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Abstract

This paper examines the way gender shaped the health behaviours, health care experiences and narratives of HIV positive men initiating antiretroviral treatment in South Africa. We conducted participant observation and in-depth, semi-structured interviews with 8 men enrolled in a public HIV treatment programme in a rural health district in KwaZulu Natal. We also interviewed their family members and programme staff. The study found that men's narratives and experiences of ART were complex. Descriptions of control and coping juxtaposed with low self-esteem and guilt. Improvements in health following treatment increased optimism about the future but were readily undermined by men's concerns about being unable to meet strongly gendered expectations in relation to family and work. Alcohol use and abuse by men themselves or by family members was found to be an important issue influencing disclosure, uptake and adherence. Given messages discouraging alcohol use during treatment, men reported self-imposed delays to enrolment while they tried to stop or reduce alcohol use, although none had sought advice or professional help in doing so. Men also felt very threatened by alcohol abuse by family members fearing accidental disclosure, insults and violence. With regards to health providers, men held strong views as to appropriate and professional behaviour by programme staff, particularly regarding confidentiality. As ART programmes in Africa become established and evolve, we not only need to identify barriers to men's access and adherence but monitor their health and treatment experiences. These findings suggest that the issue of alcohol and ART warrants further investigation. Additional training for primary health care providers and counsellors on health promotion with men may be useful.

Introduction

As public HIV treatment programmes providing antiretroviral therapy (ART) continue to expand and develop in Africa, it is important to understand how gender shapes ART access, adherence, health, treatment experience, as well as, the consequences of treatment (Hirsch, 2007; Hirsch, Parker, & Aggleton, 2007). To date, few studies in developing countries have explored the experiences of men accessing treatment (Seeley & Allison, 2005). Such a knowledge gap is regrettable given the level of participation by men in ART programmes. In South Africa, of the more than 400,000 people enrolled in public sector programmes, 45% of people receiving ART are men (Department of Health, 2007). Furthermore, there is an increasing, multi-disciplinary evidence base in developed countries documenting the influence of gender on men's health, health behaviours, and health care (Courtenay, 2000; O'Brien, 2005; Robertson, 2007). Given many ART programmes are relatively new and in a phase of expansion and development, closely observed studies of individual experiences of treatment in Africa are also timely.

In this paper we examine health, health behaviours and health care experiences of HIV positive men enrolled in a rapidly expanding rural district ART programme in KwaZulu-Natal, South Africa. The study area has high rates of HIV prevalence in the general population; in 2003/4 the peak prevalence in men was 44% (95% CI 38–49%) in 30–34 year olds (Welz et al., 2007). No declines in HIV incidence have been observed, overall HIV incidence for the period 2003–2007 was 3.4 per 100 person-years (95% CI 3.1–3.7) (Barnighausen et al., 2008).

The study uses data collected during in-depth interviews with men, as well as their family members and programme staff. We present men's case studies to provide insight into gendered dimensions to men's health and health care experiences. These include treatment disclosure, attitudes to coping and support, and men's relationship with their families and health care providers. We consider the way in which gender intersects with men's health experiences around ART.

Methods

This study is part of a larger project '*Stigma and the Social Context of Anti-retroviral Treatment in KwaZulu-Natal, South Africa*' conducted by Molly Fitzgerald (Fitzgerald, 2008). In 2005/6, in-depth interviews were conducted with 30 people (8 men, 22 women) initiating treatment in a public ART programme based at a district hospital in rural KwaZulu-Natal. Programme participants attending education sessions were invited to enrol in the research project. The sex ratio of respondents recruited was similar to that in the ART programme. A second interview was conducted after four months with 26 people (6 men, 20 women). By which time, two participants had died, one was hospitalised, and one had left the study area. Additional interviews were conducted with nine family members who acted as treatment supporters and five health service providers from the ART programme. The study used ethnographic methods, including participant observation and a daily log of informal discussions. A research team consisting of Fitzgerald (female, age 36 years) and a research assistant (female, age 29 years) was based in the hospital and lived in the study community.

