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Does accessibility to antiretroviral care improve after down-referral of patients from hospitals to health centres in rural South Africa?

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We conducted an evaluation of healthcare accessibility among patients taking antiretroviral treatment (ART) after they were 'down-referred' from hospital-based programmes to primary healthcare (PHC) centres in a rural South African setting. A cross-sectional design was used to study 109 PHC users compared to a randomly selected control group of 220 hospital-based users. Both groups were matched for a minimum duration on ART of six months. Using a comprehensive healthcare-accessibility framework, the participants were asked about availability, affordability and acceptability of their ART care in structured exit interviews that were linked to their ART-clinic record reviews. Unadjusted and adjusted regression models were used. Down-referral was associated with reduced transportation and meal costs ($p \leq 0.001$) and travel time to an ART facility ($p = 0.043$). The down-referred users were less likely to complain of long queues (adjusted odds ratio [AOR] 0.06; 95% confidence interval [95% CI]: 0.01–0.29), were more likely to feel respected by health providers (AOR 4.43; 95% CI: 1.07–18.02), perceived lower stigma (AOR 0.25; 95% CI: 0.07–0.91), and showed a higher level of ART adherence (AOR 8.71; 95% CI: 1.16–65.22) than the hospital-based users. However, the down-referred users preferred to consult with doctors rather than nurses (AOR 3.43; 95% CI: 1.22–9.55) and they were more likely to visit private physicians (AOR 7.09; 95% CI: 3.86–13.04) and practice self-care (AOR 4.91; 95% CI: 2.37–10.17), resulting in increased health-related expenditure ($p \leq 0.001$). Therefore, the results indicate both gains and losses in ART care for the patients, and suggest that down-referred patients save time and money, feel more respected, perceive lower stigma and show better adherence levels. However, unintended consequences include increased costs of using private physicians and self-care, highlighting the need to further promote the potential gains of down-referral interventions in resource-poor settings.

Keywords: adherence, affordability, antiretroviral therapy, HIV/AIDS, primary healthcare, programme evaluation, resource-poor settings, rural communities

Introduction

More than five million people are now receiving antiretroviral treatment (ART) worldwide (UNAIDS, 2010). In 2009 alone, 1.2 million people were newly initiated, representing an increase of 30% in a single year. In low- and middle-income countries, the numbers on treatment have expanded 13-fold since 2004 (UNAIDS, 2010). Many of these advances have taken place in sub-Saharan Africa, where ART services still rely on physician-supported delivery approaches in largely over-burdened hospital-based HIV clinics (Bedelu, Ford, Hilderbrand & Reuter, 2007; Boyer, Eboko, Camara, Abé, Nguini, Koulla-Shiro & Moatti, 2010).

With the high burden of HIV and AIDS in the region, the increasing demand for ART coupled with excessive patient volumes in hospital-based services have necessitated a careful re-examination of appropriate and equitable models for the delivery of ART care and support programmes (Cleary, 2010; Harries, Zachariah, Lawn & Rosen, 2010). Concerns have been raised that centralised hospital-based ART services may create barriers to access for patients, with evidence suggesting that long travel distances (Cooke, Tanser, Bärnighausen & Newell, 2010), unaffordable transportation (Kunihira, Nuwaha, Mayanja & Peterson, 2010), and long waiting times (Wouters, Heunis, Van Rensburg & Meulemans, 2008; Posse & Baltussen, 2009) potentially result in loss to follow-up (Miller, Ketlhapile, Rybasack-Smith & Rosen, 2010) and increased mortality (Lawn, Harries, Anglaret, Myer & Wood, 2008).

In response to these realities, the 'down-referral' of clinically stable ART patients — from hospitals to lower levels of the health system, mainly primary healthcare (PHC) facilities — has been suggested as a necessary evolution of sustainable ART services (Decroo, Panunzi, Das Dores, Maldonado, Biot,

Ford & Chu, 2009; Chan, Mateyu, Jahn, Schouten, Arora, Mlotha *et al*., 2010). Although the down-referral of patients is a strategy that has become increasingly important in light of the need to reduce the burden on hospitals (Decroo *et al*., 2009; Chan *et al*., 2010), very little research has been conducted on the extent to which such an intervention does indeed enhance access to ART care.

Chan *et al.* (2010) recently demonstrated the benefits of down-referral with regard to lower rates of mortality and loss to follow up. Others have cautioned that poorly implemented down-referral programmes may result in higher rates of patient attrition (Decroo *et al*., 2009). In a different form of decentralised ART care, treatment initiation and support occurs at the primary healthcare level, and such pilot programmes have been shown to be feasible and effective, resulting in increased coverage (Bedelu *et al*., 2007; Bemelmans, Van Den Akker, Ford, Philips, Zachariah, Harries *et al*., 2010) and levels of adherence, retention in care, and mortality that are comparable to hospital care (Boyer *et al*., 2010; Fatti, Grimwood & Bock, 2010). These decentralisation efforts, including down-referral, are driven by the need to increase the capacity of the supply-side to initiate and retain HIV/AIDS patients on ART in resource-poor settings (Giordano, Gifford, White, Suarez-Almazor, Rabeneck, Hartman *et al*., 2007; Lawn *et al*., 2008; Fox & Rosen, 2010).

From a demand-side perspective, closing the distance between patients' homes and their ART facilities is an intended outcome of down-referral initiatives (Decroo *et al*., 2009). However, increased proximity alone does not represent improved access to healthcare, when access is defined through a comprehensive framework of availability, affordability and acceptability (McIntyre, Thiede & Birch, 2009). Down-referral is currently underway in South Africa as well as other parts of sub-Saharan Africa, and yet very little is known about the outcomes in terms of access for patients. In this study, we examined measures of patient access in a recently initiated down-referral programme, under operational conditions in a large rural sub-district in South Africa. Our primary objective was to compare patients' experiences of access and utilisation between down-referred clinic-based and hospital-based ART-using patients, and secondarily to measure the clinical characteristics of patients in both settings.

