

*Frikkie Booysen, Shaun Anderson & Kobus Meyer*

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## Public sector antiretroviral treatment: the challenge of patient retention

Compliance with follow-up is needed to ensure that the public sector antiretroviral treatment programme in South Africa is successful and sustainable. This paper investigates the nature of factors associated with the retention of public sector ART patients in the primary health care-driven model. Data from a cross-sectional survey among patients are used. Income and social support are important facilitators of patient retention. Yet, income may also impact negatively on patient retention where entire families rely on a single breadwinner for their livelihood. Substance and alcohol abuse and stigma, according to the evidence, may impede patient retention. Avenues for further research are proposed and suggestions are put forward as to possible solutions to these policy dilemmas.

### Antiretrovirale terapie in die openbare sektor: die uitdaging van pasiëntretensie

Terapietrou met opvolg is noodsaaklik om te verseker dat die ART-program in die openbare sektor in Suid-Afrika suksesvol en volhoubaar is. Hierdie bydrae ondersoek die aard van faktore wat met die retensie van ART-pasiënte in die openbare sektor binne die primêre gesondheidsorggedrewe model geassosieer word. Data van 'n deursnee-opname onder pasiënte word gebruik. Inkomste en sosiale ondersteuning is belangrike fasiliteerders van pasiëntretensie. Nogtans kan inkomste ook negatief op pasiëntretensie inspeel waar hele gesinne van 'n enkele broodwinner vir lewensonderhoud afhanklik is. Volgens die bevindinge kan dwelm- en alkoholgebruik en stigma ook pasiëntretensie bemoeilik. Moontlikhede vir verdere navorsing word voorgestel en aanbevelings gemaak met betrekking tot moontlike oplossings vir hierdie beleidsdilemmas.

*Prof F le R Booysen, Dept of Economics and Centre for Health Systems Research & Development; Mr S Anderson, Centre for Development Support & Mr J Meyer, Centre for Health Systems Research & Development, University of the Free State, P O Box 339, Bloemfontein 9300, South Africa; E-mail: booysenf.ekw@mail.uovs.ac.za*

South Africa faces one of the highest HIV prevalence rates in the world — 2004 estimates of HIV prevalence among the total population ranged from 8.2% to 12.9% or from 3.8 to 5.6 million infected persons (Dorrington *et al* 2004). Access to free ART became a reality in the public health care sector in late 2003, when government officially introduced its treatment programme. In 2003 the Free State province was home to an estimated 29 310 of the total 388 701 new AIDS cases that would qualify for public sector ART. It was estimated that a further 35 to 46 thousand persons in the province would annually qualify for ART, compared to 463 to 625 thousand nationally (NDoH 2003). Public access to ART, however, is not universal as yet. Treatment is phased in over a five-year period, the aim being to achieve universal access by 2007 (NDoH 2003). By mid-2005, an estimated 3.1% of the estimated AIDS patients in the province who are dependent on public sector health care had commenced ART as part of the public sector antiretroviral treatment (ART) programme.<sup>1</sup> The number of public sector ART patients has since increased significantly and stands at approximately 5 000, which brings public sector ART coverage to around 13% (FSDoH 2006). As the programme expands, this number will continue to increase, making the ART programme one of the largest of its kind in the world.

According to the *Operational Plan for the Comprehensive HIV and AIDS Care, Management and Treatment*, “primary health care clinics and community health care centres [in other words, assessment sites] are the primary sites for . . . routine follow-up of HIV-positive patients” (NDoH 2003: 60). The Treatment Guidelines state that ART patients have to “attend clinics monthly to collect medication” and require nursing staff to “monitor drug tolerance, adverse events and adherence” (NDoH 2004: 7). These visits also offer important opportunities to “reinforce messages of prevention, while enabling early detection and intervention for clinical, immunological and psychological decline” (NDoH 2003: 65). Mont-

1 According to the latest available statistics, 14.9% of the Free State population has access to health care insurance (Health Systems Trust 2005). It is assumed that the remaining 85.1% of the estimated 42 934 AIDS patients in the province (Dorrington 2005) is dependent on public sector treatment. Public sector ART coverage was calculated by dividing the 1 115 public sector ART patients in the Free State province by this figure and expressing the result as a percentage.

gomery *et al* (2002) emphasise the importance of regular utilisation of PHC in improving the prognosis of patients on HAART, while Meng *et al* (2006) highlight the role of poor patient retention by explaining the mix of ART provision in rural China. The challenge, therefore, is to ensure that patients on ARVs visit assessment sites relatively frequently, given that long-term adherence and compliance with follow-up are crucial for a successful and sustainable ART programme (Turner 2002, Kent *et al* 2003, Blower 2005, Harries *et al* 2006).

The main objective of this paper is to investigate factors associated with the successful retention of public sector ART patients in such a PHC-driven model. In addition, the purpose is to make recommendations as to how problems with patient retention can be addressed via appropriate interventions. The paper is structured as follows: in the first section a brief overview of the relevant literature is provided, followed by a representation of the conceptual framework guiding the analysis. In the next two sections, the data and methods employed in the empirical analysis are described. Subsequently, the results of the quantitative analysis are discussed, followed by a conclusion detailing the main recommendations.