The in-depth interviews with programme participants began by exploring key life events and treatment history. Topic guides were used to facilitate a chronological discussion of events from the time of the individual learning about his or her HIV status to accessing ART treatment. Some of the central topics included stigma, disclosure of HIV status, social support, experiences related to treatment, including health outcomes, adherence, and relationships with staff and other participants. Responses in the first interview were explored in greater detail in the second interview with a particular emphasis on understanding the changing experience over the course of diagnosis and treatment. Most interviews were conducted in Zulu. All interviews were taped, transcribed and translated into English. A detailed analysis was conducted by the lead author (Fitzgerald, 2008). In this paper, we select narratives from, or about, male ART participants. All names used in this paper are pseudonyms.

Study area

The district health service serves approximately 168,500 people and covers an area of 1,417 square kilometres. The area is predominantly rural but also includes a township and densely populated peri-urban areas. The population is almost exclusively Zulu-speaking. Few households are engaged in subsistence agriculture, and most are dependent on waged income and state grants (Hosegood, McGrath, & Moultrie, 2009). The unemployment rate, as a percentage of the economically active, is high (39% of people aged 15–65 years in 2001) (Case & Ardington, 2004). HIV prevalence estimated through population-based surveys in part of hospital catchment area is very high. In 2005, 38% of antenatal women were HIV infected (38%) (Rice et al., 2007). In 2003/4, HIV prevalence in the general population was 22% (Welz et al., 2007).

The roll-out by the public health service of ART in the district started in September 2004. The project was conducted during a phase of rapid expansion in the district ART programme. At the start of the project in 2005, the programme provided treatment to 142 adults with all initiation and monitoring occurring in the district hospital. In 2006 when the project ended, 5,000 people were being enrolled and monitored at the hospital and local clinics. Voluntary counselling and testing (VCT) was available in all clinics throughout the period.

Results

Responses to questions about HIV treatment

Male participants were acutely aware of the risk that taking ART or attending the hospital might result in family and public gossip about their HIV status. Men's responses ranged from emphatically stating that nobody would ask them outright, to being prepared to deny that they were HIV positive or refusing to answer, should they be accused. Some men took authoritative and defensive positions suggesting that their position in the family, household and community should be protection against being challenged about their HIV status or becoming the subject of gossip.

Mandla was a 31 year old man who had been extremely ill before and after starting ART. Previously a migrant worker, he lost his job due to ill health and returned to live with his wife, children, parents and adult siblings. His family had cared for him during his repeated bouts of illness but despite their help and support, Mandla was adamant that he had not and would not discuss his HIV status with them. Being too weak to walk unaided, Mandla's father accompanied his son for his routine visits to the ART clinic. But despite this, father and son had not discussed the kind of treatment he received. Mandla at first claimed that his father did not know the reason he went to the hospital. Later he reconsidered and suggested that his family probably were aware that he was HIV positive and on treatment despite him never having told them. He described openly taking his ART pills, confident that nobody in his family would dare to ask him directly about them. *'As I said I'm not hiding my pills...I'm not shy about that. But no one can ask me why do you take that stuff, you see.'* Mandla appeared to feel that his status as a husband and adult son was enough to secure the support of his family without full disclosure, and should protect him against gossip and discrimination. However, Mandla's interactions with his family around illness and treatment were far more complicated. While he sought to create an impression during interviews of being in control, he swung between expressions of confidence and feelings of failure in his family role and desperation about his situation.

Men's desire to demonstrate confidence in being able to deal with HIV stigma and discrimination infused their language and behaviour during the interviews. Interviews, particularly the first, with men were often characterized by laughter and joking, with men seemingly casual and taking everything lightly. However, men's moods during interviews were more volatile than women's. The *bravura* with which men started the interview could quickly dissipate when they became less confident and clowning gave way to anxiety and pensiveness. Furthermore, the casual stance was at odds with the content of their responses and the extent to which they had given serious thought to issues related to their health and the implications for themselves and their families. The repeated interviews with men provided important time and rapport needed for men to moderate the style and level of reflection when responding to questions. In the first interview, men tended to focus very much on their health and employment-related experience. Although remaining largely pragmatic and with little emotional expression, in subsequent interviews, men became more expansive about social aspects such as concerns about their families or partners.