Methods

Study setting

The study was conducted in Bushbuckridge, a remote and rural sub-district of Mpumalanga Province, South Africa. Bushbuckridge is a densely-settled area home to approximately 523 000 inhabitants; many households in the area rely on remittance income from migrant labour. Low levels of education and high unemployment are typical characteristics. Over half of the district's households live on less than US$114 per month (Moodley, 2007). Antenatal HIV prevalence in the district is estimated at 34% (Department of Health, 2010). The area is served by three hospitals, two health centres and 37 primary healthcare (PHC) clinics. Two hospitals were accredited to initiate ART, beginning in September 2004 and October 2005, respectively, and the two health centres were permitted to serve as nurse-driven ART sites for down-referral as of May 2007, with the first patients down-referred by November 2007 (see Figure 1). The key requirements in the assessment of patients for down-referral were: demonstrated clinical stability on ART after a minimum of six months on treatment, thorough viral suppression and immunological improvement, and expressed willingness to be relocated.

Study design

The current study is an evaluation conducted opportunistically to test for plausibility in improvement of access variables among rural ART users following down-referral from hospital-based to PHC centres (Habicht, Victoria & Vaughan, 1999). We used a comparison group of hospital-based participants in a cross-sectional design and under real-world operational conditions to assess patient access, service utilisation and clinical outcomes associated with down-referral. Patients from all four public-sector facilities providing ART (i.e. two hospitals [the initiation sites] and two health centres [the down-referral sites]), were eligible to be included in the study. The participants initiated on ART at a hospital level and down-referred to health centres to receive follow-up ART care were compared with those initiated and remaining in the hospitals for their ART care follow-up. This study was nested within one of four sites involved in a major five-year multisite project named Researching Equity in Access to Health Care (REACH).

The study populations and sampling

At the time of the study, 120 patients were receiving ART at the PHC level, following their initiation and down-referral from the hospital level, while approximately 3 500 ART patients were hospital-based. In both settings, the patients were excluded from interviews if they were less than 18 years of age, had been on ART for less than two weeks, or were not prepared to give informed consent to participate. At the health centres, all adult patients were included in the study. At the hospitals, patients were selected for an interview through a random sampling method, using their daily patient numbers assigned for purposes of clinic patient flow. The interviews continued until 312 patients had been interviewed. Although the hospital-based component included all 312 adults on ART, we excluded those who had been on treatment for less than six months in the analysis, to ensure comparability between the two patient populations.

Data collection

The study was conducted between April and December 2008. The data were collected through ART-patient exit interviews within the health facilities, and clinic records were reviewed to retrieve data on the patients' CD4 cell count and viral load. These record reviews were conducted on the same day as the interview. The participants were interviewed by trained research assistants, in Tsonga, Sepedi or English, depending on the participant's language preference on the day of their visit to the ART service point. In addition to the patient access variables, we also collected

demographic and household asset data to create an index of socioeconomic status (SES), and assessed healthcare utilisation patterns. For the latter, the participants were asked about additional healthcare sought and related costs in the month prior to their clinic visit.

The first question asked was: 'Apart from visits to this clinic for your ARVs, have you used any other health service in the last four weeks?' The participants were prompted with a series of choices, including the PHC clinic or hospital, and a private chemist or doctor. The second question was: 'Have you spent any other money on healthcare in the past month (e.g. traditional medicines, small shops, special food, etc.)?' This question was asked to illicit information on their purchase of healthcare products and substances representing a form of self-care behaviour. In addition, the participants were asked to make suggestions for service improvements at their respective facilities. The levels of clinic-appointment attendance and ART adherence were measured using the patients' self-reports of ever-missing ART clinic visits and ever-missing doses of ART, respectively.

Conceptual framework

In this study, patient access is conceptualised as a multi-dimensional notion of the availability, affordability and acceptability of services. Availability is concerned with whether services are available in the right place and at the time that they are needed; affordability includes the costs incurred in seeking healthcare (transport costs, waiting-time costs, lost income) as well as the ability to incur or cope with these costs (access to salary income, savings, loans); acceptability includes the nature or form of service

