

Gender differences in experiences of ART services in South Africa: a mixed methods study

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Abstract

OBJECTIVES A mixed methods study exploring gender differences in patient profiles and experiences of ART services, along the access dimensions of availability, affordability and acceptability, in two rural and two urban areas of South Africa.

METHODS Structured exit interviews ($n = 1266$) combined with in-depth interviews ($n = 20$) of women and men enrolled in ART care.

RESULTS Men attending ART services were more likely to be employed (29% vs. 20%, $P = 0.001$) and were twice as likely to be married/co-habiting as women (42% vs. 22% $P = 0.001$). Men had known their HIV status for a shorter time (mean 32 vs. 36 months, $P = 0.021$) and were also less likely to disclose their status to non-family members (17% vs. 26%, $P = 0.001$). From both forms of data collection, a key finding was the role of female partners in providing social support and facilitating use of services by men. The converse was true for women who relied more on extended families and friends than on partners for support. Young, unmarried and unemployed men faced the greatest social isolation and difficulty. There were no major gender differences in the health system (supply side) dimensions of access.

CONCLUSIONS Gender differences in experiences of HIV services relate more to social than health system factors. However, the health system could be more responsive by designing services in ways that enable earlier and easier use by men.

keywords antiretroviral therapy, gender, South Africa

Introduction

Adult women make up the majority of users of antiretroviral therapy (ART) services in sub-Saharan African health systems, generally accounting for 60–70% of ART clinic patients. The findings from pooled cohort data (Braitstein *et al.* 2008) as well as systematic reviews (Muula *et al.* 2007) have concluded that the ratio of men to women in ART services is low relative to the distribution of need (i.e. HIV infection), particularly in southern Africa. Men also present later in the course of disease and have higher levels of early mortality on treatment (Cornell *et al.* 2009; May *et al.* 2010; Mills *et al.* 2011). In a household survey in urban Soweto, South Africa, self-reported HIV testing rates in men were half (28.9%) those of women (64.8%) (Venkatesh *et al.* 2011). These observations are contrary to patterns for other diseases in developing countries (see for example, Hudelson 1996)

where women face greater socio-economical and cultural barriers to care when ill than men.

Lower uptake of ART by men has become the subject of interest and concern in the literature (Hirsch 2007; Mills *et al.* 2009; Birungi & Mills 2010; Cornell *et al.* 2011). Its roots appear to lie in a set of inter-related service delivery and socio-cultural factors. Women have greater opportunities for HIV screening (i.e. pregnancy), make more routine use of reproductive and child health services, and have greater familiarity and ease with the primary health-care system. Gender norms also negatively shape help-seeking and disclosure by men with HIV (Fitzgerald *et al.* 2010). HIV undermines the ability to be physically strong as well as a 'successful' father, husband and breadwinner. HIV-positive men experience greater family disapproval and are more likely to be branded as social failures than HIV-positive women. As a consequence, they report higher levels of internalised stigma, are less likely to discuss their

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status with friends and receive less social support than HIV-positive women (Simbayi *et al.* 2007).

Using a mixed methods approach, we investigated how the gender-related health system and social barriers to access described above played out in the ART services of urban and rural South Africa. We define access as the 'degree of fit' between population needs and health system responses along dimensions of availability, affordability and acceptability (McIntyre *et al.* 2009).

Methods

Four subdistricts of South Africa, two rural and two urban, were purposefully selected as part of a programme of research on socio-economical, gender, geographical and other inequalities in access to HIV, TB and maternal health care, of which this analysis formed one component.

Mixed methods make integrated use of both qualitative and quantitative data in a single study (Creswell & Plano Clark 2007). We combined structured exit interview surveys of patients attending ART services in the four subdistricts with in-depth interviews of 20 people enrolled into ART services in three of the four subdistricts, 13 of whom were also concurrently receiving TB treatment. In the fourth district, a delayed start to the quantitative study precluded a qualitative phase.

The data were collected over a period of 2 years – between July 2008 and December 2010. Although data collection was sequential (surveys, then in-depth interviews), the two protocols were developed simultaneously, and the mixed design can thus best be described as concurrent.

