



ORIGINAL ARTICLE

Parental presence within households and the impact of antiretroviral therapy in Khayelitsha, Cape Town

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Background. While household support is an important component of effective care and treatment in HIV/AIDS, there are few insights from Southern Africa into how household support arrangements change over time for patients starting antiretroviral therapy (ART).

Objective. We hypothesised that patients initiating ART are more likely to be living with family, especially their mothers, compared with the general population, but that over time these differences disappear.

Methods. A panel survey of ART patients was matched by age, gender and education to a comparison sample drawn from adults in Khayelitsha, Cape Town.

Results. The results show that there is a substantial potential burden of care on the families of patients starting ART, particularly mothers, and that the use of ART appears to reduce this burden over time. But, even after their health is restored, ART patients are significantly less likely to have a resident sexual partner and more likely to be living in single-person households than their counterparts in the general population.

S Afr J HIV Med 2013;14(2):70-74. DOI:10.7196/SAJHIVMED.921



There is evidence that people living with HIV/AIDS (PLWHA) across sub-Saharan Africa rely on family members, especially parents, for ongoing care and support, particularly with the morbidity of advanced HIV disease. Several studies have shown that terminally ill South African (SA) adults often return to the parental home to access care and support, primarily from their mothers.^[1-4] As Haour-Knipe^[5] points out, this is to be expected in many settings where extended family serves as the 'primary social safety net'. A Ugandan study found that elderly parents, especially mothers, were the main caregivers for PLWHA^[6] and similar dynamics have been reported in Thailand.^[7] However, there are few studies exploring whether reliance on family and parental support changes after initiation of antiretroviral therapy (ART).

What sets Southern Africa – and especially SA – apart is the generally lower presence of fathers in households and the importance of 'uterine kin' (mothers, grandmothers and sisters) in providing social stability and care when necessary.^[8-10] This is a consequence of SA's history of oscillating migration and apartheid, which separated families geographically, often for long periods of time. But, it is also a consequence of declining rates of marriage, to the point that it is no longer the norm.^[11] Hunter argues that the rise of unemployment was the key factor behind this, as only the relatively well-off African men could afford to pay 'ilobolo' (bridewealth) or act as reliable providers for

their families.^[12-14] Under these circumstances, women become incentivised to form looser connections with men (sometimes several men) and closer bonds with siblings and mothers.

The phenomenon of the 'absent father' has been well documented in SA.^[15-17] What this means in terms of the supporting role of fathers, however, is unclear. According to Morrel and Richter,^[15] paternal absence implies a lack of fatherly support for children's care. However, other research emphasises how fathers can and often do maintain meaningful contact with children, even when they do not reside in the household,^[8] and that their role in providing care when they are in the household often goes unreported.^[18,19]

We investigated aspects of living arrangements for ART patients over time, at the time of ART initiation and subsequently, and compared this with the living arrangements of people of similar age, gender and education in the general population of residents of Khayelitsha, Cape Town.

Methods

Khayelitsha is a peri-urban settlement comprising about half a million predominantly Xhosa-speaking residents. Almost half of the working-age adults are without jobs and over a quarter of pregnant women are HIV-positive.^[20-22] Between 2001 (when the first ART pilot programme was established in Khayelitsha) and 2008, more than 10 000 people were successfully initiated on ART with over 93% retained in care.^[23]