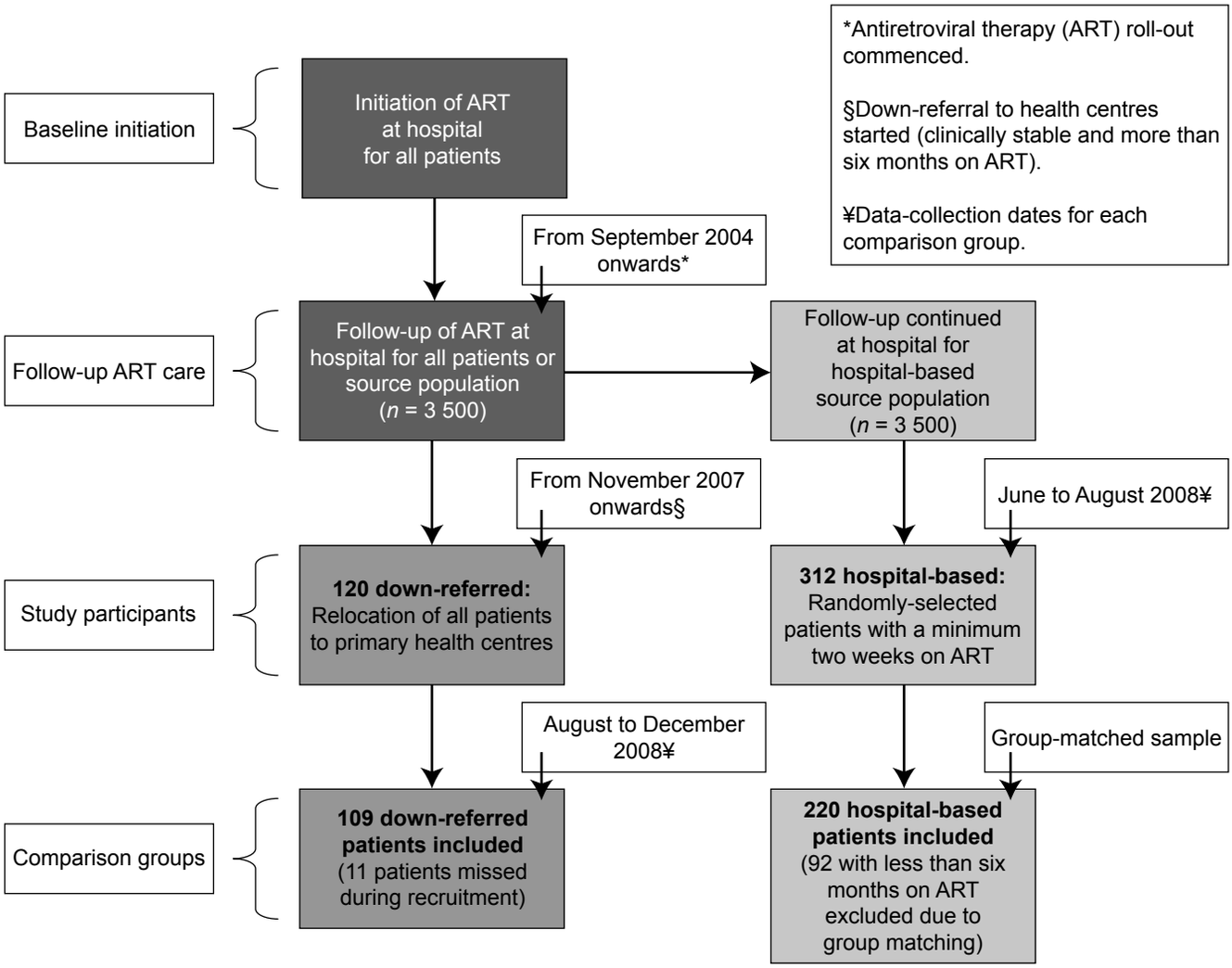

Figure 1: A flow diagram of the source population and study participants, depicting the recruitment and sampling process followed with the study design. Dates of major events in the source population are indicated to create a context for the reader. A combined population of ART patients initiated from two hospitals (*n* = 3 500), from which patients were down-referred to primary health centres (*n* = 120) for ART follow-up was also used to recruit and randomly select a study sample for the REACH study (*n* = 312). All recruited down-referred patients (*n* = 109) were compared with a representative matched sample of hospital-based users (*n* = 220)

provision and how this is perceived by patients and communities, as measured through patients' perceptions of the quality of care and their perceptions about the attitudes of doctors, among other things (Thiede, Akweongo & McIntyre, 2007).

Data analysis

The data were double-entered into a purpose-designed database in EpiData Version 3.1 and imported into Stata Version 10 for analysis. Descriptive statistics stratified by type of facility were generated, student *t*-tests were used for continuous variables, and bivariate analyses were conducted with chi-squared tests and logistic regression. Simple and multiple linear and logistic regressions were used to examine the outcomes of differential access experiences, healthcare utilisation, clinical characteristics (an increase in CD4 cell count from baseline, and viral load suppression) and adherence for the down-referred patients (where a binary independent variable takes a value of '1' for the PHC users, or '0' for the hospital-based users).

The SES index was constructed using multiple correspondence analysis, described elsewhere (see Cleary, Silal, Birch, Carrara, Pillay-Van Wyk, Rehle & Schneider, 2010). Catastrophic healthcare expenditure was defined as mean monthly healthcare-related expenditure greater than 15% of the mean monthly household expenditure. All outcome variables significant at α-level of 10% in simple regression were included in multiple regression models. All linear and logistic regression models were controlled for clustering at the ART-facility level, and the multiple regression models were adjusted for age, education level, baseline CD4 cell count and duration on ART, which were all found to be significantly different between the hospital-based and down-referred users during the descriptive analysis.

Ethical considerations

Ethical approval was obtained from the University of the Witwatersrand (Johannesburg) and the Mpumalanga Provincial Health Research and Ethics Committee. Written informed consent was obtained separately for the interview and for the HIV-clinic record review. Anonymity of the participants was maintained during the data collection, management, analysis, and reporting.

Results

Participants' characteristics

Of the 120 patients down-referred to health centres, 109 (91%) were recruited and included in the study (Figure 1). A total of 312 randomly-selected hospital-based users were included in the parent study, but 92 (29.5%) had been on ART for less than six months and were excluded from the analysis in order to match the clinic-based sample, leaving a sample size of 220 hospital-based controls. Prior to ART initiation, the down-referred users 67/109 (61.5%) were more likely ($p = 0.038$) to have been tested for HIV at a local clinic than the hospital-based users 103/220 (46.8%).There were no differences in age ($p = 0.089$), sex ($p = 0.317$), marital status ($p = 0.376$), and employment ($p = 0.707$) between the down-referred and hospital-based participants (Table 1).

Lack of formal education was associated with down-referral ($p \leq 0.001$), with a higher proportion seen among the down-referred (32/109; 29.4%) than hospital users (35/220; 15.9%). The down-referred and hospital-based users did not differ by distribution of SES ($p = 0.296$). A higher proportion of the hospital users (111/220; 50.5%) were receiving a temporary disability grant as compared with those down-referred (34/109; 31.2%), with a 46% reduction in the odds of the down-referred users receiving a temporary disability grant ($p = 0.035$). The mean CD4 cell count at initiation of ART was slightly higher among the hospital-based users (119.4 cells/uL) than the down-referred patients (96.6 cells/uL), but these differences were not significant in bivariate regression analysis. The down-referred users had a longer mean duration on ART as compared with the hospital users ($p = 0.018$). The proportion of users who had achieved viral suppression was higher among the down-referred than hospital users ($p \leq 0.001$).