## 1. Literature review

A relatively large body of literature is available on the importance of retaining patients in care and aftercare programmes, ensuring continuity of care, and particularly so in the field of mental health care and substance abuse programmes.<sup>2</sup> This literature emphasises the importance of patient retention to improve treatment outcomes, including adhe-

- 2 The term “continuity of care” is normally reserved for the integration of “vertical” services, such as availing inpatients discharged from hospitals or rehabilitation centres of services available to outpatients in PHC centres or community-based support groups (Farrell *et al* 1999, Chutuape *et al* 2001). In turn, the term “patient retention” refers not only to the retention of patients in the referral chain, as is the case in the aforementioned examples, but also to the retention over time of patients in a singular health care programme, such as a drug rehabilitation programme or PHC practice (Barber *et al* 2001, Fan *et al* 2005). In this paper the emphasis is on the latter, focusing on the retention in the PHC system of patients that have started taking ARVs.

rence, and to reduce the need for emergency care and hospitalisation, which may translate into considerable cost savings.<sup>3</sup>

This literature has investigated the importance of a variety of factors in enhancing patient retention in health care programmes. Del Rio *et al* (1997) report that patient retention declines as the time patients have been enrolled in a methadone maintenance programme increases. As can be expected, this raises serious concerns with regard to the ART programme, given that treatment is for life and requires high levels of adherence to be maintained over a long period, especially where barriers to adherence are relatively high (Kent *et al* 2003). Reece (2003) reports that stigma impacts negatively on the retention of patients in a mental healthcare programme. As Capron & Reis (2005) point out, stigmatisation and discrimination may influence the demand for care, even when services are relatively accessible in terms of geographical location. Again, this raises concern about the retention of patients on ARVs in the ART programme, given the stigma surrounding the disease.<sup>4</sup>

Greenfield *et al* (1996) found low family income, transport costs and travel time to impact negatively on retention in a methadone maintenance programme. Del Rio *et al* (1997) likewise found low income to impede patient retention in a methadone maintenance programme. These two authors also highlight the role of patients' individual substance abuse histories as they explain differences in the probability of retaining patients in aftercare programmes. Similar to Greenfield *et al* (1996), Schmitt *et al* (2003) found distance to impact negatively on the continued uptake of aftercare in an outpatient mental health care programme. Drain (2001) and Fan *et al* (2005) show quality of care to be important in retaining patients in PHC practices. Chutuape *et al* (2001) and Lash *et al* (2001/04) highlight the importance of incentives such as bus tokens and gasoline gift certificates, and the effect of social reinforcement for retaining patients in an aftercare programme following substance detoxification. Therefore, a range of factors stands to impact on patient retention.

3 Cf Christakis *et al* 2001, Chutuape *et al* 2001, Fan *et al* 2001, Hser *et al* 2001, Lash *et al* 2001, Crossen-White & Galvin 2002, Cabana *et al* 2004, Lash *et al* 2004, Saultz & Lochner 2005.

4 Cf Muyinda *et al* 1997, Busza 2001, Alubo *et al* 2002, Lau *et al* 2003, Kalichman & Simbayi 2004, Paxton *et al* 2005.

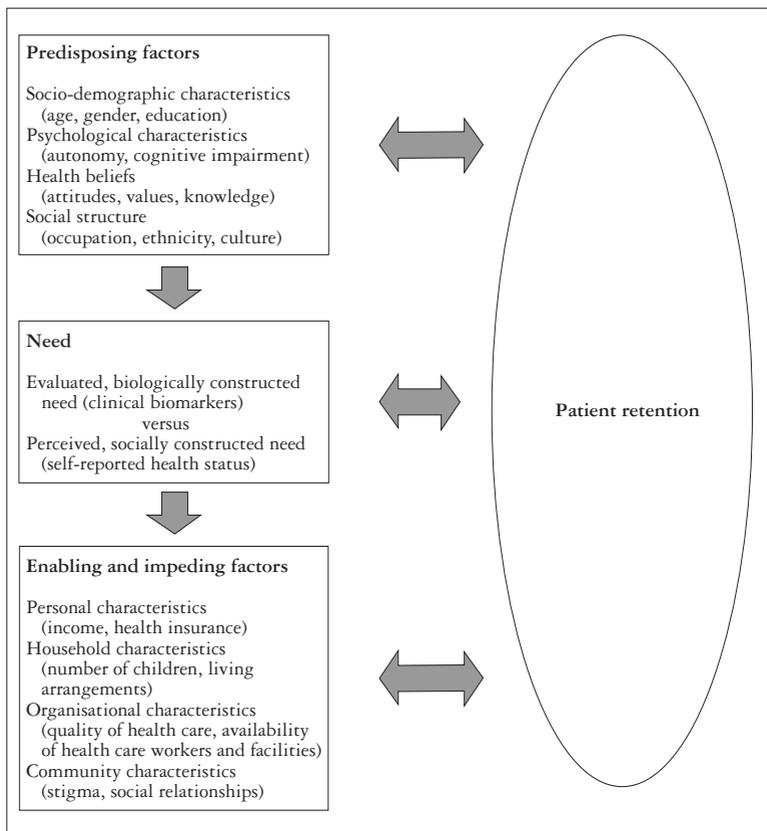
Yet, there is relatively little evidence of factors that may play an important role to enhance the retention of HIV/AIDS patients in PHC programmes, not to speak of the retention of ART patients. One exception is the work of Lo *et al* (2002), which focuses in part on the retention of HIV/AIDS patients in PHC programmes. The study highlights the importance of the availability of ancillary services in improving patient retention, including services such as mental health care, food/nutrition, housing, transportation, legal services and substance abuse treatment. Another is the study by Mizuno *et al* (2006), which investigates correlates of the frequency of outpatient visits by HIV-positive injecting drug users. The authors report access to health insurance and case management to be crucial in enhancing the retention of these patients in outpatient programmes.<sup>5</sup> In this paper, data from a survey of public sector ART patients are employed to shed light on issues of patient retention in South Africa's public sector ART programme.

## 2. Conceptual framework

The *Behavioural model of health care use* developed by Anderson in the late 1960s is employed here to investigate factors associated with patient retention in the ART programme (Figure 1).<sup>6</sup> The model assumes that "people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care" (Anderson 1995: 1).

- 5 Di Francesco *et al* (1998) and Kim *et al* (2006) investigate predictors of attrition among participants in two randomised trials on HIV prevention programmes. Given the focus on HIV prevention programmes and the fact that these two studies represent studies on attrition from research studies rather than studies on patient retention in health care programmes, the findings from these studies were not included in the literature review.
- 6 Studies on the utilisation of health care services by patients with HIV/AIDS that have employed the behavioural model, include studies by Masson *et al* (2004) and Mizuno *et al* (2006). Uphold *et al* (2005) present a review of studies on health care utilisation by HIV-positive individuals, many of which applied Anderson's model as a theoretical framework.