Table 1. Attrition analysis*

Characteristics	Loss to follow-up	In panel	Univariate probit coefficient R ² (95% CI)	Multiple regression probit coefficient R ² (95% CI)		
				ART start (wave 0)	ART (wave 2)	Khayelitsha (wave 2)
Age (years)	38	33	0.04 [†] (0.02 - 0.07)	0.04 [‡] (0.01 - 0.07)	0.04 [‡] (0.01 - 0.07)	0.04 [‡] (0.01 0.07)
Schooling (years)	8.5	9.7	-0.07 [†] (-0.13 - 0.01)	-0.03 (-0.10 - 0.04)	-0.01 (-0.08 - 0.06)	-0.02 (-0.09 - 0.06)
Female, %	75	80	-0.17 (-0.62 - 0.28)	-0.01 (-0.46 - 0.49)	-0.02 (-0.50 - 0.47)	-0.06 (-0.55 - 0.45)
Worst health ever at ART start, %	39	40	0.03 (-0.35 - 0.42)	-0.08 (-0.49 - 0.31)	-0.01 (-0.44 - 0.42)	-0.04 (-0.47 - 0.40)
Working, %	18	37	-0.54 [‡] (-0.99 - 0.09)		-0.47 [‡] (-0.93 - 0.00)	-0.40 (-0.90 - 0.11)
Disability grant recipient, %	83	72	0.33 (-0.13 - 0.80)		0.31 (-0.20 - 0.82)	0.241 (-0.29 - 0.77)
Per capita household income (ZAR)	487	630	-0.00 (-0.00 - 0.00)			-0.00 (-0.00 - 0.00)
Mother in household, %	19	23	-0.16 (-0.61 - 0.30)			0.16 (-0.95 - 1.27)
Father in household, %	5	5	-0.09 (-0.94 - 0.76)			0.08 (-0.93 - 1.10)
Parent-headed household, %	16	22	-0.21 (-0.69 - 0.26)			-0.18 (-1.39 - 1.04)
Partner in household, %	19	32	-0.40 [§] (-0.84 - 0.04)			-0.31 (-1.80 - 0.17)
Pseudo R ²				0.055	0.081	0.088
N				242	242	234
Probability > chi ²				0.018	0.007	0.064

CI = confidence interval.
*Dependent variable: 1 = loss to follow-up; 0 = in full panel study.
[†]p<0.001.
[‡]p<0.05.
[§]p<0.1.

In 2004, 242 patients receiving ART in Khayelitsha were recruited into a panel study conducted by the AIDS and Society Research Unit of the University of Cape Town. Respondents were recruited through social networks, clinic support groups and by word of mouth; hence, the sample cannot be regarded as strictly representative. However, as two-thirds of the starting ART cohort was recruited into the study, the sample can be regarded as broadly representative of the experience of the early ART patients.^[24]

The first round of the survey (wave 1) was conducted in 2004 and a second wave in 2006. Retrospective questions were posed to respondents regarding their households and health at the time that they started ART, thereby allowing us to construct a retrospective 'wave 0' (i.e. at the time of ART initiation, when they were sick with AIDS) for all respondents.

The panel study allowed examination of the changes in household characteristics of ART patients over time, but we also needed to know

how this compared with households in the general population. We therefore constructed a 'quasi control' dataset drawn from a survey of Khayelitsha residents (which can be regarded as representative of adult African Khayelitsha residents^[29]), conducted in parallel with the ART panel study. From this dataset we drew a sub-sample of 202 respondents matched (using a probit regression) by age, gender and education to respondents in the ART sample.

Ethics approval for the studies was obtained from the Ethics Committee of the Centre for Social Science Research, in line with the ethics approval process of the University of Cape Town.

Results

Within the ART panel study, loss to follow-up was 16% (of the 242 respondents interviewed in 2004, only 202 were present for all subsequent interviews). Older respondents in wave 1 were more likely to be lost to follow-up (Table 1), but the effect was small (for each additional year of age, the probability of loss to follow-up rose by 4%). Those without

jobs were more likely to be lost to follow-up (being employed cut the probability of loss to follow-up by one-half), but once controls were implemented for household income and other household characteristics, the effect of being employed became statistically insignificant. Having a resident sexual partner reduced the probability of attrition, but this effect also became statistically insignificant once controls were implemented for other factors. In multivariate analysis, there were no systematic differences in socio-economic and demographic characteristics between those lost to follow-up and those retained in care, other than small differences in age. Furthermore, the explanatory power of the regression models remained low in all specifications.