Cross-sectional quantitative study

This component collected data on the socio-demographical profile, access barriers and service utilisation of patients attending public sector ART services in the four subdistricts. Using a comprehensive framework that considered both individual/household demand-side dimensions (e.g. stigma and availability of social support) and health service supply-side components (e.g. physical access, staff attitudes) of availability, affordability and acceptability (McIntyre *et al.* 2009), we mapped the elements of access and use appropriate to ART. This formed the basis of a structured interview schedule with just over 100 response items covering demographical and socio-economical (including household asset) variables, utilisation of ART and other health services, and experiences of access. Baseline CD4 count and 6-month viral load test results were obtained from patient files.

Representative samples of public sector ART service points (facilities) and users were obtained in each of the subdistricts. The sampling of facilities was tailored to the particular model of ART service delivery in each subdistrict (Table 1). A total of 12 facilities participated in the study. In two of the subdistricts, all facilities providing ART at the time of study were included. In the remaining two, patients were interviewed in a sample of facilities, using a method that enabled the most representative selection of users – a stratified sample in one subdistrict where patients were unevenly distributed between a large teaching hospital and clinics, and a probability-proportional-to-size sample in the subdistrict that had a decentralised model of delivery. A target sample size of

Table 1 Profile of study sites (at time of study)

Subdistrict	Bushbuckridge	Hlabisa	Region D, Soweto	Mitchell's Plain
Type	Rural	Rural	Urban	Urban
Province	Mpumalanga	KwaZulu-Natal	Gauteng	Western Cape
Population	620 000	228 000	±1 million	290 000
Model of ART service provision	Centralised, hospital based	Decentralised, mainstreamed in PHC	Hospital and health centre (HC) based	Health centre based
Number of sites providing ART	2	16	6	3
Ratio female/male on ART (routine data)	2.1	1.4	1.5	2.2
Cross-sectional quantitative survey				
Facilities sampled	2	5	3	3
Sampling method	All included	Probability proportional to size	Stratified sampling (hospital/health centre)	All included
Patient sample size	312	300	331	323
Qualitative patient narratives				
Total	10	–	7	3
Male	2	–	3	2
Female	8	–	4	1

300 patients per subdistrict, distributed proportionally among facilities, was calculated based on the anticipated analysis of socio-economical inequalities in use, reported elsewhere (Cleary *et al.* 2011).

After informed consent, trained interviewers conducted structured interviews and reviewed the records of 1266 adults (+18 years), who had been on ART for at least 2 weeks, consecutively recruited, using random or systematic sampling procedures, until target sample sizes were achieved for each facility. Data were entered and analysed in Stata® 10.1.

The socio-demographical and clinical characteristics and access experiences of men and women attending ART services were compared using chi-squared (categorical variables), Wilcoxon rank sum (non-normally distributed continuous variables) and Median (baseline cd4 count) tests. Significant differences (at 5% level) on bivariate analysis in clinical and access characteristics were adjusted for other socio-demographical differences (age, marital status, schooling and employment) between men and women using logistic regression modelling. To adjust for site level factors, we also included an urban–rural variable in the multivariate models.

Qualitative patient narratives

The qualitative component served two key purposes. The first was to compensate for a limitation of facility-based surveys, which by definition cannot capture the access experiences of non-users and dropouts. Interviewees were thus recruited within, as well as beyond, facilities through other mechanisms such as TB services, non-governmental organisations and patient networks. The second major purpose was triangulation. The in-depth interviews complemented the cross-sectional survey method with an appreciation of events over time provided by individual life histories and care pathways.

Participants were selected purposefully to represent a balance of age, gender and users/non-users. Of the 20 people interviewed, thirteen were women and seven were men. The youngest participant was 23 and the oldest 59 years old.

Trained qualitative interviewers conducted interviews in the first language of the participant. These were audio-taped, transcribed and translated into English; and pseudonyms were assigned to protect confidentiality. The transcripts were thematically coded in ATLAS ti.6. The analysis focused on gender differences in the experiences of family, community and health services.

