HIV AND TB CARE AND TREATMENT: PATIENT UTILIZATION AND PROVIDER PERSPECTIVES IN RURAL KWAZULU-NATAL

Natsayi Z Chimbindi - student number 0609860W

Thesis submitted for the degree: Doctor of Philosophy

Supervisors: Prof. Till Bärnighausen

Prof. Marie-Louise Newell

SCHOOL OF PUBLIC HEALTH, FACULTY OF HEALTH SCIENCES,

UNIVERSITY OF WITWATERSRAND, JOHANNESBURG

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Title page

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Declaration

I, NATSAYI Z CHIMBINDI, declare that this thesis is my original work. It is submitted for the degree of Doctor of Philosophy, at the Faculty of Health Sciences at the University of Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination at any other University.

Natsayi Z Chimbindi

15 June 2017

Dedication

To my two girls Anita ‘Tino’ and Aimee ‘Kudzai’ - you are special

& to my hubby and best friend Basil - thank you

Acknowledgements

To my God who is able – thank you. Firstly, I am so grateful to my supervisors Prof Till Bärnighausen and Prof Marie-Louise Newell for all the support, mentorship and guidance they provided throughout this PhD project, I could not have made it without you, I am forever thankful for all your efforts. Under your leadership – I learnt new statistical skills, improved my writing skills, leadership and working independently and I have matured through the processes. The exposure and opportunities you created for me are enormous and I will forever be indebted to you.

This journey started with the words from Prof Kathy Kahn as I was finishing my Wellcome Trust Masters Fellowship with the Agincourt Unit, "whatever you do, wherever you go – do your PhD and don't delay it" and I am so glad I listened and did it. I will forever cherish such great wisdom and encouragement from you Kathy, thank you. I have always loved acquiring knowledge and am passionate about research and the past four/five years have opened new doors and avenues for me as I moved from one discipline to another and learning new things. I love what I do and this PhD has prepared me to launch more confidently into the academic arena. My desire is to bring change in people's lives – developing interventions that promote prevention of diseases, improving the quality of life and reducing the barriers people face in accessing and utilizing care especially HIV/AIDS and other conditions of public health interest. It doesn't end here with this thesis and the papers published but this is just the beginning of opportunities to do more and explore the possibilities. For me the end of HIV/AIDS lies within us, to develop evidence-based interventions targeted at behavior change – we owe it to ourselves and to the next generation.

I cannot begin to say how thankful I am for my friends and family who supported me throughout the journey and who were always there to listen, wipe the tears and to hold my hand – I cannot mention all of you by names but from the depth of my heart - thank you. The Africa Centre family - the management, and friends I made along this journey who supported me and cheered me on – thank you - Janet Michel, Olivier Koole, Silke Roth, Philippa Matthews, Nothando Ngwenya, Richard Lessells Chiedza Munikwa, Nompilo Myeni, Manisha Yapa, Jane Ferguson and Maryam Shahmanesh - especially for the opportunity to work and complete my studies - I cannot mention you all by names but I am forever grateful, Agincourt - special mention to you Liz Kimani – for the friendship, support and for being exemplary in all aspects, Wits - Mosa Moshabela thank you for your guidance in structuring

the thesis, REACH study colleagues - Bronwyn Harries you are special and oh yes the UNITAS study colleagues… my fellow PhD friends – Dumo Mkwanazi for your great sense of humor, and support groups – this is it, thank you!

To my mum Esther Eunice Chimbindi – the values you instilled are precious and I hold them close – I hope I have made you proud, I love you mama. My sisters – Vongai, Esther, Angela and my brother Mufaro – thank you for all the prayers, the love and cheers – and to you especially Angela for listening to all my whining - thank you. To Rachel Rudziva my niece – thank you for helping with the girls, I really appreciate it.

Lastly but not least, to my dear husband Basil – thank you for believing in me, allowing me to fly and for taking care of the girls while I wrote this thesis…I could not have done it without you, you are special, thank you – We did it!

Abstract/Executive summary

The epidemics of tuberculosis (TB) and Human Immunodeficiency Virus (HIV) in sub-Saharan Africa are closely related and particularly persistent, proving a considerable burden for healthcare provision, and complicating utilization of care. Concern has been expressed about patients' experience at healthcare facilities as this may impact on drug adherence, treatment success and willingness to return for regular monitoring and drug pick-up. This is particularly relevant for HIV programmes, with HIV now a chronic disease, with daily treatment necessary for life; TB treatment is limited in duration, to six months although can be as long as two years in case of multiple drug resistant TB.

Utilization of healthcare services is an important determinant of health outcomes generally, with public health relevance, particularly for HIV and TB services in areas of high prevalence**.** The main aim of universal health coverage is to make healthcare accessible without barriers based on affordability, availability or acceptability of services. Various factors have been shown to hinder or enable patient utilization of healthcare services, such as organization of services, costs of transport to and from clinics, time loss at clinics receiving care, staff attitudes, waiting times and cleanliness of facilities.

Objectives

This study aimed to determine and quantify factors associated with healthcare utilization in patients utilizing HIV care (including those not yet initiated on antiretroviral treatment (ART) - pre-ART) or TB treatments in a rural sub-district of Hlabisa in KwaZulu-Natal and to understand healthcare providers' perspectives regarding patient care and provision of quality care. The study used data from patient exit interviews, and additionally findings from interviews with healthcare providers in the local HIV treatment and care programme, structured around the responses from the patient-exit interviews.

The study had three specific objectives: 1) to establish and quantify factors associated with healthcare utilization, with utilization decomposed to availability, affordability and acceptability of healthcare services, for patients in HIV or TB treatment and care; 2) to quantify ability-to-pay for healthcare and identify associated factors for patients in pre-ART care, or on ART or TB treatment; 3) to understand the healthcare providers' perspectives regarding patient care and provision of quality HIV care.

Methods

In 2009 patient-exit interviews were conducted in six primary healthcare (phc) clinics in rural South Africa with 300 patients receiving ART and 300 patients receiving TB treatment; patients were randomly selected using a two-stage cluster random sampling approach with primary sampling units (phc) selected with probability-proportional-to-size. In 2010 an additional 200 HIV-infected patients in pre-ART care from the same clinics were interviewed. Patient-exit interviews were conducted in a private room outside the facility and all data were analysed using STATA 11. In 2012, a qualitative study was carried out with healthcare providers in eight (of 17) randomly selected phc clinics; 25 ART healthcare providers were engaged in discussion structured around patient-exit interviews feedback to assess possible challenges/facilitators ART healthcare providers face when providing care. Discussions took place in the consultation rooms when no clinical sessions were ongoing and these were recorded and transcribed; and data were managed using Nvivo 10. Thematic content analysis was conducted using both inductive and deductive approaches and clinic or healthcare provider identifiers were removed and replaced with pseudonyms.

Summary statistics describe patient characteristics by patient group and key availability, acceptability and affordability factors associated with utilization of healthcare services; separate univariate and multivariable regression models were run to assess associations between patient characteristics and these key availability, acceptability and affordability factors. Patient socio-demographic characteristics (sex, age, education, employment and marital status) were controlled for and adjusted for clustering at facility-level. Factor analysis was performed to investigate underlying patient satisfaction factors.

Results

Socio-demographic characteristics of the patients

More women than men were seen in the primary care clinic, especially among pre-ART patients (79%), followed by 62% HIV and 53% utilized TB care, with an age-sex profile comparable to previous studies in the area. Pre-ART patients were significantly younger than ART and TB patients, with a median age of 32 years for pre-ART patients, 39 years for ART patients and 37 years for TB patients. Unemployment at household level was high, up to 86% of ART patients' head of households were unemployed and only 9% of TB patients were employed.

Availability factors explored in this study included mode of transport used to travel to clinic, whether nearest clinic was used, perceptions of stigma from community for utilizing HIV/TB healthcare services and ability to utilize other healthcare services and/or provision of comprehensive care (at the same phc). Nearly all (94.3%) TB patients were offered an HIV test during their current TB treatment episode, with patients using their closest clinic being substantially more likely to have been offered HIV testing than those not using their closest clinic (aOR=12.79, p=0.05) controlling for age, sex, education, marital status, employment and whether it was their first episode of TB, whether they took their medication under observation (Directly Observed Treatment Short course (DOTS)), and whether they felt negatively judged for using healthcare services. Services seemed integrated to an extent, with HIV testing common in TB clinics, other health care easily available and HIV clinical assessment including TB screening. Almost all TB and ART patients reported to be able to access other healthcare services they needed at the same facilities. Transport to the clinic was reported to be costly and cumbersome with more than half of the patients reporting using minibus taxis to and from the clinic. Feeling of stigma related to attending the health facility for their TB/HIV treatment were reported by a substantial minority of both HIV and TB patients.

Acceptability factors included patients' perceptions on satisfaction with care provided, staff attitudes, privacy and confidentiality, queues and waiting times, cleanliness of waiting area and amenities, staff-patient contact time, communication including language, and healthcare provider preference. Although almost all HIV and TB patients (95% HIV, 97% TB) reported to be overall satisfied with the healthcare services received on the day of the interview, patients (mainly HIV patients) were dissatisfied with certain aspects of the health services such as healthcare provider lack of respect towards patients (52% of HIV and 40% of TB patients agreed that some staff did not treat patients with sufficient respect) and long waiting time (65% of HIV and 40% of TB patients agreed that health worker queues were too long) which has potentially negative effects on future patient utilization of care. Factor analysis for patient satisfaction data identified five factors underlying the HIV data and the TB data: availability, accommodation, acceptability and communication for HIV and TB patients; health worker preference for HIV patients only, and global satisfaction for TB patients only; these factors are important dimensions of access and utilization of care. However, in general patient demographic characteristics such as patients' age, sex, education level, employment status, and marital status were not significantly

associated with these satisfaction factors in multivariable analysis for either HIV or TB patients indicating that systemic structural factors could have been at play.

To assess the factors affecting **affordability and ability-to-pay** for healthcare services, time and financial costs of utilizing HIV and TB services were measured and to what extent these costs lead to financial distress, defined as patients' self-report of either borrowing money or selling assets to finance healthcare, was assessed. Pre-ART patients spent as much per month on average on healthcare as ART and TB patients.Total monthly health expenditures [USD=7.3 South African Rand (ZAR) in 2010] were ZAR171 for pre-ART, ZAR164 for ART, and ZAR122 for TB patients, mainly driven by high expenditures in alternative healthcare such as traditional healers and self-care by pre-ART patients than TB patients. For all groups, transport was the largest expense associated with clinic visits. There were considerable monthly time costs (in hours) especially for ART patients, who needed to attend monthly to pick up medication - total monthly time costs were 3.4 hours for pre-ART, 5.0 hours for ART, and 3.2 hours for TB patients, with TB patients spending considerably less time than ART and pre-ART patients due to shorter queues for TB patients. Although overall patient costs were similar across groups, pre-ART patients spent on average ZAR29.2 more on traditional healers, ZAR25.9 more on chemists and private doctors, than their counterparts, but they spent less on transport; ART patients spent ZAR34.0 more than pre-ART patients on transport to clinics.

Healthcare providers' responses and perspectives – Seven of 13 patient satisfaction findings (including aspects of overall satisfaction, communication, contact time, respect, privacy, cleanliness, and waiting times) from the 2009 ART and TB patient exit survey were selected to structure the interviews with healthcare providers to assess their perspectives towards factors affecting provision of quality of care. Two broad theoretical constructs emerged from the discussions: (1) healthcare providers' feelings of helplessness to address structural barriers within the health system and (2) their empathy and responsiveness to individual patient's challenges, despite the limitations of the healthcare system. Healthcare providers felt they were unable to respond within a health system that did not support delivery of quality care. Emerging sub-themes pointed to the challenges related to understaffing and increased workload, resulting in overwork, fatigue and burn-out. Further challenges related to lack of essential equipment and ART, leading to longer queues and increased waiting times, delayed treatment initiation, more frequent patient clinic visits, and emotional frustration for both patients and staff.

Despite the health system constraints, providers described how they devised ways to deal with the issues to provide the best care possible, e.g by using personal vehicles to collect ART from the district hospital pharmacy and working longer hours.

Conclusions and policy implications

The findings from this PhD research demonstrate almost universal HIV testing among TB patients and patients' reported considerable ability to access and utilize their closest clinics and to receive comprehensive care. The high HIV testing rates among TB patients suggest that integration of HIV/TB services enables availability and utilization of healthcare services. Global satisfaction with services provided was high among both HIV and TB patients. However, HIV and TB patients' evaluations of specific aspects of health services delivery revealed substantial dissatisfaction hidden in the global assessments of satisfaction. These differentials in satisfaction levels between HIV and TB patients are likely due to the differences in the way HIV and TB services are organized in the HIV and TB programme with shorter queues and time spent for TB than HIV patients.

Patients receiving nominally free care for HIV/TB nevertheless face large private costs, commonly leading to financial distress. The study shows evidence of high healthcare–related financial expenditures and time costs among adults using public-sector HIV and TB services, although these services are provided free at point of service. Monthly private health expenditures from the patient perspective are very large, especially in a study area with high unemployment rates. Reduction of patient costs could be made by provision of: subsidized transport, fewer clinic visit schedules and bringing drug pick-up points closer to patients' homes. Peer-support and adherence clubs to pick-up and deliver treatment have been found to reduce transport costs and clinic visits as well as encourage adherence and retention in care in patients on ART in Cape Town and Mozambique (Decroo et al., 2013; Grimsrud, Sharp, Kalombo, Bekker, & Myer, 2015; Luque-Fernandez et al., 2013) - these interventions can be adopted in the study area to reduce patient healthcare related expenses. Engaging healthcare providers in discussion and giving feedback raised significant issues in HIV programmes, potentially affecting patient's engagement in care. Healthcare providers showed resilience, endurance and coping mechanisms within limited resources to provide quality care to patients, such as using their personal resources to address patient individual challenges. The healthcare providers' responses show a commitment to providing quality care

and to their profession suggesting the need to strengthen the healthcare system to support healthcare provider's efforts.

List of PhD papers

This PhD was by publication; papers contributing to this PhD are given in the list of papers below.

Paper 1: An integrated approach to improving the availability and utilisation of TB healthcare in rural South Africa. *S Afr Med J 2013;103(4):237-240* **DOI:**10.7196/SAMJ.6423

Paper 1b: Almost universal test coverage: HIV testing among TB patients in a rural public programme. *Int J TB Lung Dis 2012; 16(5): 708* http://dx.doi.org/10.5588/ijtld.11.0754

Paper 2: Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews. *BMC Health Services 2014, 14:32* http://www.biomedcentral.com/1472-6963/14/32 **DOI:** 10.1186/1472-6963-14-32

Paper 3: Time and money: the true costs of healthcare utilization for patients receiving 'free' HIV/TB care and treatment in rural KwaZulu-Natal. *J Acquir Immune Defic Syndr 2015;70(2):e52–e60* **DOI:** 10.1097/QAI.0000000000000728

Paper 4: Engaging healthcare providers: responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal (*BMC Health Services – under review*)

List of conferences presentations related to PhD (2011-2016)

1. *Poster presentation at the* 21st International AIDS Conference 18-22 July 2016, Durban, South Africa *Healthcare providers go beyond their call of duty in an ART programme in rural KwaZulu-Natal N Chimbindi, M-L Newell, R Lessells, L Reynolds, T Bärnighausen*
2. *Poster presentation at the* 20th International AIDS Conference 20-25 July 2014, Melbourne, Australia *The comparative financial burdens of pre-ART vs. ART utilization: implications for treatment as prevention N Chimbindi, M-L Newell, F Tanser, R Baltusen, J Hontelez, S de Vlas, M Lurie, D Pillay, T Bärnighausen*
3. *Oral presentation at the* 17th Rural Health Conference – Rural Doctors Association South Africa (RUDASA), 8-10 August 2013, St Lucia, South Africa *Challenges in utilizing treatment and care: lessons learnt from HIV and TB patients in a rural ART programme N Chimbindi, M-L Newell, T Bärnighausen*
4. *Oral presentation* at the 5th SA AIDS Conference 18-21 June 2013 ICC Durban
   Coping with the price of healthcare before and after HIV treatment initiation in rural South Africa N Chimbindi, M-L Newell, T Bärnighausen
5. *Oral presentation* at the University of KwaZulu–Natal College of Health Sciences Research Symposium 12-13 September 2012 *TB patients' reported healthcare utilization barriers in a rural public programme N Chimbindi, T Bärnighausen, M-L Newell*
6. *Oral Poster presentation* at the AIDS Conference in Washington USA 22-27 July 2012 *Time and money: the costs of utilizing HIV and TB treatment in rural KwaZulu-Natal N Chimbindi, M-L Newell, T Bärnighausen*
   - ***Received a travel and accommodation scholarship from IAS***
7. *Poster presentation* at the 5th SA AIDS Conference 7-10 June 2011 ICC Durban *Acceptability of, and satisfaction with, HIV treatment and TB care in public services in rural KwaZulu-Natal, South Africa N Chimbindi, T Bärnighausen, M-L Newell*
8. *Oral presentation* at the 5th SA AIDS Conference 7-10 June 2011 ICC Durban
   Almost universal test coverage: HIV testing among TB patients N Chimbindi, T Bärnighausen, M-L Newell

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CHAPTER 1: SOUTH AFRICA AND ITS HEALTHCARE SYSTEM

Chapter 1 of this PhD study covers an overview of the South African healthcare delivery system and highlights the difficulties the system faces particularly the primary healthcare (phc) clinics. Further, this chapter describes the extent of the HIV and TB problem globally, in sub-Saharan Africa and particularly in South Africa and the challenges faced by HIV positive people who are not yet on treatment (pre-ART), patients on antiretroviral treatment (ART) and patients on tuberculosis (TB) treatment when utilizing healthcare. This Chapter sets the background of the disease-burden of the conditions this PhD study aims to investigate and the context in which healthcare for these conditions is delivered. The overall aim of this PhD study was to determine and quantify factors associated with healthcare utilization in patients utilizing HIV care (including those not yet initiated on antiretroviral treatment (ART) - pre-ART) or TB treatments in a rural sub-district of Hlabisa in KwaZulu-Natal, South Africa, and to understand healthcare providers' perspectives on patient care and provision of quality care

The South African healthcare delivery system

Health care provision in South Africa has improved since 1994 when administration of healthcare was fragmented along racial lines and vertically by service type (preventive and curative services). Inequalities existed between public health services for whites which were better than those for blacks and those in the rural areas were significantly worse off in terms of access to services than their urban counterparts.(Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Mayosi & Benatar 2014)

South Africa's health system consists of a two-tiered system that exists in parallel - a large public sector and a smaller but fast growing private sector. The public sector serves the majority of the population, but is hugely underfunded, understaffed and under-resourced while the private sector is mainly commercialized, well-resourced, serves the middle- and high-income earners and attracts most of the country's health professionals (Coovadia et al., 2009). Although the statistics are often contested, the private sector is accessible to less than 20% of the population, consumes more than 60% of the overall national healthcare expenditure and employs more than 70% of the healthcare specialists.(Padarath. A., Ntuli, & Berthiaume, 2004) Such contrasting differences have given rise to inequitable and inaccessible distribution of healthcare services to a large portion of poor South Africans. Although access in the form of physical availability and distance to the nearest clinic has improved over time (since the country got

its democratic independence in 1994), the quality of healthcare has not improved in direct proportion due to public health challenges, increased burden of diseases.(Coovadia et al., 2009) Post-1994, South Africa began a process of transforming the health system within the public sector with a political commitment to ensuring equity in resource allocation, restructuring the health system according to the District Health System (DHS) and delivering healthcare according to the principles of the primary healthcare (phc) approach.(Kautzky. K. & Tollman. S.M., 2008) The healthcare transformation process also involved building new health facilities or rehabilitating of old facilities and healthcare was made free at the point of delivery for pregnant women, young children, persons with disabilities and all with HIV and TB.

The National Department of Health (DoH) leads the public health system and is responsible for overall health policy and co-ordination and is focused on implementing an improved health system, which involves a focus on public health, as well as improving the functionality and management of the system. Implementation and delivery of health services is through the nine provinces and 284 municipalities (local government authorities). The provinces provide mainly (curative) hospital services. The District Health System is the lowest management unit that organizes healthcare delivery through clinics, health centres and district hospitals in a geographically-defined area and also covers environmental health.

Equitable and improved access to basic healthcare for all citizens is a goal and a human right in itself (Donebedian, 1973); but most healthcare systems still struggle to meet this goal, which results in continued inequalities in health and healthcare utilization. The public sector has faced challenges of transformation and re-organization, budget reform, enhancing quality of care and human resource management, while the private sector has faced cost escalations with stagnant coverage of the medical aid population. (J. E. Ataguba & J. Akazili, 2010; HSRC Policy Analysis Unit., 2008) A National Health Insurance (NHI) scheme is currently being rolled-out first in selected 11 pilot-districts in SA, phased over a 14 year period, to bring about reform that will improve service provision and healthcare delivery by addressing discrepancies within the national healthcare system, such as unequal access to healthcare amongst different socio-economic groups.(Barnighausen, 2007; National Department of Health., 2011a) Further, the NHI is aimed at promoting equity and efficiency to ensure that all South Africans have access to affordable, quality health care services regardless of their employment status and ability to make a direct monetary contribution to the NHI fund.(National Department of Health., 2011a)

Healthcare financing

In South Africa, healthcare is financed through a combination of mechanisms including general tax, private medical schemes and out-of-pocket payments.(J.E Ataguba & J. Akazili, 2010; McIntyre, 2012) Households' out-of-pocket payments directly to healthcare providers account for a significant contribution of nearly 14% of all healthcare expenditure.(McIntyre & Thiede) Further, direct out-of-pocket payments account for almost a quarter of private health care financing(McIntyre & Thiede); which is worrying as such payments are likely to lead to catastrophic expenditures which can lead households further into poverty.(S. Cleary, Birch, Chimbindi, Silal, & McIntyre, 2013 ; K. Xu et al., 2003) Definitions of catastrophic expenditures differ – some define it as if a household's financial contributions to the health system exceed 40% of income remaining after subsistence needs have been met(K. Xu et al., 2003) and others define it as healthcare expenditure exceeding 10% of household consumption expenditures.(S. Cleary et al., 2013) Out-of-pocket payments also include expenditures incurred by medical scheme members (e.g. for co-payments, and services not covered by the scheme or over-the-counter medicines not covered by schemes, extra charges for specialist services such as dental, and administration fees).

South Africa is an upper-middle income country with a Gross Domestic Product (GDP) of 350.6 billion USD (2013) and GDP per capita of USD 11,500 in 2013 and a high healthcare expenditure which amounts to 8.9% of GDP.(Index Mundi.; WHO., 2016) This level of spending is relatively high by international standards and when compared to the majority of countries of a similar level of economic development.(J.E Ataguba & J. Akazili, 2010) However, health status indicators (such as infant mortality) in South Africa are worse than that in other upper- middle income countries indicating that the key challenge facing the South African health sector is not one of a lack of resources, but rather of resources allocation and efficient and equitable distribution of the existing resources.(J.E Ataguba & J. Akazili, 2010; McIntyre, 2012)

Within South Africa there are also considerable inequalities in socio-economic status and access to social services between population groups, provinces and socioeconomic groupings, with relatively well-off provinces such as Western Cape and Gauteng having the lowest poverty rate, highest medical scheme coverage rate and public health spending per capita, and better access to potable drinking water when compared with relatively poorer provinces.(Coovadia et al., 2009; Day, Barron, Monticelli, & Sello, 2009; Mooney & Gilson, 2009) There is need to address the inefficient and inequitable

distribution of resources between the public and private health care sectors relative to the population served by each, enabling income cross-subsidies (from the rich to the poor) and risk cross-subsidies (from the healthy to the ill) in order to achieve universal health coverage. (McIntyre & Thiede; World Health Organization., 2010) It is envisaged that the NHI will contribute toward redressing existing health inequalities in the country.

Human Resources for Health in South Africa

The healthcare workforce is one of the key input components of the health system building blocks as outlined by the WHO building blocks framework. (WHO., 2010b) Healthcare human resources include clinical staff, such as physicians, nurses, pharmacists and dentists, as well as management and support staff, that is those who do not deliver services directly but are essential to the performance of health systems, such as managers, ambulance drivers and accountants. (WHO., 2010b) The ability of a country to meet its health goals depends largely on the knowledge, skills, motivation and deployment of the human resources responsible for organizing and delivering health service; there is evidence to show that population health outcomes are directly proportional to the number of health workers.(Anand. S & Bärnighausen. T., 2007) South Africa is faced with a critical shortage of health workers and some of the reasons include lack of trained health personnel and inability to fill essential posts, migration of health workers within and across countries, poor mix of skills and rural-urban inequities in the distribution of specialist and highly skilled health personnel with highly skilled health personnel concentrated within higher levels of the health care system – mainly located in urban areas. All these factors constitute a key barrier to achieving the implementation and provision of district-based health services.(Kautzky. K. & Tollman. S.M., 2008; Padarath. A. et al., 2004) These inequalities are compounded by poor infrastructure and amenities leaving rural areas with more vulnerable health status, under-served and in great need. Privatisation of healthcare has also contributed to the unequal distribution of health workers and resources across public and private sectors, with a high proportion of skilled staff in the private sector – as of 2008, about 63% of general practitioners worked in the private sector, despite the private sector meeting the needs of a minority population.(Kautzky. K. & Tollman. S.M., 2008) However, progress has been made: the number of public sector doctors increased from 7645 in 2003 to 13 614 in 2013, and the number of professional nurses registered with the South African Nursing Council from 96 715 to 129 015.(Health Systems Trust., 2015) There is need to introduce mid-level cadres, task-shifting, and integrating trained community caregivers and an integrated and comprehensive reconfiguration of

primary health care teams to improve access and utilization of healthcare by patients and quality of care provided at primary care level.(Doherty, Couper, & Fonn, 2012; Doherty, Daphney, Couper, & Fonn, 2013; Lehmann, 2008; Pillay & Barron, 2011)

In order to achieve the goal of universal coverage especially in the face of a huge HIV and TB disease burden, introduction of new HIV treatment guidelines and possible adoption of HIV treatment as prevention strategies at population level, there is need to increase availability of human resources. Results from a statistical modelling study in the study area to quantify the number of additional HIV health workers required at national level to the current HIV workforce to achieve universal access to HIV treatment in South Africa, taking into account different eligibility criteria, showed that for universal access to be achieved for all patients with a CD4≤350 cells/μl, an additional 2 200 nurses, 3 800 counsellors, and 300 doctors would be required, at additional annual salary cost of 929 million South African rand (ZAR), equivalent to US$ 141 million in 2012– and these estimated figures would be much higher to achieve universal treatment of all HIV infected people immediately upon HIV diagnosis (treatment as prevention).(Hontelez et al., 2012)

South Africa health status: challenges faced by HIV/TB programmes

South Africa is in the middle of a health transition that is characterised by a quadruple burden of disease - HIV and TB, chronic illness and mental health, injury and violence and maternal, neonatal, and child health. These epidemics, mainly HIV and TB have negated the advances that the South Africa health system had made post-independence with the country ranking low in health system performance compared to other middle income countries and even some lower income countries.

HIV/AIDS situation

South Africa currently has the world's highest number of people living with HIV, estimated at 7 million living with HIV in 2015. The adult HIV prevalence in the same year was 19.2% and AIDS-related deaths estimated at 180, 000. On the other hand, South Africa has the world's largest ART programme, with 48% of adults on ART. (UNAIDS., 2016)

According to a national survey done by the Human Sciences Research Council (HSRC) in 2012, HIV prevalence differed substantially by province, with rural informal area residents (13.4%) having a higher HIV prevalence than urban formal area residents (10.1%), and KwaZulu-Natal province being the

worst affected with an overall HIV prevalence of 16.9% while Western Cape had the lowest of 5.0%. (Shisana et al., 2014) Women are disproportionately affected by HIV, the peak HIV prevalence for women has shifted from the 25–29 year age group in 2008 to the 30–34 year age group in 2012, while for men it has shifted from the 30–34 year age group in 2008 to the 35–39 year age group in 2012 likely because of the age-disparate sexual relationships.(Maurice, 2014) HIV prevalence has remained high over the last decade due to the increased number of people on ART, which has led to a decrease in AIDS mortality and an increase in life expectancy.(Bor, Herbst, Newell, & Barnighausen, 2013; Herbst et al., 2009; Johnson et al., 2013) In South Africa, data from ART programmes in three provinces show that the life expectancy of adults receiving ART is about 80% of the normal life expectancy, provided they do not start treatment late (CD4 count below200 cells/mm^3). In a study in KwaZulu-Natal, adult life expectancy was shown to have increased by more than 10 years from 49 years in 2003 to 60.5 years in 2011due to the availability of ART in the public-sector clinics.(Bor et al., 2013) ART has been found to increase survival, reduce mortality and morbidity in HIV-infected adults and children.(Herbst et al., 2009) Additionally, a recent study in the Hlabisa study area, showed that the incidence of HIV infection fell by 17% for every 10% increase in the number of people receiving ART and an HIV-uninfected individual living in a community with high ART coverage (30 to 40% of all HIV-infected individuals on ART) was 38% less likely to acquire HIV than someone living in a community where ART coverage was low (<10% of all HIV-infected individuals on ART).(Bor, Bärnighausen, Newell, Tanser, & Newell, 2011) Such improvements in HIV treatment and care and further progress towards universal treatment for all HIV infected people call for strengthening of the primary healthcare system in terms of resources, healthcare providers and medication and equipment, to accommodate the increased demand on the health services utilization.

However, Human Sciences Research Council (HSRC) carried out a national survey in 2012 and the results indicated that by mid-2012, out of the total estimated number of 6 422 000 people living with HIV in the country, only 2 002 000 (31.2%) were exposed to ART.(Shisana et al., 2014) The probable reasons for the difference could be due to the eligibility criteria used – many people would have been positive but not yet treatment eligible as per then current CD4 threshold, health seeking behaviours, loss to follow-up (especially before ART initiation), and access and utilization barriers such as distance to the clinic, stigma and transport costs. Even when ART coverage and exposure to ART are high, issues of retaining patients in care remain (Lessells, Mutevedzi, Cooke, & Newell, 2011; Plazy, Newell, et al.,

2015; Plazy, Orne-Gliemann, Dabis, & Dray-Spira, 2015) and it is unclear how to make the services more attractive to patients as not all patients engage with care.

Tuberculosis situation

Tuberculosis is a major public health problem, in 2014 there were 9.6 million new TB cases and 1.5 million deaths from TB, including 0.4 million TB deaths among HIV-positive people worldwide.(WHO., 2015c) South Africa is one of the 22 high TB burden countries and has one of the world's worst TB epidemics mainly driven by HIV.(WHO., 2012) Millennium Development Goal (MDG) are the world's time-bound (with a deadline of 2015) and quantified targets set by the United Nations for addressing extreme poverty in its many dimensions - income poverty, hunger, disease, lack of adequate shelter, and exclusion - while promoting gender equality, education, and environmental sustainability. MDG 6C targeted to halve TB prevalence and mortality rates by 2015 compared with 1990 levels. TB incidence rate has been falling since 2000 at an average rate of 1.5% per year during the 2000−2014 period, while TB mortality and prevalence rates have fallen by 47% and 42%, respectively, during 1990−2015.(WHO., 2015c) This success has been attributed to adoption of effective strategies such as Directly Observed Treatment Short-course (DOTS) and the Stop TB Strategy by all countries, increased funding for TB prevention and strengthened partnerships and advocacy by international and technical organizations, government programmes, research and funding agencies, foundations, non-governmental organizations, civil society and community groups and the private sector. However, there has been challenges with the various TB strategies which included inability to reach missed cases, the budding drug-resistant TB epidemic, managing co-infections with HIV and inadequate funding for a full response to the global TB epidemic in low- and middle-income countries in 2015.(WHO., 2015c)

Managing TB needs multi-pronged strategies that include health education to raise awareness of disease transmission; social mobilization and case finding to track those who might be defaulting on treatment and those exposed due to contact with a TB infected person; and treatment through the DOTS strategy. Laboratory strengthening and new diagnostics (such as GeneXpert MTB/Rif) are crucial to improve the proportion of notified TB cases to close detection and treatment gaps for TB and drug-resistant TB.(Churchyard et al., 2014; UNAIDS, 2012) Globally in 2014, there were an estimated 480 000 (range: 360 000–600 000) incident cases of MDR-TB with approximately 190 000 (range: 120 000–260 000) deaths from MDR-TB, comparable to estimates published in recent global TB reports.(WHO., 2015a) In response to the large burden of MDR-TB, the National TB Programme (NTP) committed monetary

support to the MDR-TB programme, issued a series of guidelines for the management of MDR-TB, established decentralized MDR- and XDR-TB treatment units and introduced a policy framework for the decentralization and de-institutionalization of drug-resistant TB care and treatment.(Churchyard et al., 2014). Treatment for HIV is life-long while TB is short-term 6-24 months but issues of access, utilization, adherence to treatment and retention in care are crucial for treatment of both conditions to achieve optimal health outcomes.