The matching process resulted in a matched and balanced panel dataset of ART patients and Khayelitsha respondents, with almost identical average age, gender and educational profiles (Table 2). Respondents were asked to rank on a 10-point scale (with 10 being the best health that they had ever experienced)

their current health status as well as their recollections of their health at the time that they initiated ART, and three and six months later. The mean score for perceived health rose from 2.8 (standard deviation (SD) ± 2.2) at ART initiation to 5.3 (SD ± 2.0) three months later and 7.8 (SD ± 1.7) six months later – an increase in line with improvements in clinical markers (e.g. CD4 cell counts) and quality-of-life indicators found in other studies of the same Khayelitsha cohort.^[20,25-28]

Given the potential for ART to restore health and independence, we expected the ART rollout to result in changes in household characteristics, especially involving mothers and sisters. Accordingly, we hypothesised that mothers and sisters were more likely to be present in the households of patients initiating ART. We found that maternal presence in the

household decreased significantly from 31% to 19% between wave 0 (ART initiation) and wave 2 (Table 3). Indeed, by wave 2, there was no significant difference between maternal presence in ART-patient households and those of the matched Khayelitsha residents. The trend was similar and statistically significant also for households with no mother but with a sister present.

An analysis of changes in paternal presence are reported in Table 3. We found that fathers were generally less present than mothers, in both the ART and matched Khayelitsha samples. However, as was the case with maternal presence, fathers were significantly more likely to be present in the household when ART respondents were sick with AIDS, rather than later. Whether fathers were actively playing any caring or supportive role could

not be ascertained from the data. There was a statistically significant increase between wave 0 and wave 2 in the number of ART respondents who were themselves household heads (Table 4). More than half of the respondents in the ART sample were household heads by wave 2.

In addition, we examined changes in reported sexual partnerships over time, comparing ART patients with the general population. There was indeed a statistically significant increase in the number of ART patients with resident sexual partners (Table 5), but this remained significantly lower than for the matched Khayelitsha sample.

Discussion

We employed an innovative methodology to compare trends in a panel study of ART patients in Khayelitsha with a matched sample drawn from the local population. We confirmed the pattern found in the existing literature that people with AIDS rely on kin, especially mothers, for care and support.^[2-5,9] A limitation of our study was that we could not ascertain whether it was the patient or the caregiver that moved households. Even so, we were able to establish that ART patients were more likely to be living in parent-headed households when they initiated treatment than

Table 2. Matched data sets

	ART panel	Khayelitsha matched sample
Women, %	80	80
Age (wave 1), years \pm SD	33.2 \pm 6.5	33.6 \pm 7.4
Education (wave 1), years \pm SD	9.7 \pm 2.8	9.9 \pm 2.5
Total, N	202	202

SD = standard deviation.

Table 3. The presence of mothers, sisters, fathers and parent-headed households

	ART start (wave 0)	ART (wave 2)	Khayelitsha (wave 2)
Mother present in the household	62 (30.7%)	39 (19.3%)	43 (21.3%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=93.58$; $p=0.000^*$; Fisher's exact: 0.000*		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=0.24$; $p=0.621$; Fisher's exact: 0.711		
No mother but at least one sister in the household	40 (19.8%)	30 (14.9%)	26 (12.9%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=48.73$; $p=0.000^*$; Fisher's exact: 0.000*		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=0.33$; $p=0.565$; Fisher's exact: 0.666		
Father present in the household	15 (7.4%)	9 (4.5%)	19 (9.4%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=48.09$; $p=0.000^*$; Fisher's exact: 0.000*		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=3.84$; $p=0.050^{\dagger}$; Fisher's exact: 0.076 [†]		
Parent-headed household	60 (70.3%)	35 (17.3%)	42 (20.8%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=84.57$; $p=0.000^*$; Fisher's exact: 0.000*		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=0.79$; $p=0.375$; Fisher's exact: 0.447		

* $p<0.001$.