The study received ethical approval from the committees of three local universities (Witwatersrand, KwaZulu-Natal and Cape Town), and written, informed consent was

obtained from all participants. Table 1 summarises the profile of the four subdistricts and their ART services, the sampling methods adopted and sample sizes. From the facility routine data, the ratios of women to men on ART in the four subdistricts varied from 1.4 to 2.2.

Results

Quantitative findings

Response rates were 98% or more across all sites. Of the 1266 exit interviews completed, 74% ($n = 933$) were with women and 26% ($n = 333$) with men (Table 2). The mean age of the men was 40 years, and that of the women, 37 years ($P < 0.001$). Women reported a higher mean number of years of completed schooling. There were significant differences in marital status between sexes: 42% of men reported being in a stable partnership (married or cohabiting), whereas only 22% of women did ($P < 0.001$).

Men had 1.5 times the employment rates of women (29% *vs.* 20%, $P = 0.001$), although access to piped water, a household-level indicator of socio-economic status, did not differ between the sexes (68% *vs.* 67%, $P = 0.778$).

While having been on ART for the same mean duration, women had known about their HIV status significantly longer than men (mean 36 *vs.* 32 months, $P = 0.021$). Women also had higher, but not statistically significant, median baseline CD4 counts (111 *vs.* 103, $P = 0.316$) and levels of viral load suppression at 6 months (<400 copies/ml) (85% *vs.* 82%, $P = 0.276$). However, self-reported 3-day adherence rates and clinic attendance over the prior 6 months were the same for men and women.

With respect to the availability, affordability and acceptability of services, the following were statistically significant gender differences (Table 3):

- Men were more likely to report travelling by foot to the service and were less likely to have a problem with the language of communication used by providers than women.
- Given their higher employment rates, men more frequently reported having to miss work to attend the clinic.
- When asked whether they would 'prefer to be seen by a nurse nearby rather than a doctor further away', men were also significantly more likely to indicate preference for being seen by a nurse (overwhelmingly woman in this context).
- Apart from the complaint of cleanliness, which was more common in women, men did not experience the ART service differently to women on issues such as queues, attitudes of staff and privacy.

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	Female (<i>n</i> = 933)	Male (<i>n</i> = 333)	<i>P</i> -value*
Mean (median) age (years)	37 (36)	40 (39)	<0.001
Mean (median) years of schooling	8.4 (10)	7.3 (8)	<0.001
Marital status (%)			
Married	16.5	29.1	<0.001
Living with partner	5.2	12.9	
Widow/widower	10.0	5.7	
Divorced/separated	8.7	9.6	
Never married/not living with partner	59.7	42.6	
Employment rates (%)	20.0	29.0	0.001
Piped tap water in house/site (%)	67.8	67.0	0.778
Mean (median) duration (months) on ART	16 (11)	16 (12)	0.536
Mean (median) duration (months) since tested HIV positive	36 (27)	32 (23)	0.021
Median baseline cd4 count	111	103	0.316
Missed ARV clinic visit last 6 months (%)	5.6	4.8	0.591
Adherent last 3 days (%)	96.7	97.0	0.775
Disclosed to someone outside family (%)	25.6	16.5	0.001
Viral load <400 copies/ml (%)†	85.4	81.8	0.276

*Wilcoxon rank sum (age, education, duration ART and HIV positive), chi-squared (employment, water supply, missed visits, adherence, disclosure and viral load) and Median tests (baseline cd4 count).

†In those on treatment for >6 months: women, *n* = 492; men, *n* = 165.

- A higher proportion of women knew their most recent CD4 count, although this association disappeared when controlled for educational and other socio-demographical differences.

The most consistent differences between men and women related to the social and family experience of having HIV. Even after adjusting for differences in marital status, men were far more likely than women to agree with the statement 'I get all the support I need from my partner' (66% *vs.* 47%, adjusted odds ratio (aOR) 2.56, *P* < 0.001). Conversely, women were more able to draw on the support of a wider group of family members (aOR 0.62, *P* = 0.022) and friends (aOR 0.74, *P* = 0.029). Men were also less inclined to disclose their status to someone outside their family than women (17% *vs.* 26%, aOR 0.67, *P* = 0.021). In both sexes, disclosure was strongly associated with receiving the support of friends (OR 13.7, *P* < 0.001). However, men were not more likely to report feeling negatively judged by the community for attending the ART service.