Availability dimension

Down-referral was associated with a five-fold increase in the odds of receiving ART from the facility closest to participants' homes when compared with the hospital users ($p = 0.035$) (see Table 1). No statistical differences were seen in the numbers of individuals receiving home visits by health workers for HIV-care services ($p = 0.089$). In bivariate analysis, the down-referred users were more likely to walk to the ART facility for collection of ART ($p = 0.021$) and to experience lower mean travel times ($p = 0.043$) than the hospital users. Figure 2 depicts differences in the patients' mean number of hours spent waiting to be seen at the ART facility. The down-referred users had a mean waiting time of 3.2 hours (interquartile range [IQR] 2–3), which was lower than the hospital users who waited for a mean of 4.0 hours (IQR 2–6).

Acceptability dimension

The down-referred patients reported fewer concerns with service acceptability than the hospital users, including concerns about the length of queues (9/109 or 8.3% versus 103/220 or 46.8%; $p \leq 0.001$), the number of health workers (8/109 or 7.3% versus 96/220 or 43.6%; $p \leq 0.001$) and the need for cleaner facilities (4/109 or 3.7% versus 26/220; $p = 0.016$). In multivariate analysis, the down-referred users were shown as less likely to find queues too long compared to the hospital users (adjusted odds ratio [AOR] 0.06; 95% confidence interval [95% CI]: 0.01–0.29). Perceived respect for the users by the health providers at the ART facilities was 4.4-times higher ($p = 0.038$) among the down-referred (96/109; 88.1%) as opposed to the hospital-based users (137/220; 62.3%), as shown in Table 1.

Although no doctors visited them, most of the down-referred users (77/109; 70.6%) were willing to travel further to be seen by a doctor than consult with a nurse nearby, in comparison with the hospital users (91/220 or 41.4%; $p = 0.019$). This finding persisted in multivariate regression, where the down-referred patients were more than three-fold more likely to state a preference to be seen by a doctor as opposed to a nurse when compared to the hospital users (AOR 3.43; 95% CI: 1.22–9.55). In

Table 1: The down-referred primary-healthcare-centre users compared with the hospital-based users of antiretroviral treatment (ART) services; bivariate and multivariate analyses (CI = confidence interval)

		Hospital users	Down-referred users	Bivariate regression model			Multivariate regression model		
Variable	Category	*n* (%) (*n* = 220)	*n* (%) (*n* = 109)	Odds ratio	95% CI	*p*-value	Odds ratio	95% CI	*p*-value
Sociodemographic									
Age (years)	50 or older	39 (17.7)	29 (26.6)	1.68	0.92–3.06	0.089	1.29	0.85–1.96	0.231
Sex	Female	168 (76.4)	80 (73.4)	0.85	0.63–1.16	0.317	–	–	–
Marital status	Widowed/separated	96 (43.6)	52 (47.7)	1.18	0.82–1.69	0.376	–	–	–
Formal education	None	35 (15.9)	32 (29.4)	2.20	1.09–4.44	0.028	2.29	1.43–3.68	0.001
Employment	None	180 (81.8)	86 (78.9)	0.83	0.32–2.18	0.707	–	–	–
Socioeconomic status (SES)	Poorer (lowest 40%)	108 (49.1)	48 (44)	0.86	0.56–1.20	0.296	–	–	–
Disability grant	Yes	111 (50.5)	34 (31.2)	0.45	0.18–1.13	0.089	0.44	0.20–0.94	0.035
Availability of care									
Closest to home	Yes	170 (77.6)	104 (95.4)	6.00	1.23–29.18	0.027	5.14	1.12–23.60	0.035
Mode of travel	Walking	13 (5.9)	17 (15.6)	2.94	1.18–7.35	0.021	2.44	0.82–7.28	0.111
Home visits for HIV care	Yes	43 (19.6)	35 (32.1)	1.95	0.90–4.19	0.089	1.82	0.75–4.44	0.186
ART collection frequency	2-monthly or more	44 (20)	40 (36.7)	2.32	0.11–48.30	0.587	–	–	–
Travel time	Mean hours	1.3	0.8	–0.49	-0.96–0.01	0.043	–0.46	-0.97–0.06	0.066
Acceptability of care									
Waiting in queues	Too long	195 (88.6)	34 (31.2)	0.06	0.01–0.34	0.002	0.06	0.01–0.29	0.001
Providers' attitude	Respectful	137 (62.3)	96 (88.1)	4.47	0.95–21.02	0.058	4.43	1.07–18.02	0.038
Preferred provider	Doctor	91 (41.4)	77 (70.6)	3.41	1.26–9.23	0.016	3.43	1.22–9.55	0.019
Perceived community stigma	Yes	47 (21.4)	07 (6.4)	0.25	0.06–1.10	0.067	0.25	0.07–0.91	0.036
Affordability of care									
ART-visit costs (transportation and meals)	Mean (US$)	3.93	1.46	–2.48	-5.95–1.00	0.108	–	–	–
Costs of additional healthcare	Mean (US$)	6.71	12.19	5.48	-9.57–20.52	0.331	–	–	–
Easy or difficult to incur health costs	Easy	62 (28.2)	51 (46.8)	2.24	0.77–6.55	0.140	–	–	–
Additional healthcare sought while on ART (during previous 4 weeks)									
Tuberculosis clinic	Yes	3 (1.4)	6 (5.5)	4.21	1.51–11.74	0.006	3.63	1.09–12.01	0.035
Private chemist	Yes	8 (3.6)	2 (1.8)	0.50	0.08–3.01	0.445	–	–	–
Private doctor	Yes	2 (0.9)	7 (6.4)	7.48	6.18–9.05	<0.001	7.09	3.86–13.04	<0.001
Self-care practices	Yes	46 (20.9)	62 (56.9)	4.99	2.16–11.50	<0.001	4.91	2.37–10.17	<0.001
Clinical characteristics									
Short-term ART adherence	>95% for previous 3 days	216 (98.2)	108 (99.1)	2.00	0.30–13.22	0.472	–	–	–
Long-term ART adherence	No missed doses since initiation	205 (93.2)	108 (99.1)	7.90	1.03–60.44	0.046	8.71	1.16–65.22	0.035
Knowledge of recent CD4 cell count	Yes	131 (59.6)	44 (40.4)	0.46	0.33–0.64	<0.001	0.51	0.32–0.81	0.005
Duration on ART	Mean months	21.5	25.9	4.38	1.39–7.35	0.018	4.62	1.51–7.74	0.018
CD4 cell count at ART initiation	Mean cells/uL	119.4	96.6	–22.84	-64.41–18.72	0.179	–	–	–
Most recent CD4 cell count	Mean cells/uL	363.4	392.6	29.26	-32.03–90.55	0.226	–	–	–
Viral load suppression	<400 copies/ml	157 (83.5)*	70 (97.2)**	6.91	4.73–10.11	<0.001	6.21	4.33–8.94	<0.001