Figure 1: A behavioural model of patient retention



Source: Adapted from Figure 1 in Anderson *et al* (1995: 2) and Stekelenberg *et al* (2005: 69)

The model views utilisation in a non-normative way, the purpose being to identify those factors that may facilitate or impede utilisation, and employing this information to guide policy-making (Anderson 1995). The emphasis, therefore, is on what is defined as “realised” or “revealed”

access to health care services (Anderson 1995, Higgs 2004).<sup>7</sup> Indicators of patient retention, such as the total or average number of visits to a specific health care provider over a specified period, or the duration of time for which patients have been participating in the programme,<sup>8</sup> represent what Anderson (1995) and Kadushin (2004) describe as measures of the “time interval” and/or “volume” of health care utilisation respectively.<sup>9</sup>

Frameworks similar to the *Behavioural model of health care use* have been used in studies investigating predictors of patient retention in health care programmes, albeit implicitly rather than explicitly, with similar explanatory variables being included in the multivariate analysis employed for this purpose.<sup>10</sup>

### 3. Data

A patient survey was conducted to investigate patients’ experiences in the public sector ART programme in the Free State province, and to assess the impact of treatment on a variety of patient-level outcomes. The Ethics Committee of the Faculty of Humanities (University of

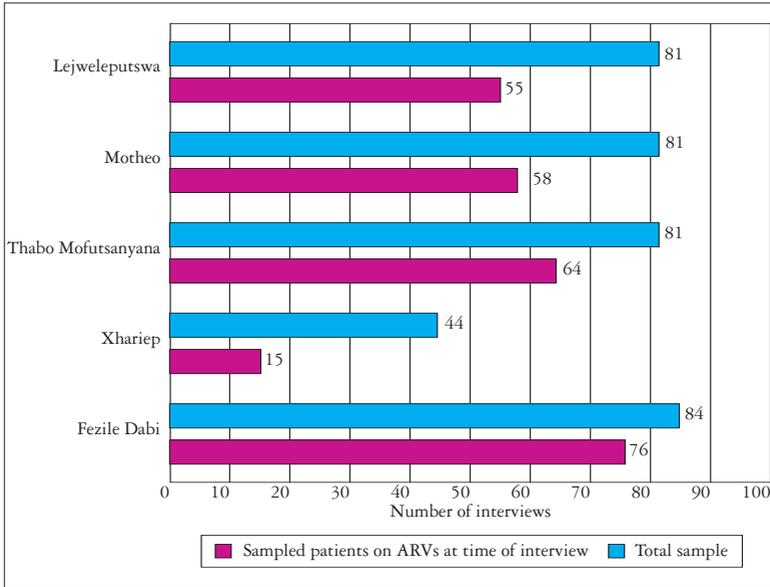
- 7 Anderson (1995: 6-7) also mentions other more normative issues of access that findings from utilisation studies were meant to inform, including potential access, equitable and inequitable access, and effective and efficient access. In respect of coverage, “revealed” access is similar to “contact coverage”. Patients visit health care facilities or make contact with health care services, assuming that services are available, accessible and acceptable to users. Furthermore, users will continue to make use of services if they perceive services to be effective (Stekelenberg *et al* 2005: 70).
- 8 Cf Klinkenberg & Calsyn 1999, Hser *et al* 2001, Lash *et al* 2001, Lo *et al* 2002.
- 9 Alternative measures of health care utilisation employed in studies of this nature include indicators of the type of service used, the specific site(s) or facility(ies) visited by users, and the purpose of visits to health care facilities (Anderson 1995: 6-8).
- 10 Cf Greenfield *et al* 1996, Del Rio *et al* 1997, Magura *et al* 1998, Farrell *et al* 1999, Klinkenberg & Calsyn 1999, Dierker *et al* 2001, Hser *et al* 2001. The *Health belief model* (HBM), which is also used in studies on health care utilisation (Hassell *et al* 2000), albeit not as extensively as Anderson’s *Behavioural model*, has also been employed in studies on patient retention (Drossaert *et al* 2003, Reece 2003). This model takes utilisation patterns to be dependent on perceptions of risks, costs and benefits associated with specific health-care seeking behaviours and actions. Two other theoretical models, namely the *Theory of planned behaviour and protection motivation theory* have also been used to guide empirical work on patient retention (Drossaert *et al* 2003).

the Free State) approved the study protocol. Trained enumerators in 2004/05 conducted structured, face-to-face interviews with 371 study participants (Figure 2). Written, informed consent was first obtained from study participants by the nursing personnel at the respective clinics. Enumerators obtained written, informed consent from study participants. Study participants were sampled randomly from a list of patients who had been assessed as ready to commence with ART in each of the five districts within the first two months of the programme, as well as patients who have actually commenced treatment.<sup>11</sup> The sampling frame excluded patients who were eligible for ART, but who were not certified as ready to commence treatment, often due to patients first having to complete two months of tuberculosis treatment. In each health district, 80 patients were sampled proportionally to the number of treatment and non-treatment patients at each health care facility in the district. In Xhariep, where fewer than 80 patients were ready to commence treatment, a census was conducted. In spite of delays between the sampling of patients, as well as in obtaining consent from study participants via the public health care system, and in conducting the actual interview, a relatively large number of interviewed patients had commenced ART by the time they were interviewed (Figure 2). The exception was Xhariep, where the introduction of the ART programme was rather slow to gain momentum due to the geographic and demographic characteristics and the nature of the health services of the district, together with the scarcity of human resources for the programme.

As this paper focuses on patient retention in a PHC-driven ART model, interviewees were asked, "How often do you currently visit the clinic/CHC regarding your ARV treatment, care and support?" Patients' responses to this question were utilised to assess patient retention. Retention is defined here as the frequency of follow-up visits to the PHC clinic or community health centre (CHC) where patients, following initiation of treatment, have to collect their drugs and return for clinical assessment. Retention, therefore, needs to be assessed in relation to treatment duration. For this reason, the analysis is restricted to the sub-sample

11 The programme did not commence simultaneously in all health districts, but was phased in over time. Assessment sites became operational in May 2004 (Lejweleputswa), June 2004 (Motho), August 2004 (Thabo Mofutsanyana), September/October 2004 (Xhariep), and December 2004 (Fezile Dabi).