Qualitative findings

In a pattern consistent with the quantitative findings, the roles of partners and families featured centrally in the patient accounts of their illness and treatment-seeking behaviour. Three of the seven men interviewed were

married, one was divorced, and three had never married. Only one of the 13 women interviewed was in a formal marital union, five were divorced, and seven had never married.

Four of the women discovered their HIV status during pregnancy, establishing them as the 'index case' in their households. Irrespective of where they came from, the interviews with women tended to produce a familiar narrative of neglect and violence (at times in life-and-death terms), often culminating in estrangement or divorce after the disclosure of their HIV-positive status to their male partners.

When Participant A, a 33-year-old woman from urban Soweto, living with her grandmother and two children, tried to discuss the HIV test findings with her boyfriend, he refused to listen and instead became 'more abusive'. Participant B, from rural Bushbuckridge, had to be rescued by her own family from her husband and in-laws after a positive test during pregnancy, as they feared for her life. Similarly, the marriage of 31-year-old Participant C (also tested during pregnancy) ended in divorce when her husband clearly did not see her need for care as a legitimate expectation of her marital home, indicating to her that she should leave as no one was willing to look after her in his home.

The accounts of the women stood in sharp contrast to those of two of the married men interviewed, both of whom were successfully taking ART. Participant Z,

Table 2 Socio-demographical and clinical characteristics of men and women attending ART services (*n* = 1266)

Table 3 Comparison of access characteristics of men and women attending ART services ($n = 1266$), adjusted for socio-demographical and site level differences

Access factor	Female ($n = 933$)	Male ($n = 333$)	P -value*	Adjusted Odds ratio†	95% CI	P -value
Availability						
Opening hours convenient (% agree)	96.2	97.9	0.153			
Travelled by foot to clinic (%)	19.9	29.2	<0.001	1.95	1.44–2.66	<0.001
Mean time spent (minutes) at clinic at last visit	167	164	0.977			
Health workers too busy to listen (% agree)	15.0	12.6	0.285			
Problems with language spoken (% agree)	14.5	8.5	0.005	0.48	0.31–0.74	0.001
Knows most recent cd4 count value (%)	74.8	65.4	0.001	0.85	0.63–1.16	0.313
Receives needed support from						
Partner (%)	47.5	67.3	<0.001	2.56	1.92–3.40	<0.001
Family (%)	83.4	75.1	0.001	0.62	0.45–0.86	0.022
Friends (%)	47.4	37.8	0.003	0.74	0.57–0.97	0.029
Affordability						
Found it easy incurring expenses for health care (%)	21.2	23.7	0.343			
If not at clinic would have been working (%)	13.2	23.4	<0.001	2.05	1.15–3.65	0.016
Receives financial help for health care (%)	68.6	63.7	0.194			
Mean cost of attending clinic (US\$‡)	3.6	5.2	0.504			
Acceptability						
Queues are too long (% agree)	66.8	63.7	0.304			
Always has privacy (% agree)	66.6	66.4	0.949			
Clinic could be cleaner (% agree)	27.5	19.5	0.006	0.70	0.51–0.97	0.033
Prefer to see a nurse nearby than a doctor further away (% agree)	64.0	71.2	0.018	1.39	1.03–1.87	0.031
Some staff do not respect patients (% disagree)	37.8	42.0	0.177			
Feel community judges negatively for using service (% agree)	16.7	13.2	0.132			

*Bivariate analysis using chi-squared (categorical) and Wilcoxon rank sum (continuous) tests.

†Logistic regression of each access factor (dependent variable) and sex (female = 0 and male = 1), adjusted for age, marital status, employment, education and rural–urban status.

‡Calculated at South African Rand: US Dollar exchange rate of 7.5.

35 years old, unemployed and from Soweto, discovered his status following a routine test conducted when admitted to hospital for a gunshot wound. He spoke of his marriage as happy and explicitly referred to his wife as a ‘caregiver’ and supporter. Similarly, Participant Y, a 51-year-old unemployed man from Bushbuckridge, was cared for by his wife during an extensive period of hospitalisation. He described her caring role in strongly redemptive terms – carrying him to the hospital when he was too weak to walk, stubbornly insisting that he eat nourishing food and staying beyond visiting hours to watch over him. Without his wife, he was ‘a parcel without no use’.

