemed remote and “too difficult”:

I can’t go into pub and go, ‘Hey can you be my partner, you know I’m HIV positive’. Who’s going to say, ‘Ok, that’s fine...I will love you too’. That’s bullshit you know (Chris).

Similarly, Ben explained:

I didn’t want to deal with it so I didn’t. You know I didn’t get involved with anyone because it was going to be too difficult.

Consequently, these men had resigned themselves not to pursue sexual relationships.

Struggling with a changed identity

During the phase immediately following diagnosis, the men commonly described disengaging from previously enjoyed occupations and roles. They reported feeling as though HIV had changed them. Matt explained: “I’m just not the person that I should be sometimes.” Some of the men described having lost the desire to socialise or being more selective in their

friendships. Reasons for withdrawal from friendships included avoiding disclosure, fear of exposure, and feeling as though they could no longer “fit in”:

I had a lot of friends. Today I have none...I've got this problem and I just want to have the least friends as possible in case one day everyone knows [I'm HIV positive]... Its not that I don't want [to fit in], but it just doesn't allow you, you know what I mean, its just something that does not allow you (Chris).

The invisibility of HIV within heterosexual society further contributed to the men's withdrawal from friendships. Some of the men described being unable to disclose to “blocky mates” as they believed they “would not understand”. Further, they did not believe the relationships they had with their male friends permitted discussions of such a topic. In order to avoid these issues, many of the men found it easier to withdraw from these relationships.

Difficulties managing medications

During this phase, many of the men began taking antiretroviral medications (ARVMs). They discussed initially experiencing disabling side effects including nausea, dizziness and diarrhoea and for many of the participants, these symptoms had a detrimental impact on their ability to work. Joel reflected on his initial experiences with his medications:

I had to be careful how I took my medication...some days I'd have breakfast and then I'd have the pill and then half an hour later by the time I got to work I'd be throwing up on the road side.

Chris recounted losing his job as he was taking too many sick days struggling with nausea and dizziness:

I got sick and so I called and said 'I'm not coming in'. They said they couldn't accept that.

Phase three: Learning to live with HIV

During this phase, participants described developing various personal strategies to assist their management of HIV. These strategies facilitated their adaptation to a HIV positive diagnosis, allowing them a greater sense of control, and the ability to manage their HIV status relatively successfully in daily life. For those who were recently diagnosed, these strategies were mostly confined to managing medications and ‘passing’ as normal. Others had developed complex

strategy schemas surrounding disclosure, intimate relationships, their changed identity, and seeking support.

Adjusting to a changed identity: Getting on with it

The men in the study commonly described feeling like their identity had been altered by HIV, as though they weren't the same person they used to be. As Ben explained:

I sort of switched off something at that point and I've sort of come around to realising a lot since then but I haven't been able to switch it back on sort of.

Similarly, Adam said:

You're always an outsider, even though you know most people don't know about it but deep down inside you feel I'm not the person I used to be. Yeah, I really feel different.

For many of the men, this internalised change resulted in them adjusting their behaviours.

They either developed strategies to integrate and manage HIV within their lives, or appeared to isolate themselves so they did not have to deal with the problems HIV posed.

Collectively however, the men described reaching some level of acceptance of their diagnoses during this phase, as highlighted by Joel:

For the first 12 months it was pretty hairy but after that when I began to realise that I could still lead a normal life, a lot of that fear sort of fell away.

They described attitudes such as "what can you do", "you have to carry on", and "it's just the way it is". Many of them believed that if they took their medications and were healthy, they would "be ok". They were generally positive about the future:

I'm hopeful that I may see a cure at some stage. But other than that, I mean what are you gonna do? Are you gonna call it quits or just get on with it? (Joel).

Strategies for managing medications

The men described trialling different strategies to reduce the impact of the side effects from their ARVMs. These strategies included adjusting the timing of their medications and meals, and moderating the amount of food they consumed prior to and after taking medications.

These strategies were largely successful with only Ben describing ongoing nausea as a

problem. The men described a general dislike of the need to take medications every day. Matt described tricking himself in order to take his ARVM:

I try and forget about it as much as I can and just take my medication just as they're antibiotics or something, I don't take them as though they are HIV medication.

However, this was in contrast to Adam who described looking forward to taking his medications as he saw them as a lifeline he was privileged to receive:

You are always looking forward to that, that's the lifeline. You always have to take the drug to feel strong and healthy.