Figure 2: Sample size, by district



Note: During the sampling procedure, a total of 367 patients were sampled for inclusion in the study. A total of four additional interviews were conducted during the survey. These observations are included in the analysis, given the random nature of the sampling.

of patients who had been on treatment for 30 days or longer. However, the starting dates of treatment, as collected from patient records, were only available for 220 (or 82.1%) of the 268 patients who had commenced ART. Of these 220 patients, 184 (or 83.6%) had been on treatment for longer than 30 days. The results of the analysis should therefore be interpreted with due caution, given the possible bias resulting from the relatively large number of missing observations.

#### 4. Methods

Simple descriptive analysis was first employed to assess the extent to which patient retention may be problematic among patients on ARVs. A probit regression model was estimated to investigate factors inde-

pendently associated with patient retention. In the estimation, robust standard errors were estimated. In addition, standard errors were adjusted for the clustering of patients in assessment sites. The model, the specification of which was informed by the literature review, took on the following form:

$$\text{PRET}_i = \alpha \text{PREDIS}_i + \gamma \text{NEED}_i + \delta \text{FACTOR}_i + \lambda \text{DISTRICT}_i + \epsilon_i$$

$\text{PRET}_i$ , a binary variable, measures the frequency of patient visits to the PHC clinic or CHC where patients have to collect their drugs and return for monthly follow-ups. The variable took on a value of '1' if patients reported visiting the assessment site once a month or more frequently, and a value of '0' if patients reported visiting the assessment less frequently. The four vectors of explanatory variables included in the model represent the predisposing factors, measures of need, and the facilitating, impeding and contextual factors that may impact on patient retention, as was explained in the conceptual framework.

$\text{PREDIS}_i$  represents a vector of individual- and household-level characteristics that may predispose patients to more frequent visits to assessment sites. These variables include the following socio-demographic characteristics: age, gender, marital status, education, size of the household, and dependency ratio.

$\text{NEED}_i$  represents a vector of measures of the need for care, which may impact on patient retention. Included here are treatment duration and self-reported health status (EQ-VAS).<sup>12</sup> Given that treatment history is also included in studies on patient retention, a distinction is drawn between patients who have received ART prior to joining the public sector ART programme, and those who have not.

Vector  $\text{FACTOR}_i$  includes variables representing factors that may facilitate or impede patient retention. Enabling factors include income,

12 EQ-VAS, which belongs to the suite of EuroQol measures of health-related quality of life, represents a visual analogue scale of self-reported health status. The question was formulated as follows: "To help people say how good or bad their state of health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. We would like you to indicate on this scale, in your opinion, how good or bad your own health is today. Please do this by drawing a line from the box to whichever point on the scale indicates how good or bad your state of health is today."

as well as access to nutritional and social support.<sup>13</sup> Social support is represented by dummy variables denoting access to a treatment buddy, HIV/AIDS support group and an emotional caregiver other than a treatment buddy. In addition, the utilisation of alternative sources of health care, including traditional health care practitioners, community health workers (CHWs) and a physical caregiver, are also included in the model.<sup>14</sup> These forms of care and support may represent either substitutes or complements to the care and support provided at assessment sites, and may affect patient retention positively or negatively. Self-reported substance and alcohol abuse is included as an explanatory variable that may impact negatively on patient retention. Other impediments to patient retention factored into the model include perceived levels of stigmatisation, the need to keep one's HIV status a secret, and being the main breadwinner in the household.<sup>15</sup> Distance between

- 13 Access to health insurance is normally employed in regression models of this nature. Treatment is provided without charge in the public health care system and access to health insurance therefore need not be important in explaining differences in patient retention. Hence, this variable is omitted from the model.
- 14 The role of traditional health care practitioners in the ART programme is an important issue. The sample employed in the analysis includes nine patients only who reported visiting a traditional health care practitioner, due perhaps to a systematic bias towards underreporting. Consequently, findings on this count need to be interpreted with the necessary care.
- 15 The stigmatisation scale represents a scale composed from the scores on eleven items pertaining to patients' perceptions of stigma. All responses were coded using five-point Likert scales. Seven items were scored on a scale ranging from 1, "strongly agree" to 5, "strongly disagree". Respondents were asked whether they agree or disagree with the following statements: "I am worried about who will look after me when I am sick; I am worried about who will look after my family when I die; I believe that having HIV/AIDS is a punishment for bad behaviour; Some members of my household do not want to share eating utensils with me because I am HIV-positive; Some members of my household do not want to touch me because I am HIV-positive; I was forced to leave my previous home due to my HIV status; I have been denied a public service because of my HIV status." Four items were scored on a scale ranging from 1, "not at all" to 5, "an extreme amount", where respondents were asked to what extent they experience the following: "People blaming you for your HIV status; You blame yourself for your HIV infection; You feel guilty about being HIV-positive; How guilty you feel when you need help and care from others." Items, where necessary, were rescaled prior to calculating the scale, so that higher scores on the scale represent higher levels of perceived stigma. The scale measures perceived stigma in percentage terms (IIC=0.221, Cronbach's  $\alpha$ =0.694).

patients' homes and assessment sites<sup>16</sup> and the cost per visit to assessment sites<sup>17</sup> represent two other factors that may impede patient retention.