The tale of two epidemics – HIV and TB

The epidemics of tuberculosis and HIV in sub-Saharan Africa are closely related and particularly persistent. The World Health Organization (WHO) estimates that more than nine million new cases of TB were reported in 2007 which increased slightly in 2014 to 9.6 million cases (likely due to better reporting rather than disease spread) and 12% of the 9.6 million new TB cases in 2014 were HIV-positive.(WHO., 2009a, 2015a) In some settings in sub-Saharan Africa, including KwaZulu-Natal in South Africa, more than 70% of patients with active TB disease are also infected with HIV.(Gandhi et al., 2009; Mukadi, Maher, & Harries, 2001; USAID., 2010; Wallrauch et al., 2010) TB is the leading cause of death in people living with HIV worldwide and in South Africa.(Department of Health., 2000 ; National Department of Health South Africa., 2004; WHO., 2009b) This intertwined relationship between the two epidemics affects the way healthcare services are demanded, utilized, arranged and delivered for patients receiving treatment and care for either or both of the conditions.

Although TB treatment has been widely available for a long time, an increase in TB case fatality has been reported over the last two decades, probably as a result of the expanding HIV epidemic.(WHO., 2009a) In a study in rural South Africa, the mortality rate among people less than 25 years who were co-infected with HIV and TB were three times higher than among those infected with TB only.(Zwang, Garenne, Kahn, Collinson, & Tollman, 2007) However, in Hlabisa sub-district, studies have recently shown that mortality at a population level and risk of acquiring HIV infection has declined due to ART roll-out since 2004(Barnighausen et al., 2008; Herbst et al., 2009) and similarly, globally, TB-related deaths in people living with HIV have also declined by 33% since 2004 (UNAIDS., 2014) probably due to the ART roll-out and HIV/TB strategies. TB patients identified to be HIV infected should start ART immediately to reduce mortality (WHO., 2009b) as such joint TB and HIV interventions have been found to be beneficial.

Organization of services: Hlabisa HIV and TB programme

The Hlabisa HIV Treatment and Care Programme (ART programme) is an initiative of the Department of Health (DoH) and was supported by the Africa Centre for Population Health (Africa Centre) between 2005 and 2013. In this ART programme, all TB patients are offered an HIV test (uptake more than 90%) because of the high HIV prevalence among TB patients and all HIV patients are screened for TB,(Houlihan et al., 2011b; National Department of Health South Africa., 2004; Wallrauch et al., 2010; Welz T, 2007) which is in line with the South African DoH strategy of provider-initiated HIV testing.(Department of Health., 2000 ; National Department of Health South Africa., 2004) Patients in the Hlabisa sub-district can thus enter the ART programme via either the HIV or the TB route. All people infected with TB develop a latent TB infection, that is, they harbor the tuberculosis bacterium without any TB symptoms and cannot spread the infection to others, but they are at risk of developing an active infection that is both symptomatic and contagious.(Wikipedia) HIV infection increases the development of latent and recently acquired TB to active TB and as well as increased susceptibility to new TB infections. In the ART Programme, TB prevalence among HIV-positive patients on ART was 25% and incidence of new infections in the ART group was 6.9 per 100 person years which is high compared to figures reported elsewhere in South Africa and sub-Saharan Africa.(Houlihan et al., 2010)

In some areas where TB and ART services are not integrated or decentralized to primary healthcare, co-infected patients may have a greater challenge utilizing care than those with either TB or HIV alone.(Gandhi et al., 2009) In the Hlabisa ART Programme, TB and HIV services are mostly integrated and decentralized to 17 largely nurse-led primary healthcare clinics to improve utilization of services.(Houlihan et al., 2011b) In each clinic, a team is responsible for HIV treatment and care services (HIV testing, CD4 count measurement, and initiation and monitoring of antiretroviral therapy).(Wallrauch et al., 2010) The integration plan included close proximity of TB and HIV teams in the hospital and clinics to facilitate patient flow, introduction of a central TB clinic on the hospital premises for referral of smear-negative and suspected extra-pulmonary TB, training of TB healthcare workers in HIV-related topics and HIV staff in TB-related topics, and development of a Microsoft Access database to store basic demographic and clinical data relating to HIV patients for monitoring and evaluation.(Wallrauch et al., 2010) Despite the decentralization and integration of services, differential utilization patterns between TB and HIV services remain likely due to organizational differences in the

structure and schedules of TB and HIV services, patient socio-demographic characteristics, differences in nature of disease conditions or geographical differences in healthcare need relative to clinic locations.

Pre-ART services

HIV testing rates have steadily increased over time resulting in more people knowing their HIV status thus enabling the detection of disease earlier and an increasing group of those with known infection who need management - pre-ART services are important to managing this latter group.(Frost & Reich, 2009; Jha et al., 2002) The CD4 count cut-off for initiation onto treatment has increased over the years, from 200 to 350 to 500 cells/mm^3, and are likely to be extended even further in line with the 2015 WHO recommendations.(WHO., 2015b) In the ART programme, individuals who are HIV positive but not yet eligible for treatment (pre-ART) because their CD4 count is above the cut-off and they do not have clinical stage 3 or 4 disease, continue to access and utilize healthcare facilities for CD4 count monitoring and treatment of opportunistic infections in Hlabisa sub-district (in 17 phc clinics), similar to some areas in sub-Saharan Africa.(Frost & Reich, 2009; Lessells et al., 2011; World Health Organization., 2006) Until 2012, doctors were responsible for initiating patients on ART and the clinical follow-up at 6-monthly intervals, and as from 2012, ART is initiated at primary healthcare clinics by nurses trained in Nurse Initiated Management of ART (NIMART) after standard pre-ART evaluation and three treatment literacy sessions.(Mutevedzi et al., 2010) Pre-ART care spans the period between a person testing positive for HIV and needing ART which in some people is very short, just at the time for assessment, while for others, this could be a period of years. A short period of pre-ART may result from delayed presentation for testing or a delay between receiving the initial test result and seeking or receiving HIV care. Efforts to retain patients in care have been focused mainly on patients enrolled in ART while those not yet eligible for ART (pre-ART) are equally important to focus on especially in the era of treatment as prevention strategies (TasP). Studies in South Africa have shown a high rate of loss-to-follow-up (LTFU) immediately after enrolling in pre-ART care and particularly for younger individuals and those at an earlier stage of infection.(Lessells et al., 2011; Plazy, Dray-Spira, Orne-Gliemann, Dabis, & Newell, 2014; Plazy, Orne-Gliemann, et al., 2015; World Health Organization., 2006) Reasons for LTFU for pre-ART patients include– waiting times, transport costs, staff attitudes, feelings of well-being indicated by a higher baseline CD4 count and less advanced disease stage and frequent clinic visits to give a blood sample for CD4 count and returning for the CD4 count results.(Houlihan et al., 2010; Tanser, Hosegood, Benzler, & Solarsh, 2001; World Health Organization., 2006)

The co-existence of HIV and TB and the continued scale up of ART in South Africa, particularly in Hlabisa sub-district, is likely to lead to an increased demand for healthcare services.(WHO., 2009b) Health systems particularly in resource-limited settings may need to be strengthened and reoriented in order to improve utilization of healthcare and the quality of care especially in high epidemic areas where ART roll-out is scaling up and initiation guidelines are changing to a higher CD4 count cut-off or according to the new WHO guidelines recommending treatment initiation for all HIV positive individuals.(National Department of Health South Africa., 2004; Schneider, Blaauw, Gilson, Chabikuli, & Goudge, 2006; WHO., 2015b) The healthcare utilization challenges faced by pre-ART, ART and TB patients are complex because of the nature of the conditions - long-term follow-up for ART, short-term for TB patients though there can be relapses and multi-dimensional for pre-ART; and the different pathways of care and population needs and expectations.

Access and Utilization

Health system scholars have argued that access is an instrumental or intermediate goal of health systems.(Gilson & Schneider, 2007; Gulliford et al., 2002; Schneider et al., 2006) However, access to healthcare is only important if it leads to improved population health, patient satisfaction, disease prevention or health promotion otherwise utilization of healthcare is more relevant. Although research often focuses on utilization of healthcare as a proxy for access, these two concepts are different where access is the *capacity* to utilize healthcare services given need and utilization is the *actual* uptake.(Aday & Andersen, 1981) Access may be difficult to measure because it requires knowledge of need among those who do not come to the healthcare facilities; thus access is a more complex concept than utilization. However, utilization and not access, contributes to health outcomes and is a function of both access (availability, acceptability and affordability of healthcare)(Gulliford et al., 2001) and an individual's willingness to seek needed healthcare. Health policy can of course also affect individual's willingness e.g., through information campaigns.

Some emerging evidence on utilization of HIV and TB treatment and care in rural South Africa has shown that there is a gap in research on understanding access and utilization of both types of care.(Barnighausen T, 2008; Cooke, Tanser, Barnighausen, & Newell, 2010; Department of Health., 2004) It is therefore important to assess the factors affecting utilization of healthcare in patients receiving HIV and TB treatment. The 1996 South African Constitution states that everyone has the right to access to healthcare services but inaccessibility and low utilization of healthcare services for patients

in need, particularly poor populations, still exist. Since the beginning of the ART scale-up in sub-Saharan Africa, concerns about structural barriers to ART access − demographic, financial and socioeconomic (low ability to pay out-of-pocket healthcare expenditures and low socioeconomic status),and geographical factors (migration and residence in rural and remote areas far away from the nearest ART clinic) and knowledge about where to obtain diagnosis and treatment free-of-charge, have been reported. (Barnighausen, 2007; Bärnighausen, Herbst, Mutevedzi, Mossong, & Newell, 2013; Cooke et al., 2010; Penchansky & Thomas, 1981; Welz T, 2007)

There is need to focus on quality of service in health systems as one of the factors associated with utilization, particularly in developing countries where resource use has to be optimized to expand population coverage. The process of improvement and scaling up should be based on sound strategies to ensure that the best possible results are achieved.(WHO., 2006) One of the WHO six building blocks for strengthening health systems is "a well-performing health workforce which is responsive, fair and efficient, to achieve the best health outcomes possible, given available resources and circumstances. i.e. there are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive."(WHO., 2010b) Engaging healthcare providers in research and intervention formulation is important in assessing the feasibility and acceptability of interventions by the healthcare providers. It also provides healthcare providers with an opportunity to choose which interventions they would like to focus on and suggest interventions that are likely to work specific to their facilities based on research findings.(WHO., 2006)

CHAPTER 2: LITERATURE REVIEW - UNDERSTANDING ACCESS AND UTILIZATION OF HIV/TB TREATMENT AND CARE

In addition to the background given in the previous chapter, a literature review was carried out to understand issues of access and utilization of healthcare services in general and more specific to HIV (pre and post ART initiation) and TB – exploring factors that have been shown to be associated with the various aspects of utilization. This chapter identified the extent of the utilization globally and in the context of the South African health system, identifying the knowledge gaps this PhD aimed to address. This PhD study aimed to determine and quantify factors associated with healthcare utilization - decomposed to availability, affordability and acceptability of healthcare services, in patients utilizing HIV care (including those pre-ART) or TB treatment and care in a rural sub-district of Hlabisa in KwaZulu-Natal and to understand healthcare providers' perspectives regarding patient care and provision of quality care. Clarification of the definition of the terms 'access' and 'utilization' is given at the end of the chapter, leading to Chapter 3, which provides the methods used to address the aim and objectives of this PhD. A summary is drawn at the end of this chapter to highlight the key points of the literature review and the gaps that this PhD research addresses.

Barriers and facilitators to patient healthcare utilization

In this PhD research, data on those in need but not utilizing care were not collected, and therefore true access cannot be measured; the utilization measure is a function of access measuring hurdles in patients utilizing care. It is important to point out that it can be difficult to identify those in need but not utilizing care because not only are they less likely to access health facilities, they may not even be aware of their HIV or TB status which hinders identification of such cases in the general population unless through a focused population survey with collection of biomarkers and/or clinical information or through modelling techniques.(Barnighausen, 2007)

Various factors related to availability, acceptability and affordability of care affect or enhance uptake of healthcare services among users at different levels and there is need to inform understanding of such factors so as to improve quality of care and service provision in order to retain patients in care and advice policy on possible ways to reduce or lessen the barriers to utilization and strengthen/encourage the enabling factors. Increasing utilization barriers, if not addressed, in the long run could impact

negatively on treatment uptake, adherence, retention and disease prevention which would affect patients' health outcomes.

Availability of healthcare services

There is a continued increase in ART roll-out which may lead to improved identification of TB and an increase in TB treatment demand and uptake, while on the other hand, ART may decrease TB disease, especially when initiated early. However, with an increasing demand for, and expanding availability of, ART there has to be a proportional increase in the upgrade of health system – availability of facilities, drugs, services and providers.(Schneider et al., 2006) The recent South Africa National guidelines and WHO recommendations for relating to HIV treatment expanded treatment eligibility for ART by CD4 cut–off from 200 cells/mm³ to 350 cells/mm³ (Department of Health., 2000 ; South Africa National Department of Health., 2004) and to 500 cells/mm³ in early 2015 in SA and late in 2015 WHO (adopted in South Africa late 2016) recommendations were upgraded even further to propose universal treatment for all HIV infected people immediately upon HIV diagnosis (WHO., 2015b). Not only would that increase the number of people eligible for treatment, it would then also include in care a large number of people who initiate ART when not yet HIV-symptomatic. This will have consequences for the burden on care and the type of care to be provided.

Utilization of healthcare services is an important determinant of health that has public health relevance and has been recommended by the World Health Organization as a basic primary healthcare concept. (WHO., 2009b, 2010b) The main aim of universal health coverage is to make healthcare accessible without barriers in utilization of services when in need, based on affordability, availability which includes physical accessibility and adequacy, or acceptability of services.(Pillay & Barron, 2011; WHO., 2009b) Pre-ART, ART and TB patients are likely to seek care, be retained in care, and adhere to treatment if they are satisfied with the nature and delivery of health services and if they face few access and utilization barriers of can overcome any barrier that remains. More recently, HIV and TB healthcare access and utilization has included a variety of providers, services and facilities which can either facilitate or disable patients' uptake of care, retention in care and adherence on treatment.

Shortage of healthcare inputs, such as staff, drugs and equipment, often means quality comprehensive care is not available or cannot be utilized. A household survey conducted in South Africa in 2004-5 found that unavailability of services at clinics for chronic care, poor diagnosing and prescribing and

interrupted drug supplies were major barriers to utilizing care for patients and were costly to patients as they had to make many trips to the clinics to check if their results were available, paying a consultation fee at each visit and transport costs resulting in some patients not attending care or shopping around at different primary care clinics and other providers, and self-treatment thereby delaying treatment.(Goudge, Gilson, Russell, Gumede, & Mills, 2009a) However, self-treatment and provider shopping has been found to be common in South Africa even in settings where services are generally available.(N. Chimbindi et al., 2015; Moshabela, Schneider, Silal, & Cleary, 2012)

A qualitative study conducted in the Eastern Cape, South Africa, in 2014 with nurses, doctors and pharmacy personnel revealed that intermittent drug shortages for TB, HIV, diabetes and depression were due to poor supply chain management, particularly in rural facilities where there was no dedicated transport to distribute drugs from the storage place to the facilities, which affected patient utilization of healthcare in terms of loss of confidence with the system, poor quality service and patients not using their nearest facility.(Magadzire, Budden, Ward, Jeffery, & Sanders, 2014) Availability of drugs and services has to be strengthened in the primary healthcare service delivery especially in light of the expanding SA and WHO HIV treatment guidelines which will likely increase demand for reliable supply of drugs.

Physical accessibility - travelling distance to clinics

A study in Hlabisa sub-district using longitudinal data collected in a household demographic surveillance survey explored the effects of socio-economic factors - sex, age, education, wealth, distance to the nearest ART clinic, urban/rural residence, and migration status – on ART enrolment in relation to ART need.(Bärnighausen et al., 2013) Women who were ART-eligible were more than twice as likely to be taking ART as men, and every additional kilometre distance from the nearest clinic decreased the likelihood of ART used by approximately 20%. Other socio-economic factors - education, wealth, and migration did not affect ART access, similar to what other studies in the area have found.(Bärnighausen et al., 2013; Cooke et al., 2010)

A study in Eastern Cape in 2014 showed that patients travelled long distances to the facilities, relying on public transport which was often absent or not reliable, resulting in patients overcrowding certain more urban facilities as they were more accessible.(Magadzire et al., 2014) Another study in South Africa similarly showed that vulnerable or poorer households could not afford transport costs to the clinics and

there were not ambulances to take patients to the clinics or hospitals, whereas patients from better off households could afford the transport cost or had relatives' cars to use would be able to access care more easily.(Goudge et al., 2009a)

In a separate study conducted within the PhD research study area to assess physical accessibility of healthcare services and clinic usage using survey data, geographical information system and modelling techniques, the median travel time from a household to the nearest clinic was estimated at 81 minutes and 65% of homesteads would need to travel one hour or more to attend the nearest clinic; clinic usage declined with increasing travel time.(Tanser, Gijsbertsen, & Herbst, 2006) In a study in Ghana in 2005, patient travelling times to receive ART services were even longer, ranging from two to 12 hours for 30% of the patients, with some patient requesting to be transferred to an even further clinic for fear of stigma.(Addo-Atuah et al., 2012) Subsequent studies in the Hlabisa study area showed that most patients used their nearest clinics and used public transport, with a considerable proportion walking to their clinics.(N. Z. Chimbindi, Barnighausen, & Newell, 2013)

It is important to assess the barriers and facilitators of patient utilization of care in an area with a high HIV and TB prevalence, so as to plan appropriately for those in need but not utilizing care and how to overcome the challenges by for example bringing services closer to the people in need.

Accommodation and organisation of services

The availability, accommodation and organization of services can affect uptake of healthcare. Organizational differences may exist in the TB and HIV programmes which may lead to differences between groups, or enhance utilization for one group of patients more than the other.

Accommodation refers to the extent to which the healthcare delivery system is organized in ways that meet the expectation of the patient, their ease of accessing and utilizing care, such as convenience of operating hours and ability to receive care without prior appointments.(McLaughlin & Wyszewianski, 2002) Decentralized and integrated HIV/TB services are most likely to ensure timely initiation of HIV treatment and optimal TB care and provide patient entry to care through either the HIV or TB route as well as providing a one-stop-shop for patients who are co-infected, potentially making utilization of care for patients easier by reducing the number of visits and thus travelling distance and time.(Gandhi et al., 2009; Wallrauch et al., 2010) A systematic review of 133 records (63 papers and 70 abstracts) was conducted in 2010 which showed there are five types of integration models a) TB service, referring for

HIV testing and treatment b) TB service, testing for HIV and referring for treatment c) HIV service, referring for TB screening and treatment d) HIV service, screening for TB and referring for treatment e) single facility where TB and HIV service are provided within the same facility.(Legido-Quigley et al., 2013; Legido-Quigley et al., 2010) The following disadvantages were identified for referral-based models; if referral criteria or pathways were complex they were likely to fail and that they increased patient costs by attending multiple clinics while the single facility model had more advantages and likely the ideal model to provide integrated care – which is the model adapted in this study area primary healthcare clinics.(Wallrauch et al., 2010) It is therefore important to examine the utilization differentials to care for patients in this setting with an integrated decentralized rural programme to be able to identify areas of potential improvement among those HIV infected only, TB infected only or those pre-ART in utilization of healthcare services as there are likely differentials because of the nature of the diseases or conditions.

Not all referred patients usually end up linked to care when HIV and TB services are provided separately, as shown in a study in Zambia where only 28.6% of TB patients referred to an ART clinic actually enrolled in care.(Miyano et al., 2013) Factors associated with failure to enroll in care included being a man, having been previously on TB treatment and having registered at a facility that did not provide ART indicating the importance of having well organized health services systems such as having both HIV and TB healthcare services provided in the same facility or an effective referral system to ensure patients are enrolled in care particularly men.(Miyano et al., 2013)

Convenience of operating hours is generally considered essential for utilization of HIV and TB care especially for small children, patients working in the formal sector, young adults and men because of the need to utilize the facility when it best suits them for example after work, the need to avoid long queues and to some extent fear of stigma.(Scott et al., 2009) A study in Ghana showed that healthcare providers devised means of accommodating special groups of patients – serving teachers and those employed first in the queues as they needed to go back to their work or those with young children.(Addo-Atuah et al., 2012)

Healthcare providers shortages and delivering quality care and patient utilization

The expanded roll-out of ART programmes and integration of HIV and TB services has led to increased patient demands on the health system for accessible and quality healthcare services. This demand will

likely be further amplified as new guidelines recommend initiation of HIV infected people on ART at ever higher CD4 count cut-off and early in the course of their infection as well as increased identification of TB patients.(WHO., 2013, 2015b) This would call for increased healthcare providers to meet the demand and provide quality care. Based on the results from an earlier time and motion study conducted in three HIV clinics in the rural, primary care-based HIV treatment programme in Hlabisa it was estimated that for universal access to HIV treatment for all patients with a CD4 cell count of ≤350 cells/mm³ to occur (which is lower than the current WHO and SA recommendations, but in place in 2009) an additional 2 200 nurses, 3 800 counselors, and 300 doctors would be required at national level, at additional annual salary cost of 929 million South African rand (ZAR), approximately equivalent to US$ 141 million.(Hontelez et al., 2012) Further, for universal treatment of all HIV infected adults immediately after HIV diagnosis, a further three times the healthcare providers would be required at an additional annual salary cost of ZAR 2.6 billion (US$ 400 million) but for a limited period until the HIV-positive population is expected to decline to low levels.(Hontelez et al., 2012) However, in South Africa there is a chronic shortage of healthcare providers, particularly in the public sector which serves the majority of the population, which might affect the quality of care provided in the public sector facilities. Yet, studies have shown a positive correlation between quality of care provided and utilization of care with the number of healthcare workers delivering the healthcare services.(Department of Health., 2011) The healthcare workforce is one of the crucial components of any healthcare system delivery and a major building block in the WHO health system framework that affects access, utilization and quality of care for improved health. (WHO., 2010b)

Strategies have been put in place to try and increase healthcare providers and retain those that are already in the workforce including training increased number of community health workers, which can undertake specific aspects of care and introduction of mid-level cadres such as clinical assistants. (Houlihan et al., 2011b) Healthcare providers play an important role in healthcare delivery and their behaviour is likely to influence the successful outcomes of ART scale-up and TB programmes and quality care provision particularly in ensuring patients are satisfied with care and therefore continue to utilize care and are retained in care.(Harris et al., 2011; O'Connor & Michie, 2012) In South Africa, the Batho Pele “People First” principles and the National Core Standards for Health Establishments in South Africa have been developed to guide service providers in improving patient relations, satisfaction and service delivery. (Department of Public Service and Administration., 1997; National Department of Health., 2011b; Pillay & Barron, 2011) It is imperative to understand healthcare providers’ perspective

of the challenges to, and facilitators of, improving quality of care provision by engaging them in a discussion based on evidence-based findings. Communication with healthcare providers provides healthcare providers with an opportunity to identify and develop those interventions they could apply which are likely to work specific to their facilities and provide a space to reflect on their actions.(WHO., 2006)

Acceptability of healthcare services

Acceptability of healthcare services provided depends to a large extent on the health workers' attitudes and practices and the patients' expectations. The concept of acceptability is broad and captures the extent to which the patient is comfortable with the provider including the providers' characteristics such age, sex, language, and ethnicity, reflecting social and cultural norms and values.(Goudge et al., 2009a; McIntyre, Thiede, & Birch, 2009) Acceptability is also understood as the social and cultural distance between health care systems and their users.(Gilson, 2007) Patients' views, including aspects of satisfaction, are important for understanding populations' perceptions of quality of care in both public and private sector healthcare, to inform development of measures to increase the utilization of primary health care services as they are likely associated with whether patients will attend clinics or continue to uptake healthcare services. Several factors are reported to be associated with acceptability of services including perceptions of staff attitudes, confidentiality and privacy, characteristics of the health services, staff efficiency, user's attitudes and expectations, community and cultural preferences, facility cleanliness, length of queues and community judgement (as a proxy for stigma).(Bakeera et al., 2009; Harris et al., 2011; McIntyre et al., 2009)

A study conducted in the Free State in South Africa showed high overall satisfaction among patients receiving public-sector ART, similar to studies in KwaZulu-Natal.(N. Chimbindi, Barnighausen, & Newell, 2014; Wouters, Heunis, van Rensburg, & Meulemans, 2008b) However, patients have been found to be dissatisfied with specific aspects of service delivery such as long waiting times, and staff attitudes which likely affect present and future utilization of care.(Bakeera et al., 2009; N. Chimbindi et al., 2014; Harris et al., 2011; Wouters et al., 2008b) Poor acceptability of healthcare services provided and poor patient health-seeking behaviour can lead to delayed-care seeking by patients.(Harris et al., 2011) A nationally-representative household survey showed that desire for respectful treatment influenced the health-seeking behavior of 22.3% of patients attending private-outpatients services, 4.1% accessing public phc services and 5.7% using public hospitals – indicating a lower expectation of quality

care delivery in public than private sector care, similar to reported from a study in Uganda in 2007. (Bakeera et al., 2009; Harris et al., 2011) The latter, qualitative, study found that service acceptability depended on health worker attitudes and practices, with patients reporting they were treated badly "like they were not human beings"(Bakeera et al., 2009) while in the South Africa national survey more than half (54.7%) of respondents felt that patients at public hospitals were not treated with respect and dignity.(Harris et al., 2011) The study conducted in Uganda revealed that patients were also dissatisfied with the time taken waiting to receive care, cleanliness, privacy and confidentiality – similar to other studies in sub-Saharan Africa. (N. Chimbindi et al., 2014; Harris et al., 2011) A cross-sectional facility-based study conducted in Central Ethiopia in 2009 showed that some neglected aspects of health worker-patient interactions such as perceived health worker empathy, which is being sensitive to information and emotional part of communication, and perceived technical competency were important factors affecting patient satisfaction.(Birhanu, Assefa, Woldie, & Morankar, 2010)

Sex discrimination has been reported in a study in Uganda, where healthcare workers mistreated women because they did not always have money, unlike men, making services unacceptable for women.(Bakeera et al., 2009) Acceptability of ART services has been reported to be lower in rural patients than urban patients, with patients residing in rural areas less likely to report being respected by healthcare providers than patients in urban areas, probably because rural facilities are often poorly resourced, compromising the quality of care provided compared to urban facilities.(S. M. Cleary, Birch, Moshabela, & Schneider, 2012) High patient workload and limited resources could burden the healthcare system and lead to a compromise in the quality of healthcare service resulting in lowered patient satisfaction, limiting the successes of the ART and TB programmes of treatment uptake, adherence and retention in care.(Schneider et al., 2006; Wouters et al., 2008b) A study in Ethiopia in 2012 found task-shifting of ART services (from physicians to nurses) associated with high levels of patient satisfaction in underserved areas facing human resources shortages.(Asfaw et al., 2014) Patients receiving ART services from nurses in this latter study reported greater satisfaction with friendly services, information about medications, prompt attention and provision of all services needed than those receiving services from physicians or health officers.(Asfaw et al., 2014)

Scale-up of ART should not only focus on increasing coverage and number of patients on treatment but also the acceptability of healthcare services, patient satisfaction and quality of care to ensure sustainability of HIV/TB programmes and patient retention in care.

Affordability of healthcare services

Although treatment and care for HIV and TB is provided free of charge in the public sector in South Africa, there are still financial barriers that pre-ART, ART and TB patients need to overcome when utilizing care or continue to use care. Such barriers include transport costs to the facilities, food during waiting times, and maybe need for childcare services and the opportunity costs of time and income lost, all which add up to a substantial amount.(Onwujekwe et al., 2010; Rosen, Ketlhapile, Sanne, & Bachman DeSilva, 2007) There are direct and indirect costs that patients bear when utilizing care resulting in not all patients in need of care utilizing care and those utilizing care adopting coping mechanisms or foregoing some necessities.

Economic status is an important determinant of health care utilization, since it reflects individual or household ability to pay for health services. Although **s**ocial grants in South Africa have reduced absolute poverty and they are a lifeline for most poor households, most South African cannot afford medical insurance and depend on public sector care, provided free-of-charge at the point of care.(Goudge et al., 2009a; Govender, Fried, Birch, Chimbindi, & Cleary, 2015) Unemployment is high in the Hlabisa study area (about 80%) in the general population and up to 90% of those on ART and TB treatment receive disability grants.(Barnighausen T, 2008; Tanser et al., 2008)

A study in Nigeria showed that the mean cost of treatment and mean percentage of income spent on treatment by families with HIV/TB co-infected patients was significantly higher than for those with TB or HIV only mainly because, as the clinics were not integrated, they had to utilize separate TB and HIV clinics.(Sadoh & Oviawe, 2007)

Illness, including HIV and TB, has social and economic implications on households as it can contribute to poverty and impoverishment, broadly defined as processes of household asset depletion and income loss that cause consumption levels to fall below minimum needs.(Bachmann & Booysen, 2006; Russell, 2004) The issue of ability-to-pay to utilize healthcare is crucial for policy because some people forego essential services to access and utilize healthcare and others may borrow money from relatives, friends or in the communities; while others facing more dire financial constraints resort to selling of assets or taking loans from money lenders.(Economic Commission for Africa.; Kruk, Goldmann, & Galea, 2009; Leive & Xu, 2008; Russell, 1996) While these coping mechanisms may alleviate the problem in the short-term, in the long run they may lead to catastrophic situations and impoverishment especially in

cases where they repay loans with high interest and especially in areas with high HIV and TB prevalence where there is a limit as to who can provide the means and nearly all have to borrow.(Economic Commission for Africa.; Goudge et al., 2007; Kruk et al., 2009; Leive & Xu, 2008; Russell, 1996)

There has been a growing literature comparing the direct costs of health care to households' ability-to-pay through assessing catastrophic levels of health care spending. These studies have different definitions and cut-offs for catastrophic expenditures, some use a reference point of either 10% of household income consumed by health care expenditure (S. Cleary et al., 2013 ; Prescott, 1999; Ranson, 2002) or health care costs exceeding 40% of non-food household expenditure.(K Xu et al., 2003) On the other hand, impoverishment refers to households pushed below the poverty line due the direct costs of health care. (Van Doorslaer et al., 2006; Wagstaff & van Doorslaer, 2003) The NHI reforms aim to improve access and utilization of healthcare services by removing the affordability barrier and facilitate pooling of funds to provide quality care to all especially the poor.(Pillay & Barron, 2011)

Out-of-pocket payments for user fees, medication, transport, food and care, particularly among people with chronic conditions such as HIV, could cumulatively amount to a lot of money over the long-term.(Kruk et al., 2009; Leive & Xu, 2008) Different diseases are likely to impose different direct and indirect cost burdens with different risks for household livelihood sustainability.(Russell, 1996) Individuals and households with patients who have conditions such as TB, with limited treatment periods, or patients pre-ART could possibly face different financial challenges from those with more chronic diseases when utilizing healthcare in that TB is curable and hence the financial demands for healthcare are for a limited period of time whereas HIV is for a lifetime and long-term. Pre-ART patients may need regular clinic follow-up visits for CD4 count monitoring (at the time of the study 2010 and this may change with the new guidelines which recommend immediate ART initiation for all who test positive), treatment of opportunistic infections and, once becoming ART eligible, attending peer support groups prior to initiation which may cost considerable amounts for travelling and food.(Lessells et al., 2011; Rosen & Fox, 2011) Pooling risk through public or private insurance, tax-based social health insurance or voluntary insurance would offer financial protection to users from the costs of illness. However, other healthcare-related expenses such as transport to the clinic and food needed when utilizing care will continue to exist.(Kruk et al., 2009) Research focused on the affordability and coping mechanisms of those who are pre-ART is scarce, yet it is important for policy makers because it is an important indicator of patients' ability to utilize and be retained in care once they

are initiated on ART (Rosen et al., 2007) although this might no longer be an area of concern if the new guidelines to initiate onto ART immediately after testing HIV positive are effective. Rather, understanding how the factors affecting patients going on ART early in HIV are different from those going on when they are ill and how that influences decisions regarding finding transport money to attend clinic visits would be more relevant.