*Out of 188 patients.**Out of 72 patients.

addition, the down-referred users showed a 75% reduction in the odds of perceived community stigma, measured by self-perceived negative judgement in their communities, as compared with the hospital-based users.

Affordability dimension

Figure 3 shows that the down-referred users had lower median ART-facility visit costs (including transportation and meals while waiting) as compared with the hospital users (down-referred 1.3 [IQR 0.7–1.5] vs. hospital-based 3.0 [IQR 1.6–7.1]; $p \leq 0.001$). However, the saving of US$2.48 by the down-referred users in terms of mean visit costs was not statistically significant in bivariate regression after controlling for clustering ($p = 0.108$). Other costs incurred through the use of additional healthcare over and above ART services were US$5.48 higher for the down-referred patients versus the hospital users ($p = 0.331$). The down-referred users were seven-fold more likely to have visited a private physician in the preceding four weeks than were the hospital users ($p \leq 0.001$) and their self-care practices were five-fold higher ($p \leq 0.001$). As shown in Figure 4, catastrophic healthcare expenditures above 15% of the total household expenditure were much more prevalent among the down-referred users (29/109; 26.6%) than the hospital users (24/220; 10.9%) ($p \leq 0.001$).

Clinical characteristics

Reported three-day adherence rates to ART above 95% were 108/109 (99.1%) and 216/220 (98.2%) for the down-referred and hospital-based users, respectively, which was high for both, but not statistically different ($p = 0.472$). However, long-term adherence to ART measured by ever-missing a dose since initiation differed significantly between the two groups, with the down-referred users found to be eight-times more likely to adhere to ART than the hospital-based users after controlling for confounders and cluster effects ($p = 0.035$). None of the down-referred users (0/109) reported missing a clinic appointment in the six months prior, as compared with 11/220 (5%) of the hospital users. In addition, the down-referred users were more likely to report use of a tuberculosis-treatment clinic than did the hospital users (AOR 3.63; 95% CI: 1.09–12.01). The patients' knowledge of their most recent CD4 cell count was 49% lower among the down-referred users as compared with the hospital users (AOR 0.51; 95% CI: 0.32–0.81). In a subsample of users, viral load suppression was more likely to be associated with down-referral than with hospital usage (AOR 6.21; 95% CI: 4.33–8.94).

Discussion

This study examined dimensions of access to care and the treatment outcomes among ART patients in a rural setting in South Africa, comparing those managed at a specialised hospital-based HIV clinic with down-referred patients managed by nurses in health centres. Relative to the hospital-based patients, the down-referred patients had fewer access barriers to their ART care, lower levels of expenditure on meals and transportation, and reduced perceived stigma when receiving their ART in a primary care setting. Down-referral was also associated with improved levels of ART adherence. There was also evidence of parallel concerns regarding the quality of care. Despite their use of nurse-driven clinics, the down-referred patients showed an overwhelming preference to be seen by doctors

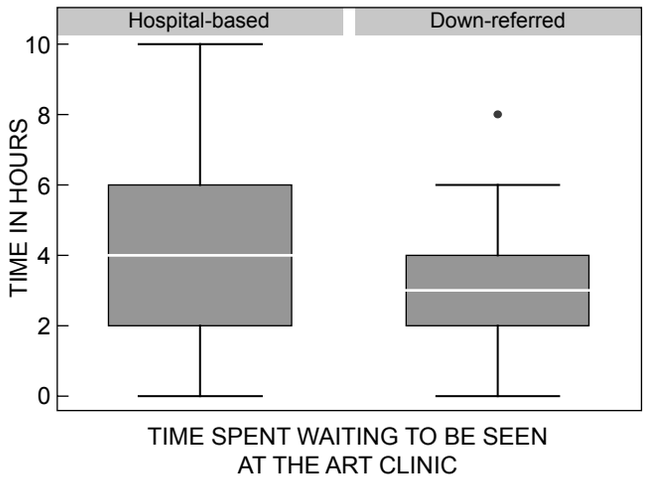

Figure 2: A box-plot diagram of the patients' time spent waiting to be seen by a provider in the ART facility, showing a median waiting time of 3 and 4 hours for the down-referred and hospital-based users, respectively. The most number of hours that the down-referred and hospital-based users had spent waiting for a provider were 8 and 10 hours, respectively. The interquartile ranges for the down-referred and hospital-based users were 2–4 and 2–6 hours, respectively. Therefore, the down-referred users demonstrated a reduced waiting time as compared with the hospital-based users