In respect of organisational characteristics,<sup>18</sup> the model includes a measure of satisfaction with health care services at assessment sites, as well as a binary variable denoting the type of assessment site visited by patients. The "1x3" model adopted in the Free State province allows for three assessment sites (clinics) to refer patients to a nearby treatment site (hospital). In Xhariep district, which is characterised by substantial distances between health care facilities in sparsely populated areas, the Free State, however, opted for a so-called "combined treatment-assessment" model. Combined sites represent health care facilities where patients go to be screened for their eligibility for treatment, to be assessed clinically, and for future follow-up during the course of the ART programme. Patient retention may be less problematic at these combined sites, seeing that patients visiting these facilities are also able to access those services provided by the multi-disciplinary health care teams at treatment sites. These teams are made up of a medical officer, professional nurses, a pharmacist and/or pharmacist's assistant, a nutritionist or dietician, a social worker or psychologist, lay counsellors, an administrative clerk and a data capturer. According to the Treatment Guide-

- 16 Measures of "distance between patient and provider is a mainstay of multivariate models of variations in utilisation behaviour" (Nemet & Bailey 2000: 1197). Distance here represents the Euclidian (or straight-line) distance between each patient's home and the specific assessment site where the patient accessed ART. These map distances were calculated based on address information collected during the patient survey and the geographical co-ordinates of all health care facilities in the Free State province, using GIS tools. In the case of only seven patients (three on ARVs) the available information was inadequate for calculating map distance.
- 17 In the patient survey, respondents were asked: "Please specify the costs incurred in connection with each of the following, as it relates to your ARV care and support when visiting the [assessment, treatment or combined site]: travel costs when travelling to and from the facility; accommodation (if you needed to stay over) during visit; subsistence (food) during visit; medication received at facility; consultation fee; and other expenses." These costs were added up to represent a proxy of the out-of-pocket expenditures incurred by patients when visiting ART facilities.
- 18 The sub-sample employed in the analysis includes six patients only from combined sites. It is not surprising therefore that the statistical and econometric analysis revealed no statistically significant difference in patient retention in combined sites as opposed to conventional assessment sites.

lines, such an “integrated and comprehensive team approach to health care will maximise the chance for treatment success” (NDoH 2004: 65). On occasion of such visits, patients therefore may also present to staff for routine follow-up as they would at so-called conventional assessment sites.<sup>19</sup>

$DISTRICT_i$  represents a set of district dummies. The error term is represented by  $\epsilon_i$ , while the terms  $\alpha$ ,  $\gamma$ ,  $\delta$  and  $\lambda$  are vectors of parameters for each of the respective vectors of independent variables.

Prior to estimating the regression model, bivariate analysis was conducted to explore factors associated with patient retention. The tools employed in these statistical analyses among others include t-, chi<sup>2</sup>- and Fischer exact-tests as well as one-way analysis of variance (ANOVA). Given the dynamic nature of the model (refer conceptual framework), similar tools were employed to assess select bivariate and multivariate associations between independent variables, and thus to inform the discussion of the regression results. The descriptive statistics for the dependent and independent variables included in these analyses are reported in Appendix A.

Three things should be kept in mind when interpreting the results of the statistical and econometric analysis. Firstly, it is difficult in certain instances to decide to which group of factors a specific explanatory variable should be assigned. In the literature, for example, measures of living arrangements and household composition in some studies

19 The satisfaction of services scale is composed of twelve items that respondents answered on a five-point Likert scale, ranging from 1, “very satisfied” to 5, “very dissatisfied”. Respondents were asked to rate their satisfaction with the following: Medical care provided at the facility; complaint procedures at the clinic or CHC; cleanliness of facility; privacy during examinations; confidentiality of your medical record; respect shown by nurses; health information provided to you about HIV/AIDS; information provided to you about ARV medication by nurse(s); opportunity to ask questions; language used during consultations; hours that the clinic or CHC is open, and waiting time before consultations. Items were rescaled to represent positive outcomes prior to calculating the scale, which represents the percentage of satisfaction with health care services (IIC=0.211, Cronbach’s  $\alpha=0.867$ ). In order to explore the impact on patient retention of the general view on, or satisfaction with services of patients visiting specific ART facilities, mean satisfaction scales calculated for the 16 individual assessment sites were assigned to patients visiting specific sites.

are designated as facilitators or impediments, and in others as predisposing factors. The approach followed here was to assign variables to factors as commonly practised in the theoretical and empirical literature on health care utilisation, unless there was sufficient reason to assign the variable to an alternative factor in the context of the analysis.

In the second instance, the multivariate cross-sectional analysis presented here suffers from endogeneity, given the recursive and dynamic nature of the model, particularly insofar as measures of need and barriers to retention such as distance and cost are concerned. For this reason, the emphasis here is on correlates rather than on predictors of patient retention.<sup>20</sup> In the multivariate analysis, care was taken, however, to exclude collinear independent variables from the model. The objective, therefore, was to specify as parsimonious as possible a model, but without omitting independent variables that impact significantly on patient retention.

Finally, it also needs to be pointed out that the model, due to the nature of the data available from the patient surveys, omits measures of other factors that may influence patient retention. Furthermore, some measures included in the model may represent imperfect proxies of factors that do influence patient retention. Examples of the former shortcomings of the model include the omission from the model of clinical biomarkers such as CD4 counts and viral loads, psychological characteristics of patients on ARVs, as well as attitudes, beliefs and knowledge regarding ART. Examples of the latter limitations include measures of distance and costs employed as proxies of physical access, and the reliability of self-report on substance and alcohol abuse and the use of traditional medicine.<sup>21</sup> As a result, the findings of the analysis should be interpreted with the necessary caution.

20 Given the lack of suitable instruments in the dataset, it was not possible to employ instrumental variables analysis to adjust for endogenous relationships between the independent and various dependent variables.

21 Map distance represents a relatively poor indicator of accessibility, given that it does not take into account other aspects of physical access such as road distance, travelling time, which is dependent on typography, quality of roads and mode of transport, the ability to pay for transport, and the availability of health care in people's daily activity space (Nemet & Bailey 2000, Perry & Gesler 2000). Moreover, out-of-pocket expenditures on transport, subsistence and accommodation represent only the direct costs incurred by patients visiting ART facilities. A more