Joel described developing a strategy to ensure his need to take medications did not impinge on his social life:

[I keep] a little kit in the car just under the seat with a toothbrush, toothpaste and my pills (laughs) so if I'm out late or stay at a mate's place or whatever I've got my medication with me.

Strategies for disclosure

The two men in the study who had lived with HIV for the longest time described specific and highly regulated rules and strategies surrounding disclosure. Ben who had lived with HIV for more than 10 years recounted "getting the cold shoulder" and losing friends as a result of disclosure. He explained his frustration at being treated differently following disclosing his status: "I've sort of gotten sick of having people feel sorry for me ... I'd rather just be normal you know." For this reason, Ben described choosing not to disclose anymore.

Joel who described having numerous intimate relationships since receiving his HIV positive diagnosis had developed a highly tuned strategy for disclosing within those relationships:

My strategy is I figure I've got three months to decide whether or not this relationship is going anywhere and if it is, then I would disclose... and of course in that three month period I keep them absolutely safe, there's no unprotected sex or anything high risk.

He clearly perceived disclosure as a threat to his relationships, explaining the reason behind this strategy being:

I feel if I disclose up front, people won't get to see me or know me, they would just see the disease

(Joel).

The other men in the study who had been living with HIV for a shorter period of time had not disclosed to anyone outside of their select few.

Strategies for 'passing'

Collectively, the men spoke about developing various strategies allowing them to avoid unwanted exposure and to "pass" undetected in society. These strategies included concealing signs of illness from their family, children and friends, and also attributing the need for medications and regular medical appointments on other health conditions. Joel related his strategy for concealing his status:

If anyone's ever been really nosy and wanted to know why I take medication or why I go to the doctor all the time I just say it's cardiac related or something like that.

Similarly, Chris described how he concealed his status from his family:

Even if I'm sick I don't let them see I'm sick, I do whatever I used to do. Even if I'm in pain I'll pretend I'm not in pain or anything, I'm still the same person. I never show them any sort of sign that I'm sick or anything.

Seeking support and accessing services

An integral part of learning to live with HIV was seeking support and accessing services.

Knowledge regarding the prognosis of a HIV positive diagnosis was important to all participants. Accurate knowledge of their prognoses allowed the men to prepare for the future and disprove the myths that had pervaded. The hospitals and WAAC were collectively viewed as important sources of information and support, particularly by the men who had disclosed to limited others. Many of the men expressed gratitude towards the staff at the WAAC:

The AIDS council was the only place that helped me through this, big time. It was them, truly them and I owe them (Chris).

For some of the men, the WAAC was viewed as a lifeline which had reassured and supported them when they were desperate and alone. “They were fundamental in keeping me afloat,” Joel said.

Whilst they were appreciative and generally happy with the services they had received, some of the men described feeling like “outsiders” within these HIV services, like they did not “fit in.” They expressed feelings that the services were predominantly targeted towards gay men:

Anywhere to do with HIV has always got the posters and brochures and that sort of thing for the assistance, information or whatever for gay men and that’s it... They are more about gay men than straight men... like this (the WAAC) is for gay men basically... yeah but they’ll see me too (Ben).

The men described these perceptions as the main reason they did not attend support groups.

Chris explained:

That’s why I’m not attending some of these groups and again, no disrespect, but I don’t really fit in that group. You know, I’m not against them but I don’t fit in with them.

The men expressed a belief that while many of the needs and issues of gay men living with HIV were likely to be similar to their own, being heterosexual and positive made them different. The men felt that they were missing valuable information and support due to lack of access to other HIV positive heterosexual men. Joel spoke about his desire to meet other positive heterosexual men:

I kept saying for a long time you know where’s all the heterosexual guys, I wanna meet them, I wanna relate to them, I wanna do stuff with them, and there was nothing. I found you know there were a couple of events where they were supposed to be heterosexual and the guys weren’t, they were bi or gay.

The men articulated concern that their desires for heterosexual based services and supports would be seen as being homophobic, a label they resisted. This fear of being labelled prevented them from expressing their concerns and desires to others. The men found it easier to simply not attend support groups and to engage with HIV services as little as possible.

Discussion

Overall, the findings from this study revealed the uniqueness of the experience of living with HIV for heterosexual men in Western Australia. For these men, the relative invisibility and obscurity of HIV in Australian society, and community perceptions of HIV as a '*gay man's disease*' impacted almost every aspect of their experience. These findings reflected those of Persson and colleagues (2006 & 2009), who also described the complexity of the experience of living with HIV for heterosexual men in Australia. Although many HIV related issues are consistent across all groups of positive individuals, many of these issues are ascribed alternate meanings and prioritised differently by heterosexual men (Persson, Richards, Barton & Reakes, 2009). As described by Persson and colleagues (2009), there appears to be a 'cultural difference' between being HIV positive and gay or heterosexual.