Seeking help from health care providers

Male participants held strong opinions about the behaviour of health service providers, particularly staff in the treatment programme. It was of the utmost importance to men that staff behaved professionally and that they could be trusted to maintain confidentiality. These high expectations created a potentially fragile relationship between male participants and staff, one in which men might readily stop attending if they perceived a breach in trust or an unsupportive reaction. The identity of health providers as being a 'professional' was felt by some participants as the reason why only health providers should be 'allowed' to talk about HIV and AIDS. S'bu, a 43 year old participant felt that it would be wrong to talk about his own or another persons' HIV status: *'You have to keep that secret. You don't have to tell him straight... No, it's not right because he will ask "How do you know? You are not a doctor!"'* On the other hand, when male participants felt confident that the health care professionals would assure their privacy, they sought, or reported wanting to seek, their advice and support. Elaborating about his anxiety over disclosure to his fiancé, 26 year old Jabulani explained *'No I didn't inform her [nervously laughing]. I went to the clinic hoping that would give me advice about informing her. They were too busy'*

Shifting roles and identities

Men's confidence about their future was undermined by how they, and others, perceived their roles within their families. Most men were unemployed, many having lost their jobs because of illness. In an area of high unemployment, not having paid work is not necessarily stigmatised, however, male participants were unable to be seen to be even actively looking for work given continued illness and the need to regularly attend the hospital. Thus, having failed to fulfil their primary roles as household breadwinners or fathers who provided for their children, many young male men felt that they did not have an essential role in their families.

The story of Dingane and Mandla illustrates the extent to which HIV stigma is layered upon pre-existing norms related masculinity and fatherhood. Dingane, a 26 year old man had moved back to live with his parents when he became very ill, lost his job, and his girlfriend died. Dingane had not disclosed his HIV status to anyone in his family. His father, an alcoholic, used abusive and stigmatizing language towards his son. His parents' disappointment and accusations related primarily to their son's 'failure' to start and provide for a family of his own. This was combined with blaming and moral judgements about the cause of Dingane's illness whilst not directly referring to HIV: *'...the prostitutes have finished you.'* his father was reported to have told him. Mandla, a 31 year old married man whose father had also made disparaging remarks about his inability to provide for his wife, children and parents, appeared to have internalised these negative sentiments: *'Previously I handled [driving in building posts] myself. But now am not able. Maybe I try to do something...and then, I fail. Yes [whispering]...like building a house, I used to build for myself....I was a breadwinner and all - a lot of things.'*

Strongly gendered expectations that fathers should only be proud of strong, masculine and successful sons placed an enormous strain on relationships between fathers and their sick adult sons. Such a profound influence was not observed between fathers and their HIV positive daughters. For men, the low self-esteem resulting from failing as a son, father, husband and

breadwinner, also appeared to reinforce a particular resistance to disclosing HIV status or treatment to other men. The need to protect oneself against disapproval or being ‘...made fun of’ by other men, particularly those who drank heavily, was a deep concern for men. Fears about the consequences of disclosing to other men had in some cases hindered men’s ability to secure care and support from their families.

Men’s feelings of failure with regards to their families differed by age. When in confident spirits, younger men were often hopeful that they could succeed in being household heads, partners and fathers. However, such buoyancy was fragile and younger men would readily switch to feelings of failure in building and supporting families. Older men appeared to have a more resigned attitude to their circumstances. Some older men described themselves as having been ‘beaten’ by life and others were sanguine about their ability to fulfil family and community expectations regardless of their HIV status.

Alcohol and ART

Several men described how, knowing that the ART programme discouraged alcohol use, they had waited to start treatment until managing to stop or reduce alcohol use. While all the men in this study had eventually started treatment, some described having been unsure in the past about whether ART was in fact an option for them at all given that they drank. Those men who initiated changes in their alcohol use themselves, did so without seeking advice or support from health providers. Men differed in their attitudes to long-term treatment and alcohol use. While some men matter-of-factly reported that they did not drink anymore because of treatment, other men were more conflicted. Alcohol was described as an important way that men cope with the kind of anxiety and stress brought about by being HIV-positive. Nonetheless these justifications were accompanied by considerable guilt about drinking while taking ART.

Men also frequently referred to alcohol when discussing HIV disclosure; emphasizing they neither could confide in, nor rely on support from, family members or friends who used alcohol. For Dingane, his fathers’ history of alcohol abuse had fostered a sense that he could not rely on his father for support. Furthermore, in trying to cope with HIV, Dingane’s father was now an actual threat given the risk of uninhibited talk, rudeness, and violence: ‘*How can I put it? My father is a drunk. Maybe he will talk about it anywhere he is. Maybe he is in taverns with neighbours [...] I have to look at him and see how he reacts at home [...]*’

Discussion

In 2007, Jennifer Hirsch wrote ‘*The intersection of gender and ART represents a critical area for further research to identify the structures that create disparities in access, in order to consider how they might be transformed.*’ This study is one such starting point with its documentation of men’s experiences of ART in a rural district of South Africa.