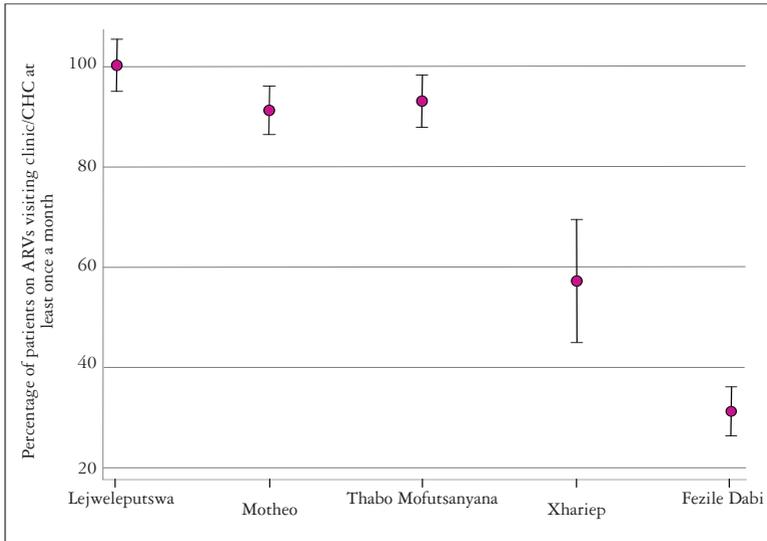
## 5. Descriptive analysis of patient retention in the PHC system

On aggregate, 76.5% of patients visited the assessment site at least once a month. Thus, almost a quarter of patients reported that they visited the clinic or CHC less frequently. Patient retention, however, varies significantly across the five health districts in the province, ranging from 100% in Lejweleputswa to as low as 31.3% in Fezile Dabi (Figure 3). It is interesting to note that retention seems to have declined markedly over the course of the rollout of the ART programme. Patient retention is highest in Lejweleputswa, where the programme was launched in May 2004. Retention is slightly but significantly lower in the Motheo and Thabo Mofutsanyana, where assessment sites became operational in June and August 2004 respectively. Retention is significantly lower in Xhariep, which started enrolling patients from September/October 2004, and even lower in Fezile Dabi, where the first patients were assessed for eligibility for ART in December 2004.

Obviously, these results do not represent conclusive evidence as to the presence of a genuine downward trend in patient retention over the course of the ART programme. Other patient- or facility-level characteristics not accounted for in these analyses may explain the observed differences. Nevertheless, the low patient retention reported in some districts raises some concerns about the sustainability of the programme. For this reason, it is important to look into the factors that may explain these observed differences in patient retention.

complete estimate of these costs could have been obtained if it was also possible to put a value to the opportunity cost of visiting an ART facility, including the time of the actual consultation, waiting time and travelling time. In the absence of such information, however, these two measures represent the best possible proxies of what Stekelenberg *et al* (2005) defines as physical and financial accessibility of health care services respectively.

Figure 3: Patient retention by district (n=183)

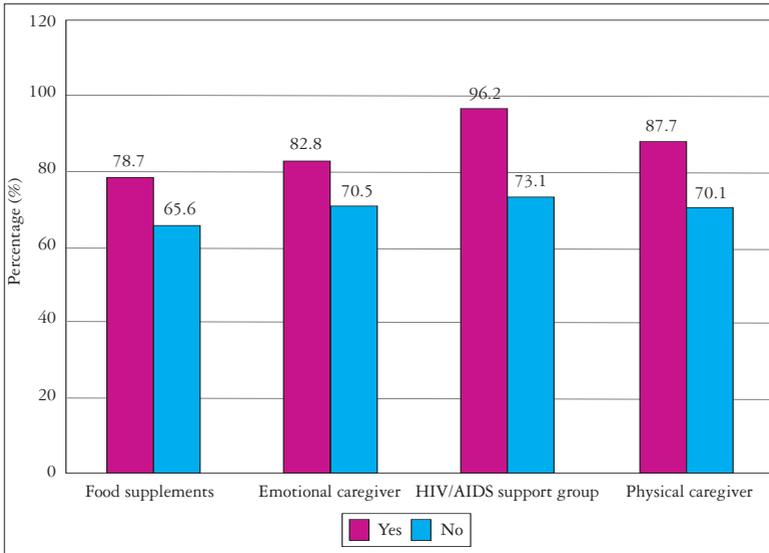


Note: The reported differences are statistically significant ( $p < 0.001$ ).

## 6. Factors associated with patient retention in the PHC system

The literature suggests that ancillary and social support often translate into higher patient retention in health care programmes. This is also the case in the public sector ART programme. According to the evidence presented in Figure 4, ART patients receiving nutritional supplements are significantly more likely to have visited assessment sites once a month, or more often, compared to patients not receiving such supplements. Patient retention is also significantly higher among patients with access to an emotional caregiver and among patients who belong to an HIV/AIDS support group. Likewise, ART patients who have access to a physical caregiver are significantly more likely to have visited the clinic or CHC at least once a month.

Figure 4: Access to nutrition, social support and care as facilitators of patient retention in the PHC system



Note: The difference in patient retention for those having access to nutritional support is statistically significant at the 10% level, while that for patients having access to an emotional caregiver is statistically significant at the 5% level. The other differences are statistically significant at the 1% level.

Similar to other studies on patient retention in healthcare programmes, the results of the analysis show patient retention to be positively and significantly associated with income and their satisfaction with health care services (Table 1). Patients with higher levels of income are significantly more likely to have visited assessment sites once a month, or more frequently. Patients who reported to be more satisfied with the health care services provided at these clinics or CHCs, also are more likely to have visited the facility where they accessed ART at least once a month.

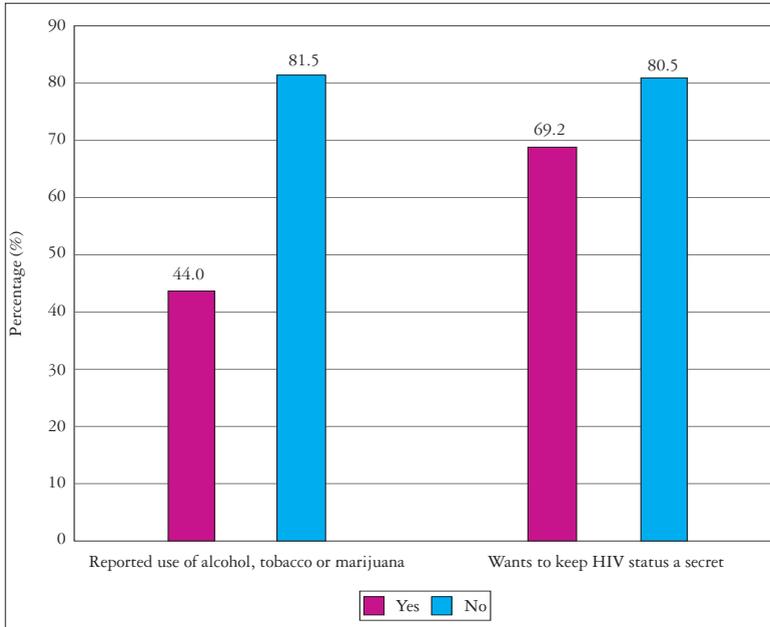
Table 1: Association between patient retention in the public ART programme and income, distance and satisfaction with health care services