The phased nature of the experience of living with HIV has been described in previous qualitative research (Baumgartner, 2007; Persson et al., 2006) and is consistent with descriptions of adjustment to other chronic or serious illness such as cancer, vision impairment, multiple sclerosis and arthritis (Salick & Auerbach, 2006; Livneh, Lott & Antonak, 2004; Kralik, Brown & Koch, 2001). In a qualitative study evaluating the coping responses of people with HIV, Chidwick and Borill (1996) found that participants' ability to cope with their HIV positive diagnoses developed over the course of living with the virus. The longer the individual had HIV, the greater their ability to adapt and integrate their positive status into their identities (Baumgartner, 2007). Similarly, Kylma and colleagues (2001) referred to the experience of living with HIV as a process requiring positive individuals to continuously deal with their evolving self and new life with HIV/AIDS. Clearly, living with HIV requires individuals to undergo a constant process of negotiation where the progression from desolation to acceptance and resolution is individualised and complex (Persson et al., 2006).

The heterosexual men in this study experienced considerable difficulties managing HIV within their sexual relationships, a finding reflected in previous research with heterosexual individuals (van der Straten et al., 1998; VanDevanter, Thacker, Bass & Arnold, 1999; Missildine, Parsons & Knight, 2006; Persson et al., 2006; Skurnick et al., 1998; Grierson & Misson, 2002; Brashers et al., 2003; Cranson & Caron, 1998). Problems with sexual relationships are common for people coping with other chronic illnesses such as cancer, multiple sclerosis and arthritis (Sundquist & Yee, 2003; Khan, 2002; Bird & Thorpe, 2003). However, these problems are typically associated with physical or emotional barriers. For serodiscordant couples, difficulties within sexual relations are compounded by the risk of infecting the negative partner, presenting an added barrier with potentially, dire consequences (Missildine et al., 2006; VanDevanter et al., 1999).

The men in this study described either avoiding sexual relations or using denial to continue participating in unprotected sex. This finding reflects those of previous qualitative research which has also documented the behaviours of HIV positive heterosexual men within sexual relationships (VanDevanter et al., 1999; Missildine et al., 2006; Semple, Patterson & Grant, 2002; Skurnick et al., 1998). Persson and Richards (2008) suggest that the absence of a safe sex culture within heterosexual society compounds the stress associated with physical intimacy for heterosexual men who are HIV positive. Clearly, there is a critical need for targeted behavioural interventions, support and information encouraging heterosexual men to safely manage HIV within their sexual relationships.

The men's decisions regarding disclosure and the way they approached disclosure varied over the phases. Consistent with previous qualitative research, the men in the present study described a policy of limited or non-disclosure following initial diagnosis due to the fear of judgement and discrimination from others (Mayfield-Arnold, Rice, Flannery & Rotheram-Borus, 2008; Persson et al., 2006; Holt et al., 1998; Baumgartner, 2007). Holt and colleagues (1998) suggested that by initially avoiding disclosure, individuals have time to

come to terms with their diagnoses without the added stress of dealing with others' reactions. As others have found, disclosure for the men in this study was later used as a coping mechanism with reasons for disclosure primarily being to receive support and inform others of risk of infection (Holt et al., 1998; Mayfield-Arnold et al., 2008; Persson et al., 2006). Clearly, disclosure is an important component in successfully accepting and adjusting to a HIV positive diagnosis.

In this study, the men's difficulties disclosing to others were undoubtedly compounded by the stigma and obscurity of HIV within heterosexual society. Persson and colleagues (2006) found that participants in their Straightpoz study "fiercely guarded their secret," and attributed this to the complete absence of a HIV culture within mainstream Australian society (Persson & Richards, 2008, p. 75). The men's reluctance to disclose out of fear of being labelled as gay or an IDU also reflected the findings of Persson and colleagues (2006). The absence of HIV within mainstream society clearly complicated disclosure for positive heterosexual men.