A key gap identified in this work was understanding patients' ability-to-pay for healthcare services and costs incurred by pre-ART and on ART patients, and those on TB treatment to understand the challenges those waiting to be initiated onto treatment face compared to those already on treatment and those on TB treatment, and whether financial challenges are different for these patients. These findings will help develop policies that ensure that patients waiting to be initiated continue to be monitored until they are initiated and those on treatment are retained in care. Although healthcare is free at the point of delivery, the cost of basic healthcare is high for most people in sub-Saharan Africa. The emergence of the twin epidemics of TB and HIV has increased the burden on the household; healthcare systems and on the average annual per capita expenditure on health and essential drugs and services provision.(Msamaga & Fawzi, 1997)

Definition of terms

Access and utilization are terms often used interchangeably to reflect on whether people are receiving the services they need or not. Access is a multi-dimensional concept and utilization is a function of access. In this study, the two concepts are distinct and defined below.

Access

Access is a multi-dimensional term whose comprehensive measurement requires a systematic assessment of physical, financial and socio-psychological access to services. Access is the degree-of-fit or an interaction between healthcare systems (supply-side) and individuals (demand-side) defined within specific dimensions of care.(McIntyre et al., 2009) Access is a measure of 'fit' between demand for healthcare and the ability of the healthcare system to meet the demand.(McIntyre et al., 2009) In this PhD research, access is defined contextually (but not synonymous to availability) and within the following dimensions of care: affordability, availability and acceptability of a health service(Penchansky, 1977) for those who have a need for the service.

Access dimensions of care

Affordability, availability and acceptability are related concepts that measure access.(Gilson & Schneider, 2007; McIntyre et al., 2009; Penchansky, 1977) These dimensions of access are a pre-condition for quality of care provided and a function of utilization.

Availability

Availability is related to the number and type of services available to those in need. It refers to the physical access or reachability of services that meet a minimum standard in terms of the elements of service delivery such as basic equipment, drugs and commodities, health workforce, and guidelines for treatment.(Gilson & Schneider, 2007; Gulliford et al., 2002; McIntyre et al., 2009; Penchansky, 1977) Availability of services also includes issues such as hours of service provision; the type, range, quantity and quality of health services relative to the health needs of the population (with these aspects being in turn influenced by the number and mix of staff, availability of equipment and medicines etc.).

Affordability

Affordability refers to the cost of services, treatment and patients' ability to pay out of pocket as well as indirect costs such as travel time, time spent at the healthcare facility and distance travelled. The extent to which the service is affordable depends on the clients' ability to pay. (Gilson & Schneider, 2007; McIntyre et al., 2009; Penchansky, 1977) Affordability of services, include the full range of direct and indirect costs associated with using a health service and the ability of patients to cover these costs. There is a strong relationship between the affordability dimension of access and financial protection issues in health systems including the National Health Insurance goals in South Africa.(McIntyre, 2012; Pillay & Barron, 2011)

Acceptability

Acceptability has a socio-psychological dimension which is related to the fit between service providers and patient attitudes, perceptions, beliefs, towards, and expectations of, each other.(Gilson & Schneider, 2007; McIntyre et al., 2009; Penchansky, 1977)

Utilization

Utilization is defined as the extent to which a population gains access or uses a particular service in a specified period. This ability to use healthcare services depends on financial, organizational and social or

cultural factors that limit/enable the utilization of services. Thus utilization is dependent on the affordability, availability and acceptability of services and not merely adequacy of supply.(Aday & Andersen, 1981; Gulliford et al., 2001)

Each access dimension is captured by a number of variables; the list outlined in the table 2.1 below was included in this PhD study, informed by established questions from literature to understand access and utilization.(Gilson & Schneider, 2007; Goudge et al., 2009a; McIntyre et al., 2009; Penchansky & Thomas, 1981)

Table 2.1: Dimensions of access

Availability	Affordability	Acceptability
• Mode of transport • Travel time to facility • Waiting time at facility • Geographic accessibility • Service location • Availability of health workers, drugs, equipment	• Direct and indirect health care costs • Travel costs • Ability to borrow or sell assets to pay for healthcare • Perceived ease/difficulty of incurring expenses • Costs and prices of services • Household resources and willingness to pay • Opportunity cost of time lost - waiting and travelling time • Overall expenditure on healthcare (including expenditure to reach ART facility, expenditure on self-care and expenditure on other providers) • Receipt of government 'disability' grants	• Perceptions of staff attitudes, confidentiality, and privacy • Acceptability of characteristics of the health services • Facility cleanliness, length of queues • Management/staff efficiency • User's attitudes and expectations • Community and cultural preferences, attitudes and norms towards users • Perceptions of staff attitudes, • Community judgement (as a proxy for stigma) • Information on health care choice/providers – health worker preference

Summary of literature review

In conclusion, in this chapter factors related to the different dimensions of care by patient group, pre-ART, ART and TB, have been identified. Concerns remain regarding distance to clinics and the mode of travel and association with availability, physical accessibility of facilities and affordability of travelling expenses. Integrated HIV/TB services were shown to facilitate utilization of care by reducing travel distances and time as well as providing comprehensive care. There is a lack of literature relating to pre-ART patients across the access dimensions, although this is an important group as they are at the start of

long-term term engagement with care. Gaps in affordability and acceptability of healthcare services were noted, which might affect adherence, retention in care and improved health outcomes.

Table 2.2 below shows a summary of the key points and gaps identified from the introduction and literature review and highlights the objectives of the PhD study aimed at addressing these gaps.

Table 2.2: Summary of key points and gaps identified from the literature review and the PhD research objectives to address the gaps

Key points	Gaps identified	Research objectives
• Despite everyone having a right to access to healthcare services in South Africa, inaccessibility and low utilization of healthcare services for patients in need still exist • Concerns about structural, financial and geographical barriers to HIV and TB healthcare have been identified • Quality of service has been found to be associated with healthcare utilization, retention and adherence • Joint TB and HIV interventions have been found to be beneficial in reducing mortality and improving health outcomes among patients • HIV testing rates have steadily increased over time resulting in more people knowing their HIV status and thereby increasing the number of those with known infection who need management • Changes in National guidelines and WHO recommendations relating to HIV treatment and eligibility for ART may lead to increased demand and uptake of healthcare services • Different models of healthcare delivery were identified in the literature – integrated, decentralized and referral-based models • In South Africa there is a chronic shortage of healthcare providers in the public sector which might affect the quality of care provided in the public sector facilities • Most South Africans cannot afford medical insurance and depend on the public sector care, provided free-of-charge at the point of care	• There is need to understand the complex utilization challenges faced by pre-ART, ART and TB patients because of the nature of the conditions and their inter-relatedness, the different pathways of care, population needs and expectations • There is need to focus on quality of service in health systems to expand population coverage and ensure that the best possible results are achieved • Efforts to retain patients in care have been focused mainly on patients enrolled in ART while those not yet eligible for ART (pre-ART) are equally important • There is need to inform efforts to strength and reorient health systems in resource-limited settings in order to improve utilization of healthcare and the quality of care • There is need to understand the perceptions of healthcare providers to patients needs and barriers to healthcare utilization • There is need to increase the number of healthcare providers or develop strategies to maximize the efforts of the available healthcare providers to improve utilization of healthcare • Research focused on the affordability and coping mechanisms of those who are pre-ART is scarce, yet it is important for policy makers because it is an important indicator of patients' ability to utilize and be retained in care once they are initiated on ART	1. To quantify factors associated with healthcare utilization, with utilization decomposed to availability, affordability and acceptability of healthcare services, for patients in HIV or TB treatment and care 2. To quantify the ability-to-pay for healthcare and identify associated factors for patients in pre-ART care, or on ART or TB treatment 3. To understand healthcare providers' perspectives regarding patient satisfaction and provision of quality HIV care, in order to identify areas for improvement

CHAPTER 3: METHODS AND STUDY SETTING

The third chapter outlines the aim and objectives of the PhD study and describes the study area, study setting and the various methods and the data sources used to provide the context for the study. Further, a description of the study design, data collection methods used and data management techniques employed, the sampling procedures used to answer the PhD research questions is given, with the conceptual framework developed to inform this study. The objectives of the study, the research questions to be addressed and the overview of the scientific papers that contributed to this PhD are explained.

Study aim and objectives

The overall aim of this study was to determine and quantify factors associated with healthcare utilization in patients in HIV care (including those not yet initiated on ART (pre-ART)) or on TB treatment in a rural sub-district of Hlabisa in KwaZulu-Natal and to understand the healthcare providers' perspectives regarding patient care and provision of quality care. The study used data from patient exit interviews, patient records, and from interviews with healthcare providers in the local HIV treatment and care programme.

The PhD study hypothesis was that utilization differentials exist across the various access dimensions of care by patient group (pre-ART care, HIV treatment and care only, and TB treatment only) in Hlabisa sub-district, rural South Africa. The study had three specific objectives:

Objective 1

To quantify factors associated with healthcare utilization, with utilization decomposed to availability, affordability and acceptability of healthcare services, for patients in HIV or TB treatment and care

Objective 2

To quantify the ability-to-pay for healthcare and identify associated factors for patients in pre-ART care, or on ART or TB treatment

Objective 3

To understand healthcare providers' perspectives regarding patient satisfaction and provision of quality HIV care, in order to identify areas for improvement

Table 3.1 below shows the expected outputs/papers and how they fit with the study objectives.

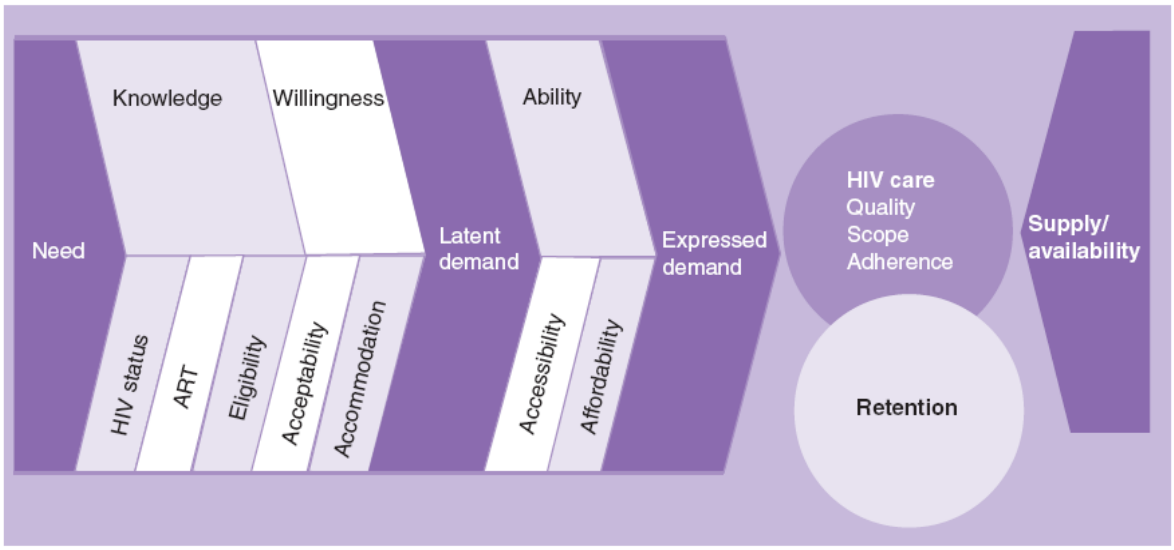
Table 3.1: Expected outputs/papers and how they fit in the study aim

Objectives	**Outputs/Papers**			
	Paper 1: An integrated approach to improving the availability and utilisation of TB healthcare in rural South Africa. *S Afr Med J 2013;103(4):237-240* **Paper 1b:** Almost universal test coverage: HIV testing among TB patients in a rural public programme. *Int J TB Lung Dis 2012; 16(5): 708*	**Paper 2:** Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews. *BMC Health Services 2014, 14:32*	**Paper 3:** Time and money: the true costs of healthcare utilization for patients receiving 'free' HIV/TB care and treatment in rural KwaZulu-Natal. *J Acquir Immune Defic Syndr 2015;70(2):e52-e60*	**Paper 4:** Engaging healthcare providers: responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal *(under review BMC Health Services*)
Objective 1 To quantify the factors associated with healthcare utilization, with utilization decomposed to availability, affordability and acceptability of healthcare services, for patients in HIV or TB treatment and care	**X**	**X**		
Objective 2 To quantify the ability-to-pay for healthcare and identify associated factors for patients in pre-ART care, or on ART or TB treatment			**X**	
Objective 3 To understand healthcare providers' perspectives regarding patient satisfaction and provision of quality HIV care, in order to identify areas for improvement				**X**

Conceptual framework

Penchansky and Thomas (1981) describe access using five dimensions of care covering the degree-of-fit between patients and the health system including – availability, acceptability, and affordability.(Penchansky & Thomas, 1981) A review article by Bärnighausen (2007) (Figure 3.1), incorporating Penchansky and Thomas' dimensions of care indicates that rather than a linear (non-ordered) model, access to ART should be viewed as hierarchical (ordered).(Barnighausen, 2007)

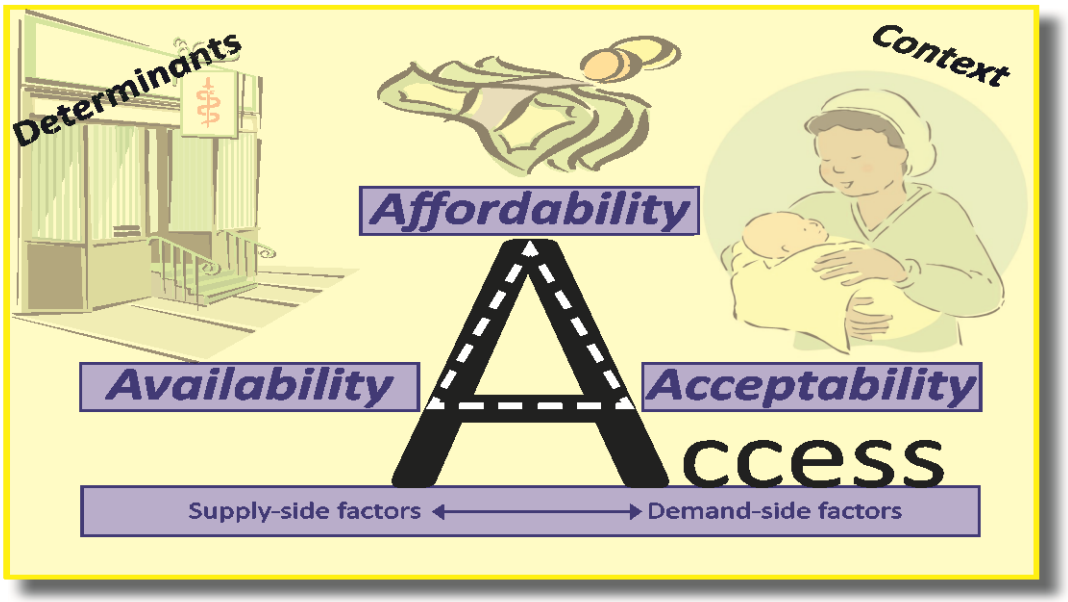
Figure 3.1 Framework to analyse access to ART



ART: Antiretroviral treatment

The Researching Equity in ACcess to Healthcare (REACH) study 2008, adopted an 'A' conceptual framework for access (availability, acceptability and affordability) (Figure 3.2), which views access as a dynamic process of interaction between health system (supply-side) and individual (demand-side) issues.(Donebedian, 1973) However, both healthcare system (supply-side) inequities in the distribution of resources and individual (demand-side) factors need to be understood, in order to identify the gaps that affect patient utilization of healthcare services and healthcare providers' provision of quality care.

Figure 3.2 The 'A' framework for access

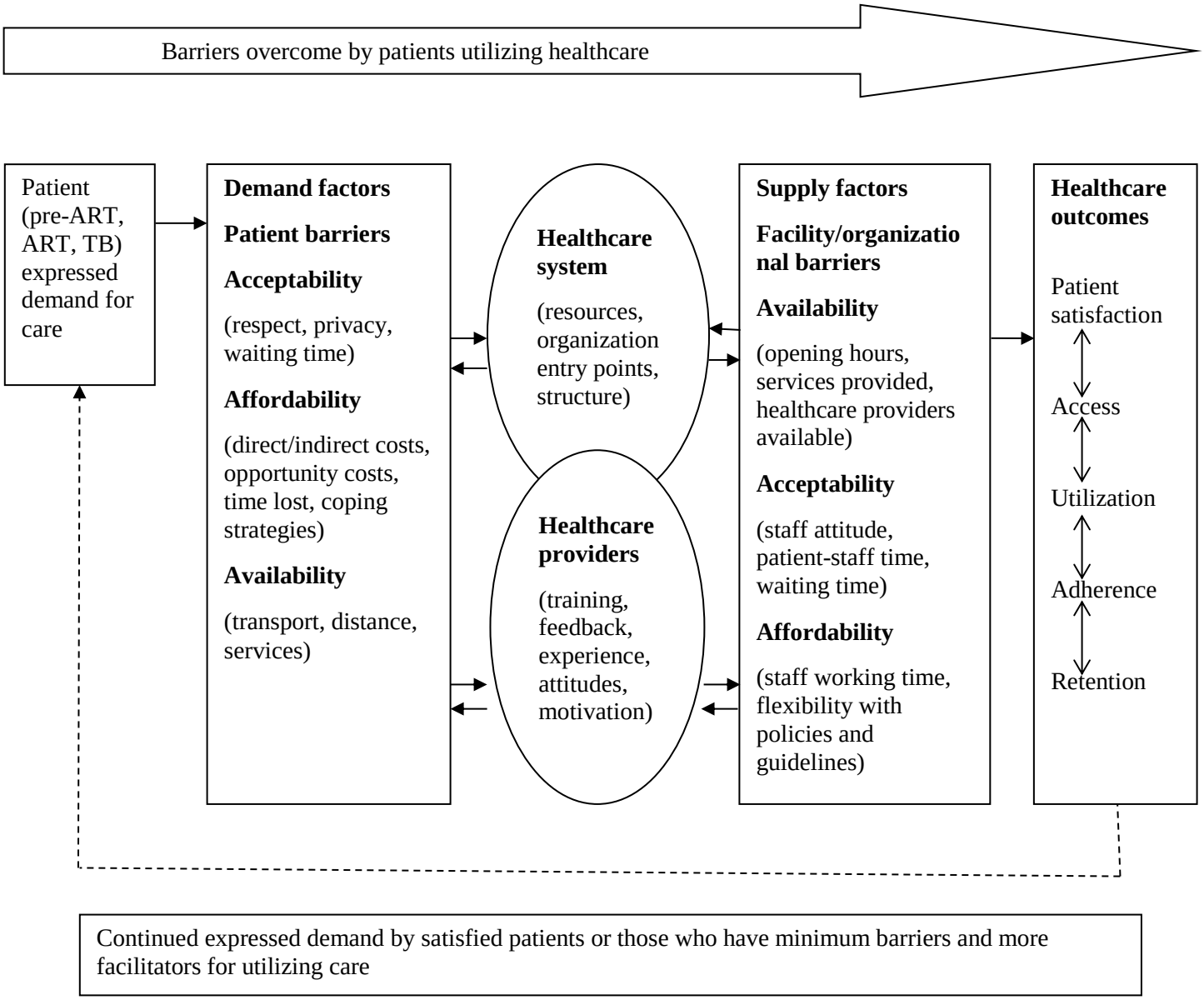


This PhD study was informed by a framework (Figure 3.3) which is adapted from the three frameworks mentioned (Penchansky and Thomas (1981), Bärnighausen (2007) and REACH (2008)). A decentralized integrated healthcare system has been suggested to improve uptake of treatment, adherence and retention in care, and increases utilization of combined treatment for those co-infected.(Coetzee, Hilderbrand, Goemaere, Matthys, & Boelaert, 2004; Legido-Quigley et al., 2010; Wallrauch et al., 2010) However, an integrated system requires additional resources – financial, human, infrastructure to ensure infection control - to set-up, implement and coordinate the two services than vertical systems.(Legido-Quigley et al., 2013)

Users of HIV and TB services express their demand for healthcare by actively seeking or utilizing healthcare (Figure 3.3). Patient expressed demands and expectations relating to acceptability, affordability and availability of services have to be met by the health system to ensure continued uptake of treatment and retention in care. The health system should be able to respond to and satisfy patients' demands, although it may or may not be able to immediately alter the availability/physical hurdles that patients face. Supply factors should be able to address most if not all of the patients' demands for patient satisfaction to be realized and this feeds back into continued expressed demand. The challenges/facilitators faced at each level/dimension of care may be different for those utilizing HIV

care including pre-ART, and TB treatment only. Although these patients are already utilizing care, understanding the factors affecting their utilization is important in shedding more light on the proximate challenges those in need but not accessing or utilizing care may be facing and pointing to areas that policy makers need to improve on to increase patient uptake, retention and adherence to treatment.

Figure 3.3: Conceptual framework of this PhD study



Study setting and study area

KwaZulu-Natal is one of the biggest provinces in South Africa and hardest hit by HIV. In 2005, approximately 40% of pregnant women in the province were living with HIV; in a general population of adult residents in rural KwaZulu-Natal in 2004, the overall HIV prevalence was 27% among 15-50 year old females and 14% in 15-54 year old males,(Welz T, 2007) with incidence remaining high from 2003 until 2010.(Barnighausen T, 2008) Hlabisa sub-district in KwaZulu-Natal is predominantly rural (76.8% of the population) with urban (3.3%) and peri-urban (19.9%) pockets, typical of many South African settings, and has a population of about 228,000 people who are mostly Zulu-speaking.(Tanser et al., 2001) The rural population lives in scattered homesteads that are not concentrated into villages or compounds.

This PhD study includes HIV-infected people on ART and those not yet on ART but in care (pre-ART) that is those who have tested HIV positive but not yet initiated onto ART whose CD4 count is being monitored (at the time of the study, patients would be initiated once their CD4 count is below 200 cells/mm^3), as well as those seeking TB treatment. In 2009, patient-exit interviews were conducted in six of 17 primary healthcare clinics in Hlabisa sub-district with 300 patients receiving ART, and 300 patients receiving TB treatment; patients were randomly selected using a two-stage cluster random sampling approach with primary sampling units primary healthcare clinics (phc) selected with probability-proportional-to-size sampling. In 2010 an additional 200 HIV-infected patients in pre-ART care from the same clinics were interviewed in a follow-on study called the Impact of ART on HIV epidemic dynamics. Patient-exit interviews were conducted in a private room outside the facility and all data were analysed using STATA 11.(StataCorp., 2009)

In 2012, a qualitative study was carried out (called the Healthcare providers' study) with healthcare providers in eight (of 17) randomly selected primary healthcare clinics; 25 ART healthcare providers were engaged in discussion structured around the responses from the patient exit interviews to assess possible challenges/facilitators ART providers face. Discussions took place in the consultation rooms when no clinical sessions were ongoing and these were recorded and transcribed; and data were managed using Nvivo 10.(QSR International Pty Ltd., 2012) Thematic content analysis was conducted by the PhD

candidate using both inductive and deductive approaches; clinic or healthcare provider identifiers were removed and replaced with pseudonyms.

The DSA is situated in the southern part of the Hlabisa sub-district, uMkhanyakude district KwaZulu-Natal and is approximately 430km² and includes about 40% of Hlabisa sub-district (Figure 3.4).(Tanser et al., 2008) Approximately 11,000 households, with a total population of about 90,000 resident and non-resident members in each round, are surveyed three times a year and routine demographic information is collected on births, deaths, migrations and pregnancies. A number of studies and programmes are nested within the DSA – wholly or partially, which include the REACH study, the Impact of ART on HIV epidemic dynamics study and the Healthcare providers' study (all described in detail below).

Figure 3.4 Maps of the location of the study area

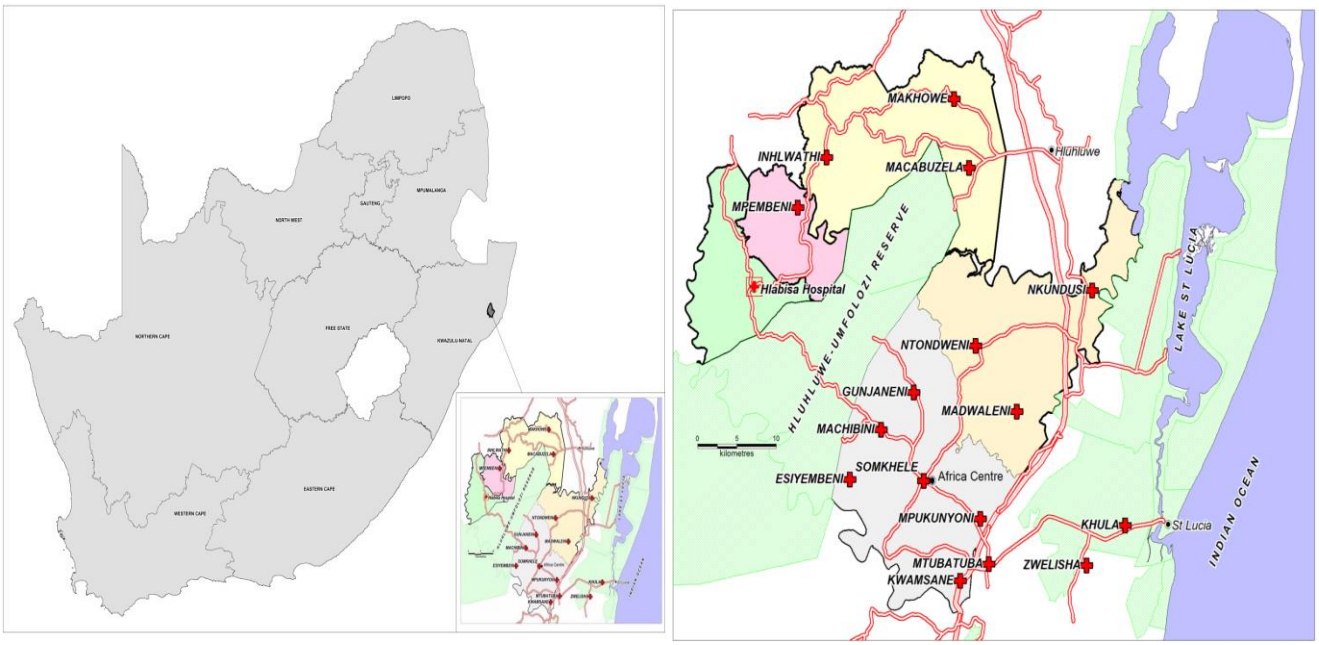


Figure 3.4 Maps showing location of Hlabisa sub-district in KwaZulu-Natal South Africa (left) and the 17 primary healthcare clinics (right) in the sub-district.

Healthcare delivery system

The Hlabisa HIV Treatment and Care Programme (ART programme) was a joint initiative of the Department of Health (DoH) and the Africa Centre for Population Health (Africa Centre).("Africa Centre for Population and Health Studies," 2010) The ART programme was supported by the Africa Centre from 2006 until early 2013, to provide free ART and TB treatment and care at primary care level. HIV treatment and care is offered in 17 nurse-led primary healthcare clinics within the Hlabisa sub-district, most of whom underwent the Nurses Initiated Management of ART (NIMART) programme since 2011 (before then ART initiation and clinical follow up was the responsibility of doctors, which operated at sub-district level from the Hospital).(Houlihan et al., 2011b) The ART programme utilized a decentralized model of healthcare delivery and supported the integration of HIV services into phc, aiming to link treatment and care with prevention services.(Houlihan et al., 2011b)

The Africa Centre supported data management and provided some staff who worked alongside jointly-trained DoH staff. All 17 clinics offered ART initiation and follow-up for eligible patients in accordance with the standard South African regimens (based on WHO guidelines) on HIV diagnosis, ART eligibility, screening, treatment regimens and follow-up(South Africa National Department of Health., 2004). As of 2012 the programme had initiated approximately 28,000 patients onto ART ; patient clinical information is captured in a database for monitoring and evaluation (ARTEmis database).(Houlihan et al., 2011a) The ART programme is like any typical rural African programme with adherence and retention-in-care issues. (Lessells et al., 2011; Mutevedzi et al., 2010; Plazy et al., 2014; Plazy, Newell, et al., 2015; Plazy, Orne-Gliemann, et al., 2015)

Individuals newly diagnosed with HIV have their blood taken for CD4 measurement and if it is above 200 cells/mm^3 (pre-ART according to guidelines when the study was conducted, according to the most recent South African guidelines it is CD4>500 cells/mm^3) they are asked to return to the primary healthcare clinic every six months for CD4 count monitoring and clinical assessment to determine eligibility for ART, and to prevent and treat HIV-related illnesses. Patients receive individual counseling, advice on healthy living, disclosure, partner notification and testing, transmission risk reduction measures, family planning and peer-support groups.(Lessells et al., 2011) Patients with a CD4

count of 200 cells/mm^3 or less or those who have symptoms of advanced HIV disease are eligible for ART.

The DoH TB control programme is well integrated with the ART Programme and works in all the 17 clinics and the Hlabisa hospital. Hlabisa district hospital is a 250-bed hospital with a 40-bed TB ward including isolation rooms for drug-resistant cases. All TB patients requiring inpatient services or those with complications are referred to Hlabisa hospital as well as those with multi-drug resistant TB (MDR-TB) and extensively-drug resistant TB (XDR-TB). After completing their hospitalization period (usually two months) patients are continued daily on an outpatient basis, with monthly clinic follow-up.

Data sources

The three data sources for this PhD were the REACH study; the Impact of ART on HIV epidemic dynamics study and the Healthcare providers' study.

REACH study

REACH was a multi-centre study funded by Global Health Research Initiative (GHRI), conducted between 2009 and 2010 in four sub-districts in four different provinces of South Africa, namely Gauteng, Western Cape, KwaZulu-Natal and Mpumalanga. The aim of the study was to develop a better understanding of the barriers to obtaining healthcare faced by people living in South Africa. REACH was conducted from March to October 2009 in six primary healthcare clinics in Hlabisa sub-district. A two-stage cluster random sampling approach was used; with six primary sampling units (primary healthcare clinics) selected with probability-proportional-to-size sampling from the then 16 (now 17) primary healthcare clinics in Hlabisa sub-district. Patient-exit interviews followed by patient record reviews were conducted with 300 HIV and 300 TB randomly selected patients. (Methods are explained fully in Paper 2 (N. Chimbindi et al., 2014) – Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews). Data was collected for three conditions: HIV, TB and maternal health (collected from Hlabisa hospital's maternity unit).

The questionnaire [Appendix 1] for this study was constructed based on overall access to healthcare-related questions and access domains of care (availability, affordability and acceptability) from literature

for validation. Consultation with expert researchers involved with health systems research and similar studies and literature review was done which contributed towards development of a context-adapted patient access questionnaire.

Four fieldworkers were trained by the PhD candidate and were involved in data collection using structured questionnaires. They conducted interviews in isiZulu, the local language, with patients who came for treatment of either TB or HIV at the clinics, as well as those who came for delivery at the hospital maternity unit who were aged 18 years and above. Data from all sites was entered in Cape Town and shared with every site.