Variable	Visited clinic/CHC less frequently	Visited clinic/CHC at least once a month
Monthly income (Rand)	508	786**
Distance between home and assessment site (Km)	6.6	12.6**
Satisfaction with services scale (%)	80.2	87.3***

Note: Differences denoted by three asterisks are statistically significant at the 1% level. Differences denoted by one and two asterisks are statistically significant at the 10% and 5% levels respectively.

ART patients who reported visiting assessment sites once a month or more, often travel significantly further to visit these clinics or CHCs. Generally, health care utilisation is expected to decline as distance increases. Yet, Nemet & Bailey (2000) point out that distance decay functions are not always negative, because distance is only one of a variety of factors explaining observed differences in health care-seeking behaviour. In addition, distance travelled to access ART may represent a measure of demand for treatment. In this case, the results simply show that patients who have a greater need for treatment are willing to travel further and are also more likely to be retained in the Public ART Programme. Yet, this particular finding may also be the result of other complexities in the health-care seeking behaviour of ART patients, complexities that may become evident when considering the results of the multivariate analysis of factors associated with patient retention.

Figure 5: Factors impeding patient retention in the PHC system



Note: The difference in patient retention due to substance and alcohol abuse is statistically significant at the 5% level, while the difference in patient retention due to secrecy is statistically significant at the 1% level.

The results of the bivariate analysis suggest that there are two factors that may impede the retention of ART patients in the PHC system. Interestingly, patients on ARVs that reported using tobacco, alcohol or marijuana are significantly less likely to have reported visiting assessment sites frequently, as are patients who want to keep their HIV status a secret. The question, however, is whether these factors still are significantly associated with patient retention when adjustments are simultaneously made for other factors that may influence patient retention.

The probability of retaining patients in the PHC system is significantly bigger for married than for single persons. There is also a significant education gradient in patient retention, with persons with some formal education all being significantly more likely to have visited the clinic or CHC at least once a month, compared with patients with no formal education.

Interestingly, patient retention remains positively and significantly associated with income when adjusting for other factors that may impact on patient retention. Income need not, however, represent a facilitating factor under all circumstances. Among ART patients who reported to be the main breadwinner in their household, increases in income actually impeded patient retention.<sup>22</sup>

Retention increased with treatment duration. Social support proved an important facilitator of retention. Access to a CHW, to a physical caregiver and to an HIV/AIDS support group are positively and significantly associated with retention. Substance and alcohol abuse, however, significantly impeded patient retention, as did the need to keep one's HIV status secret, albeit weakly. Patient retention is also positively and significantly associated with the satisfaction with health care services.

## 7. Conclusion

Retention of ART patients in the PHC system is important, given the importance of routine follow-up in enhancing adherence, in monitoring the effectiveness of treatment and in strengthening the prevention campaigns. The evidence suggests that a relatively large proportion of public sector ART patients are attending PHC clinics and CHCs relatively infrequently following on the initiation of treatment. The results of the statistical and econometric analysis do not only suggest that policy-makers are faced with a number of key challenges in this regard, but it also provides food for thought in terms of possible solutions to these dilemmas. Three matters are of particular importance.

Firstly, the findings highlight the importance of social support, in particular that of CHWs, physical caregivers and HIV/AIDS support groups, in enhancing the retention of patients in the PHC system. As further research is required in this area, the treatment buddy model does not need to represent a one-size-fits-all for patients on ARVs. HIV/AIDS support groups and CHWs may, for example, play an equally important role in making a success of the programme. In-depth qua-

22 Further analysis aimed at determining whether dependence on income from employment or income from a disability grant impacts more negatively on patient retention, revealed no significant difference regarding patient retention and its relation to dependence on different sources of income.

Table 2: Independent correlates of patient retention in the public ART programme

Independent variable	Coefficient
Gender (male=1, female=0)	0.556
Age (years)	0.053
Marital status (comparison group=single)	
Married and cohabiting	0.865**
Married but not cohabiting	1.303***
Education (comparison group=none)	
Primary education	-1.598***
Some secondary education	-1.930***
Matric, diploma or degree	-2.453***
Household size	0.056
Dependency ratio	0.106
Monthly income ('000 Rand)	1.367**
Main breadwinner * Monthly income ('000 Rand)	-1.148***
Distance between home and assessment site (Km)	0.006
Average cost per visit to assessment site (Rand)	0.007
Received ART prior to joining the programme (yes=1, no=0)	-0.071
Health-related quality of life (EQ-VAS)	0.008
Treatment duration (days)	0.024***
Visited a traditional health care practitioner (yes=1, no=0)	-0.292
Visited by a community health care worker (yes=1, no=0)	1.402***
Has a physical caregiver (yes=1, no=0)	0.649*
Has an emotional caregiver (yes=1, no=0)	0.140
Member of an HIV/AIDS support group (yes=1, no=0)	1.661***
Has a treatment buddy (yes=1, no=0)	0.007
Receives food supplements (yes=1, no=0)	0.055
Reported abuse of alcohol, tobacco or marijuana (yes=1, no=0)	-1.568***
Stigmatisation scale (%)	0.008
Wants to keep HIV status a secret (yes=1, no=0)	-0.280*
Satisfaction with services scale (%)	0.661**
Accessed ART at a combined site (yes=1, no=0)	16.815
Sample (n)	179
Pseudo R <sup>2</sup>	0.638
Success of prediction (%)	91.1

Note: Results are for a probit model, which includes district-level dummies. Coefficients with three asterisks are statistically significant at the 1% level. Coefficients with one and two asterisks are statistically significant at the 10% and 5% levels respectively.

litative research can assist in investigating the preferences of patients for specific models of care, with the findings of such research being used to re-evaluate the current model of care adopted in the public sector ART programme.