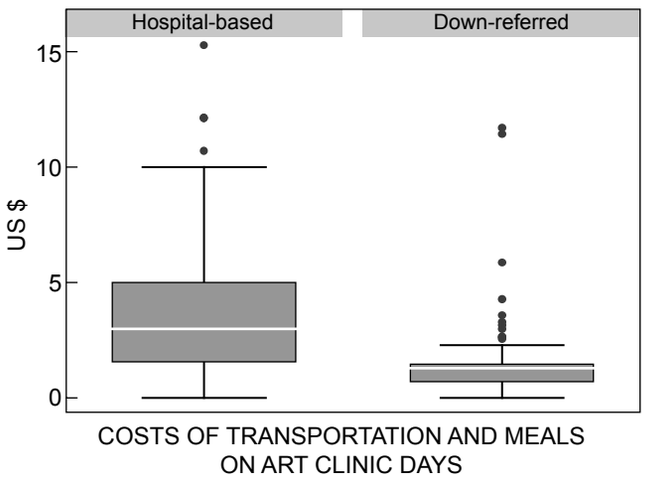

Figure 3: A box-plot diagram of expenditures incurred by the down-referred and hospital-based users on the day of their clinic visit, in terms of transportation and meals, showing lower costs (US$) among the down-referred users. The median costs were US$1.3 and US$3.0 (interquartile ranges $0.7–$1.5 and $1.6–$7.14) for the down-referred and hospital-based users, respectively. Therefore, cost-savings were associated with down-referral

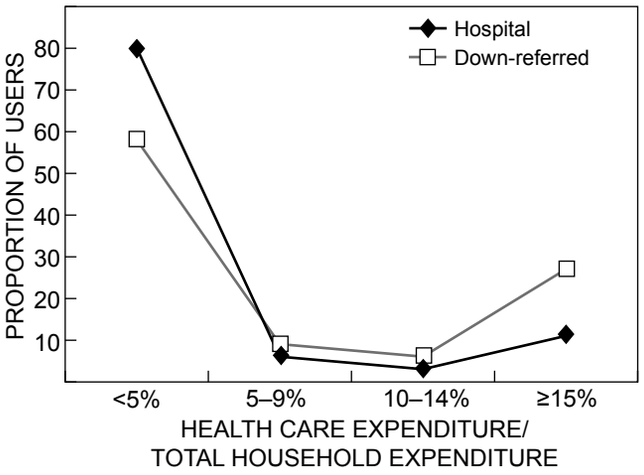

Figure 4: For users who sought additional healthcare to complement their regular ART care during the four weeks prior to the interview, the severity of their expenditure was calculated as a proportion of the total household expenditure. Among those incurring expenditures less than 5% of the total household expenditure, 56% and 80% were down-referred and hospital-based users, respectively. Among those incurring expenditures more than 15% of the total household expenditures (which is regarded to be catastrophic), 27% were down-referred, and only 11% were hospital-based users. Therefore, a higher proportion of the down-referred users incurred a catastrophic level of expenditure from seeking additional healthcare than did the hospital-based users

rather than nurses. In addition, the patients' knowledge of their most recent CD4 cell count was poorer among the down-referred. Finally, the down-referred users complemented their healthcare with private doctors and self-care practices, resulting in threats of catastrophic healthcare expenditure greater than 15% of the total household expenditure.

In terms of gains, the down-referred patients saved time and money on their clinic days. Their mean travel time and time spent clinic queues were shorter, and their ART-visit costs for travel and meals showed lower trends than those for the hospital-based patients. The reduction in ART-visit costs associated with down-referral may increase the likelihood of economic risk protection for vulnerable individuals and households (Xu, Evans, Carrin, Aguilar-Rivera, Musgrove & Evans, 2007). Higher levels of ART adherence suggest a potential long-term benefit of down-referral, but this finding necessitates prospectively designed studies. The down-referred patients' perception of respectfulness among the health providers suggests more humane care at the primary healthcare level. In addition, the down-referred patients perceived lower levels of community stigma — an unexpected finding in favour of down-referral. Several factors may explain this observation. First, the comprehensive nature of primary healthcare may reduce perceptions of HIV stigma (Topp, Chipukuma, Giganti, Mwango, Chiko, Tambatamba-Chapula *et al*., 2010). Second, patients who reported less perceived stigma may have self-selected by agreeing to the process of down-referral. Finally, a longer duration on ART may mean that the down-referred patients were less obviously physically ill. However, this finding persisted after controlling for the patients' duration on ART and their severity of illness at baseline. Perceived stigma, known to increase attrition (Assefa, Van Damme, Mariam & Kloos, 2010; McGuire, Munyenyembe, Szumilin, Heinzelmann, Le Paih, Bouithy & Pujades-Rodriguez, 2010), may compromise efforts to decentralise care.

Conversely, the down-referred patients were less likely to know their most recent CD4 cell count, they preferred to be seen by a doctor, and were more likely to seek additional healthcare through private doctors and self-care practices, suggesting possible inadequacies regarding the perceived quality of care. Indeed, adequate quality of care needs to be achieved at the primary healthcare level (Pfeiffer, Montoya, Baptista, Karagianis, De Morias Pugas, Micek *et al*., 2010), and may be subject to further improvements as programmes mature over time. For example, the down-referred patients' lower level of knowledge about their recent CD4 cell count is a finding that may put into question the capacity of health centres to track and manage laboratory results or the effectiveness of patient-provider communication (Goudge, Gilson, Russell, Gumede & Mills, 2009a; Cornell, Grimsrud, Fairall, Fox, Van Cutsem, Giddy *et al*., 2010). Nevertheless, active management of patient expectations during down-referral may be necessary with regard to the standard of care and the skill level of health providers. The availability of doctors and more experienced nurses in hospital-based ART services may raise expectations among down-referred patients and increase their demand for higher-skilled medical staff, although nurse-monitored care is not necessarily inferior to doctor-monitored care in a primary-care setting (Sanne, Orrell, Fox, Conradie, Ive, Zeinecker *et al*., 2010). Initiating ART at the primary healthcare level may serve to reduce these expectations, although discrepancies in the packages of care between hospitals and PHC clinics must be addressed (Bedelu *et al*., 2007; Decroo *et al*., 2009). Finally, the identified threat of catastrophic healthcare expenditure associated with additional healthcare-seeking behaviour may adversely affect the livelihoods of patients and their households (Goudge, Gilson, Russell, Gumede & Mills, 2009b).