Impact of ART on HIV epidemic dynamics study

The Impact of ART on HIV epidemic dynamics study was an extension of the REACH study to include people who are HIV infected but not yet eligible for ART (pre-ART). Pre-ART people visit the clinic for monitoring of their CD4 count every six months to assess when they should be initiated onto ART as well as for any other healthcare needs. The aim of the study was to estimate the cost associated with attending HIV services prior to initiating ART among people attending primary healthcare clinics in the ART programme. The study was carried out from August to December 2010 in Hlabisa sub-district, in four of the six clinics offering ART care that were selected for the REACH study; and a sample size of 200 patients was enrolled.

Four fieldworkers (the same as used in the REACH study) were trained by the PhD candidate and employed to collect data from HIV positive people who were utilizing care at the selected clinics, using structured questionnaires [see Appendix 2]. The questionnaires had patient cost-related questions similar to those collected for HIV/TB patients in the REACH study. The study was funded by National Institutes of Health (NIH), Washington, DC. Data was entered, coded and cleaned at the Africa Centre.

Healthcare providers' study

A qualitative study was designed and conducted to understand the healthcare providers' perspective regarding patient care and provision of quality HIV care. The study was carried out from November 2012 to January 2013. Eight of the 17 phc clinics in the sub-district were randomly selected for interviews which were structured around the results from the ART patient-exit interviews from the

REACH study; a total of 25 ART healthcare providers (facility operational managers - senior nurses in-charge of the facility, ART nurses, and ART counsellors) were involved in discussion about perceptions on barriers/facilitators to providing quality care. An interview topic guide [Appendix 3] was developed to guide the discussions. All discussions were tape-recorded and transcribed.

Study datasets

REACH data set

The dataset contained information on access to healthcare services for a total of 900 patients receiving ART, TB and maternal health care services (sample size 300 for each condition) collated in 2009. The dataset contained data to measure affordability, acceptability and availability of healthcare services. Further, this dataset provided data on socio-demographics of the participants and their healthcare utilization patterns. Data was collected for participants aged 18 years and above who had been on ART treatment for at least two weeks, and for those on TB treatment for at least two months. This data was used to assess utilization of healthcare by TB (n=300) and HIV (n=300) patients utilizing care at primary healthcare clinics

The Impact of ART on HIV epidemic dynamics data set

Data was collected from 200 HIV infected people who were not yet on ART (pre-ART) who were monitored for their HIV disease progression to determine when ART should be initiated, who utilized the same primary healthcare clinics selected for the REACH study in 2010. The dataset contained data on the patient cost of utilizing HIV care services, as well as patients' ability-to-pay for healthcare. The questionnaire included a number of detailed questions about travel time, costs of transport, missed opportunity costs, how patients financed their healthcare expenditures – borrowing money or selling household assets, and costs associated with their complementary utilization of traditional healers and private providers, as well as patient demographic data. Cost data collected was similar to REACH data for comparison purposes of pre-ART and patients already on ART or TB treatment.

Healthcare providers' data set

REACH study data on patient satisfaction with ART healthcare services was used to structure discussions with ART healthcare providers in order to elicit the healthcare providers' perceptions

regarding patient care and quality of care provision. Twenty-five ART frontline healthcare providers from eight primary healthcare clinics were interviewed and these interviews were tape recorded and transcribed. Data was managed using Nvivo and coded; content thematic analysis used for analysis. This dataset was used to analyze healthcare providers' perceptions regarding patient care and the challenges/facilitators they face in providing care and identified areas of improvement.

Table 3.2 shows a summary table of the research questions and the data sources, sample size, outcome and independent variables and the type of analyses done to address the research questions.

Table 3.2: Summary of the data sources, sample size, variables and analysis type used by the study objectives

Objectives	Data Source	Sample size	Outcome Variable(s)	Independent Variables	Analysis Type
Objective 1 To quantify the factors associated with healthcare utilization, with utilization decomposed to availability, affordability and acceptability of healthcare services, for patients in HIV or TB treatment and care	REACH	600 (300 HIV 300 TB)	HIV testing in TB patients Patient satisfaction	Age Sex Education Marital status Employment	Descriptive and Multivariable logistic regression Factor analysis
Objective 2 To quantify the ability-to-pay for healthcare and identify associated factors for patients in pre-ART care, or on ART or TB treatment	REACH Impact of ART on HIV epidemic dynamics study	800 (300 HIV and 300 TB from REACH 200 HIV from Impact study)	Financial distress defined as either borrowing money and or selling assets to pay for healthcare	Age Sex Employment Healthcare related costs Time spent utilizing care	Descriptive and Multivariable logistic regression
Objective 3 To understand healthcare providers' perspectives regarding patient satisfaction and provision of quality HIV care, in order to identify areas for improvement	Healthcare providers feedback study	25 Healthcare providers	Emerging themes	Emerging themes	Content thematic analysis

Analysis

Descriptive analyses were used to summarize the socio-demographic characteristics of patients and to characterize factors associated with healthcare utilization among pre-ART, HIV and TB patients in Hlabisa sub-district. Chi-square (χ^2) tests for associations, t-tests and summary statistics (means, medians and interquartile range) were conducted for descriptive and bivariate analysis. Logistic regression models for separate outcome indicators adjusting for clustering at clinic level were used in multivariable analysis to determine the factors associated with barriers to healthcare utilization (for key availability, affordability, acceptability dimensions of care outcomes) in patients on HIV treatment and care and those on TB treatment controlling for patient socio-demographic characteristics and other selected factors.

Factor analysis was conducted in Paper 2 to investigate underlying patient satisfaction variables in the HIV and TB data. Factor analysis with oblique rotation (oblimin rotation) was performed to identify the latent variables, or factors, which generated the patient satisfaction data.(Matsunaga, 2010) Oblique rotation was used because on theoretical grounds it is likely that different patient satisfaction factors were related to each other. The Kaiser criterion (eigenvalue >1.00) was used to guide decisions regarding which factors to retain and inspection of the factor loadings was used to determine which aspects of patient satisfaction the identified factors capture. All quantitative data cleaning and analysis was done using STATA 11. (StataCorp., 2009)

Qualitative data from the healthcare provider feedback study was analyzed using a content thematic analysis approach. An inductive/deductive approach was used to identify and code for the emerging and deductive themes in the transcripts in two steps; first through open coding which generated an initial list of ideas, patterns and codes and then identified the emerging themes which were a broader level of overarching themes. The emerging themes were then reviewed; a process that involved merging and refining of themes.(Braun & Clarke, 2006 ; Huberman, Michael; M., & Matthew B., 1994) All qualitative analysis was done using Nvivo 10. (QSR International Pty Ltd., 2012)

Table 3.3 summarizes the study methods used for the integrating narrative.

Table 3.3: Summary of methods for the integrating narrative

	Quantitative Study	Qualitative Study
Papers	**Paper 1:** An integrated approach to improving the availability and utilization of TB healthcare in rural South Africa. **Paper 1b:** Almost universal test coverage: HIV testing among TB patients in a rural public programme. **Paper 2:** Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews **Paper 3:** Time and money: the true costs of health care utilization for patients receiving 'free' HIV/TB care and treatment in rural KwaZulu-Natal.	**Paper 4:** Engaging healthcare providers: responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal
Design	Cross-sectional studies	Discussions using in-depth interviews
Setting	Hlabisa sub-district (rural)	Hlabisa sub-district (rural)
Study population	HIV patients on ART for at least 2 weeks TB patients on treatment for at least 2 months HIV positive patients in care but not yet on treatment (pre-ART)	ART frontline healthcare providers – operational managers, nurses and counsellors
Sample size	300 ART 300 TB 200 pre-ART	25 healthcare providers
Study period	2009 2010	2012
Data collection tools and methods	Patient exit interviews using structured questionnaires	One-on-one discussion using an in-depth-interview guide
Research topics	1. Socio-demographic data 2. Utilisation of TB and ART services 3. Availability of TB and ART care services 4. Affordability of TB, pre-ART and ART care services 5. Acceptability of ART and TB care services	1. Patient satisfaction 2. Barriers to healthcare utilization 3. Quality of care
Data analysis	Descriptive statistics, multiple regression analysis, factor analysis	Content thematic analysis

Ethical considerations

Ethical clearance for the REACH study (BE174/08) and the Impact of ART on HIV epidemic dynamics study (BF072/09) were obtained from the University of KwaZulu-Natal [Appendix 4 and 5]. The Healthcare providers' study was submitted and approved as an amendment to the existing REACH

ethics by the University of KwaZulu-Natal Biomedical Research Ethics Committee [Appendix 6]. Additional ethical clearance was sought and granted from the University of the Witwatersrand Committee for Research on Human Subjects (Medical) for the PhD study [Appendix 7].

Fieldwork staff for the studies was well trained on all ethical issues related to the studies prior to the commencement of the study. Signed informed consent was obtained from participants in all studies before participation. Data collected was anonymized to remove personal identifiers to maintain anonymity and was kept in confidentiality.

Role of the candidate

The PhD candidate was the local study coordinator of the multicentre REACH and the Impact of ART on HIV epidemic dynamics studies, responsible for the finalization of the questionnaires, translation and back-translation, printing and all the operational logistics of the fieldwork. The candidate was responsible for a team of four fieldworkers who administered the questionnaires in isiZulu, and held debriefings with the team weekly and quality control and assurance checks daily with the team. Data entry was managed at one of the multicentre sites – Cape Town - but the PhD candidate was responsible for all the data cleaning and management of the Hlabisa data.

The candidate designed the qualitative component of the PhD, consisting of interviews with relevant local healthcare providers and assessing their response and perceptions. All 25 interviews were conducted by the candidate alone, the candidate transcribed about 20% of the interviews and an independent transcriber at Africa Centre the reminder. The candidate coded and managed the transcripts in Nvivo10(QSR International Pty Ltd., 2012); the principal supervisor (TB) reviewed the initial set of codes for inter-interviewer agreement and checking their validity.

The candidate was involved in the conceptualization of each of the papers, analyzed the data and interpreted results with the critical support of both supervisors and co-authors. The candidate wrote the draft manuscripts of all the papers, which were critically reviewed by both supervisors and the co-authors before submission by the PhD candidate for peer review.

Acknowledgement of funders

Part of this work (REACH study) was carried out with support from the Global Health Research Initiative (GHRI), a collaborative research funding partnership of the Canadian Institutes of Health Research, the Canadian International Development Agency, Health Canada, the International Development Research Centre, and the Public Health Agency of Canada. The Impact of ART on HIV Epidemic Dynamics study was funded by a US National Institutes of Health grant (1R01MH083539), including part of the candidate' s PhD fees. The Africa Centre for Population Health is supported by a Grant from the Wellcome Trust (082384/Z/07/Z) and they funded the Healthcare providers' study. The Hlabisa HIV Treatment and Care program was funded by the generous support of the American people through the United States Agency for International Development (USAID) and the President's Emergency Plan (PEPFAR) under the terms of Award No. 674-A-00-08-0001-00.

CHAPTER 4: AVAILABILITY OF HEALTHCARE SERVICES AND PATIENT UTILIZATION PATTERNS

The following four chapters (Chapter 4-7) constitute the results section of this PhD thesis pulling findings from the contributing papers to the PhD (Appendix 8-12).

This chapter focusses on results on availability of healthcare services and patients' healthcare utilization patterns drawing mainly from Paper 1 and Paper 1b (see Appendix 8 and 9) with additional findings. A summary of the pre-ART, ART, and TB patients' socio-demographic characteristics is given to understand the background of all the respondents, and is relevant to all papers.

HIV and TB patients face various challenges in accessing care, and an integrated service that offers comprehensive healthcare package could be preferable for them as it would ensure timely HIV treatment initiation and optimal TB care. Factors affecting healthcare utilization including HIV testing uptake, adherence to treatment and retention in care may be related to patient socio-demographic characteristics, physical/geographical factors, organizational, accessibility and location of facilities. Hence understanding these factors could improve TB and HIV utilization of healthcare services.

The DoH-TB control programme is integrated with the Hlabisa HIV Treatment and Care (ART programme) which received additional staff support and database management from the Africa Centre for Population Health studies (Africa Centre). The ART programme utilizes a decentralized approach with integration of TB and HIV services into primary healthcare, linking treatment, care and prevention services.(Wallrauch et al., 2010) Figure 4.1 shows the arrangement of HIV and TB services within the 17 primary healthcare clinics where the pre-ART, ART and TB patients attended for their HIV and TB treatment and care in the Hlabisa sub-district. The HIV and TB services are integrated at programme level where both services are provided within the same facilities including close physical proximity of HIV and TB consultation rooms to allow for communication/information exchange between HIV and TB staff as well as easy flow of patients from one facility to another.

Figure 4.1 Integrated HIV and TB services model of care

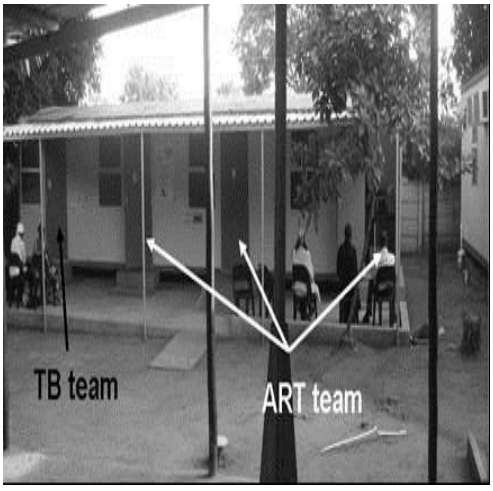


Figure 4.1: Showing the close physical proximity of the ART and TB facilities and the refurbished facilities (right picture). (Left picture is reproduced with kind permission from *Wallrauch C, Heller T, Lessells R, Kekana M, Barnighausen T, Newell ML. S Afr Med J. 2010 Mar;100(3):146-7*)

The REACH study was conducted in 2009 to examine barriers to healthcare access, and data was collected on factors affecting healthcare availability and utilization of TB and HIV patients attending phcs in the study area. Six hundred patients (300 TB and 300 HIV patients) were randomly selected in a two-stage-sampling scheme with five primary healthcare clinic sampling units selected with probability proportional to size and data were collected using a structured questionnaire. Key availability and utilization factors were assessed and particularly factors associated with being offered an HIV test in multiple regressions controlling for age, sex, education, marital status, employment and whether it was their first episode of TB, whether they took their medication under observation (Directly Observed Treatment Short course (DOTS)), and whether they felt negatively judged for using healthcare services.

Socio-demographic characteristics of pre-ART, ART and TB patients

Table 4.1 shows socio-demographic characteristics of patients utilizing HIV and TB treatment and care services. Across all patient groups, more women than men utilized healthcare, especially among pre-ART patients (79%), followed by 62% HIV and 53% utilized TB care, with an age-sex profile comparable to previous studies in the area.(Houlihan et al., 2010; Wallrauch et al., 2010) Pre-ART patients were significantly younger than ART and TB patients, with a median age of 32 years for pre-ART patients, 39 years for ART patients and 37 years for TB patients. Unemployment at household level was high, up to 86% of ART patients' head of households were unemployed and only 9% of TB patients were employed.

Table 4.1: Socio-demographic characteristics of pre-ART, ART and TB patients

Characteristics	**Pre-ART N = 200**	**ART N = 300**	**TB N = 296**	***P-value**
Sex				
Female	158(79%)	186(62%)	156(53%)	<0.01
Male	42(21%)	114(38%)	140(47%)	
Age (years)				
Mean†	33.4	39.7	38.0	<0.01
95% CI	32.0-34.8	38.6-40.9	36.7-39.4	
Median age (Q1-Q3) (years)	32(25.5-39.0)	39(32.0-46.0)	37 (30.0-45.0)	
Head of household employment status				
Employed	53(27%)	42(14%)	55(19%)	<0.01
Unemployed	147(74%)	258(86%)	240(81%)	
Respondent head of household	-			
Yes		125 (42%)	121 (41%)	
No		175 (58%)	175 (59%)	0.85
Employed				
Yes	-	36(12%)	28(9%)	0.36
No	-	264 (88%)	268 (91%)	
Education				
None	-	55(18%)	50(17%)	0.43
Primary		104(35%)	92(31%)	
Secondary		101(34%)	101(34%)	
Matric‡ and higher		40(13%)	53(18%)	
Marital status§				
Never married	-	238(80%)	249(84%)	0.15

*P-value based on Pearson's χ^2 test for differences in proportions across patient groups.
†P-value based on F statistic test for differences in means across patient groups.
‡Matric is the final year of high school in South Africa.
§Ever married: currently married, divorced or separated, widowed.
-Data on employment, education and marital status was not available for pre-ART patients

As the study with pre-ART patients was done at a later stage than the study with ART and TB patients, pre-ART patients are excluded from further analyses presented in this chapter.

Utilization by treatment types and length in care

The majority of TB patients (75%) were attending care for a first TB episode. Most TB patients 81% (228/280) had pulmonary TB, but 17% (48/280) had extra-pulmonary TB and 1% (4/280) had primary TB. Pulmonary TB patients had been on treatment for a mean of 4.52 (standard deviation (sd) = 4.65, 95% CI 3.9-5.1) months, median 3.77(Q1-Q3 2.43-5.8) months. Four patients had primary TB for a mean 3.87 (sd=1.24, 95% CI 1.1-8.2) months, median 3.68(Q1-Q3 3.05-4.68) months and extra-pulmonary TB/any other TB patients were on treatment for mean 4.21 (sd 1.92, 95% CI 3.6-4.8) months, median 4.05(Q1-Q3 2.40-5.77) months.

ART patients had been on treatment for more than a year, mean 18.88 (sd 13.92, 95% CI 17.3-20.5), median 15 (Q1-Q3 7-29) months, and the mean most recent CD4 count was 347.9 cells/mm^3 (sd 212.41, 95% CI 321 - 375), median 331 (Q1-Q3 184-459) cells/mm^3.

Availability of services and determinants of utilization

Almost all TB patients (94%) reported having been offered an HIV test during the current TB treatment episode, most had been diagnosed with TB at the same clinic at which they were receiving their TB treatment. All HIV patients were screened for TB in the phc clinics. Overall, 9% (27/300) of ART patients had used the health service in the last four weeks for TB treatment and 28% (83/296) of TB patients had used the health service for ART.

Table 4.2 shows the factors affecting availability and utilization of healthcare services in TB and HIV patients. Almost all TB (96%) and ART (98%) patients reported that they were able to access other healthcare services they needed at the same facilities they utilized for their TB or HIV treatment. The other services HIV patients (n=5) were unable to access at the facility included medication for general ailments (headache, need to see the doctor and get medication, flue and rash treatment). Twelve TB patients reported they could not get other services they needed, of which two patients stated the services

they could not get, one could not get drugs for hypertension and heart disease and the other patient was told to go to their nearest clinic.

More than a tenth of the patients (ART (12%) and TB (14%)) reported receiving treatment from a facility other than the current primary healthcare clinic (phc) that is they were moving between healthcare facilities, during the current TB episode or HIV treatment. About a fifth of HIV (21%) patients and a tenth of TB (12%) patients felt people in the community judged them negatively for attending the facilities for their HIV or TB treatment.

Table 4.2: Factors affecting healthcare utilization in TB (N=296) and HIV (N=300) patients

Factors affecting healthcare utilization		**TB n (%)**	**HIV n(%)**
Is this your first time you have had TB?		(n=294)	-
	Yes	221 (75%)	
	No	73 (25%)	
Have you been offered an HIV test (during this current treatment episode)			-
	Yes	279 (94%)	
	No	17 (6%)	
Besides TB/ART, are you able to get the other health services you need in this facility?		(n=286)	(n=283)
	Yes	274 (96%)	277(98%)
	No	12 (4%)	6(2%)
Do you feel that people in the community judge you negatively for attending this facility for your TB/HIV treatment?		(n=257)	(n=219)
	Yes	31 (12%)	45(21%)
	No	226 (88%)	174(79%)
Since you first started coming to this facility, have you ever left without being helped?		(n=296)	(n=300)
	Yes	38 (13%)	31(10%)
	No	258 (87%)	269(90%)
During this current treatment episode, have you received treatment from a clinic other than this one?		(n=293)	(n=292)
	Yes	40 (14%)	35(12%)
	No	253 (86%)	257(88%)
Are the opening hours of this clinic convenient for you?		(n=294)	(n=297)
		291 (99%)	290(98%)
	Yes	3 (1%)	7(2%)
	No		
Is this the closest clinic to your home that offers TB/HIV treatment?		(n=296)	(n=298)
	Yes	287 (97%)	264(89%)
	No	9 (3%)	34(11%)

Reasons for ever leaving clinic without being attended to

Although almost all patients reported that clinic opening hours were convenient, more than a tenth of patients stated that since they first started coming to the clinic, they had left at least once without being attended to (Table 4.2). The main reason for patients leaving without being attended to was that they were told there was no treatment was available at the clinic on the day – TB patients (n=27/38, 71%) and HIV patients (n=12/31, 39%).

Reasons for not using closest clinic for HIV and TB patients

While almost all TB patients (97%) were accessing the clinic closest to their home for TB treatment, only 89% of ART patients were using their closest clinic (Table 4.2).

Self-reported reasons for not using the closest clinic for TB patients (n=9) were that the clinic they attended was closer to their workplace (n=2), that they were offered good service at the present clinic (n=1), that the nearest clinic did not give correct treatment (n=1) or had too many patients and long queues (n=1) (*"the nearest clinic have got too many patients")*, lack of knowledge on how to change clinics (n=1), treatment course almost completed and therefore no need to change clinics (n=1), and changes in place of residence after initiating TB treatment at the present clinic (n=2).

Self-reported reasons for not using the closest clinic for ART patients (n=34) were that they were being offered good service at the present clinic (n=12) (*"they treat us well here have good service, they have doctor - enough treatment")*, there was no nearby clinic close to their homes (n=4), lack of knowledge on how to change or not willing to change from the clinic where they were first tested or initiated (n=10), fear of stigma from the community (n=4) (*"I'm safe here, at nearest clinic there are many family members that I married to their son"),* there was a problem in the nearby clinic (n=1).

Characteristics of patients not using their closest clinic for their HIV and TB care

Overall, nine TB patients and 34 ART patients were attending a clinic that was not the closest to their home. Of the nine TB patients who were not using their closest clinic, 2 (22%) were female; of ART patients, 25 (76%) were female. The median age of TB patients was 39 years (Q1-Q3 35-48 years) and 37 years (Q1-Q3 32-45 years) for ART patients. In terms of education levels, 5 (56%) TB and 6 (18%) ART patients had little or no education. The majority of patients had never married; 6 (67%) for TB and 25 (76%) for ART. Lastly, most of the patients were unemployed, 7 (78%) for TB and 30 (88%) for ART.

Table 4.3: Factors associated with using the closest clinic for HIV and TB patients

Characteristics	**HIV n=298**	OR	p-value	aOR	**HIV** p-value	**TB n=296**	OR	p-value	aOR	**TB** p-value
Sex Male	104(39%)	1.81	0.15	1.31	0.01	133(46%)	0.25	0.08	0.23	0.09
Age (years)		1.02	0.42	1.04	0.12		0.99	0.66	1.06	0.20
20-29	38(14%)					59(21%)				
30-39	101(38%)					99(34%)				
40-49	77(29%)					75 (26%)				
>50	48(18%)					42(15%)				
Education										
Primary	92(35%)	0.96	0.94	1.42	0.62	92(32%)	(omitted)		(omitted)	
Secondary and higher	124(47%)	0.97	0.95	1.73	0.49	150(52%)	4.17*	0.04	8.23**	<0.01
Employed Yes	32 (12%)	1.03	0.95	0.88	0.88	26(9%)	0.35	0.21	0.57	0.54
Marital status Ever married	52 (20%)	0.77	0.54	0.1	0.49	44(15%)	0.36	0.16	0.13	<0.01

*95%CI 1.07-16.17 **95% CI=3.55-19.09 TB patients - very wide CI, data should be interpreted with caution

Factors associated with being offered an HIV test in TB patients

Controlling for age, sex, education, marital status, employment and other factors (Table 4.4), patients using their closest clinic were more likely to be offered HIV testing than those not using their closest clinic (adjusted odds ratio 12.79, p=0.05). Those who were offered an HIV test were categorised as 1 otherwise 0 for those not offered. In the logistic regression, the other variables controlled for were selected because they were likely to influence access or utilization and availability of services such as;

whether it was their first time having TB, proximity to the clinic, treatment support, use of other clinics for the same TB episode, and perception of or fear of stigma.

Table 4.4: Factors associated with being offered an HIV test in TB patients (N=296)

Offered HIV testing (yes)	n(%)	OR (95%CI) N=296	p-value	aOR (95% CI) N=252	p-value
Sex					
Female	146 (52%)	1			
Male	133(48%)	1.30(0.48-3.52)	0.60	1.71(0.54-5.36)	0.33
Age (years)		0.99(0.95-1.03)	0.51	0.97(0.92-1.03)	0.37
<25 years	32 (11%)				
25-40 years	132 (47%)				
40-60 years	101 (36%)				
>60 years	14 (5%)				
Education					
None	47 (17%)	1		1	
Primary	88 (32%)	1.40(0.31-6.54)	0.67	0.51(0.08-3.13)	0.46
Secondary	96 (34%)	1.23(0.28-5.35)	0.79	0.38(0.05-2.80)	0.35
Matric and higher	48 (17%)	0.61(0.14-2.71)	0.52	0.16(0.02-1.35)	0.09
Employed					
No	251 (90%)	1		1	
Yes	27 (10%)	1.72(0.22-13.49)	0.61	5.43(0.41-71.91)	0.20
Marital status					
Never married	236(85%)	1		1	
Ever married	43 (15%)	0.59(0.18-1.90)	0.38	0.58(0.13-2.66)	0.48
Is this your first time you have had TB? (n=294)					
No	70(25%)	1		1	
Yes	207 (75%)	0.63(0.18-2.27)	0.48	0.58(0.15-2.32)	0.45
Is this the closest clinic to your home that offers TB treatment?					
No	6(2%)	1		1	
Yes	273 (98%)	9.75(2.21-43.1)	<0.01	12.79(1.98-82.48)	<0.01
Who checks that you have taken your TB treatment each day?					
DOTS supporter (clinic, community, work DOTS)	110 (39%)	1		1	
Family, friends, relatives, neighbors	114 (41%)	2.07(0.61-7.08)	0.25	2.20(0.59-8.23)	0.24
No-one	55 (20%)	0.80(0.25-2.56)	0.71	0.79(0.22-2.83)	0.72
Do you feel that people in the community judge you negatively for attending this facility for your TB treatment? (n=257)					
No	212 (88%)	1		1	
Yes	28 (12%)	0.62(0.17-2.28)	0.47	0.58(0.15-2.29)	0.44
During this current treatment episode, have you received treatment from a clinic other than this one? (n=293)					
No	238 (86%)	1		1	
Yes	38 (14%)	1.20(0.26-5.45)	0.82	1.08(0.21-5.57)	0.93

*****DOTS - directly observed treatment strategy supporter-DOTS (clinic, community, work DOTS)

In Table 4.4, perception/fear of stigma variable had a lot of missing values – however, when removed from the adjusted model there was no difference in the OR for all the factors, and very wide confidence intervals for the significant variable. This could be explained by the small number of events in the outcome variable.

Availability of support services for ART and TB patients

Few ART patients reported to belong to a support group, 13% (40/299), or to have a treatment buddy, 25% (75/300). About two-fifths, 39% (117/297), of the patients had a pill-box and 23% (69/298) reported ever having been visited at home for HIV (home visit). There were no similar support questions for TB patients as the main TB support activity is DOTS reported below.

Sixty-three percent (63%) of ART patients reported to receive support from their family in taking ART, leaving 37% who reported to have no-one to support them. Only one of the 300 patients reported to be supported by a community health worker. Similarly, most TB patients reported to be supported by family, 40% (118/296), or a directly observed treatment strategy supporter - DOTS (TB DOTS sister or counsellor, community worker or workplace DOTS), 40% (118/296), but 20% (60/296) did not take their TB medication under observation.

Missed doses and reasons for missing clinic visits for ART and TB patients

Generally, both HIV and TB patients were adhering to treatment and clinic visits, only 3% of HIV patients and 1% of TB patients reported missing taking their treatment the previous day (Table 4.5). Among the other reasons for missing clinic visits for both patient groups was lack of money, patient too ill to travel and having other responsibilities to take care of. Of note, none of the patients' reasons for missing a visit were related to service availability or delivery.

Table 4.5: Patient missed doses and reasons for missing clinic visits for ART and TB patients

Characteristics	ART N=300	TB N=296	p-value
Did you miss taking any of your ART/TB tablets yesterday? Yes	10 (3%)	3 (1%)	0.05
Did you miss taking any ART/TB tablets the day before yesterday? Yes	5(2%)	2 (1%)	0.23
Did you miss taking any ART/TB tablets 3 days ago? Yes	4 (1%)	3 (1%)	0.51
Apart from the last 3 days, have you ever missed taking any tablets?	15 (5%)	10 (3%)	0.23
Missed: ART visit in past 6 months	8 (3%)	-	
Missed: daily DOTS visit (n=224)	-	1(1%)	
Missed: nurse doctor clinic visit (n=295)	-	4(1%)	
Missed: TB treatment collection (n=296)	-	1(0.3%)	
Reasons for missing an ART(n=8) or TB (n=4) visit *(multiple responses)*			
Lack of money	1(13%)	2(50%)	
Lack of time	1(13%)	0(0%)	
Felt better	0(0%)	0(0%)	
I could not take time off from work	2(25%)	0(0%)	
No transport	0(0%)	0(0%)	
Too ill to travel	2(25%)	1(33%)	
Other responsibilities	2(25%)	1(25%)	
Treatment is not effective does not make me feel better	0(0%)	0(0%)	
The queues in the facility are too long	0(0%)	0(0%)	
The staff are rude or uncaring	0(0%)	0(0%)	
I have had bad experiences with staff in the past	0(0%)	0(0%)	
Other reasons: Tablets were enough	1(12%)	0(0%)	
Other reasons: It was raining and I walk	0(0%)	1(33%)	
Other reasons: No injection in the clinic	0(0%)	1(33%)	
Other reasons: Not heard that the doctor would be available	0(0%)	1(33%)	

Mode of transport as proxy of availability of services

More than half of the patients 57% TB and 63% ART reported using minibus taxis to and from the clinic for their visit and about a third walked (see Figure 4.2).