[†] $p<0.1$.

Table 4. Respondent-headed and single-person households

	ART start (wave 0)	ART (wave 2)	Khayelitsha (wave 2)
Respondent as head of household	65 (32.2%)	110 (54.5%)	85 (42.1%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=55.37$; $p=0.000^*$; Fisher's exact: 0.000*		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=6.20$; $p=0.013^†$; Fisher's exact: 0.017 [†]		
Single-person households	8 (4%)	17 (8.4%)	7 (3.5%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=9.14$; $p=0.002^†$; Fisher's exact: 0.021 [†]		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=4.33$; $p=0.038^†$; Fisher's exact: 0.056 [†]		

* $p<0.001$.† $p<0.05$.‡ $p<0.1$.**Table 5. The presence of sexual partners in households**

	ART start (wave 0)	ART (wave 2)	Khayelitsha (wave 2)
Partner present in the household	22 (10.9%)	69 (34.2%)	94 (46.5%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the ART sample	Pearson $\chi^2=12.71$; $p=0.000^*$; Fisher's exact: 0.001 [†]		
Testing the statistical significance of the difference between wave 2 of the ART and Khayelitsha samples	Pearson $\chi^2=6.43$; $p=0.011^†$; Fisher's exact: 0.015 [†]		

* $p<0.001$.† $p<0.05$.

they were after their health had been restored by ART. This implies that significant numbers had returned to the parental home to receive care when they were sick with AIDS.

Our study goes beyond the existing literature on the relationship between AIDS and household structure, by showing that ART reverses the burden of care on kin. Our analysis showed that by wave 2, i.e. when ART patients had been stabilised on treatment, the ART sample and the matched Khayelitsha sample were indistinguishable with regard to the presence of mothers and sisters and parent-headed households. The shift in living arrangements away from parent-headed households and the declining presence of uterine kin is strongly indicative of the effect of ART on restoring health and independence for young adults living with HIV.

Fathers were less present than mothers (consistent with the broader socio-economic literature^[11,12-17]), but even so, ART patients were more likely to be living in households

with a father present when they were sick with AIDS than they were once their health had been restored. It is possible that all or some of these fathers were providing the kind of care and support found in other studies,^[8,18,19] but our data do not speak to this issue.

There is some evidence to suggest that HIV stigma, rather than falling as a result of the ART rollout, may well have risen in Cape Town in the early- to mid-2000s. Using data from the Cape Area Panel Study of young adults, Maughan-Brown^[31] found that AIDS stigma increased in the African population between 2003 and 2006 and that fear of infection was the key driver. We therefore hypothesised that the presence of sexual partners in the households of ART patients was likely to have increased over time as health was restored, but in the context of ongoing AIDS stigma and fear of infection, ART patients were probably less likely than their counterparts in the general population to be living with a sexual partner. This hypothesis was supported by the data.

These results are consistent with what we know about the potential for ART to restore health and promote greater independence for PLWHA. However, there may also have been push factors at work – notably, some ART patients may have been forced/encouraged to leave by other household members once they were able to take care of themselves. The fact that there were statistically significantly more single-person households in wave 2 (compared with wave 0 of the ART sample, and wave 2 of the Khayelitsha sample) is consistent both with ART patients exercising greater independence and potentially experiencing persistent stigma and subsequent social isolation.

We found that the number of ART patients with sexual partners rose over time, but compared with the matched comparison sample, ART patients were more likely to be living alone and without sexual partners, even after their health had been restored. This is suggestive of the continued existence of stigma against PLWHA. Medical professionals should

remain alert to the possibility that stigma may be affecting some of their patients, especially those living alone, and that they may be suffering from social marginalisation.

Acknowledgements. We acknowledge Celeste Coetzee and Takwanisa Machedmedze for help in drawing the matched and balanced sample.

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