The men's unwillingness to seek support and information is consistent with other research into men's health related behaviours (Addis & Mahalik, 2003; Galdas, Cheater & Marshall, 2005; Moller-Leimkuhler, 2002). Addis and Mahalik (2003) suggest that the reason for men's reluctance to access health services is due to incongruence between available services and traditional masculine roles. Heterosexual men's reluctance to access supports and services has also been reported in HIV literature (Kartikenyan et al., 2007; Persson et al., 2006; Grierson & Misson, 2002). The men's descriptions of feeling like "outsiders" within currently available HIV services reflect the findings of previous qualitative research (Persson et al; Beedham & Wilson-Barnett, 1995; Thorpe, Grierson & Pitts, 2008). For heterosexual men with HIV, the anticipation of stigma or rejection has been identified as a significant barrier to seeking support (Brashers, Neidig & Goldsmith, 2004). These findings highlight the

need for the development of more appropriate supports which are targeted towards heterosexual men in order to minimise the barriers to service access and utilisation.

Due to the qualitative nature and the small sample size of this study, the results must be interpreted with caution. Redundancy in descriptions was not achieved due to the time frame available for an honours project. In addition, participants were recruited through the WAAC and for this reason, may not reflect the experiences of heterosexual men who do not access this service. The findings from this study cannot be generalised, however similarities in the experience may be identified.

Conclusion

This study provides valuable insight into the experience of living heterosexually with HIV for men in WA. Additionally, the finding highlights the prominent impact of the invisibility of HIV within mainstream heterosexual society, and the numerous problems this presents. Clearly, heterosexual men living with HIV in Australia present with unique issues. It is crucial that we gain a better understanding of their experiences and support needs in order to begin to develop targeted, applicable and effective services and supports for this vulnerable and marginalized population.

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Appendix A

Interview Guide

Demographic Information

Age:

Employment status:

Year of HIV+ diagnosis:

Co existing illnesses:

Relationship status:

Country of origin:

Involved in any other research projects?

Q: What has been your experience living with HIV?

1. What was your experience of receiving a HIV+ diagnosis

Probes

- *Why tested, late presentation??*
- *Circumstances surrounding*
- *Knowledge of HIV prior to diagnosis*
- *Reaction*

2. Are you confident in disclosing your positive status to others?

-Have you disclosed to anyone?

-What has been your experience disclosing your status to others?

Probes

- *To you family, partner, male friends*
- *Reason for disclosure or non disclosure*
- *Reactions from others*
- *Experience of stigma and discrimination*
 - *From who: circumstances surrounding, why?*
 - *Feelings/ reaction*

Do you know many other people living with HIV?

3. How has having HIV impacted on your relationships with family, friends, colleagues etc?

Probes

- *Relationship changes due to disclosure, health reasons, withdrawal etc*
- *Positive or negative impact*
- *Why?*

4. How has having HIV impacted your intimate relationships?

Probes

- *Perusal/ maintenance of relationships*
- *Managing HIV within relationship – sexual intimacy*
- *Disclosure to sexual partners (always, sometimes, never)*
- *Feelings as a man in the relationships (masculinity)*
- *Having children*

5. What has been the emotional impact of HIV?

Probes

- *Experience any depression, anxiety, mood swings etc*
- *How managed*
- *Impact on daily life*

6. What is your experience managing the medications/symptoms of HIV?

Probes

- *Attending appointments*
- *Taking medications (side effects)*
- *Impact on daily life*

7. What has been the physical and functional impact of HIV...are there things you would like to but cannot do or things you gave up for HIV related reasons?

Probes

- *Impact on roles: father, husband, worker etc*
- *Impact on social, leisure, work participation*
- *How has it impacted on other things you like to do such as partying, playing sport, going out at night, recreational drug taking or drinking etc?*

8. What if any forms of support do you (or have you) received to assist with the management of your HIV and what would you like to see developed for heterosexual men living with HIV?

Probes

- *What sort of services*
- *How much use – why/why not*
- *What do you like/dislike about the services on offer*
- *What is most useful service and why?*
- *What sort of services would be beneficial for you*
- *What services would be useful for others?*

9. What if anything, would make your journey with HIV easier or at least more manageable?

10. Is there any more you would like to say about your experience living with HIV as a heterosexual man?

Appendix B

Table 1

Phases	Sub-themes
Initial diagnosis	Shock at receiving a HIV positive diagnosis Perception of HIV as a 'gay man's' disease Belief that HIV was a death sentence Fear of disclosure
Struggle to accept and adjust to a positive diagnosis	Self destructive and reckless behaviours Struggle with emotions Disclosure to a select few Managing HIV within intimate relationships Struggling with a changed identity Difficulties managing medications
Learning to live with HIV	Adjusting to a changed identity: Getting on with it Strategies for managing medications Strategies for disclosure Strategies for 'passing' Seeking support and accessing services

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