Figure 4.2: Mode of transport for TB and HIV patients

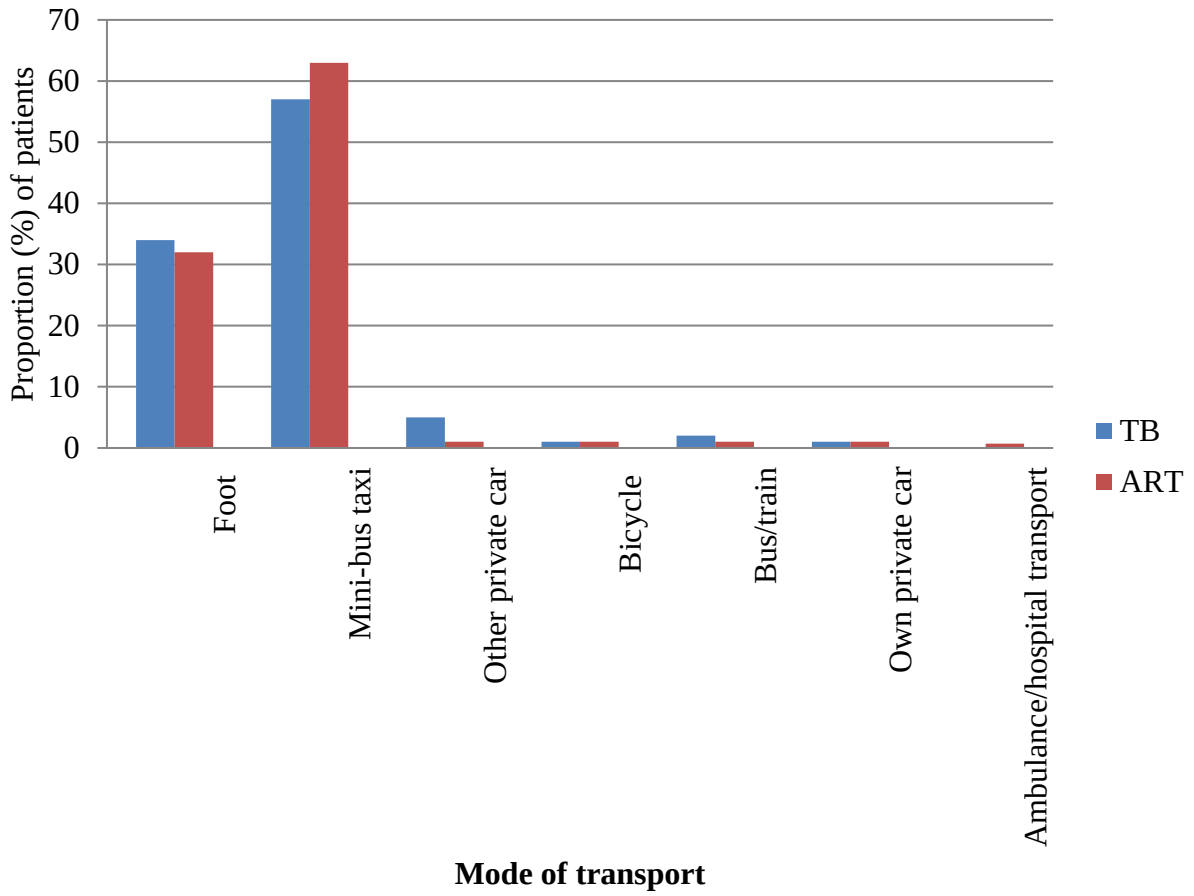


Fig. 4.2: Modes of transport used by TB (n=296) and HIV (n=300) to travel the primary healthcare clinics to utilize TB/HIV treatment

Summary of main findings

This chapter demonstrates that almost universal HIV testing rates among TB patients in a rural public programme in a high TB and HIV burden area are achievable. The decentralized programme appears largely successful in attaining high HIV testing and TB treatment in TB and HIV patients. Further, patients reported that services are generally available in terms of ability to receive comprehensive care and other health services they required. However, there is scope for further improvement such as in DOTS delivery and HIV treatment support including support groups or treatment buddies to support adherence to TB and HIV treatment. Although TB and HIV patients mostly used their closest clinic for

both TB treatment and HIV testing and care, the small number of patients who were not using the closest clinic were far less likely to undergo HIV testing, possibly indicating vulnerability expressed both in the location of seeking TB treatment and HIV testing uptake.

CHAPTER 5: PATIENT SATISFACTION AND QUALITY OF CARE

This chapter covers the acceptability dimension of access, including aspects of patient satisfaction and quality of care, and addresses the first objective and research question of the thesis: to establish and quantify the factors associated with healthcare utilization which are related to availability, affordability and acceptability of healthcare services, for patients utilizing HIV or TB treatment and care. This section draws mainly from Paper 2: Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews [Appendix 10], with some additional analysis contributing to this thesis.

The aim of the paper was to determine the underlying factors of patient satisfaction explained in the data for HIV and TB patients attending phc clinics in the study area. Patient-exit interviews were conducted with 300 HIV and 300 TB patients using a two-stage cluster random sampling approach with primary sampling units (primary healthcare clinics) selected with probability-proportional-to-size sampling. Factor analysis was performed to investigate underlying patient satisfaction factors in the data. Factor analysis is a data reduction method that can be used to explore the data for patterns, or reduce the many variables to a more manageable number.(Matsunaga, 2010) The purpose of factor analysis is to explore the underlying variance structure of a set of correlation coefficients. Thus, factor analysis is useful for exploring and verifying patterns in a set of correlation coefficients.(Matsunaga, 2010)

Five factors were retained after factor analysis on HIV and TB patient data and these were taken to represent the underlying patient satisfaction data. In this chapter, results from additional analysis on demand side and cultural access barriers to care which included aspects of disclosure, utilisation and support structures in receiving care and treatment are also presented.

The overall findings showed that HIV and TB patients were globally satisfied with the service they received on the day of the interview, however, their evaluations of specific aspects of health services delivery revealed substantial dissatisfaction hidden in the global assessments of satisfaction.

Acceptability, patient satisfaction and quality of care of ART and TB services

Table 5.1 shows the constructs which measured acceptability, patient satisfaction and quality of care of healthcare services HIV and TB patients received. Demand-side factors and perceptions influencing utilization and patient satisfaction with services and supply-side factors (healthcare provider attitudes towards the patients and system related factors which affect the acceptability and quality of care provided) were explored. The HIV and TB questionnaires included questions addressing the access constructs of care (availability, affordability and acceptability) and focused questions within each construct of care were developed to better understand the barriers and challenges HIV and TB patients experience accessing healthcare.

Table 5.1 shows the 13 questions from the acceptability construct from the overall access dimensions of care questionnaire that measure patient satisfaction and quality of care.

Table 5.1: Constructs for measuring patient satisfaction, quality of care and acceptability of healthcare services for HIV and TB patients

Constructs	Indicator	Response
Demand side cultural access	1. Have you told anyone besides the health care workers that you are HIV positive/ that you have TB?	Yes/no
	Receives needed support:	Agree/disagree/ don't know/not applicable
	2. "I have all the support from my partner that I need to cope with my illness"?	
	3. "I have all the support that I need from my family"	
	4. "I have all the support that I need from my friends"	
	5. Do you feel that people in the community judge you negatively for attending this facility for your ARV treatment?	Yes/no/don't know
	6. Have you ever not used ART/TB services when you needed them?	Yes/no
Global satisfaction	1. How satisfied were you with the service today?	Very satisfied, satisfied/neither satisfied nor dissatisfied/dissatisfied, very dissatisfied/don't know
Staff attitudes-patient communication	1. The doctors and nurses (health workers) discussed the treatment fully with me	Agree/disagree/both agree and disagree/ don't know, not sure
	2. I find it easy to tell the health workers when I have missed taking my tablets	
	3. Patient information is kept confidential in this clinic	
	4. Some staff do not treat patients with sufficient respect	
	5. The health workers I see respect me	
	6. It is a problem that health workers do not speak my language	
Acceptability of staffing and amenities	1. The health workers are too busy to listen to my problems	Agree/disagree/both agree and disagree/ don't know, not sure
	2. The facilities (including waiting area and toilets) are dirty	
	3. The queues to see a doctor or nurse are too long at this facility	
	4. In this clinic are you able to talk to the doctors or nurses in private?	Always/sometimes/ never
Acceptability of nurse based care	1. For your ARV treatment (TB care) what would you prefer: a) To see a nurse in a nearby clinic or b) To travel further to see doctor	Nurse/doctor/ indifferent/don't know
How to improve health services delivery/ expectations	1. How do you think the service in this clinic could be improved? a) Shorter queues b) More health workers c) Cleaner facilities d) Better patient facilities (toilets, waiting room area etc) e) Don't know f) Other specify	Yes/no

Demand side and cultural access barriers to care

Table 5.2 shows the demand-side and the cultural factors associated with accessing and utilizing care for HIV and TB patients. Although almost all patients reported to have disclosed their condition to someone, usually a family member, more HIV (4.3%) than TB (0.7%) patients had not told any person other than the health worker that they were HIV positive (p=0.004).

In terms of receiving support, more TB than HIV patients reported they received support from their partners (83% v 52% p<0.001), family (94% v 84% p<0.001) and friends (79% v 66% p<0.001) respectively. Similarly, with regards to feelings of stigma, significantly more HIV patients (20.6%) than TB patients (12.1%) (p=0.012) reported that they felt the community judged them negatively for using HIV or TB services.

About 5% of HIV (13/300) or TB (16/294) patients had ever not used services when they needed them, with 9/13 of the HIV patients providing their reasons for not using services but all 16 TB patients providing their reasons for not using services. The main reason for not utilising services among both patient groups was lack of medication (n=5 for HIV patients and n=11 for TB patients), or they were using Zulu remedies or being treated by a traditional healer (n=3 for TB and n=2 for HIV). Other demand side factors included process of getting medication was too long (n=1 TB patient) and convenience of opening hours where a patient arrived after 12 noon and they were not served because they were late (n=1 HIV).

Table 5.2 Demand side and cultural factors affecting HIV/TB patients' access and utilisation

	Types of care		
Variable	**HIV (n=300)**	**TB (n=296)**	**p-value§**
Have you told anyone besides the health care workers that you are HIV positive/ that you have TB?			
Yes	287(96%)	294(99%)	0.004
No	13(4%)	2(0.7%)	
Who did you disclose to?	n=287	n=294	
Partner (husband/wife/boyfriend/girlfriend)	71(25%)	63 (21%)	0.011
Other family members (general,grand/parents,siblings,children,in-laws,other)	190(66%)	219(75%)	
Friends	19(7%)	5(2%)	
Neighbours	7(2%)	6(2%)	
Employer	-	1(0.3%)	
Receives needed support : "I have all the support from my partner that I need to cope with my illness"?	n=225	n=202	
Agree	157(70%)	168(83%)	0.001
Disagree	68(30%)	34(17%)	
"I have all the support that I need from my family"	n=288	n=290	
Agree	242(84%)	273(94%)	0.001
Disagree	46(16%)	17(6%)	
"I have all the support that I need from my friends"	n=253	n=266	
Agree	166(66%)	211(79%)	0.000
Disagree	87(34%)	55(21%)	
Do you feel that people in the community judge you negatively for attending this facility for your ARV/(TB) treatment?	n=219	n=257	
Yes	45(21%)	31(12%)	0.012
No	174(79%)	226(88%)	
Have you ever not used ARV/TB services when you needed them?	n=300	n=294	
Yes	13(4%)	16(5%)	0.531
No	287(96%)	278(95%)	
Why did you not use ARV/(TB) services? Include all factors – personal and facility-related	n=9 Lack of ARVs =5 Patient was using Zulu remedies =1 Patient was being treated by traditional healer=1 There was a misunderstanding at my household=1 I arrived late after 12 noon they said I must come back tomorrow=1	n=16 Lack of TB drugs=11 Patient was using Zulu remedies =3 Process of getting treatment was delaying=1 Patient was denying to come to the clinic for TB screening=1	

§ P-values shown are for differences between HIV and TB patients based on Pearson's $\chi 2$ test for two-sample test of proportions.

Disclosure of HIV or TB

Of the two patients who reported to not have disclosed that they were on TB treatment to anyone other than the health workers, one was a man aged 59 years and the other a woman aged 18 years. Both were unemployed, never married and had no or only primary level education. Of the 13 HIV patients who did not disclose, median age was 43 (Q1-Q3 35-57) years, 8 (61.5%) were female and 3 (38.5%) were male. Eleven (84.6%) were never married. About half, 6 (46.2%), had no formal schooling, 5(38.5%) had primary level education and 2(15.4%) had secondary or more level schooling.

Table 5.3 shows the univariable analysis of factors associated with disclosure among HIV patients; with every one year increase in age, HIV patients were less likely to disclose (OR=0.93 p=0.024) and patients with higher (primary and secondary school p=0.020) educational attainment were more likely to disclose than those with no schooling. Patients receiving support from their partners, family and friends were likely to disclose than those receiving none from partners, family or friends (p<0.05 for all).

Table 5.3 Factors affecting disclosure in HIV patients (n=300)

ART disclosure	**ART n=300**	
	OR 95% CI	**p-value**
Sex		
Female	1	
Male	0.98(0.39-2.45)	0.97
Age	0.93(0.88-0.99)	0.024
Marital status		
Never married	1	
Ever married	1.43(0.46-4.44)	0.536
Employment status		
Not employed	1	
Employed	1.67(0.67-4.15)	0.272
Educational status		
No schooling	1	
Primary	2.42(1.15-5.13)	
Secondary or more	8.51(3.16-22.93)	0.020
Support received		
None	1	
Partner	5.89(1.48-23.52)	0.012
Family	8.92(2.41-33.04)	p<0.001
Friends	4.02(0.98-16.51)	0.053

Table 5.4 shows how various patient satisfaction and quality of care indicators varied between the patient groups – HIV and TB, by the different constructs. Although these services are integrated at the facility level [Chapter 3], treatment and care services are not offered by the same frontline health workers and the two programmes have different organizational structures, histories and lengths of operation.

Table 5.4 Indicators of reported satisfaction of patients utilizing HIV (N = 300) and TB (N = 296) treatment

Variable	Types of care		
	HIV	TB	p-value§
Global satisfaction			
How satisfied were you with the service today?	n = 293	n = 296	
Very satisfied/satisfied	278 (95%)	286 (97%)	p = 0.31
Staff attitudes-patient communication			
The doctors and nurses (health workers) discussed treatment fully with me	n = 300	n = 294	
Agree	300 (100%)	283 (96%)	p ≤ 0.001
I find it easy to tell the health worker when I have missed taking my tablets	n = 226	n = 205	
Agree	204 (90%)	194 (95%)	p = 0.09
It is a problem that health workers do not speak my language	n = 300	n = 294	
Agree	4 (1%)	4 (1%)	p = 0.63
Patient information is kept confidential in this clinic	n = 262	n = 230	
Agree	251 (96%)	217 (94%)	p = 0.43
Some staff do not treat patients with sufficient respect	n = 226	n = 191	
Agree	118 (52%)	77 (40%)	p = 0.02
The health workers I see respect me	n = 300	n = 294	
Agree	279 (93%)	282 (96%)	p = 0.15
Acceptability of staffing and amenities			
The health workers are too busy to listen to my problems	n = 288	n = 290	
Agree	42 (15%)	43 (15%)	p = 0.93
The facilities (including waiting area and toilets) are dirty			
Agree	58 (21%)	58 (21%)	p = 0.98
The queues to see a doctor or nurse are too long at this facility	n = 298	n = 288	
Agree	195 (65%)	115 (40%)	p ≤ 0.001
In this clinic are you able to talk to the doctors or nurses in private?	n = 286	n = 295	
Always	241 (84%)	262 (89%)	p = 0.12
Acceptability of nurse based care			
For your ARV/(TB) treatment what would you prefer:	n = 300	n = 296	p = 0.21
To see a nurse in a nearby clinic or	299 (100%)	291 (99%)	
To travel further to see doctor	1 (0%)	4 (1%)	
How to improve health services delivery/expectations			
How do you think the service in this clinic could be improved?	n = 299	n = 296	
Shorter queues: Yes	170 (57%)	104 (35%)	p ≤ 0.001
More health workers: Yes	171 (57%)	132 (45%)	p ≤ 0.001
Cleaner facilities: Yes	65 (22%)	68 (23%)	p = 0.72

Better patient facilities (toilets, waiting room area): Yes	201 (67%)	161 (54%)	$p \leq 0.001$

§ P-values shown are for differences between HIV and TB patients based on Pearson's $\chi 2$ test for two-sample test of proportions.

Global satisfaction

Almost all patients (95% HIV and 97% TB) reported to be overall satisfied with the healthcare services received on the day of the interview. However, patient satisfaction with specific aspects of the health services acceptability and quality of care was substantially lower.

Staff attitudes-patient communication

The majority of patients (96% TB and 100% HIV) agreed that doctors and nurses discussed treatment fully with them. However, 10% of HIV patients and 5% of TB patients did not find it easy to tell the health worker when they had missed taking tablets. Very few patients (1% for both HIV and TB) agreed that it was a problem that some health workers did not speak the local language. A significant proportion of HIV (52%) and TB (40%) patients agreed with the statement that some staff do not treat patients with sufficient respect. However, a high proportion of patients (96% HIV and 94% TB) agreed that patient information is kept confidential at the clinic.

Acceptability of staffing and amenities

Overall, more than one in ten of the HIV and TB patients (15%) agreed that health workers were too busy to listen to their problems. Patients were not always able to talk to health workers in private, more than a tenth of the patients (16% of HIV patients and 11% of TB patients) reported that they had either sometimes or never been able to talk in private to their doctors and nurses in their past clinic visits. A considerable proportion of patients utilizing either HIV or TB services indicated that the amenities were not quite acceptable - 21% of both HIV and TB patients agreed that the facilities (including waiting area and toilets) were dirty. Further, a significantly higher proportion of HIV (65%) than TB (40%) patients ($p \leq 0.001$) agreed that the queues to see a doctor or nurse were too long at the facility they utilized care.

Acceptability of nurse-based care

Nurse-based care for HIV and TB treatment and care was highly acceptable to respondents (100% for HIV and 99% for TB).

How to improve health services delivery and patient expectations

A significantly higher proportion of HIV than TB patients reported they would like shorter queues (57% v 35%), more health workers (57% v 45%) and better patient facilities (67% v 54%), as ways of improving the services at the facilities.

Open-ended responses on how to improve health services delivery and patient expectations

More specific sources of dissatisfaction or areas of improvement of healthcare services (Table 5.5) that patients highlighted in open-ended responses included food support and support groups, improvement in infrastructure, access to treatment, transport and staff efficiency. Lack of a water dispenser and cups to drink from, shortage of seats in the waiting area, and lack of a proper shelter in the waiting area were cited as some of the infrastructure needs, while availability of staff (doctors) and improved efficiency came up as ways of improving care, with some patients suggesting staff need to work shifts.

Patients in both the HIV and TB programmes highlighted that provision of transport to and from clinics could substantially improve their satisfaction with the treatment experience. A few HIV patients hoped the health delivery system would make it easier for them to access medication at the hospital pharmacy, and TB patients wanted enough medication, preferably delivered to their homes or to collection points close to their homes.

Table 5.5 Open-ended responses on how to improve health services delivery and patient expectations

Patient expectations	HIV (n=10)	TB (n=16)
Support-related	Provision of food parcels =1 Need for support groups at the clinics = 1	Need for support grants =1 Provision of good service = 1
Infrastructure	Provision of decent waiting area/shelter =3 Need for a water dispenser and cups to drink from =1	Provision of decent waiting area/shelter and enough seats =1
Access to: Treatment Transport	Easy access to medication =1 Request for transport to clinics =2	Enough treatment/bringing treatment closer to patients = 9 Request for transport to clinics =1
Staff efficiency	Health workers to work faster/improved efficiency =1	Health workers to work shifts/improved efficiency =2 Doctors availability all the time=1

Factors underlying the patient satisfaction data

Factor analysis was employed to explore the factors underlying the HIV and TB patient data, and five factors which had eigenvalues > 1.00 were retained. Eigenvalues are calculated and used in deciding how many factors to extract in the overall factor analysis. The common approach to select how many factors to retain is to select the number of factors with eigenvalues of 1.00 or higher (the K1 rule), other approaches include examining a scree plot of eigenvalues plotted against the factor numbers; analyzing increasing numbers of factors and stopping when all non-trivial variance is accounted for; and lastly using the number of factors that a selected theory would predict.(Matsunaga, 2010) The five factors retained in this study accounted for 58% of the variance in satisfaction for HIV patients and 60% for TB patients. Table 5.6 shows the factor loadings for each of the variables for patient satisfaction; factor loadings refer to the correlations of each of the variables in the study with the factor. Based on the factor loadings (shown in grey shading), the five factors underlying the HIV data and the TB data were labelled as follows - availability, accommodation, acceptability, and communication for both HIV and TB, and health worker preference for HIV and global satisfaction for TB. The labels capture the content

of the different variables that load heavily on the individual factors. Individuals with missing information were excluded from the factor analysis and for one variable on discussion of treatment with HIV patients – all (100%) patients reported the doctors and nurses discussed treatment fully with them because there was no variation in the variable.

Table 5.6 Factor loadings for indicator variables for assessing patient satisfaction for HIV (n = 265) and TB (n = 259) patients

Variable	HIV					TB				
	1	2	3	4	5	1	2	3	4	5
	Availability	Accommodation	Acceptability	Communication	Health worker preference	Availability	Accommodation	Acceptability	Communication	Global Satisfaction
How satisfied were you with the service today?	−0.14	−0.17	0.77	−0.02	0.09	−0.12	−0.02	0.03	−0.06	0.84
The doctors and nurses (health workers) discussed treatment fully with me‡	-	-	-	-	-	0.07	−0.01	0.01	0.54	0.51
It is a problem that health workers do not speak my language	0.02	−0.02	0.08	0.83	0.02	−0.09	−0.06	0.08	−0.77	0.12
The health workers are too busy to listen to my problems	−0.04	0.42	0.35	−0.47	0.09	−0.14	−0.18	0.47	0.42	−0.04
The health workers I see respect me	0.08	0.20	0.66	0.15	−0.15	−0.42	0.49	−0.03	0.13	−0.20
In this clinic are you able to talk to the doctors or nurses in private?	−0.04	0.48	0.09	0.34	0.14	−0.10	−0.21	0.76	−0.06	0.22
For your ARV (TB) treatment what would you prefer: to see a nurse in a nearby clinic or to travel further to see doctor	0.02	0.02	−0.00	0.01	0.94	0.09	−0.27	−0.75	0.02	0.16
The facilities (including waiting area and toilets) are dirty	−0.17	0.76	−0.10	−0.09	0.03	−0.21	−0.49	0.14	0.39	0.12
The queues to see a doctor or nurse are too long at this facility	−0.73	0.02	0.06	0.01	−0.12	−0.77	0.06	0.03	−0.13	0.21
How do you think the service in this clinic could be improved? Shorter queues	0.80	−0.24	0.03	0.06	0.08	0.84	0.06	−0.12	−0.05	−0.01
More health workers	0.72	−0.06	−0.13	−0.00	−0.24	0.69	0.33	−0.04	0.06	0.08
Cleaner facilities	0.16	−0.74	−0.01	0.00	0.04	0.40	0.65	−0.01	−0.16	−0.10
Better patient facilities (toilets, waiting room area)	0.46	−0.02	0.11	−0.21	0.10	0.06	0.74	0.05	0.13	0.12

‡For HIV patients, this variable was dropped from the factor analysis, because there was no variation in the variable – all (100%) patients agreed that the healthcare providers discussed treatment fully with them (see Table 5.4).

Determinants of patient satisfaction with care

Generally, patient demographic characteristics (sex, age, education, marital status and employment status) were not significantly associated with the satisfaction factors in multivariable analysis for either HIV or TB patients (Table 5.7). Multivariable logistic regression models were run separately for each of the five factors underlying the HIV data and the TB data - availability, accommodation, acceptability, and communication for both HIV and TB, and health worker preference for HIV and global satisfaction for TB, controlling for age, sex, educational level, marital status and employment status. Male HIV patients were less likely to be satisfied with the availability of resources than female HIV patients (coeff -0.21 p=0.02), while among TB patients male patients (coeff -0.20 p=0.05) and patients who had ever been married (coeff -0.43 p=0.01) were less satisfied than female patients or patients who had never been married with the degree to which the health systems structures and processes accommodated their demands. TB patients with secondary and higher level of education were more likely to be satisfied with the quality of communication than those with no education. Employment status and age of either HIV or TB patients were not statistically significantly associated with patient satisfaction.

Table 5.7 Factors associated with patient satisfaction for patients utilizing HIV (n = 265) and TB (n = 259) treatment

Patient demographic characteristics	HIV coefficient (95% CI) p-value*					TB coefficient (95% CI) p-value*				
	1	2	3	4	5	1	2	3	4	5
	Availability	Accommodation	Acceptability	Communication	Health worker preference	Availability	Accommodation	Acceptability	Communication	Global Satisfaction
Sex: Male	**−0.21** (−0.35– -0.07) 0.02	0.13 (−0.41–0.67) 0.51	0.05 (−0.37 – 0.47 0.74	0.05 (-0.25–0.35) 0.63	0.10 (−0.33–0.54) 0.50	−0.22 (-0.66-0.15) 0.17	**−0.20** (-0.39- -0.00) 0.05	−0.31 (-0.39-0.33) 0.82	−0.06 (-0.32-0.20) 0.55	−0.11 (-0.53-0.32) 0.53
Age	0.01 (−0.03–0.04) 0.56	0.01 (−0.03–0.46) 0.49	0.01 (−0.02-0.03 0.53	−0.01 (–0.03-0.02) 0.47	−0.02 (−0.08–0.04) 0.45	-0.01 (-0.03-0.02) 0.36	0.00 (-0.01-0.02) 0.53	0.01 (-0.00-0.02) 0.06	0.02 (-0.00-0.04) 0.10	-0.01 (-0.02-0.01) 0.28
Education: Primary	0.05 (−0.57–0.67) 0.80	0.18 (−0.50–0.87) 0.45	0.04 (−0.16-0.25) 0.57	0.24 (–0.25-0.72) 0.22	0.15 (−0.12–0.43) 0.17	0.10 (-0.25-0.44) 0.48	0.37 (-0.23-0.97) 0.16	0.29 (-0.37-0.95) 0.29	0.37 (-0.07-0.82) 0.08	0.01 (-0.11-0.13) 0.77
Secondary and higher	0.10 (−0.47–0.67) 0.62	0.58 (−0.17–1.33) 0.09	0.09 (−0.19 -0.36) 0.39	−0.09 (−0.62–0.43) 0.62	−0.18 (-1.06-0.70) 0.57	−0.12 (−0.77–0.54) 0.64	0.02 (−0.86–0.90) 0.96	0.22 (−0.32–0.76) 0.32	**0.56** (0.32–0.79) 0.00	−0.38 (−0.90–0.14) 0.11
Employed: Yes	0.27 (−0.36–0.91) 0.27	−0.30 (−1.01–0.40) 0.26	−0.08 (−0.36-0.19) 0.41	0.20 (−0.97–1.36) 0.63	−0.05 (-0.19-0.09) 0.33	0.14 (−0.34–0.62) 0.46	0.21 (−0.22–0.64) 0.25	−0.17 (−1.19–0.85) 0.67	0.06 (−0.55–0.68) 0.79	0.22 (−0.36–0.79) 0.35
Marital status: Ever married	−0.04 (−0.22–0.14)	−0.03 (−8.88–0.83)	0.10 (−0.30–0.51)	−0.04 (−0.22–0.13)	0.04 (-0.28-0.36)	0.01 (−0.36–0.38)	**−0.43** (−0.71- -0.14)	−0.15 (-0.66-0.37)	0.06 (-0.17- 0.2)	−0.08 (-0.52-0.35)

	0.57	0.93	0.48	0.49	0.73	0.94	0.01	0.48	0.50	0.62

*Coefficients that are statistically significant at the 0.05 level are shown in bold font.

Summary of main findings

This chapter findings show that patients attending HIV and TB treatment services reported high levels of global satisfaction with their experience at the healthcare facility on the day of the interview. However, patients expressed dissatisfaction with particular aspects of the services, including availability of health workers, health workers attitudes in the form of respect they showed patients, waiting times, and cleanliness of facilities. A higher proportion of HIV than TB patients reported to be less satisfied with some aspects of quality of care and acceptability of services, in particular respectfulness of treatment, waiting times, and availability of waiting areas and toilets. Low levels of disclosure among HIV patients than TB patients were reported and more TB patients receiving support with their illness from their partners, families and friends. A range of patient satisfaction variables could be reduced to a few underlying factors that align broadly with concepts previously identified in the literature as affecting access to healthcare.

CHAPTER 6: COSTS OF UTILIZING HEALTHCARE SERVICES

Chapter 6 of this PhD looks at the third dimension of access – affordability of healthcare services, including a range of direct and indirect costs associated with using a health service and the ability of patients to cover these costs and the coping mechanisms they adopt to finance these expenditures such as borrowing money and selling household assets to pay for utilizing healthcare services. This chapter draws mainly on Paper 3 of the thesis - Time and money: the true costs of health care utilization for patients receiving 'free' HIV/TB care and treatment in rural KwaZulu-Natal [Appendix 11].

Data was collected in two surveys – the Researching Equity in Access to Healthcare (REACH) which was conducted in 2009 with HIV and TB patients and the Impact of ART on HIV epidemic dynamics conducted in 2010 which included HIV-infected patients not yet on ART (pre-ART). Data was collected using a structured questionnaire and patient-exit interviews were conducted with a representative sample of 200 pre-ART patients, 300 ART patients, and 300 TB patients receiving care in randomly selected primary healthcare clinics in the sub-district. HIV patients on ART in this chapter will be referred to as ART patients to distinguish them from pre-ART who are also HIV patients.

This study was performed within the public-sector ART program of Hlabisa sub-district, situated in northern KwaZulu-Natal, South Africa – an area with high HIV prevalence among adults and a high TB disease burden. All primary healthcare (phc) clinics within the ART programme operate in accordance with the prevailing South African Department of Health (DoH) guidelines on HIV and TB management. Both HIV and TB care and treatment require repeated clinic visits to diagnose and manage these infections and because of the integration of these services ART and TB treatment can be collected on the same visit for co-infected patients. When a patient tests HIV-positive, blood samples are sent to the National Health Laboratory Services at Hlabisa district hospital for CD4 cell count measurement, and patients return to the clinic for their results within a week from sample collection. Individuals who are not yet eligible for ART are instructed to return

to the clinic every 6 or 12 months, depending on CD4 count. ART eligible patients attend three adherence counselling sessions and then initiate therapy. Patients initiated on ART are instructed to visit the clinic monthly to refill medications and for clinical observation.

Health expenditures were calculated for each patient group in different spending categories, time spent traveling to and at services, and how patients financed their spending. Costs included that incurred to visit the clinic (at the time they were interviewed), specifically money spent on transport to the clinic, food, phone calls or accommodation during the visit or delivery, service user fees or medicine payments, and payments made to others to take over tasks (including childcare) while they visited the clinic. [Questionnaires Appendix 1 and 2] In addition to the costs associated with the visit, patients were asked about any other health related expenditure during the preceding one-month period. Patients were asked about utilization and expenditure on chemist/pharmacy, private doctor, traditional healer, other public or private hospital/clinics - inpatient stay or emergency/outpatient department. To capture costs associated with self-care, patients were asked about spending on non-prescriptive items "any other healthcare in the past month (e.g. traditional medicines, spaza shop (convenience store), special food etc)." The above health expenditures were aggregated to calculate "total expenditures in the last four weeks." All expenditures were reported in South African Rand (USD 1 = ZAR 7.3, at the time of the study in 2010). HIV and TB patients' costs were standardized to 2010 for comparability with pre-ART patient costs (as the studies were carried out at different times, REACH in 2009 and the follow-on with pre-ART patients in 2010) taking into account inflation (4.3% from 2009 to 2010).

In addition, data were collected on time-related costs associated with clinic visit, as time (in hours) spent traveling to the clinic, and time spent at the clinic; these times were aggregated to calculate "total time costs" associated with clinic visits.

For both financial and time-related costs, pre-ART costs were divided by three to adjust for the different visit schedules (to get monthly costs by dividing the financial cost and time by three (pre-ART patients have an average two visits per year but these translate into four clinic visits as

blood collection and CD4 count results are communicated on a subsequent visit)). ART and TB patients have monthly clinic visits.

To enable comparisons between time and financial costs, time spent in hours was converted into equivalent monetary expenditure using an estimate of the opportunity cost of time, calculated as follows: Rate of income per hour worked = Gross Domestic Product (GDP) per capita for KwaZulu-Natal divided with the working hours per year; and obtained an average hourly wage of ZAR 17.49 in 2010. To obtain time costs in Rand, the monthly time spent during clinic visits and the travel times to the facility for pre-ART, ART and TB patients was multiplied by ZAR 17.49.

Lastly, to explore affordability constraints from a different perspective and mechanisms for coping with the burden of direct costs, patients were asked how they paid for medical care with the questions "In the last month did you have to borrow money to pay for healthcare?" and "In the last month did you have to sell personal or household items in order to pay for healthcare?" An indicator of "financial distress" was constructed which took the value of one if individuals reported either borrowing money or selling personal or household items to pay for healthcare in the last month and zero otherwise.(S. Cleary et al., 2013) Multivariable logistic regressions were done to determine associations between patient group and differences in patient costs as well as to assess the association between patient costs and financial distress; controlling for socioeconomic covariates and clustering standard errors at the clinic level.