Study limitations

The study had limitations. First, the design of the down-referral project required patients to be stable prior to relocation, as determined by an increased CD4 cell count and a reduced viral load, as of six months on ART. This selection bias, when added to the problem of missing laboratory results, means that findings about better virological outcomes among down-referred patients cannot be used to make conclusions about the clinical effectiveness of the down-referral strategy. Second, patient willingness as one programmatic criterion for down-referral could have biased the study's findings. However, this criterion forms an integral part of the down-referral programme and had to be included in this study. Third, the cross-sectional design of the study did not allow for adequate assessment of the direction of cause and effect, and some of the patients' responses may have been affected by recall and

social-desirability biases. Future studies on down-referral may benefit from longitudinal designs, better tracking of biological markers, and random assignment of clients to hospital or down-referral intervention arms. Fourth, the early stages of the down-referral programme meant that the total number included in the down-referred group was small. As programmes mature, this limitation can be addressed by including larger numbers of participants.

Conclusions

The results of this study suggest that the down-referral of stable ART patients may be an effective decentralisation strategy for improving and sustaining access to ART care in the context of rural South Africa. Down-referred patients appear to save time and money, feel more respected, perceive lower stigma and show better adherence. However, there is evidence of unintended consequences as shown by increased rates of utilisation and greater costs in terms of both private physicians and self-care practices. As programmes evolve to support and eventually initiate ART at the primary healthcare level, these findings highlight the critical importance of parallel efforts to ensure that the quality of care is maintained, such as through adequate staff training, supervision, and laboratory support. While these efforts are clearly important to optimise clinical decision-making and referral in their own right, they also serve to strengthen patients' confidence in the service. Any erosion of this confidence may result in undesirable and costly care-seeking practices with the potential to reverse early gains realised through the down-referral strategy in resource-poor settings.

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References

Assefa, Y., Van Damme, W., Mariam, D.H. & Kloos, H. (2010) Toward universal access to HIV counseling and testing and antiretroviral treatment in Ethiopia: looking beyond HIV testing and ART initiation. *AIDS Patient Care and STDs* 24(8), pp. 521–525.

Bedelu, M., Ford, N., Hilderbrand, K. & Reuter, H. (2007) Implementing antiretroviral therapy in rural communities: the Lusikisiki model of decentralized HIV/AIDS care. *The Journal of Infectious Diseases* 196(supplement 3), pp. S464–S468.

Bemelmans, M., Van Den Akker, T., Ford, N., Philips, M., Zachariah, R., Harries, A., Schouten, E., Hermann, K., Mwagomba, B. & Massaquoi, M. (2010) Providing universal access to antiretroviral therapy in Thyolo, Malawi, through task-shifting and decentralization of HIV/AIDS care. *Tropical Medicine and International Health* 15(12), pp. 1413–1420.

Boyer, S., Eboko, F., Camara, M., Abé, C., Nguini, M.E.O., Koulla-Shiro, S. & Moatti, J.-P. (2010) Scaling up access to antiretroviral treatment for HIV infection: the impact of decentralization of healthcare delivery in Cameroon. *AIDS* 24(supplement 1), pp. S5–S15.

Chan, A.K., Mateyu, G., Jahn, A., Schouten, E., Arora, P., Mlotha, W., Kambanji, M. & Van Lettow, M. (2010) Outcome assessment of decentralization of antiretroviral therapy provision in a rural district of Malawi using an integrated primary care model. *Tropical Medicine and International Health* 15(supplement 1), pp. S90–S97.

Cleary, S. (2010) Equity and efficiency in scaling up access to HIV-related interventions in resource-limited settings. *Current Opinion in HIV and AIDS* 5(3), pp. 210–214.

Cleary, S., Silal, S., Birch, S., Carrara, H., Pillay-Van Wyk, V., Rehle, T. & Schneider, H. (2010) Equity in the use of antiretroviral treatment in the public healthcare system in urban South Africa. *Health Policy* 99(3), pp. 261–266.

Cooke, G.S., Tanser, F.C., Bärnighausen, T.W. & Newell, M.-L. (2010) Population uptake of antiretroviral treatment through primary care in rural South Africa. *BMC Public Health* 10; doi: 10.1186/1471-2458-10-585.

Cornell, M., Grimsrud, A., Fairall, L., Fox, M.P., Van Cutsem, G., Giddy, J., Wood, R., Prozesky, H., Mohapi, L., Graber, C., Egger, M., Boulle, A. & Myer, L.; International Epidemiologic Databases to Evaluate AIDS in Southern Africa (IeDEA-SA) Collaboration (2010) Temporal changes in programme outcomes among adult patients initiating antiretroviral therapy across South Africa, 2002–2007. *AIDS* 24(14), pp. 2263–2270.

Decroo, T., Panunzi, I., Das Dores, C., Maldonado, F., Biot, M., Ford, N. & Chu, K. (2009) Lessons learned during down referral of antiretroviral treatment in Tete, Mozambique. *Journal of the International AIDS Society* 12; doi: 10.1186/1758-2652-12-6.