The study suggests that men’s experiences need to be seen in the context of their life course and age. Important stressors for younger men in the programme were feelings of being thwarted in their relationships, ability to form their own household, provide financially for their families, and

thus, be unable to meet their own and others' normative expectations. Older men established in their social roles were more secure and better able to disclose and negotiate family support. Other authors have suggested that older HIV positive people face specific challenges for example, social age-related differentials in HIV disease progression and treatment effects and health provider attitudes around sexuality and perceptions of risk (Auerbach, 2003; Knodel, Watkins, & VanLandingham, 2003; Levy, Ory, & Crystal, 2003), and exclusion from HIV prevention and education programmes (Cooperman & Arnsten, 2007; Lieberman, 2000). We observed the greatest variation in treatment experiences by life stage rather than simply age, i.e. whether men had a living and geographically accessible wife, partner or parents, in particular mothers.

The study identified alcohol as an important aspect of men's lives before and during treatment. Men described the impact that alcohol use had on their treatment experience. Several men reported a self-imposed delay in starting treatment until they had been able to stop or reduce alcohol use. It is possible that for some HIV positive men, alcohol dependence allows self-exclusion from treatment programmes, fostering denial about their HIV status. Respondents also thought using alcohol was a particularly masculine way of coping with the stresses of HIV, illness and treatment. Alcohol as a method of coping has been previously reported in studies of recently diagnosed HIV positive men and women in South Africa (Olley, Zeier, Seedat, & Stein, 2005). In rural KwaZulu-Natal, strong gender norms exist about alcohol use behaviour and desirability bias may influence drinking behaviour and reporting. In interviews we conducted with 22 women participating in the programme (Fitzgerald, 2008), none mentioned alcohol in connection to their own treatment. In our study we are unable to assess what role that alcohol use and abuse in men's experiences of depression, psychological distress or ability to adhere to treatment. Alcohol use has been shown to be negatively associated with treatment adherence in South Africa (Dahab et al., 2008), but unexplored as a barrier to treatment uptake.

The findings suggest that building understanding about alcohol and substance abuse by participants themselves, and their family and household members, might be useful complement for primary health care and programme providers and counsellors. Increasing awareness by health promoters of issues related to alcohol during the pre-treatment period may assist in timely initiation among alcohol-dependent HIV positive men. Based on the results of a clinical intervention trial to reduce alcohol use by HIV positive people, Kalichman et al. (2007) suggest intensive alcohol risk reduction and maintenance interventions may be required. The finding that alcohol may be used as a coping strategy among HIV positive men on treatment has potentially important implications for HIV prevention too. The inter-relationships between alcohol use, HIV/STD transmission risk and intimate partner violence has been well documented in South Africa (Dahab et al., 2008; Dunkle et al., 2007; Kalichman et al., 2007; Olley et al., 2005) and other African countries (Wolff et al., 2006).

To what extent are our findings generalisable? Two aspects need to be noted. First, the participants we interviewed were newly enrolled in the ART programme. As a consequence, their narratives are strongly interwoven with their experiences of recent or ongoing illness. The intensity with which men described their loss of identity and role within families might have been less acute had we interviewed participants longer established in the programme who were responding well to treatment (Nguyen, Ako, Niamba, Sylla, & Tiendrébégo, 2007; Smith &

Mbakwem, 2007). Second, the study was conducted at the start of the public ART programme. Since then, it has expanded considerably and received considerable inputs in terms of staff and training. However, it is unlikely that the gendered influences on HIV positive men's health and treatment experiences have undergone any similarly substantive change since 2005/6.

Local treatment programmes require the support of the public health system. In the South African national guidelines on treatment or adherence (Department of Health, 2004), no specific reference is made to issues related to men and treatment. Furthermore, while the guidelines encourage providers to facilitate support for programme participants by engaging with families and communities, no further guidance is offered about how this may vary with the age or gender of participants. Research and programmatic efforts related to gender and ART need to be broader than merely identifying barriers to men's access and adherence to treatment. As ART programmes become established and develop, it is also important to examine how HIV positive men understand and experience health and treatment.

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