In terms of households receiving social grants1 from the government, a high percentage of households with a member receiving ART (92%) and TB (89%) treatment were receiving a social grant, with households with patients on ART receiving a significantly higher average grant

[1] Social grants are temporal grants (eg disability grants, child grants, old age etc) issued by the South African government to alleviate poverty and inequity. The disability grant is a temporal grant issued out to people with a physical or mental disability which makes them unfit to work for a period of longer than six months - many ART and TB patients are eligible to receive to compensate for disease and disability-related employment loss.

amount (mean=South African Rand (ZAR) 1503, standard deviation (sd) =ZAR 974) than TB households (mean=ZAR 1198, sd =ZAR 922).

Patient expenditures and time costs associated with clinic visits

Clinic visit costs were constructed from the question, "In coming to receive treatment today, how much did you pay for: transport (one way), clinic/hospital fees, medicines, someone to take over your tasks while you are here including childcare, accommodation if you need to stay the night nearby, food during the visit, telephone, other, specify." For all patient groups, transport was the largest expense associated with clinic visits, with a monthly cost for: pre-ART visits of ZAR 5 (95% CI 4-6), for ART visits of ZAR 37 (95% CI 29-45) and for TB visits ZAR 24 (95% CI 21-28) (USD 1 = ZAR 7.3, at the time of the study in 2010) (Table 6.1) because of frequent clinic visits, mostly by public transport. Other expenses not for transport were categorized as non-transport costs; food costs during the clinic visit also contributed to monthly expenditures associated with clinic visits: for pre-ART visits ZAR 2 (95% CI 2-3), for ART visits ZAR 9 (95% CI 8-10) and for TB visits ZAR 6 (95% CI 5-8). As expected, none of the patients paid for medicines, and small amounts were reported to have been spent on childcare, overnight accommodation, cell phone airtime.

Total monthly costs of clinic visits (excluding time costs) were higher for ART patients (ZAR 46; 95% CI 38-55) and TB patients (ZAR 33; 95% CI 27-39) than for pre-ART visits (ZAR 8; 95% CI 6-9), mainly due to the frequency of visits – ART and TB patients visit the clinics monthly while pre-ART patients at least every six months even after taking this into consideration. (Table 6.1)

Patients were asked "Did you find it easy or difficult to incur these expenses?" and the majority of patients indicated it was difficult to bear these expenses (pre-ART 135 (81%), ART 203(86%) and TB 185 (92%) p=0.01). Further, about a third of the patients reported they had no-one to help them financially (cash, buying food, providing transport etc) with their HIV/AIDS or TB disease, (pre-ART 71(36%), ART 102(34%) and TB 83(30%) patients).

Looking at healthcare expenditure per month (per clinic visit costs plus expenditures on other healthcare services), patients in the three groups spent about the same amount of money per month on healthcare – ZAR 171 (95% CI 134-207) for pre-ART patients, ZAR 164 (95% CI 140-187) for ART patients, and ZAR 122 (95% CI 104-140) for TB patients (Table 6.1).

However, the three patient groups differed widely in the composition of their financial expenditures: pre-ART patients spent more on traditional healers (ZAR 29), chemists (ZAR 17), and private doctors (ZAR 30) (Figure 6.1, Table 6.1) compared to their counterparts; although they spent less on transport (ZAR 5). All three groups reported large expenditures on self-care which included buying and using traditional medicines, health foods from spaza shops, or special foods to boost the immune system (Table 6.1).

Table 6.1: Descriptive table of financial costs, time costs, total costs and financial distress

Financial and time costs (per month)	**Pre-ART** N=200 Mean (SD)	**ART** N=300 Mean (SD)	**TB** N=296 Mean (SD)	**p-value**[‡]
Costs associated with visits to HIV/TB clinic (ZAR/month)				
Transport costs (return trip)	5.0 (6.8)	36.9 (67.4)	24.4 (29.4)	<0.001
Non-transport costs	2.7 (3.8)	9.4 (11.7)	8.2 (36.1)	0.004
Subtotal	**7.6 (8.5)**	**46.4 (71.8)**	**32.7 (52.0)**	**<0.001**
Costs incurred for use of other healthcare services (ZAR/month)				
Chemist or pharmacy	17.4 (81.9)	0.8 (4.7)	2.0 (16.6)	<0.001
Public clinic	0.8 (10.6)	0.7 (8.1)	0.7 (10.8)	0.999
A private doctor	30.2 (77.7)	23.4 (82.8)	15.5 (55.3)	0.081
A traditional healer	29.1 (117.1)	0.2 (3.0)	1.5 (14.9)	<0.001
Public hospital	1.0 (7.8)	0.4 (4.0)	0.0 (0.0)	0.053
Private hospital	0.1 (1.4)	0.0 (0.0)	0.1 (1.2)	0.520
Self-care-traditional medicines, spaza shops, special foods	84.5 (141.2)	91.7 (153.0)	69.8 (118.5)	0.145
Subtotal	**163.1 (262.5)**	**117.3 (181.3)**	**89.5 (139.8)**	**<0.001**
Total financial costs	**170.7 (262.9)**	**163.7 (204.0)**	**122.2 (154.7)**	**0.012**
Time costs (hours/month)				
Time spent at clinic	1.2 (0.7)	2.8 (2.0)	1.1 (1.3)	<0.001
Time spent travelling	2.2 (1.8)	2.2 (1.8)	2.0 (1.5)	0.105
Total (hours/month)	**3.4 (0.7)**	**5.0 (2.8)**	**3.1 (2.0)**	**<0.001**
Total monetized time costs (ZAR/month)	**59.2 (12.7)**	**87.1 (49.4)**	**54.7 (35.2)**	**<0.001**
Total financial + monetized time costs (ZAR**)**	**230.2 (262.7)**	**250.7 (218.5)**	**177.0 (158.5)**	**<0.001**
Financing health expenditure (% yes)				
Borrowed money	29 (22-35)	36 (31-42)	39 (33-45)	0.054[¥]
Sold assets[§]	5 (2-7)	8 (5-11)	6 (3-9)	0.365[¥]
Borrowed money OR sold assets to pay for healthcare[†]	31 (24-37)	39 (34-45)	41 (35-47)	0.051[¥]

*Time spent at clinic for pre-ART patients was divided by 3 to allow for the number of visits for pre-ART patients; for ART and TB patients their visits are monthly. **Time cost were calculated as time spent per-visit or time travelling multiplied by ZAR 17.49. Sample was [§]282 and [†]296 for ART patients due to missing data. [¥]p-value based on Pearson's χ^2 test for differences in proportions across patient groups. [‡]p-value based on F statistic test for differences in means across patient groups. ZAR = South African Rand, SD = standard deviation.

Figure 6.1 Average monthly direct and indirect health care expenditures (ZAR) incurred by pre-ART, HIV, and TB patients

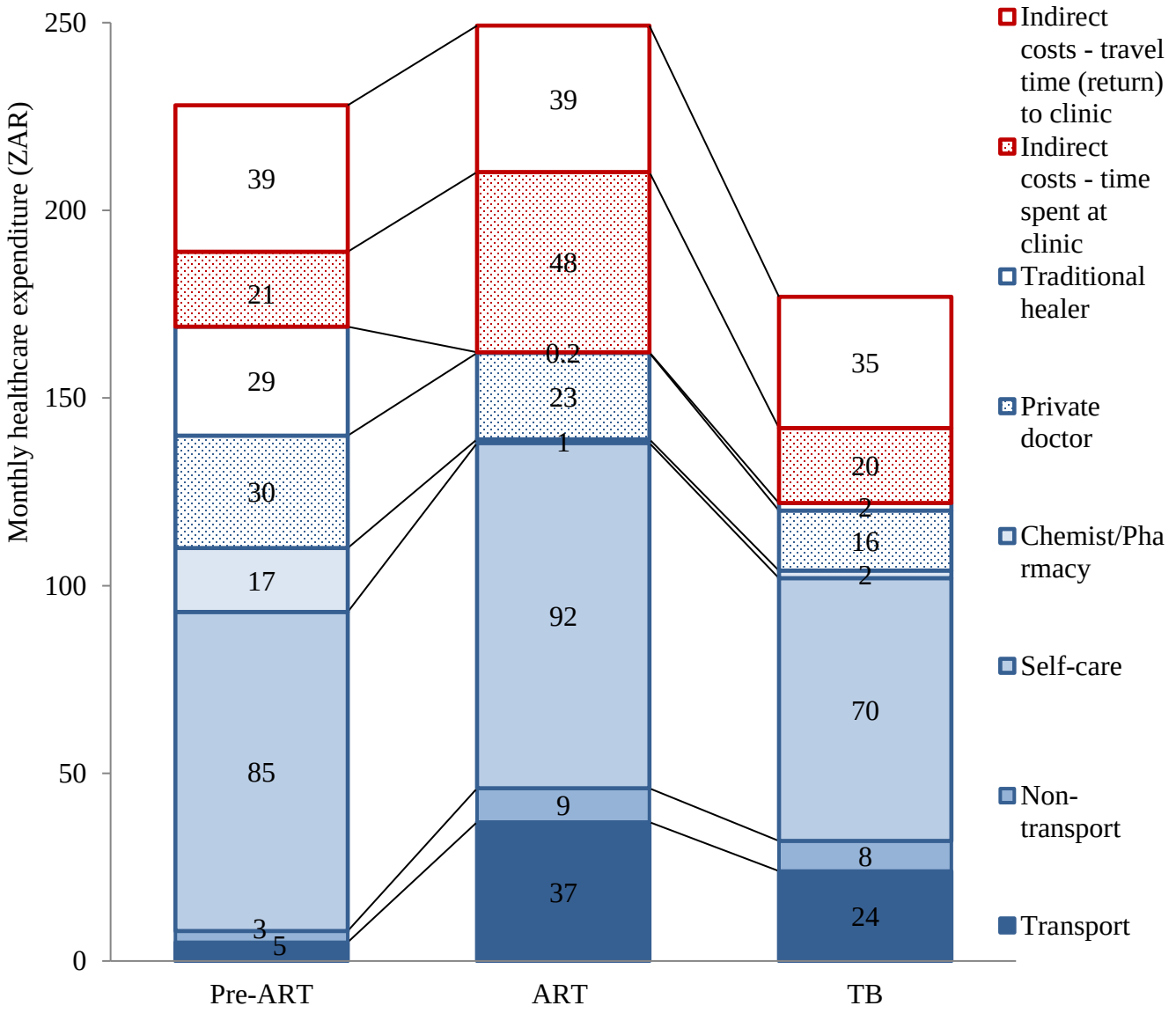


Figure 6.1 Average monthly direct and indirect health care expenditures (ZAR) incurred by pre-ART, HIV, and TB patients. Self-care, use of traditional medicine, spaza shops, and special foods; Chemist/Pharmacy, use of the chemist/pharmacy; Private doctor, use of the private doctor; Traditional healer, use of the traditional healer; Transport, transport cost for a return trip to clinic; Non-transport, costs of clinic/hospital fees, childcare, overnight accommodation, food, cell phone airtime; Indirect costs, time spent at the clinic; Indirect costs, travel time (return) to the clinic.

*Indirect costs are presented using the average hourly wage in the province of KwaZulu-Natal as monetary value of time.

Table 6.2 shows the multivariable logistic regression results of the different patient healthcare expenditure costs by patient groups, controlling for patient socio-demographic characteristics - age, sex, and head of household employment status, adjusting for clustering at the clinic level and the crude difference regression models for each spending category by patient group. Pre-ART patients spent less on transport costs (coefficient=-34.0; 95% CI -57.0- -11.0) than ART patients. However, pre-ART patients spent significantly more on traditional healers (coefficient=29.2; 95% CI 12.2-46.2) and private chemists/private doctors (coefficient=25.9; 95% CI 10.3-41.6) than ART patients, who spent very little on traditional, complementary, or alternative sources of care. There was no significant difference in healthcare expenditure between ART and TB patients, except on private chemists/private doctors; TB patients spent significantly less on private chemists/private doctors (coefficient=-4.9; 95% CI (-9.0--0.8) than ART patients.

For a single clinic visit, pre-ART patients reported spending significantly more hours at the clinic (3.5; 95% CI 3.2-3.8) than both TB (1.1; 95% CI 1.0-1.3) and ART patients (2.8; 95% CI 2.5-3.0); ART patients spend significantly more time than TB patients (Table 6.1 and Figure 6.2). However, the translated average monthly time spent at the clinic for pre-ART patients (1.2; 95% CI 1.1-1.3 hours) was much lower than the monthly time spent at the clinic for ART patients. There was no significant difference in the average travel time for a return trip to the clinic across the groups (Table 6.1).

Figure 6.2 Time (hours) spent by pre-ART, ART and TB patients attending clinic visits

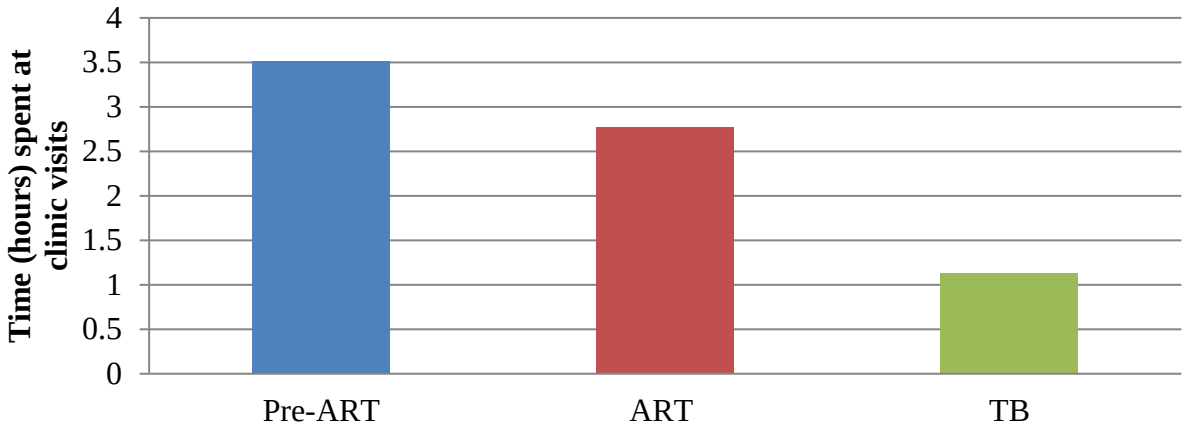


Figure 6.2 showing the average time (in hours) patients spend attending clinic visits

Financing patient expenditures

Financial Distress

More than a third of patients borrowed money in the last month to cover the costs of health services: 39% of TB patients, 29% of pre-ART patients, and 36% of ART patients. Less than a tenth of patients had sold personal or household items to finance healthcare expenditures (Table 6.1) probably because they had nothing to sell or the expenditure did not warrant selling of items. Although borrowing money to finance healthcare use was the common coping strategy, of those who borrowed, there was no significant difference in the average amount borrowed by patient group; pre-ART patients borrowed ZAR 178 (95% CI 128-229; median 100; interquartile range (IQR) 50-200), ART patients ZAR 177 (95% CI 97-256; median 104; IQR 42-209) and TB patients ZAR 154 (95% CI 108-201; median 94; IQR 31-209). Financial distress (as indicated by either borrowing or selling assets) was high in all groups: TB patients (41%), pre-ART (31%), and ART (39%) (Table 6.1).

Factors associated with financial distress due to utilizing healthcare

In multivariable analyses, adjusting for age, sex, employment status of head of household, time and financial costs of healthcare, being male (aOR=2.40, 95% CI 1.14-5.05) and having an unemployed head of household (aOR=1.97, 95% CI 1.21-3.22) were independently associated

with more than twice the odds of being financially distressed for pre-ART patients (Table 6.3). However, age was not statistically significantly associated with the likelihood of being financially distressed in any of the three patient groups. Every additional ZAR 100 spent on total monthly healthcare visits increased the odds of reporting financial distress by more than 30% in all patient groups (40% in pre-ART patients, 32% in ART patients and 50% in TB patients). For every hour spent at the clinic, the probability of reporting financial distress increased significantly among ART and TB patients. TB patients were twice as likely (aOR=1.92, 95% CI 1.29-2.87) to report being financial distressed than ART patients and there was significant difference in financial distress between pre-ART and ART patients.

Table 6.2: Crude and covariate-adjusted differences in health expenditures by patient type and spending category

	Total financial health expenditure	**Transport**	**Traditional healers**	**Self-care**	**Chemist and private doctors**	**Time costs** (monetized)
	Mean (95% CI) p-value	Mean (95% CI) p-value	Mean (95% CI) p-value	Mean (95% CI) p-value	Mean (95% CI) p-value	Mean (95% CI) p-value
Crude difference						
Pre-ART *minus* ART	7.1 (-46.2-60.4) 0.747	-32.0 (-54.1--9.8) 0.014	28.9 (12.4-45.3) 0.006	-7.2 (-37.9-23.5) 0.572	23.4 (6.7-40.1) 0.016	-27.9 (-38.8--17.1) 0.001
TB *minus* ART	-41.5 (-106.8-23.9) 0.164	-12.5 (-35.8-10.8) 0.227	1.2 (-0.7-3.2) 0.158	-22.0 (-58.9-15.0) 0.187	-6.7 (-11.7--1.7) 0.018	-32.4 (-52.5--12.3) 0.009
Adjusted difference*						
Pre-ART *minus* ART	1.3 (-57.0-59.7) 0.955	-34.0 (-57.0--11.0) 0.013	29.2 (12.2-46.2) 0.007	-13.2 (-46.0-19.7) 0.350	25.9 (10.3-41.6) 0.008	-26.7 (-38.0--15.3) 0.002
TB *minus* ART	-41.2 (-103.2-20.7) 0.148	-12.6 (-34.7-9.5) 0.203	1.2 (-1.8-4.2) 0.340	-23.8 (-59.2-11.7) 0.145	-4.9 (-9.0--0.8) 0.029	-31.5 (-51.4--11.6) 0.010

*Controlling for age, sex, head of household employment status and adjusted for clustering at the clinic level. All values are in South African Rand.

Table 6.3: Factors associated with financial distress due to utilizing healthcare in pre-ART, ART and TB patients

Patient either borrowed money or sold assets to pay for health care	Pre-ART N=200		ART N=294		TB N=295		All patient groups N=789	
	aOR	95% CI*	aOR	95% CI*	aOR	95% CI*	aOR	95% CI*
Sex								
Female	1		1		1		1	
Male sex	2.40	1.14-5.05	1.09	0.63-1.88	1.15	0.54-2.45	1.29	0.92-1.79
Age (in years)	0.99	0.97-1.02	0.98	0.96-1.01	1.01	0.97-1.04	1.00	0.98-1.01
Head of household								
Employed	1		1		1		1	
Unemployed	1.97	1.21-3.22	1.49	0.52-4.27	2.31	0.78-6.87	1.86	1.22-2.85
Total monthly costs of utilizing healthcare (per ZAR 100)	1.40	1.19-1.65	1.32	1.18-1.47	1.54	1.25-1.90	1.38	1.26-1.51
Time spent during clinic visit per month (in hours)	1.04	0.92-1.17	1.21	1.05-1.40	1.65	1.22-2.24	1.31	1.17-1.45
ART		-		-		-	1	
Pre-ART		-		-		-	1.10	0.69-1.73
TB		-		-		-	1.92	1.29-2.87

*Adjusted for clustering at the clinic level. Hosmer-Lemeshow goodness-of-fit test for pre-ART model p=0.46; ART model p=0.35; and TB model p=0.06. **Marginal effects of the regression with all patient groups: change in total monthly costs of utilizing healthcare per ZAR 100 = 6.6 percentage points (p-value<0.001, 95% CI 4.9-8.3); change in time spent during clinic visit per month (hours) = 5.5 percentage points (p-value<0.001, 95% CI 3.4-7.6). CI = confidence interval, aOR = adjusted odds ratio, ZAR = South African Rand, ART = antiretroviral treatment, TB = tuberculosis.

Summary of main findings

Although HIV and TB patients nominally receive free care at the clinic, they still face considerable costs due to healthcare expenditures and the time costs of seeking care. Large expenditure on alternative care was reported, especially among pre-ART

patients, and these large private costs led to financial distress. Transport costs were the main per clinic visit expense across all patient groups.

CHAPTER 7: HEALTHCARE PROVIDER RESPONSES FROM INTERVIEWS BASED ON PATIENT SATISFACTION EXIT SURVEY RESULTS

Chapter 7 of this PhD explores the responses of healthcare providers to discussion structured around ART patient exit survey findings on patient satisfaction and to understand the healthcare provider's perspective of the barriers and enablers to improving quality of care provision. This chapter draws mainly from Paper 4 of the thesis - Engaging healthcare providers: responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal [Appendix 12].

In 2012, eight of 17 primary healthcare (phc) clinics in the study area were randomly selected for a qualitative study with healthcare providers for this PhD study. Twenty-five frontline antiretroviral therapy (ART) healthcare providers were engaged in discussion about challenges faced by them and their patients, to inform understanding of healthcare providers' perceptions of factors affecting provision of quality care. Interviews were structured around the results from the patient exit surveys carried out in 2009, in particular around aspects of satisfaction (the REACH study described in more detail in Chapter 3: Methods) in the same setting. Healthcare providers directly involved in providing ART care (nurses, counsellors and operational managers who are the senior nurse in charge of the phc clinic) were conveniently selected to participate. The initial plan was to hold focus group discussions with staff but this was not possible because the clinics were often busy and focus group discussions would have been disruptive and delay patients even longer. Appointments with healthcare staff were set prior to the discussions. Each clinic was visited not more than three times to identify participants and healthcare providers were approached once, if they declined they were replaced and if they were too busy but willing to participate the PhD candidate would wait for them until it was convenient. An operational manager responsible for the clinic and at least one ART counsellor and one nurse were selected from each clinic.

Seven of 13 patient satisfaction findings (including aspects of overall satisfaction, communication, contact time, respect, privacy, cleanliness, and waiting times) were selected for discussion (Table 7.1). These variables were selected because they covered the common aspects of patient satisfaction and showed some variance (not skewed to one end of the response/likert scale) in responses. A topic guide with broader issues than patient satisfaction findings was developed based on general quality of care framework to stimulate discussion and assess possible challenges/facilitators that ART healthcare providers face when providing care (Table 7.1). This would enable eliciting healthcare providers' perceptions of patients' opinions of care received, current patient challenges that may not have featured in the REACH survey, the healthcare providers' interaction with the healthcare system and the challenges/facilitators faced and the changes that may have occurred during the time between the REACH survey and the interview (Table 7.1). Discussions were done by the PhD candidate in the consultation rooms when there were no clinical sessions going on.

Table 7.1: Indicators of patient satisfaction with service and the topics explored during feedback discussion with healthcare providers

Statement/question in REACH study (n=300) that were included in the feedback discussion
1. How satisfied were you with the service today? *93% Very satisfied/satisfied* *2% Neither satisfied nor dissatisfied* *3% Dissatisfied/very dissatisfied* *2% Don't know*
2. I find it easy to tell the health workers when I have missed taking my tablets *63% Agree* *7% Disagree* *21% Never missed* *4% Don't know/not sure*
3. The health workers are too busy to listen to my problems *13% Agree* *82% Disagree* *1% Both agree and disagree* *4% Don't know/not sure*
4. Some staff do not treat patients with sufficient respect *38% Agree* *36% Disagree* *1% Both agree and disagree* *25% Don't know/not sure*
5. The facilities (including waiting area and toilets) are dirty *16% Agree* *72% Disagree* *3% Both agree and disagree* *9% Don't know/not sure*
6. The queues to see a doctor or nurse are too long at this facility *49% Agree* *34% Disagree* *16% Both agree and disagree* *1% Don't know/not sure*
7. In this clinic are you able to talk to the doctors or nurses in private? *80% Always* *7% Sometimes* *8% Never* *5% Don't know/not sure*
Topics explored in the topic guide used in the discussion
• Current patient utilization barriers • Healthcare provider's role and how they help patients overcome their utilization challenges • Healthcare provider's experiences and challenges in providing ART treatment and care to patients • Changes (structural, organizational, governance etc) that have occurred in the facility since 2009 (when the REACH study was done) that you think may have they affected healthcare provision • Any other issues that may be holding back provision of quality care for ART patients in this clinic for example from the patients' side, your side or the health system, or even the community).

All discussions were recorded (the average discussion duration was 37 minutes (range 26 – 54 minutes)) and transcribed. Data were managed using Nvivo 10 (QSR International Pty Ltd., 2012) and thematic content analysis used to identify emerging themes and patterns within the data. Clinic or healthcare provider identifiers were removed and replaced with pseudonyms.

The patient load per clinic ranged from 409 to 9056 patients utilizing ART at the clinics in 2012, with clinics with a smaller patient load being fairly new and some started initiating ART patients at a later stage than the older bigger clinics. (Table 7.2)

Table 7.2: Patient load and staff complement by clinics end of 2012

Clinics and their description	Patient load (number of patients active on ART end of 2012)	*Number of nurses delivering HIV care end of 2012	*Number of HIV counsellors end of 2012
A Urban, big clinic and very busy	6077	2	7
B Urban, big clinic and very busy	9056	4	11
C Rural, small clinic and very busy	3200	2	5
D Rural, big clinic and very busy	4001	1	3
E Very rural, small clinic and less busy	409	0	1
F Rural, medium new clinic and busy	2444	2	3
G Rural, medium clinic and busy clinic	2231	1	3
H Rural, small clinic and not so busy	1176	1	2

* In this sub-district clinics still allocated specific nurses and counsellors to cover HIV services including counsellors doing HIV testing and counselling only

Results

Most healthcare providers were female (n=23) and only two were male; median age for all 25 healthcare providers was 42.5 (Q1-Q3 37-50) years. The median duration of employment at the current clinic was three (Q1-Q3 1-5) years and median duration of employment in their profession was five (Q1-Q3 1-6) years (Table 7.3).

Table 7.3: Characteristics of healthcare providers (N=25)

Characteristics of respondents	n(%)
Healthcare providers cadre	
Nurses	9 (36)
Operational managers*	7 (28)
Counsellors	9 (36)
Employer	
Department of Health	19 (76)
Africa Centre	6 (24)
Sex	
Female	23 (92)
Male	2 (8)
§**Age** Median (Q1-Q3) years	42.5 (37 – 50)
Length in employment at current clinic	
Median (Q1-Q3) (years)	3.0 (1-5)
Time in profession Median (Q1-Q3) (years)	5.0 (1-6)

*Operational managers are the senior nurse in charge of the primary healthcare clinic
§3 healthcare providers refused with their age

Two broad theoretical constructs[2] emerged: (1) healthcare providers' feelings of helplessness to address structural barriers within the health system and (2) their empathy and responsiveness to individual patients' challenges, despite the limitations of the healthcare system (Table 7.4). Emerging sub-themes pointed to the challenges related to understaffing and increased workload, resulting in overwork, fatigue and burn-out. Further challenges related to lack of essential equipment and drug stock-outs, leading to longer queues and increased waiting times, delayed treatment initiation, more frequent patient clinic visits, and emotional frustration for both patients and staff. Despite the health system constraints, providers showed resilience and described how they devised ways to provide the best care possible, e.g by using personal vehicles to collect ART from the hospital pharmacy or by working longer hours

[2] A theoretical construct is a set of general, modifiable propositions that help explain, predict, and interpret events or phenomena of interest (Auerbach & Silverstein 2003)

Table 7.4: Repeating ideas, themes and theoretical constructs emerging from the healthcare providers' feedback

	Repeating ideas *(same or similar words and phrases to express the same idea)*	**Themes** *(an implicit topic that organizes a group of repeating ideas)*	**Theoretical constructs** *(a set of general, modifiable propositions that help explain, predict, and interpret events or phenomena of interest)*
I			I feel helpless with the system (Feelings of helplessness with the system)
A		It's not all my fault	
1 2 3 4	"I see too many patients" – Understaffing and increased workload "I motivate for equipment but no-one is helping me"- Equipment and Infrastructure "They are useful but no-one cares to explain what they mean" - Policies and guidelines "The clinic is dirty" - Cleanliness and hygiene		
B		I am frustrated with the system	
1 2	"I feel unappreciated" - Staff motivation, interpersonal relationships and working conditions "I'm frustrated, and the patients are also frustrated with ART shortages"		
C		Treatment literacy and negative caregiving practises	
1	"I try to explain but they don't understand"		
D		Sustainability of research collaborations	
1	"I am scared worried what will happen when AC leaves"		
II			I feel for the patients (Healthcare provider responsiveness with patients)
A		"We care about our patients" Healthcare providers empathy and responses to patient challenges	

1 2 3 4 5	Waiting times and queues “Travelling to the clinic is a huge burden for patients” “We encourage them to eat a balanced diet, but they are poor” – Health talks and practicality “Our patients need the grant” – Social grant and patients’ socio-economic status A working patients’ dilemma : health versus wealth - Healthcare providers support		

Understaffing and increased workload - "I see too many patients"

In response to the issue of comments about long queues, poor contact time and lack of respect, healthcare providers pointed to the fact that they were short-staffed, overworked, fatigued and emotionally and mentally tired most of the time. One healthcare provider explained that staff shortages could not simply be rectified by employing more staff only but also required expansion of working space in the clinics as there were few rooms for staff to work in most clinics (Clinic F). The issue of space was also raised as affecting patient privacy and the quality of care provided. Healthcare providers also admitted that their stress may be taken out on patients, but blamed their full workload.

"...I like working with people so if we are short-staffed, sometimes when you are seeing more patients and you are tired physically and mentally you end up taking it to the client and the client won't understand that you are tired and overworked." (Clinic G, Nurse)

Lack of sufficient nurses trained in Nurse Initiated Management of ART (NIMART) at the time of the discussion (during the REACH study, only doctors initiated patients on ART) limited staff adaptability in times of shortages compromising the quality of patient care. At times temporary ART nurses, not NIMART trained (Clinic D), stood in for ART nurses because of such shortages.

"...there are queues because they do not have a Sister that is working in the ART clinic. Since I have moved from there, there are lot of problems because we are short staffed at the main clinic, so the matron said I must come back to main clinic because the clinic needs me a lot." (Clinic D, Nurse 1)

Staff shortages contributed to long patient queues and waiting times, although healthcare providers reported sacrificing lunch breaks until they finished the queue; and while they were not happy with the situation, they felt "there was no alternative". Conversely, patients were said to be always in a hurry and healthcare providers had to rush through consultations.

"There isn't much really we can do, but then we don't take long lunches and we don't take lunch at all sometimes… we don't go for tea so that we can just work right through. We are not happy [with the arrangement] but then we have to cope, we have to work, we are not happy." (Clinic B, Nurse 2)

Healthcare providers indicated that patient selection of which facility to use was based on location, fear of being known or issues of stigma and disclosure. Facilities located in urban settings were overcrowded because of ease and lower costs for individuals who combined work, shopping and treatment pick-up.

"…people like to come in town, so the queues are too much, too much…If the appointment date is 29, so on the 29th they do both grocery and clinic." (Clinic A, Counsellor)

Equipment and Infrastructure - "I motivate for equipment but no one is helping me"

One of the barriers healthcare providers faced in providing quality care was lack of essential equipment such as HIV testing kits (Clinic C) and haemoglobin meter strips (Clinic F) needed for ART initiation of pregnant women (at the time of the study, prevailing guidelines stated that all HIV positive pregnant women should be initiated on treatment immediately regardless of tests). Lack of domestic fridges for nurses resulted in compromised cold chain system as staff used vaccine fridges for their personal food.

Healthcare providers (Clinic E) motivated for repairs and equipment to the district hospital but there was no response.

"We always write letters and they say they are going to come and help us with cupboards. We do not have medicine trolleys, so if you are just concentrating on the patient and then there is a phone call for you, you have to say to the patient "get out a little" and tell them nicely because you are afraid they are going to take these panados, ibobrufen which is not allowed. Like we are sitting on this table, (table leg was broken) we just write in the repair book and we phone the main stores to come and help us. We wait for them to come and help us, even wheelchairs, we don't have wheelchairs, and our stretcher is broken." (Clinic E, manager)

Space for filing patient records was increasingly problematic with increased patient load and paperwork (Clinic A, Clinic D). Water shortages and electricity power cuts were major challenges in most clinics. However, some clinics were making the effort to provide clean drinking water in the waiting area and for washing hands after toilet use.