In the second instance, retention of patients in the Public ART Programme stands to be constrained by two factors. Substance and alcohol use and secrecy were shown to impact negatively on patient retention. It may therefore be necessary to seriously consider expanding the substance use component in the drug readiness training programme so as to do more than just impress on patients the need to abstain from alcohol, tobacco and marijuana when on ARVs. In fact, it may be justified to integrate a substance abuse programme with the ART programme, depending on the scope of the problem, or to link the ART programme to such initiative. Where such programmes exist, social workers should at least refer patients with substance abuse problems for appropriate treatment and counselling.

As for stigma, efforts are required to lower the stigmatisation of and discrimination against PLWA. Media campaigns and the distribution of information, however, do not seem to have succeeded in lowering stigma (Cobb & De Chabert 2002). This may be the result of using inappropriate channels to enforce messages of this kind and to share such information with target populations (Busza 2001). Abadía-Barrero & Castro (2006) argue that the establishment of universal access to treatment will contribute to breaking down the stigma associated with HIV and AIDS. In South Africa, however, the rollout of the public sector ART programme is still in an early phase; only time and rigorous research suitable for such purpose would help to establish whether access to treatment can contribute to the fight against stigmatisation.

Finally, the importance of income, both as a possible facilitator and an impediment to the retention of ART patients in the PHC system poses important questions about the role of the social welfare system and poverty alleviation programmes in the ART programme. Almost half of the patients received a disability grant, while almost six out of ten patients reported to be the main breadwinners in their family. Yet, ART patients, once they have recovered sufficiently, lose their disability grant. Such a decline in income can impact negatively on the retention of patients in the public ART programme. Moreover, the reliance

of entire families on the employment or grant income of the infected person may also impact negatively on patient retention. As a result, it is of critical importance to consider how patients on ARVs can be empowered to make a living and so maintain the basic income security required to adhere to treatment and stay in the programme.

Social workers, being part of the team of professionals who see patients at the treatment site, currently assist patients with social grant applications. It might be feasible to appoint a trained development officer as an additional member of the treatment team. Such person can for example assist previously employed ART patients to access workman's compensation or unemployment insurance benefits (if they have not done so, but qualify for such benefits). He or she can also help facilitate entry into the expanded public works programme or youth employment projects for unemployed patients who have recovered sufficiently from their illness. This person could likewise liaise with local NGOs, churches and community-based organisations to impart knowledge of any local development initiatives or projects to ART patients. Furthermore, such person could empower ART patients with specific knowledge about livelihood practices and entrepreneurship knowledge that individual or groups of ART patients can, in combination with the above knowledge, use to start their own micro-enterprises or small businesses. In this way, the ART programme presents an ideal platform for the mainstreaming of a developmental approach to HIV/AIDS. Such approach may also be necessary for realising dividends on the substantial investment that government is making in the ART programme. Research is required, however, to investigate the effectiveness, cost-effectiveness and sustainability of alternative models for mainstreaming development into ART programmes.

Appendix A: Descriptive statistics

Variable	Mean	Standard error	95% Confidence interval	Sample
Patient retention (%)	76.5	3.1	70.3 - 82.7	183
Predisposing factors: socio-demographic characteristics:				
Age (years)	34.2	3.5	27.3 - 41.2	184
Gender (male=1, female=0)	38.2	0.6	36.9 - 39.5	184
Marital status				
Single	49.5			91
Married and cohabiting	33.2			61
Married but not cohabiting	17.4			32
Education (%):				
No education	3.3			6
Primary education	30.4			56
Some secondary education	45.1			83
Matric, diploma or degree	21.2			39
Size of the household	3.9	0.2	3.5 - 4.2	184
Dependency ratio	0.589	0.054	0.482 - 0.695	183
Characteristics of need:				
Health-related quality of life (EQ-VAS)	66.4	1.4	63.6 - 69.2	184
Treatment duration (days)	79.9	2.8	74.4 - 85.3	184
Received ART prior to joining the programme (yes=1, no=0)	9.8	2.2	5.4 - 14.1	184

Appendix A: Descriptive statistics (continued)

Variable	Mean	Standard error	95% Confidence interval	Sample
Enabling and/or impeding factors:				
Main breadwinner (yes=1, no=0)	72.1	6.3	59.8	844
Monthly income (Rand)	58.2	3.6	51.0	184
Receives food supplements (yes=1, no=0)	82.0	2.8	76.3	183
Has a treatment buddy (yes=1, no=0)	42.6	3.7	35.4	183
Has an emotional caregiver (yes=1, no=0)	48.1	3.7	40.8	183
Member of an HIV/AIDS support group (yes=1, no=0)	14.2	2.6	9.1	183
Visited by a community health care worker (yes=1, no=0)	9.3	2.2	5.0	183
Visited a traditional health care practitioner (yes=1, no=0)	4.9	1.6	1.7	184
Has a physical caregiver (yes=1, no=0)	35.5	3.5	28.5	183
Reported abuse of alcohol, tobacco, or marijuana (yes=1, no=0)	13.7	2.5	8.6	183
Stigmatisation scale (%)	42.0	0.9	40.2	183
Wants to keep HIV status a secret (yes=1, no=0)	35.3	3.5	28.4	184
Distance between home and assessment site (km)	11.1	1.7	7.8	182
Average cost per visit to assessment site (Rand)	11	1	9	184
Satisfaction with services scale (%)	85.6	0.4	84.9	184
Accessed ART at a combined site (yes=1, no=0)	3.3	1.3	0.7	184
Distribution of sample by district (%):				
Lejweleputswa	21.2			39
Motheo	26.1			48
Thabo Mofutsanyana	22.8			42
Xhariep	3.8			7
Fezile Dabi	26.1			48

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