Department of Health [South Africa] (2010) *National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa, 2009*. Pretoria, South Africa, National Department of Health.

Fatti, G., Grimwood, A. & Bock, P. (2010) Better antiretroviral therapy outcomes at primary healthcare facilities: an evaluation of three tiers of ART services in four South African provinces. *PLoS ONE* 5; doi: 10.1371/journal.pone.0012888.

Fox, M.P. & Rosen, S. (2010) Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review. *Tropical Medicine and International Health* 15(supplement 1), pp. 1–15.

Giordano, T.P., Gifford, A.I., White Jr, A.C., Suarez-Almazor, M.E., Rabeneck, L., Hartman, C., Backus, L.I., Mole, L.A. & Morgan, R.O. (2007) Retention in care: a challenge to survival with HIV infection. *Clinical Infectious Diseases* 44(11), pp. 1493–1499.

Goudge, J., Gilson, L., Russell, S., Gumede, T. & Mills, A. (2009a) Affordability, availability and acceptability barriers to health care for the chronically ill: longitudinal case studies from South Africa. *BMC Health Services Research* 9; doi: 10.1186/1472-6963-9-75.

Goudge, J., Gilson, L., Russell, S., Gumede, T. & Mills, A. (2009b) The household costs of healthcare in rural South Africa with free public primary care and hospital exemptions for the poor. *Tropical Medicine and International Health* 14(4), pp. 458–467.

Habicht, J.P., Victoria, C.G. & Vaughan, J.P. (1999) Evaluation designs for adequacy, plausibility and probability of public health programme performance and impact. *International Journal of Epidemiology* 28(1), pp. 10–18.

Harries, A.D., Zachariah, R., Lawn, S.D. & Rosen, S. (2010) Strategies to improve patient retention on antiretroviral therapy in sub-Saharan Africa. *Tropical Medicine and International Health* 15(supplement 1), pp. 70–75.

Kunihira, N.R., Nuwaha, F., Mayanja, R. & Peterson, S. (2010) Barriers to use of antiretroviral drugs in Rakai district of Uganda. *African Health Sciences* 10(2), pp. 120–129.

Lawn, S.D., Harries, A.D., Anglaret, X., Myer, L. & Wood, R. (2008) Early mortality among adults accessing antiretroviral treatment programmes in sub-Saharan Africa. *AIDS* 22(15), pp. 1897–1908.

McGuire, M., Munyenyembe, T., Szumilin, E., Heinzelmann, A., Le Paih, M., Bouithy, N. & Pujades-Rodriguez, M. (2010) Vital status of pre-ART and ART patients defaulting from care in rural Malawi. *Tropical Medicine and International Health* 15(supplement 1), pp. 55–62.

McIntyre, D., Thiede, M. & Birch, S. (2009) Access as a policy-relevant concept in low- and middle-income countries. *Health Economics, Policy and Law* 4(2), pp. 179–193.

Miller, C.M., Ketlhapile, M., Rybasack-Smith, H. & Rosen, S. (2010) Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Tropical Medicine and International Health* 15(supplement 1), pp. 48–54.

Moodley, K. (2007) Mpumalanga Province. In: Barron, P., Day, C. & Monticelli, F. (eds.) *The District Health Barometer 2007/08.* Durban, South africa, Health Systems Trust.

Pfeiffer, J., Montoya, P., Baptista, A.J., Karagianis, M., De Morais Pugas, M., Micek, M., Johnson, W., Sherr, K., Gimbel, S., Baird, S., Lambdin, B. & Gloyd, S. (2010) Integration of HIV/AIDS services into African primary health care: lessons learned for health system strengthening in Mozambique — a case study. *Journal of the International AIDS Society* 13; doi: 10.1186/1758-2652-13-3.

Posse, M. & Baltussen, R. (2009) Barriers to access to antiretroviral treatment in Mozambique, as perceived by patients and health workers in urban and rural settings. *AIDS Patient Care and STDs* 23(10), pp. 867–875.

Sanne, I., Orrell, C., Fox, M.P., Conradie, F., Ive, P., Zeinecker, J., Cornell, M., Heiberg, C., Ingram, C., Panchia, R., Rassool, M., Gonin, R., Stevens, W., Truter, H., Dehlinger, M., Van Der Horst, C., McIntyre, J. & Wood, R. (2010) Nurse versus doctor management of HIV-infected patients receiving antiretroviral therapy (CIPRA-SA): a randomised non-inferiority trial. *The Lancet* 376(9734), pp. 33–40.

Thiede, M., Akweongo, P. & McIntyre, D. (2007) Exploring the dimensions of access. In: McIntyre, D. & Mooney, G. (eds.) *The Economics of Health Equity.* Cambridge, UK, Cambridge University Press.

Topp, S.M., Chipukuma, J.M., Giganti, M., Mwango, L.K., Chiko, L.M., Tambatamba-Chapula, B., Wamulume, C.S. & Reid, S. (2010) Strengthening health systems at facility-level: feasibility of integrating antiretroviral therapy into primary healthcare services in Lusaka, Zambia. *PLoS ONE* 5; doi: 10.1371/journal.pone.0011522.

UNAIDS (2010) *UNAIDS Report on the Global AIDS Epidemic 2010*. Geneva, UNAIDS.

Wouters, E., Heunis, C., Van Rensburg, D. & Meulemans, H. (2008) Patient satisfaction with antiretroviral services at primary health-care facilities in the Free State, South Africa — a two-year study using four waves of cross-sectional data. *BMC Health Services Research* 8; doi: 10.1186/1472-6963-8-210.

Xu, K., Evans, D.B., Carrin, G., Aguilar-Rivera, A.M., Musgrove, P. & Evans, T. (2007) Protecting households from catastrophic health spending. *Health Affairs* 26(4), pp. 972–983.