In the absence of support from partners or in-laws, women generally turned to their biological families – siblings, parents, grandparents and sometimes friends – for emotional and material support. Participant A, who described her partner as abusive, had a very supportive family and friends who stood by her ‘through thick and thin’. Their attitude to her disclosure was of acceptance, with her grandmother reassuring Participant A that ‘she

was not the first person to have this and was not going to be the last one with this’.

For two of the single men, both from Soweto, unemployed, in their thirties, and with histories of missing clinic visits and interrupting treatment, family relations were absent or remote, even abusive. Participant X eked out a living selling ice cream and washing cars. He had made connections with an HIV-positive person in his neighbourhood who sometimes collected tablets for him. Female members of his church were a source of some emotional support. Participant W, who sometimes worked as a car guard, lived with two male relatives (a younger and an older one), neither of whom provided any real support. He lived in a state of social alienation, seldom speaking to or ‘reporting’ to anybody, had lost contact with his aunt who lived nearby and was told he was ‘useless’.

Although women experienced greater acceptance from extended families and had access to earlier testing, as with men, their trajectories from testing to enrolment into

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long-term care and ART were neither linear nor rapid, even when ill-health created some urgency. All but one (man) of the 20 interviewees described bouts of ill-health pre-ART and fairly complex processes of seeking care from various providers prior to ART.

None of the interviewees was employed in the formal sector. Employment opportunities where they existed were in the informal sector and at best part-time. Making a living in a precarious economic environment meant juggling work opportunities with visits to collect treatment. Participant X had missed a visit, which left him uncomfortable, when he found short-term work some distance from home and did not have money to pay his neighbour to collect his treatment for him.

Discussion

The study found a number of gender differences in experiences of HIV and ART care. Men tested later than women, despite the fact that women faced a real risk of abuse or abandonment by their partners. Men were also less likely to disclose their HIV status, which may have hindered access to support from family and friends. However, the reverse could also hold: that the inability to draw on a range of sources of social support – whether emotional, informational or instrumental – provides a social context that inhibits earlier entry into testing and care.

One of the key findings was the important role of women as mediators of care for their male partners. This was literally the case of Participant Y, whose wife carried him to receive care. Men who were not married or who did not have a close relationship with a female relative appeared to face particular challenges, and this may explain the relative absence of unmarried men in the patient population.

Marital status could have also conferred advantage for men in indirect ways. As proposed by Fitzgerald *et al.* (2010), if men have fulfilled certain social expectations such as marriage and fatherhood, they are freer to take on the sick role. Employment may have the same function of proving one's social worth, but its direct effects are mixed – on the one hand, it increases the affordability of care, but there are greater opportunity costs to attending services if it requires missing work; and where livelihoods are precarious, making use of work opportunities may outweigh attendance for follow-up visits.

Once having overcome the barriers to entry into testing and treatment, adherence to drugs, attendance at follow-up visits and ongoing access appeared no different between men and women. If anything, the men in our study reported fewer difficulties with the availability and acceptability of services than women.

This analysis has limitations. Firstly, the cross-sectional nature of the survey method makes assumptions regarding directions of causality. Secondly, we surveyed user populations, whose experiences may be different to those of non-users. The focus on partial users in the qualitative study partly compensated for this. Thirdly, the ratio of men to women in the final sample was higher than the ratios of attendees (obtained in routine data), and the sample of men may have been biased in some way. Finally, we pooled data from four purposefully selected sites, and while we believe they represent typical urban and rural realities and user populations within these settings, the combined sample is not representative of South Africa.

In conclusion, gender differences in experiences of HIV services appear to relate more to gender norms than to health system factors. While the solutions to this lie principally at a social level, the health system could play its part in providing HIV services that enable earlier and easier use by men. Starting points could be provider-initiated and other testing campaigns that seek to normalise testing, and the development of intervention strategies that facilitate access for young, unemployed and unmarried men.

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