Cleanliness and hygiene - "The clinic is dirty"

In response to patient comments on facilities' cleanliness, healthcare providers (Clinic B, Clinic D, and Clinic G) reported water shortages, old buildings, use of portable toilets or pit latrines rather than flush toilets as the major drawbacks to their efforts to keep the facilities clean. Cleanliness was not only viewed as hygienic and essential for infection control but as a basic patient right.

"While we still talking about the rights of patients, really the toilets here are not enough. Gents and ladies use one toilet. These toilets are dirty and there is no water at all. There are a lot of infections, what we call poor quality management" (Clinic D, Nurse2)

In one clinic (Clinic E), community women helped with cleaning; while in other clinics healthcare providers opted to clean for themselves (Clinic C).

Policies and guidelines - "They are useful but no one cares to explain what they mean"

There were mixed feelings concerning the relevance of HIV treatment policies and guidelines and the National Core Standards for Health Establishments in South Africa (National Department of Health., 2011b) in facilitating provision of quality care to patients. Most nurses indicated that the policies were useful because they could now initiate patients on ART and the guidelines provided direction.

"…yes [they are relevant] because I do not have to wait for the doctor to initiate and they [patients] don't have to wait for a long time before they can be initiated… they are very helpful and relevant because if I am having a problem I can refer to the policies and the protocol" (Clinic G, Nurse)

Some clinics discussed the National Core Standards during in-house meetings but with no follow-up supervision, while other clinics (Clinic F) conducted in-service training of all nurses on ART issues so that staff could be flexible when short-staffed.

However, other healthcare providers, particularly counsellors and those from remote clinics, felt no one cared to explain what the guidelines meant and there was need for on-going guidelines training, as their clinics were inaccessible due to bad roads and they were sometimes left out from trainings and workshops (Clinic E). Despite the frustrations, healthcare providers responded by "making a plan" they thought practical and helpful for them and their patients.

"…they just give us those packet of papers and say these are the rules and regulations but if you go through this you find it's not practical…Ok, I'll be honest with you, this is what we do, we keep 'your' papers in the wall, we do things that will help our patients because some of the things that are written down are not practical and they are not helping our patients as you want to help them. We are fast-tracking everyone to initiate…it cuts on the visits and it helps them a lot…we making decisions on what to prioritize in the guidelines given the time-constraints due to staff shortages or resources" (Clinic B, Counsellor 2)

Healthcare providers felt national ART guidelines were general and "instructions from higher order" which did not apply to specific facility situations e.g. they did not have facilities for point-of-care CD4 count tests or tuberculosis (TB) screening and blood tests to ascertain kidney function before initiating patients on Tenofovir for same-day patient initiations.

Sustainability of health system without partner support - "I am worried what will happen when the Africa Centre leaves"

This study happened at a time when there were major changes in terms of the ART programme and the funding period. The ending of the Africa Centre support, which at times could work around the issues more flexibly than the Department could, invoked anxiety and worry in most clinics staff (Clinic B, Clinic A, Clinic G, Clinic F) and although this may have been unnecessary it was nevertheless a real worry. Issues of worry were to do with staffing, clinic maintenance, training support and the implied adjustments which could affect positively or negatively the quality of care and patient satisfaction.

"I just got worried when I heard that the Africa Centre staff are ending in December...that will mean long queues for our patients because I'll be the only counsellor...yah that is my biggest fear" (Clinic B, Counsellor 2)

Staff motivation, working conditions and interpersonal relationships - "I feel unappreciated"

Healthcare providers indicated need for basic amenities and better working conditions as lack of such affected their morale.

"We eat here [in the consulting rooms] and while we eat, the queue grows longer because we all eat together so that we can start working again because we don't have a place to eat" (Clinic A, Counsellor)

In another clinic (Clinic B) healthcare providers felt 'dictated to' and that their opinion was not taken into consideration during meetings. Further, healthcare staff felt that the leadership did not appreciate and support their good work. The nursing apartments in one clinic (Clinic E) were reported to be in an appalling state and not fit for accommodating the nurses on call, which is demoralising and may result in failure to retain staff in the long-run.

"If you can go and see where I sleep, it is not a proper place for a nurse to sleep and wake up and do work the next day." (Clinic E, manager)

Drug stock-outs and healthcare providers responsiveness - "I'm frustrated, and the patients are also frustrated with ART shortages"

Healthcare providers indicated that working in a resource-limited setting was frustrating and made them and their patients feel helpless. At the time of study, there were temporary ART shortages and people due to start treatment were either sent home or referred to the district hospital.

"Tenovifir, almost all of them are in short supply. We keep on phoning [the district hospital] and they say they are coming. So we send back our patients to come back tomorrow" (Clinic D, Nurse 2)

In response to drug shortages, some healthcare providers delayed initiating people on treatment, or used paediatric formulations for adults; this approach may result in poor treatment response, poor health outcomes and reduced patient confidence in the health system. Healthcare providers 'borrowed' treatment from other clinics and sometimes used their own cars to collect patients' treatment.

"I leave the patients and go to other clinic and ask for it and I have to use my own transport…It is because I want to assist the patients, so that the patient does not have to stay without treatment" (Clinic G, Nurse)

Treatment literacy and negative caregiving practises - "I try to explain but they don't understand"

Healthcare providers complained that poor caregivers' treatment literacy levels and caregiving practises were frustrating and hindered providing quality care. Elderly caregivers of young children on treatment were reported to lack understanding of treatment administration due to old age, similar to elderly patients on treatment. In response some healthcare providers pre-packed paediatric medication for some elderly caregivers.

"You teach her [granny] how to take and give treatment to the child and you think that she understand, only to find that she didn't understand anything, no. The granny is too old. So if they have to give Kaletra I just take selotape (sticky tape) or something and cover it on the top (syringe)... Like if the child is supposed to get three millilitres, so that's easy for them" (Clinic F, Nurse)

"Travelling to the clinic is a huge burden for patients"

Although transport issues were not directly related to healthcare providers' ability to provide quality care, they were a major cause of dissatisfaction for patients. Healthcare providers indicated that access to clinics

was difficult for most patients because most of the facilities were rural, patients travelled either on foot or public transport.

"I can say some, not all of them, have got a money problem since the clinic is far from them. They have to use transport [taxis] to come to the clinic. The ones that are from down, I understand per trip its seven to ten rands so it means you need to have twenty rands just to come here. I can say mostly the chronics are affected because they have to come monthly for their treatment." (Clinic D, manager)

Need for food support and social grant

Healthcare providers reported that some people in the study area were poor and healthcare providers found it difficult to counsel them about adhering to treatment, with people unable to afford clinic visit costs or food

"They don't have food but they also have to take treatment, so it is something that bothers me...Some of them ask for porridge from Sister." (Clinic F, Counsellor)

Some healthcare providers reported their patients needed a social disability grant for money for transport and food to help them continue to utilize care. However, others reported (Clinic E) that patients were deliberately throwing away treatment so they would remain sick and be entitled to a grant.

Challenges of a working patient - Healthcare providers support

Healthcare providers reported that working patients (Clinic F, Clinic B, Clinic A, Clinic G, Clinic D) had specific challenges accessing treatment and highlighted that employers, particularly farmers, were reluctant to give time off to workers for initiation sessions and picking up treatment (Clinic G), resulting in some people being lost before they could start treatment.

"the challenges that the patients are facing, 1) the challenges of their employers, who do not want them to be absent at work because when we prepare them for ART, of course we are going to need them in some 2 or 3 days to visit the clinic, of which the patients complain that their employer doesn't want them to be absent for almost the whole morning in one day, and that gives us a problem because sometimes we see the client for one or two days before we complete the session or the process, then the client is lost. And then on the next month, you see that client again and then you say, "why did you not come because we told you that you should come so that we could this and that and that?", and they say "no I didn't get

time and my employer was refusing to release me, and I'm afraid I might lose the job". You see, those are the challenges, especially the farmers here in this area…" (Clinic G, Counsellor)

Most people were paid hourly rates and time spent travelling and utilizing care meant lost income. Some healthcare providers (Clinic A) were sympathetic, "my conscience would haunt me" and delivered treatment disguised as take-away foods to patients' workplaces within town or left treatment in the clinic for collection after work.

"Nothing I can do because if I didn't do that my conscience [would haunt me], because he or she is running short of tablets. And she told me that "I don't have tablets for tonight", so I have to do what I can do...so we put them [ARVs] inside these kfc (Kentucky Fried Chicken) bags and then we deliver…Sometimes I put in the policy room and they come and fetch it there, in the clinic. You put it in an envelope and write a name, and a return date inside the envelope" (Clinic A, Counsellor)

In other clinics (Clinic F, Clinic B, Clinic A) priority was given to working patients and they were allowed to send their relatives to pick-up their treatment. However, sometimes patients needed to be seen and assessed in person.

"…and we try to make sure that in the morning we attend to those who are rushing to work…so we try to explain to them that they must please, first start with those who are rushing to work so that they don't go late to work…so we to attend to them as quickly as possible…it's a big problem but those who like go in at 7:30, by 7 o'clock we are here so we attend to them and as quickly as possible but others it's difficult" (Clinic F, Nurse)

"…so sometimes they find it difficult because if they come, the clinic is packed they have to rush back…sometimes they send their relatives and sometimes you find that maybe, if they've sent their relative and maybe the [blood test] results are not good they need to see the patient in person, and that will take a long time for her to do that because if you look at maybe their work situation it doesn't allow her to come to the clinic every now and then" (Clinic B, Counsellor 2)

Summary of findings

This chapter shows the challenges healthcare providers face in providing HIV care in a resource-limited setting, taking into account the structural and systemic limitations they face. Healthcare providers' response towards patients shows a commitment to providing quality care and to their profession. The issues raised in this study are salient to HIV care and may affect patient's engagement in care. Engaging

healthcare providers in a regular discussion may empower staff to be active agents of change and provide the ability to deal with the reality of constraints within a quality improvement framework.

CHAPTER 8: DISCUSSION AND CONCLUSION

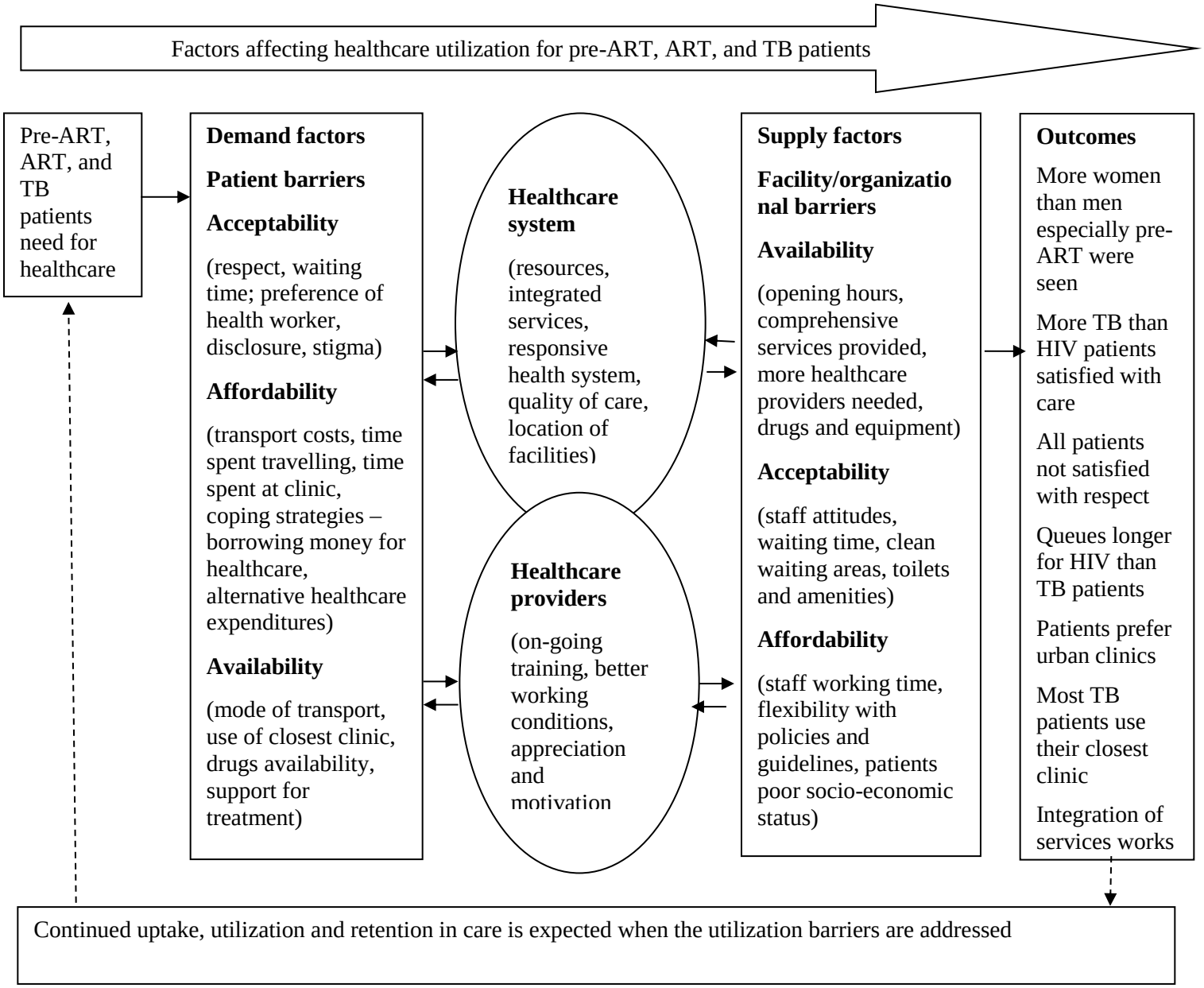
This last chapter of the PhD speaks to the research gaps identified in the literature review, with specific focus on South Africa and HIV/TB and how this study attempted to address them and contributed to scientific knowledge and understanding. A summary of the themes emerging from this PhD and how they cut across all the papers is presented in Table 8.1.

Table 8.1: Summary of significant findings by cross-cutting themes and papers

Themes	**Paper 1:** An integrated approach to improving the availability and utilization of TB healthcare in rural South Africa.	**Paper 2:** Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews.	**Paper 3:** Time and money: the cost of utilizing HIV and TB treatment and care in rural KwaZulu-Natal	**Paper 4:** Engaging healthcare providers: responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal
Availability of healthcare services and patient utilization patterns	Integrated HIV and TB services Availability of comprehensive (and support) services Travel time and modes of transport	Availability of comprehensive services and care	Travelling time to healthcare facilities to utilize care	Service utilization and quality of care Modes of travel and transport costs Distance to facility
Patient satisfaction and quality of care	Patient factors to accessing and utilizing healthcare services Reasons for not using closest clinic Preference of healthcare provider	Quality of care indicators Preference of healthcare provider Suggestions to improve care		Healthcare providers perspective on patient satisfaction Role of healthcare providers in quality of care provision Staff working conditions
Costs of utilizing healthcare services	Free-of-charge HIV and TB care at the point of care Travel time Mode of travel		Financial and time costs of utilizing care Borrowing and selling assets to finance healthcare Expenditure on alternative and private healthcare services Disability grants	Disability grants Patient food and transport affordability
Healthcare provider perspectives to patient care and quality of care delivery		Health system enablers and barriers to quality of care	Patient expenditures utilizing healthcare Waiting time at facility to utilize care Disability grants	Perceived challenges to providing quality of care Response to patient perspectives with care

Findings across all the themes are discussed guided by the conceptual framework presented in Chapter 3, revised and presented below in Fig 8.1 to show the factors identified in the study.

Figure 8.1: Conceptual framework of this PhD study – showing the factors identified in the study



A reflective piece is included to put the study findings in context – taking into consideration the time elapsed between the studies that contributed to this PhD and the changes in policies that might have affected the way results are interpreted or used to inform policy. Lastly, the Chapter finishes with study strengths and weaknesses; recommendations and questions for future research.

The study findings suggest almost universal HIV testing among TB patients which is encouraging [Chapter 4 Paper 1 and Paper 1b]; compared to rates reported in 2010, the current rate of 94% is an improvement most likely due to the Provider Initiated Testing and Counselling (PITC) policy and the Stop TB campaign and changes in WHO guidelines, which encouraged screening of TB in all HIV patients and HIV testing in all TB patients and healthcare providers offering HIV testing to all patients regardless of the care they were seeking. (WHO., 2010a) Integration of TB and HIV services in primary healthcare (phc) services ensures improved patient accessibility to comprehensive healthcare as demonstrated here.(Coetzee et al., 2004; Gandhi et al., 2009; Wallrauch et al., 2010) Both ART and TB patients reported they were able to utilize other healthcare services when needed, including antenatal care, treatment of minor ailments and drug pick-up of chronic diseases such as high blood pressure, within the clinic facility [Chapter 4 Paper 1 and Paper 1b] and that the operating hours were convenient, indicating that joint delivery of TB and HIV in phcs serves to support availability and good accessibility to comprehensive healthcare in the study area.

Integration of services on its own may not be sufficient, but merely serve to improve ease of access of services and be time-saving by enabling utilization of combined TB and HIV treatment at the same phc during the same visit. Drug stock-outs for other ailments including headache, flue and rashes or chronic medication such as for heart disease, diabetes and hypertension were reported in this PhD and meant patients had to travel further to seek care or go without treatment in some cases which affects the affordability of healthcare services [Chapter 4 Paper 1 and Chapter 7 Paper 4]. The issues of intermittent drug shortages particularly ARVs - tenofovir was highlighted in Chapter 7 Paper 4 which was reported to affect service delivery and the quality of care the healthcare providers could deliver to the patients. However, drug shortages are not unique to this study area, but are a frequent national problem with its effect felt greatest in the rural settings due to poor supply chain management and limited resources.(Bateman, 2013) Further, TB and ART patients reported to have been sent away for lack of treatment, which may impact on treatment outcome, viral load suppression and drug resistance for ART

patients and development of drug resistance for TB patients. Further, with the new WHO guidelines recommending immediate treatment for all upon HIV diagnosis, consistent availability of drugs in facilities will be key (WHO., 2015b) There is need also to improve TB and HIV healthcare support services in respect of DOTS delivery for TB patients and provision of support groups such as treatment buddies and home visits and pillboxes for ART patients to support sustained adherence to treatment.(Coetzee et al., 2004; Gandhi et al., 2009) The gap in the DOTS delivery system identified in this PhD, creates an opportunity to strengthen the current TB programme, e.g. through community-based linkages and DOTS support on the part of policymakers and district management teams, as proposed in efforts to reform the SA health system. (National Department of Health., 2011a; Pillay & Barron, 2011) In Cape Town South Africa, ART adherence clubs have been found to be both effective in supporting adherence and retention in care as well as reducing patient time and costs to travel and pick-up treatment at the facilities every month.(Grimsrud et al., 2015; Luque-Fernandez et al., 2013; Wilkinson, 2013). Healthcare providers need to be empowered through on-going training and workshops to take responsibility of the programs running at their facilities to respond to specific needs of their patients and improve health delivery and quality of care they provide. Programs delivered through facilities need the buy-in and support of healthcare providers for them to be efficient and effective.

In this study area, the average travelling time for HIV and TB patients attending phcs is two hours for a return trip [Chapter 4 Paper 1 and Chapter 6 Paper 3]; such time losses arising from accessing HIV and TB treatment are a potential threat to treatment uptake and retention in care as well as adherence; some patients [Chapter 4 Paper 1] reported missing clinic visits due to lack of money for transport. Policymakers could consider providing subsidized transport for all patients with chronic conditions, including HIV and TB patients and establishing ART adherence clubs as has been done in Cape Town and Mozambique.(Decroo et al., 2013; Grimsrud et al., 2015) Increasing the geographical density of phcs including mobile clinic points in rural areas to increase availability and accessibility of services could be another possible option.

This PhD study found that healthcare-related costs for HIV and TB patients using the phc clinics for their treatment and care are real and quite substantial, despite HIV and TB services provided free of charge at point of service. More than half of the patients were using minibus taxis to and from the clinic [Chapter 4 Paper 1, Chapter 6 Paper 3 and Chapter 7 Paper 4]. Monthly health expenditures on travelling

and seeking alternative healthcare were high, close to ZAR 200 which would translate to about 27USD at that time [2010] each for pre-ART, ART and TB care visits [Chapter 4 Paper 3]. Transport was the single largest cost component for all patients groups, similar to what has been reported elsewhere, and contributed to high expenditure among HIV and TB patients who have frequent clinic visits.(S. Cleary, Birch, Chimbindi, Silal, & McIntyre, 2013; Goudge, Gilson, Russell, Gumede, & Mills, 2009b; Hardon et al., 2007; Kruk et al., 2009; Onwujekwe et al., 2010; Rosen et al., 2007) Both TB and HIV patients are instructed to make monthly clinic visits to collect their medicines, whereas those not yet eligible for ART are instructed to make about four clinic visits per year. Two of these four visits in pre-ART care are for physical examination and blood taking for CD4 counts; the other two are to receive the CD4 count results and to decide on treatment eligibility. Clinic visits were reported to be more frequent during drug stock-out periods [Chapter 7 Paper 4], which thus increased overall costs for patients. These healthcare expenditures are very large from a patient standpoint, especially in a study area with high unemployment rates and dependency on social grants for food and transport needs [Chapter 7 Paper 4].(Gradin C., 2014) The high healthcare expenditures often led to financial distress defined as borrowing money or selling household assets to pay for healthcare which may drive patients into debt or foregoing essential basic needs such as food and education to pay for healthcare.

In addition to financial expenditures, patients face substantial time costs associated with care seeking, primarily due to the time required to travel to clinic visits. These patient costs are very likely large enough to influence ART and TB treatment uptake, adherence, and retention. Interventions to reduce the private costs of care could increase early treatment initiation and sustained viral suppression with benefits for patients and potentially large spillover effects in reducing onward transmission. A critical gap in the HIV cascade of care has been the transition from pre-ART to ART, with high attrition from pre-ART care,(Lamb MR et al., 2014; Lessells et al., 2011; Mulissa, Jerene, & Lindtjorn, 2010) and many patients are still initiating ART at low CD4 counts.(Lessells et al., 2011; Mulissa et al., 2010) One common explanation for this gap is the perception that the patient-borne costs of ART are significantly higher than the costs during pre-ART due to the burden of frequent and lengthy clinic visits to pick up medicines and that these costs discourage patients from initiating as early as they might. However, this theory is not supported by the data in this setting as financial distress was not significantly different from between the patient groups. Further, with the new WHO guidelines, there might no longer be the pre-ART patient group if all people who test HIV positive are immediately initiated onto ART. However,

this perception may still deter people to access ART if they are not symptomatic as found in the Treatment as Prevention (TaSP) trial just completed in the study area.(Iwuji et al., 2016)

Patient health-seeking behaviors such as seeking care from alternative healthcare providers including traditional healers, pharmacies, and private doctors were proving expensive for HIV and TB patients. Pre-ART patients spent a significantly larger amount of money on traditional healers, pharmacies, and private doctors than HIV and TB patients [Chapter 7 Paper 4]. Use of alternative healthcare providers is common in South Africa and can result in hidden costs of illness not captured in facility-based costing studies.(S. Cleary et al., 2013; Moshabela, Pronyk, Williams, Schneider, & Lurie, 2011; Rosen et al., 2007; Russell, 2004) Usually HIV patients, if not yet eligible for ART, tend to seek alternative (and likely less efficacious) forms of therapy, which could imply that the demand for treatment for HIV is high among HIV patients.(Moshabela et al., 2011; Peltzer, Preez, Ramlagan, & Fomundam, 2008) Much has been made of the pattern in which HIV patients use both ART and traditional, complementary, and alternative medicines simultaneously.(Moshabela et al., 2011) In Chapter 4 Paper 1, seeking care from alternative healthcare providers, including for traditional medicines, was reported as a reason for not using care when needed by both HIV and TB patients. Interestingly, private expenditures on alternative sources of care all but disappeared for patients who had initiated ART, suggesting that in fact ART and alternative medicines may be substitutes rather than complements in this population.(S. Cleary et al., 2013; Moshabela et al., 2011; Rosen et al., 2007; Russell, 2004) A likely explanation is that once patients initiated ART, they no longer had the symptoms for which they were seeking alternate sources of care and also doctors in the ART programme were strict about telling patients not to use traditional medicine – whether they did or not, they may have reported not as they know the doctors did not like it. These findings have powerful implications for the rollout of HIV universal test and treat programmes, suggesting that initiating ART earlier may not impose large financial burdens on patients, but rather relieve them from other health expenditures on less efficacious therapies such use of traditional medicines, self-care or over the counter treatment. However, experience in the TasP trial evaluating HIV Treatment as Prevention in the study area recently, found slow linkage to care for asymptomatic patients, which was not explained by distance to clinic, long queues or lack of dedicated health care professionals.(Iwuji et al., 2016)

Although this did not specifically come out of this PhD work, there is a possibility that patients may seek care from alternative healthcare providers probably because of the poor quality of care and lack of satisfaction with the care provided in the public sector – despite it being provided free of charge. This relationship shows the link between the acceptability and affordability dimension of care. Patient satisfaction with the quality of care received is an important factor associated with overall patient satisfaction and can possibly affect health outcomes because it determines long-term retention in care as well as adherence. In Chapter 5 Paper 2 and Chapter 7 Paper 4 of this study, findings suggest that the way scaling-up of HIV and TB treatment and care is delivered is equally as important as increasing accessibility, availability and geographical coverage of services to increase the number of patients on treatment to decrease HIV-related mortality and transmission. Patients attending HIV and TB treatment services in the study area reported high levels of overall satisfaction with their experience with utilizing healthcare services on the day of the interview. However, as has been found in other studies (Alemayehu, Bushen, & Muluneh, 2009; Appiah et al., 2009; Wouters, Heunis, van Rensburg, & Meulemans, 2008a) high overall satisfaction level masked substantial dissatisfaction with particular aspects of the services, including the availability of health workers and drugs and equipment [Chapter 4 Paper 1 and Chapter 7 Paper 4], the respect health workers showed patients, waiting times, and cleanliness of facilities [Chapter 4 Paper 1, Chapter 6 Paper 3 and Chapter 7 Paper 4].

In this study, there were significant differences in satisfaction levels between HIV and TB patients, with more HIV than TB patients reporting being less satisfied with some aspects of quality of care (in particular respectfulness of treatment, waiting times, and availability of waiting areas and toilets). More HIV than TB patients reported feelings of stigma [Chapter 4 Paper 1] probably indicating the nature of disease condition – HIV is for life and TB treatment is for 6-24 months - could influence satisfaction and utilization of services. Further, differences in satisfaction levels between HIV and TB patients may be partly due to historical differences in the organizations of healthcare delivery and the speed of increase of patient load; unlike the TB treatment programme, the HIV treatment programme experienced an extremely rapid increase in patient load, which is likely to have led to temporary mismatches between human and physical resources for service delivery and patient demands.(N. Chimbindi et al., 2014)

Health facilities may not always be well-prepared for rapid increases in patient load due to scale-up of programmes brought about by changes in guidelines and policies, with as a result poor quality of care.

Shortage of staff came up as a challenge to providing good care in almost all the papers [Chapter 4 Paper 1, Chapter 5 Paper 2 and Chapter 7 Paper 4]; healthcare providers sometimes felt pressured by the large patient load to see many patients in a short space of time, leading to concerns by some patients that the health workers were too busy to listen to their problems (Chapter 7 Paper 4). In response to the latter comment, healthcare providers blamed their bad staff attitudes on the clinic being short-staffed relative to the patient load and as a consequence they were burnt-out and fatigued (Chapter 7 Paper 4). Lessons learnt from this PhD study for scale-up of programmes include the need to increase resources (human, equipment, infrastructure) in the facilities in proportion to the increased patient load as well as provide support mechanisms (improved working conditions, on-going training, increased providers' decision making space and motivation) for the healthcare providers to cope with the increasing work load. The PhD study also demonstrates that patient barriers to healthcare utilization are not uniform across patient groups - therefore programmes should not be a one-size-fits-all but tailored to meet patient needs in their different settings or contexts. Patient affordability (transport and time costs) and acceptability barriers (respect, stigma and disclosure) will likely remain despite good programme initiatives at the facility-level, therefore there is need to include community-care givers to support community-based programs (such as establishing adherence clubs, DOTS supporters, bringing drug pick up points closer to patients homes) for adherence and retention in care of patients in the communities.

Similar to this study, several previous studies have found waiting times due to queues to be a main determinant of patient satisfaction.(Lyatuu, Msamanga, & Kalinga, 2008; Mfinanga et al., 2008; Wouters et al., 2008b) Comparing both patient groups, HIV patients were significantly more dissatisfied with the length of the queues than TB patients. Based on observation and practice in both programmes, queuing times for TB treatment were usually shorter than for HIV patients because of the processes involved in receiving care - TB patients join one queue to collect their treatment; the data clerk and TB nurse are in the same room to provide the patient clinic file and offer counselling before giving out treatment whereas HIV patients normally have to join two queues – first to see a counsellor and then to see a nurse for clinical assessment and medication. The queues were even longer due to ART drug stock outs which meant frequent patient clinic visits or delayed patient treatment initiations [Chapter 7 Paper 4]. With the proposed WHO guidelines to initiate HIV ART immediately upon HIV diagnosis for all, there is need to improve on the supply chain management to ensure ARVs are always available.(WHO., 2015b) It was interesting to get the assumed patient and provider role through the recommendations

from patients and reported efforts from healthcare staff regarding improving the queuing system– in Chapter 5 Paper 2 patients suggested health workers should work in shifts to make queuing a more pleasant experience and provide food rations, and transport to reduce travel times to and from the clinics. On the other hand – healthcare providers indicated working long hours and not taking lunch breaks in order to serve their patients [Chapter 7 Paper 4].

There is a need to strengthen the health systems in terms of human resources and availability of drugs, especially in light of the new adopted WHO ART initiation guidelines(WHO., 2015b) for universal treatment with likely further increasing numbers of HIV positive people on treatment. Although there is no evidence that patient satisfaction directly improves clinical outcomes, patients' disengagement in care has been suggested to be associated with quality of services, implying an indirect relationship between patient satisfaction and retention in care.(N. C. Ware et al., 2009; N.C. Ware et al., 2013; WHO., 2011)

The South African rural healthcare delivery systems struggle due to inequities in resource allocation including human resources (RHAP & Partners., 2013; Versteeg & Couper, 2011) and this is worsened by high disease burden including HIV.(Mayosi et al., 2012; Padarath A. & English R., 2013) Most clinics in this study were rural and patient load relative to the staff complement was high. Poor working conditions and lack of drugs [Chapter 4 Paper 1, Chapter 5 Paper 2 and Chapter 7 Paper 4] and equipment, and uncertainty regarding staffing and funding of the ART programme at the time of the study may have destabilized working teams in facilities, which may have affected morale, as well as other factors such as training, remuneration/incentives, management and leadership at facility level.(Cane, O'Connor, & Michie, 2012; Michie, van Stralen, & West, 2011)

South Africa DoH guidelines for ART eligibility have changed over time, in line with WHO guidelines.(South Africa Department of Health., 2013; South African National Department of Health., 2010) Consequently, on-going training of staff on the new ART policies and treatment guidelines is required to ensure that they are implemented well. Some staff improvised the guidelines, prioritizing what was practical for their facilities given the limited resources as well as making adjustments that helped reduce transport costs which are a major cost for patients [Chapter 6 Paper 3 and Chapter 7 Paper 4]. However, it is unclear whether such innovation is beneficial in retaining patients in care in the long run. The issues raised in this study are salient to HIV care and may affect patient's engagement in care.

Engaging healthcare providers in a regular discussion may empower staff to be active agents of change and provide the ability to deal with the reality of constraints within a quality improvement framework. There is need to strengthen human resources for health especially in light of the new ART initiation guidelines for universal treatment to support healthcare provider's efforts.

Reflective piece of the PhD work

The time elapsed between the studies – the REACH study was conducted in 2009, the Impact of ART on HIV epidemic dynamics in 2010 and the Healthcare providers' study in 2012, could have implications on how the data presented now is interpreted as some things might have changed over time and new policies introduced which might affect the way findings are interpreted today. In the three years between the patient survey and the Healthcare providers' study, changes in the system included the introduction of NIMART (Nurses Initiating and Management of ART), increased patient load, and changes in the local programme with resulting job insecurity and temporary drug shortages. Further, patient satisfaction with healthcare services varies with time and context. Patient satisfaction could have improved due to changes in guidelines for initiation on treatment from CD4 count 200 cells/mm^3 during the time the study was conducted to the current <CD4 500cells/mm^3 and in September 2016, to test and treat which may result in improved health outcomes due to early initiation onto treatment. However, the changes in ART guidelines could have also worsened patient satisfaction if the health system particularly healthcare providers and drug availability did not change proportional to the increased patient demands for healthcare. If the new recommended WHO guidelines (which have been also adopted in South Africa), to immediately initiate onto treatment all those who test positive are followed, then the healthcare costs incurred by pre-ART patients may be eliminated altogether, only if the patients link to care immediately. However, because such policy has only been recently rolled out (end of 2016) in the lifetime of this PhD in the sub-district, to address the affordability challenges pre-ART, HIV and TB patients face, this PhD study findings remain important for informing policy makers with regards to affordability of care.

The difference in time between the REACH study and the Healthcare providers' study was three years. Clinic staff who were working in the clinics in 2009 during the REACH study whose attitudes the patients complained about, may have left the clinics by the time the Healthcare providers' study was done. However, the REACH ART patient view remained important for facilitating open discussions with

healthcare providers as the staff responded very well and could relate with both past and present challenges the patients faced. One of the major changes that occurred was the introduction of NIMART trained nurses in 2011 who could now initiate patients on ART and did not have to defer to doctors as previously. This change probably led to shorter waiting times at the clinics and improved access to comprehensive care as they did not have to wait for the doctor anymore. Although, the Hlabisa sub-district is not a pilot site for the National Health Insurance (NHI) scheme that South Africa is gradually rolling-out, some adopted NHI policies in the study area such as the National Core Standards for Quality Improvement in health establishments might have improved the quality of care provided at the facilities. Further, the Ideal clinic model (National Department of Health South Africa.) rolled out by the South African National Department of Health in 2013, clinics are encouraged to adopt in order to systematically improve primary healthcare facilities and the quality of care they provide have also changed the state of the clinics in terms of cleanliness, availability of drugs and equipment and improved systems of delivering care. However, the findings of this PhD study (2012) still remain relevant in providing lessons learnt for scale-up of such programmes. For example, this PhD study highlighted the importance of cleanliness of facilities for both patient satisfaction with services provided and healthcare providers' perception of the quality of care they can provide, with dirty facilities being attributed to shortage of water and old buildings. In summary, the findings of this PhD study remain relevant and inform policy-makers and decision-making despite the time elapsed and they have to be interpreted in the context of the time the events occurred.

Strengths and limitations of this PhD study

This study had several limitations. First, due to the nature of the clinic-based sampling strategy, people in need of health care who did not access health care, including those who did not access health care because they could not afford it were excluded. Second, it is possible that the cross-sectional comparisons across patient types—pre-ART, ART, and TB were confounded by unobserved factors which could influence effect estimates although the study controlled for employment status of household head and basic demographics. Lastly, because these were a series of cross-sectional studies causal-inference cannot be made, however associations identified are useful for generation of hypotheses and identification of further research areas such development of interventions and systems to reduce patient costs and waiting times. This PhD study used mixed methods – both quantitative and qualitative methods and was multi-phased in time which allowed for one study to feed into/inform the other as well as triangulate findings and fill in gaps to give a more complete picture. Further , this PhD study

addressed the main challenge of chronic care provision from initiation of individuals onto treatment, remaining on treatment (patient side barriers) and challenges with ability to provide quality of care for better treatment outcomes and patient satisfaction (healthcare provider side barriers). A variety of methods (both quantitative and qualitative) were used to capture patient and healthcare providers data at different points in time (2009, 2010 and 2012) to describe the changes that happen with time. The PhD candidate investigated the utilization challenges patients face at different stages of diseases – pre-ART and while using ART and also for a common HIV co-infection -TB, with the disease conditions having different duration periods – HIV is for a lifetime and TB is for a limited-time although there can be relapses in TB disease, which provides a rich picture of the similarities and contrasting utilization challenges different, but related, patient groups face when utilizing healthcare.

Conclusions and policy implications

The findings from this PhD demonstrate almost universal HIV testing among TB patients and patients' reported considerable ability to access and utilize their closest clinics and to receive comprehensive care. The high HIV testing rates among TB patients suggest that integration of HIV/TB services enables availability and utilization of healthcare services. Global satisfaction with services provided was high among both HIV and TB patients. However, HIV and TB patients' evaluations of specific aspects of health services delivery revealed substantial dissatisfaction levels between HIV and TB patients which are likely due to historical differences in the organizations of healthcare delivery in the HIV and TB treatment programmes.

Patients receiving nominally free care for HIV/TB face large private costs, commonly leading to financial distress. The study shows evidence of high healthcare–related financial expenditures and time costs among adults using public-sector HIV and TB services, although these services are provided free at point of service. Monthly private health expenditures from the patient perspective are very large, especially in a study area with high unemployment rates. Policymakers could consider reducing the number of visits ART patients have to make, increasing the time between visits, establishing treatment groups with rotating clinic attendance as is the case with ART adherence clubs, and increasing and training community healthcare workers and teams based closer to the people responsible for health

profiling of these families. Fewer clinic visit schedules for stable patients and bringing drug pick-up points closer to patients' homes could ease patient transport costs.

Engaging healthcare providers in discussion raised significant issues in HIV programmes, potentially affecting patient's engagement in care. Healthcare providers showed resilience, endurance and devised coping mechanisms within limited resources to provide quality care to patients, such as using their personal resources to address patient individual challenges. The healthcare providers' responses show a commitment to providing quality care and to their profession suggesting the need to strengthen the healthcare system to support healthcare provider's efforts. Task-shifting, using a patient appointment system and ensuring an efficient supply chain management to avoid drug stock outs are some of the means to strengthen and support healthcare providers' efforts and reduce frequent patient clinic visits, long queues and waiting times. Improvement in infrastructure may also assist in making the patient environment acceptable and in line with the quality of care guideline framework.

Further research is recommended to understand factors affecting utilization in those in need of but failing to use care. The current primary healthcare delivery system may need to be re-engineered to accommodate the WHO (and SA) HIV treatment guidelines, which now include universal (and repeat) testing, with immediate ART for all people diagnosed with HIV, irrespective of their HIV disease progression; these new guidelines have the potential to overwhelm an already overburdened system with increased patient demand, who need to be initiated on ART for life. Further increased cases of TB are also likely to be identified in the process and increase the patient load at the facilities. However, these changes might lead to reduced stigma of HIV as more asymptomatic people will come to the clinic for ART. Stable patients on treatment for more than a year, need to be provided with ART for three (rather than one) month at a time, to reduce patient load at the clinic. Setting up drug dispensing points within the communities for stable patients on chronic care including diabetes, asthma and hypertension can assist to destigmatize HIV and also reduce patient load at the clinics. Adherence clubs and support groups could help cut back on transport costs for patients and especially working patients who were found in this PhD study to fear losing income while utilizing care.

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Appendices

REACH

PATIENT INTERVIEW CONSENT FORM

TRACER: ART

CONSENT TO PARTICIPATE IN THE INTERVIEW

Facility: *[enter name of facility]*_____

I HAVE BEEN INFORMED ABOUT THE PROJECT *RESEARCHING EQUITY IN ACCESS TO HEALTH CARE*, AND I UNDERSTAND THAT IT IS UP TO ME WHETHER OR NOT TO BE INTERVIEWED.

I understand that there will be no consequences of any kind through my responding to this questionnaire; in particular, there will be no impact on the care that I receive in this hospital.

I understand that I can ask the person interviewing me to stop the interview at any time.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are analysed.

Yes, I give my permission for the interview ☐

_____ _____
Interviewee's signature Date

_____
Interviewer's name (please print)

_____ _____
Interviewer's signature Date

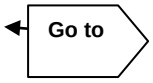
REACH PATIENT INTERVIEW QUESTIONNAIRE TRACER: ART	
0.1 Date of interview	dd mm yyyy
0.2 Interviewer name	_____
0.3 Patient number	**Place sticker here**
0.4 Start time of interview	_____:_____ hour min
0.5 Site (name of facility)	_____

Instructions for interviewers:

This research is part of a multi-center study and the questionnaire has therefore been adapted to suit the different sites. In your site, questions that do not need to be asked are blocked out in dark grey and the font is in a lighter grey.

Questions or parts of questions that do not always need to be read out and instructions are in highlighted text.

Skips indicating which questions can be left out are indicated by arrows



Unless specifically asked to do so, options do not need to be read out.

SECTION 1: SOCIOECONOMIC AND DEMOGRAPHIC BACKGROUND QUESTIONS ABOUT THE RESPONDENT, HIS/HER HOUSEHOLD AND HOUSEHOLD HEAD

READ OUT

I am going to start by asking you a few questions about you and your household. A household is a social group of one or more individual members. The members are usually, but not always, related. They share in the joint household resources and know each other well enough to provide information about each other.

In each household, one of the members is considered to be the head of the household. This person is usually, but not always, a senior male member of the household.

1.1 Sex	Male	1
	Female	2

1.2 Note the race of the respondent. If you are not certain, ask: How would you describe yourself racially?	African/Black	1
	Coloured	2
	Asian/Indian	3
	White	4
	Other	97
	If other, specify	

1.3 What was your age at your last birthday? Fill in one block only	Year born	Years

1.4 Who is the head of your household? This is the person who is considered by the other household members to be their head. Indicate relationship e.g. father, mother not name.	Relationship	**If respon-dent HHH, go to 1.9**

1.5 Code sex of HHH. If not clear ask: What is the sex of your HHH?	Male	1
	Female	2

1.6 Code position in HH of respondent. If unclear, ask: What is your position in the household, in relation to the household head such as …read out a few relevant options. Circle one only	Head/acting head	1
	Husband/wife/partner	2
	Son/daughter/stepchild/adopted child	3
	Brother/sister/step brother/step sister	4
	Father/mother/step father/step mother	5
	Grandparent/great grandparent	6
	Grandchild/great grandchild	7
	Other relative (e.g. in laws or aunt/uncle)	8
	Non-related persons (tenant, boarder, lodger)	9
	Don't know	99
	Other	97
	If other, specify	

1.7 What was the age of your HHH i.e. husband / father / mother etc**.** at his/her last birthday? fill in one block only	Year born	Years

1.8 Does your HHH i.e. husband / father / mother etc**.** stay with you for at least 2 weeks each month?	Yes	1
	No	0

1.9 What is your current marital status? Circle one only		
	Married	1
	Living with partner	2
	Widow/widower	3
	Divorced or separated	4
	Never married (single)	5
	Other	97
	If other, specify	

1.10 What is YOUR highest level of education? Circle one only If the person is NOT the HHH ask What is the highest level of education of your HHH i.e. husband / father / mother etc.	**Type of education**	**You**	**Your HHH**
	No schooling	0	0
	Highest grade passed in school (1-12)		
	Completed diploma/certificate	13	13
	Completed degree	14	14
	If other, specify	**You**	**Your HHH**

1.11 Are you currently employed working or earning money? If the person is NOT the HHH ask Is your HHH i.e. husband / father / mother etc. currently employed?	**Type of employment**	**You**	**Your HHH**	
	Yes, full-time	1	1	**If no or don't know go to 1.13**
	Yes, part-time	2	2	
	No	3	3	
	Don't know	99	99	

1.12 If respondent employed ask: Are you self-employed or do you work for someone else? If HHH employed, ask: Is your HHH i.e. husband / father / mother etc. self-employed or does HE/SHE work for someone else?	**Type of employment**	**You**	**Your HHH**	
	Self-employed	1	1	**Go to 1.14**
	Employee	2	2	
	Don't know	99	99	

1.13 If respondent not employed ask: What are the reasons that you are not employed? Circle "Yes" or "No" on every row.	**Reason**	Yes	No
	Studying	1	0
	Looking for work	1	0
	Retired or pensioner	1	0
	Sick or injured	1	0
	Pregnant or caring for own children	1	0
	Caring for other children	1	0
	Caring for sick/injured	1	0
	Retrenched	1	0
	Nothing	1	0
	Don't know	99	
	Other	97	
	If other, specify		

1.14 Including yourself, how many adults **(18 years or older)** live in your household? When I talk about your household, I am talking about people that share in the joint household resources and know each other well enough to provide information about each other.	_____ No. Adults 18 or older
1.15 How many children **(younger than 18 years)** live in your household?	_____ No. Children under 18

1.16 Does anyone in your household receive a government grant OR income from the government such as…….read out each option and circle yes or no.

IF YES ask:
How many of each type of grant is received (i.e. how many people receive each?)

Type of grant	Yes	No	If yes, number received
Unemployment insurance (UIF)	1	0	
Worker's compensation	1	0	
State old age pension	1	0	
Disability grant	1	0	
Child support grant	1	0	
Care dependency grant	1	0	
Foster care grant	1	0	
Grant in aid	1	0	
Social relief	1	0	
Other	1	0	
Don't know	99		

If no DG go to 1.19

1.17 If someone in the household receives a disability grant, ask: Is it you that receives the disability grant?	Yes	1
	No	0

If no go to 1.19

1.18 If YES ask: What is the reason that you receive this disability grant?	_____ _____ _____

1.19 If NO ask: Have you applied for a disability grant?	Yes	1
	No	0

1.20 Where were you born? READ OUT I know this is a sensitive question to ask at this stage, but we are asking because we want to see if health services treat South Africans differently to those who are not from South Africa.	South Africa	1
	If other, specify	

If other go to 1.22

1.21 **If respondent born in South Africa, ask:** Which province were you born in? Use current province borders	Western Cape	1
	Eastern Cape	2
	Northern Cape	3
	Free State	4
	KwaZulu-Natal	5
	North West	6
	Gauteng	7
	Mpumalanga	8
	Limpopo	9
	Don't Know	99

Go to 1.23

1.22 If respondent not born in South Africa, ask: Do you have a South African ID document?	Yes	1
	No	0
1.23 Are you covered by a Medical Aid or any scheme that helps you pay for health-care services or medicines?	Yes	1
	No	0

SECTION 2: UTILISATION OF HIV AND OTHER HEALTH SERVICES AND INDIRECT COSTS OF THE DISEASE

READ OUT: In this section I am going to be asking you some questions about the health care that you have used for your HIV.

2.1 When did you find out you were HIV positive?	_____ MM YYYY
2.2 When did you FIRST begin receiving antiretroviral (ARV) treatment?	_____ MM YYYY
2.3 Where were you diagnosed with HIV?	_____ Facility name/mobile clinic/at home _____ Province/city/village/township

2.4 How often do you collect your ARV treatment here at the clinic?	Monthly or less (weekly/bi-weekly)	1
	2-monthly	2
	More than 2 monthly	3

2.5 Who supports you in taking your ARV treatment each day? indicate relationship e.g. sister, friend etc, can be more than one	_____ Relationship _____ Relationship _____ Relationship _____ Relationship

2.6 Have you received ARV treatment from a clinic other than this one?	Yes	1
	No	0

2.7 Besides ARVs, are you able to get the other health services you need in this facility?	Yes	1 ←	**If yes go to 2.9**
	No	0	
2.8 If NO ask: What services do you have to get elsewhere?	_____ _____ _____ _____		

READ OUT: Some people find it quite hard to stick to the ARV treatment and might not always be able to make their appointments at the clinic. We are now going to ask you about whether you have had any of these sorts of problems and what the reasons might be.

2.9 Did you miss taking any of your ARV tablets YESTERDAY?	Yes	1	
	No	0	
2.10 Did you miss taking any ARV tablets the day before YESTERDAY?	Yes	1	
	No	0	
2.11 Did you miss taking any ARV tablets 3 DAYS AGO? Specify the calendar day in relation to the day of the interview	Yes	1	
	No	0	
2.12 Apart from the last three days, have you ever missed taking any ARV tablets?	Yes	1	
	No	0	
2.13 Have you missed any visits to the ARV clinic in the last 6 months?	Yes	1	
	No	0 ←	**If no go to 2.16**
2.14 IF YES How many visits did you miss?	_____ No. visits		

2.15 What was the reason(s) for missing the visits? Do not read the list aloud; probe respondent to give you up to three reasons. Circle up to three yes options and circle all others no	**Reason**	**Yes**	**No**
	Lack of money	1	0
	Lack of time	1	0
	I felt better	1	0
	I could not take time off from work	1	0
	No transport	1	0
	Too ill to travel	1	0
	Other responsibilities	1	0
	The treatment is not effective / does not make me feel better	1	0
	The queues in the facility are too long	1	0
	The staff are rude or uncaring	1	0
	I have had bad experiences with staff in the past	1	0
	Don't know	99	
	Other	97	
	If other, specify (1)		
	If other, specify (2)		

2.16 Apart from visits to this clinic for your ARVs, have you used this clinic or any other health service in the last four weeks? Specify in relation to the calendar date Read out each option one at a time. IF YES ask: How many visits (or inpatient days) did you have? Then ask: How much did you have to pay the provider for each? Circle all that apply "Yes" and others "No"	**Type of facility or service**	**Yes**	**No**	**If yes, times used**	**If yes, amount spent**
	Chemist/pharmacy	1	0		
	This clinic (not for ARVs)	1	0		
	A different public clinic	1	0		
	A private doctor	1	0		
	A traditional healer	1	0		
	A public hospital emergency/ outpatient department	1	0		
	Inpatient stay in a public hospital	1	0		
	A private hospital emergency/ outpatient department	1	0		
	Inpatient stay in a private hospital	1	0		
	TB clinic	1	0	**Leave blank**	
	Antenatal clinic [women only]	1	0		
	Other	1	0		
	If other, specify				

2.17 Have you spent any other money on health care in the past month (e.g. traditional medicines, spaza shops, special food, etc). IF YES, how much have you spent?	Yes	1
	No	0
	If Yes, specify amount _____ (Rand)	

SECTION 3: AFFORDABILITY

READ OUT: I am now going to ask you some questions about the financial difficulties you might face in seeking health care for your HIV/AIDS.

3.1 In the last month did you have to borrow money to pay for healthcare?	Yes	1
	No	0

If no go to 3.3

3.2 If YES How much money did you borrow?	_____(Rand)

3.3 In the last month did you have to sell personal or household items in order to pay for healthcare?	Yes	1
	No	0

3.4 How much time did you spend at the clinic last time you came to collect your ARV treatment?	_____ hrs _____ minutes
3.5 How much time did you spend at the clinic last time you came to see the doctor/nurse for your ARVS?	_____ hrs _____ minutes

3.6 What would you have been doing if you weren't at the clinic today?

Circle "Yes" or "No" on every row.

Activity	Yes	No
Working for pay	1	0
Doing unpaid community work or volunteer work	1	0
Doing household chores such as cleaning, cooking, shopping for food, maintenance and repairs, working in the garden, gathering wood, gathering water, housework etc.	1	0
Taking care of children	1	0
Leisure activities (sport, watching TV, listening to music, reading, visiting friends and family, going to movies etc)	1	0
Attending school or other educational institution	1	0
Nothing	1	0
I don't know	99	
Other	97	
If other, specify		

3.7 In coming to receive treatment today, how much did you pay for:

Read out each item. If no money spent, code as "0" for each item

Category	Rand
Transport (one way)	
Clinic/hospital fees	
Medicines	
Someone to take over your tasks while you are here including childcare	
Accommodation if you need to stay the night nearby	
Food during visit	
Phoning or sms'ing	
Other, specify:	

If no expenses go to 3.9

3.8 Did you find it easy or difficult to incur these expenses? Refer to expenses in 3.7

Easy	1
Difficult	2
Neither easy nor difficult	3
Don't know	99

3.9 If respondent is working for pay
Did you lose income from the time you took from your job to come here today?

Yes	1
No	0

If no go to 3.11

3.10 If YES:
How much money did you lose? _____ (Rand)

3.11 Who has been helping you financially, i.e. with cash, buying food, providing transport etc, with your HIV/AIDS?

Circle "Yes" or "No" on every row.

Person	Yes	No
Husband/wife	1	0
Father/mother	1	0
Boyfriend/girlfriend	1	0
Other relatives	1	0
Friends	1	0
Nobody	1	0
Employer (over and above normal wages)	1	0
Don't know	99	
Other	97	
If other, specify		

SECTION 4: AVAILABILITY

4.1 Is this the closest clinic to your home that offers ARV treatment?	Yes	1	If yes go to 4.3
	No	0	
4.2 If NO Why do you prefer this facility?	_____ _____ _____		
4.3 Are the opening hours of this clinic convenient for you?	Yes	1	
	No	0	
	Don't know	99	

4.4 How did you get here today? Circle "Yes" or "No" on every row.	**Transport mode**	**Yes**	**No**
	By foot	1	0
	Bicycle	1	0
	Minibus taxi	1	0
	Bus / Train	1	0
	Own private car	1	0
	Other private car (can be meter taxi, hired car, catching a lift)	1	0
	Ambulance / hospital transport	1	0
	Other	1	0
	If other, specify		

4.5 How long did it take you to get here? (one way only) time taken from leaving home to arriving at facility	_____ hrs _____ minutes		
4.6 Do you currently belong to a support group	Yes	1	If yes go to 4.8
	No	0	
4.7 If NO Have you ever belonged to a support group in the past?	Yes	1	
	No	0	
4.8 Do you have a treatment buddy?	Yes	1	
	No	0	
4.9 Do you have a pillbox [show] for keeping your tablets?	Yes	1	
	No	0	
4.10 Since you learnt about your HIV status, has anyone from the health service ever visited you at home for your HIV?	Yes	1	
	No	0	
4.11 Are you able to give me the result of your latest CD4?	Yes	1	
	No	0	If no go to 4.13
4.12 If YES write result	CD4 count result		

READ OUT Please tell me if you think the following two statements are true/correct or false/incorrect:

4.13 It is acceptable to stop ARVs after gaining weight	True / correct	1
	False / incorrect	2
	Don't know	99

4.14 ARVs cure HIV/AIDS	True / correct	1
	False / incorrect	2
	Don't know	99

SECTION 5: ACCEPTABILITY

5.1 Have you told anyone besides the health care workers that you are HIV positive?	Yes	1	
	No	0	**If no go to 5.3**

5.2 IF YES Who have you told about your HIV status? indicate relationship e.g. sister, friend etc, not name	_____ Relationship _____ Relationship _____ Relationship _____ Relationship

READ OUT For the following three questions, please tell me whether you agree or disagree with the statements I make.

5.3 "I have all the support from my partner that I need to cope with my illness"?	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.4 "I have all the support that I need from my family"	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.5 "I have all the support that I need from my friends"	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.6 Do you feel that people in the community judge you negatively for attending this facility for your ARV treatment?	Yes	1
	No	0
	Don't know	99
5.7 For your ARV treatment what would you prefer: a) To see a nurse in a nearby clinic or b) To travel further to see a doctor	Nurse	1
	Doctor	2
	Indifferent	3
	Don't know	99
5.8 In this clinic are you able to talk to the doctors or nurses in private?	Always	1
	Sometimes	2
	Never	3

READ OUT: Can you tell me whether you agree or disagree with these statements when thinking about your general experience in this clinic?		
5.9 The queues to see a doctor or nurse are too long at this facility	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.10 The doctors and nurses (*health workers)* discussed the treatment fully with me	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.11 It is a problem that the *health workers* DO NOT speak my language.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.12 I find it easy to tell the *health workers* when I have missed taking my tablets	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
	Not applicable	98
5.13 The *health workers* are too busy to listen to my problems	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.14 Patient information is kept confidential in this clinic	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.15 Some staff DO NOT treat patients with sufficient respect	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.16 The health workers I see respect me	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.17 The facilities (including waiting area and toilets) are dirty	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99

5.18 How satisfied were you with the service today?	Very satisfied/ Satisfied	1
	Neither satisfied nor dissatisfied	2
	Dissatisfied/ Very dissatisfied	3
	Don't know	99

5.19 Since you first started coming to this facility, have you ever left without being helped?	Yes	1
	No	0 ← **If no go to 5.21**
5.20 IF YES Can you explain what happened?	_____ _____ _____	
5.21 Have you ever not used ARV services when you needed them?	Yes	1
	No	0 ← **If no go to 5.23**
5.22 IF YES Why did you not use ARV services? Include all factors – personal and facility-related	_____ _____ _____ _____	

5.23 How do you think the service in this clinic could be improved? Circle "Yes" or "No" on every row.	**Improvement**	**Yes**	**No**
	Shorter queues	1	0
	More health workers	1	0
	Cleaner facilities	1	0
	Better patient facilities (toilets, waiting room area etc)	1	0
	Don't know	99	
	If other, specify		

SECTION 6: DWELLING CHARACTERISTICS, HOUSEHOLD INCOME, EXPENDITURE AND HOUSEHOLD ASSETS

READ OUT Finally, we want to ask you some questions about the characteristics of the house where you live and type of facilities available within your household

6.1 Where do you live?	_____village or community _____area or township

6.2 Which best describes the type of house in which you live? **Clarify answer** **Circle one only**	House or brick structure on a separate stand or yard or on farm	1
	Traditional dwelling/hut/structure made of traditional materials	2
	Flat	3
	Town/cluster/semi-detached house (simplex, duplex or triplex)	4
	Unit in retirement village	5
	Dwelling/house/flat/room in backyard	6
	Informal dwelling/shack IN the backyard of a formal house	7
	Informal dwelling/shack NOT in backyard e.g. in an informal/squatter settlement or on farm	8
	Room/flatlet not in backyard but on a shared property e.g granny flat	9
	Caravan/tent	10
	Worker's hostel	11
	Other	97
	If other, specify	

6.3 What is the main material of your house's walls? **Clarify answer** **Circle one only**	Bricks & plaster/finished	1
	Bare brick/cement block	2
	Corrugated iron/zinc	3
	Wood	4
	Plastic	5
	Cardboard	6
	Mixture of mud and cement	7
	Wattle and daub	8
	Mud	9
	Other	97
	If other, specify	

6.4 What is the main material of your house's roof? **Clarify answer** **Circle one only**	Tiles	1
	Corrugated iron/zinc	2
	Thatching	3
	Asbestos	4
	Plastic	5
	Cardboard	6
	Other	97
	If other, specify	

6.5 How many rooms, including kitchens, does your house have? Interviewer, prove and exclude bathrooms, sheds, garages, stables, etc. from the total unless people are living in them.	_____No. rooms	
6.6 What is the main source of **drinking water** for members of your household? Clarify answer Circle one only	Piped (tap) water in dwelling	1
	Piped (tap) water on site or in yard	2
	Borehole on site	3
	Rain water tank on site	4
	Neighbour's tap	5
	Public/communal tap (either free or paid)	6
	Water carrier/tanker	7
	Borehole off site/communal	8
	Flowing water/stream/river	9
	Stagnant water/dam/pool	10
	Well	11
	Spring	12
	Other	97
	If other, specify	
6.7 What type of toilet does your household use? Clarify answer Circle one only	Flush toilet (connected to sewage)	1
	Flush toilet (with septic tank)	2
	Chemical toilet	3
	Pit latrine with ventilation pipe	4
	Pit latrine without ventilation pipe	5
	Bucket toilet	6
	No facility/bush/field	7
	Other	97
	If other, specify	
6.8 What is the main source of energy for cooking in your household? Clarify answer Circle one only	Electricity from mains	1
	Electricity from generator	2
	Gas	3
	Paraffin	4
	Wood	5
	Coal	6
	Animal dung	7
	Solar energy	8
	Other	97
	If other, specify	

6.9 Does your household have any of the following items in good working order? Read out each item and circle "Yes" or "No" on every row.		**Yes**	**No**
	Telkom / landline phone	1	0
	Cell phone	1	0
	Radio	1	0
	Television	1	0
	Video recorder/DVD player	1	0
	Electric stove with oven	1	0
	Bicycle	1	0
	Personal computer at home	1	0
	Internet facilities at home	1	0
	Fridge	1	0
	Car/truck/bakkie	1	0
	Primus cooker, Sikeni	1	0
	Electric hot plate	1	0
	Gas cooker	1	0
	Electric kettle	1	0
	Sewing machine	1	0
	Block maker	1	0
	Motorcycle or scooter	1	0
	Kombi, lorry or tractor	1	0
	Bed	1	0
	Table and chairs	1	0
	Sofa or sofa set	1	0
	Kitchen sink	1	0
	Car battery for electricity	1	0
	Wheelbarrow	1	0
	Hoe, spade or garden fork	1	0
	Bed nets	1	0
	Cattle	1	0
	Other livestock (chickens etc)	1	0
6.10 Does your household own cattle, livestock or chickens?		Yes	1
		No	0

If no go to 6.16

6.11 **IF YES** How many cattle does the household own?	_____ (No. cattle)	
	None	0
	Don't know	99
6.12 **IF YES** How many goats does the household own?	_____ (No. goats)	
	None	0
	Don't know	99
6.13 **IF YES** How many chickens does the household own?	_____ (No. chickens)	
	None	0
	Don't know	99
6.14 **IF YES**	_____ (No. pigs)	

How many pigs does the household own?	None	0
	Don't know	99
6.15 **IF YES** Does the HH own any other farm animals? **IF YES** What are they How many [other] does the household own?	If other, specify (No. other)	
	None	0
	Don't know	99
6.16 In general how much does your household usually spend in a month? If the respondent does not give you a precise estimate ask him/her In which of the following ranges, would you say your household EXPENDITURE generally falls? Circle one only	_____Rand	
	R0 – R399	1
	R400 – R799	2
	R800 – R1 199	3
	R1 200 - R1 799	4
	R1 800 - R2 499	5
	R2 500 - R4 999	6
	R5 000 - R9 999	7
	R10 000 or more	8
	Don't know	99
	Refuse	97
6.17 Do you have anything else that you would like to tell us about your experience of seeking or receiving care at this facility?	_____ _____ _____ _____ _____ _____ _____ _____ _____ _____	
6.18 Note the end time of the interview	_____:_____ hour min	

Thank the interviewee and indicate that you would now like to ask his/her permission to examine his/her medical record

REACH

PATIENT INTERVIEW CONSENT FORM

TRACER: TB

CONSENT TO PARTICIPATE IN THE INTERVIEW

Facility: *[enter name of facility]*_____

I HAVE BEEN INFORMED ABOUT THE PROJECT *RESEARCHING EQUITY IN ACCESS TO HEALTH CARE*, AND I UNDERSTAND THAT IT IS UP TO ME WHETHER OR NOT TO BE INTERVIEWED.

I understand that there will be no consequences of any kind through my responding to this questionnaire; in particular, there will be no impact on the care that I receive in this hospital.

I understand that I can ask the person interviewing me to stop the interview at any time.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are analysed.

Yes, I give my permission for the interview ☐

_____ _____
Interviewee's signature Date

_____
Interviewer's name (please print)

_____ _____
Interviewer's signature Date

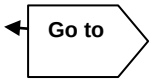
REACH PATIENT INTERVIEW QUESTIONNAIRE TRACER: TB	
0.1 Date of interview	dd mm yyyy
0.2 Interviewer name	_____
0.3 Patient number	**Place sticker here**
0.4 Start time of interview	_____:_____ hour min
0.5 Site (name of facility)	_____

Instructions for interviewers:

This research is part of a multi-center study and the questionnaire has therefore been adapted to suit the different sites. In your site, questions that do not need to be asked are blocked out in dark grey and the font is in a lighter grey.

Questions or parts of questions that do not always need to be read out and instructions are in highlighted text.

Skips indicating which questions can be left out are indicated by arrows



Unless specifically asked to do so, options do not need to be read out.

SECTION 1: SOCIOECONOMIC AND DEMOGRAPHIC BACKGROUND QUESTIONS ABOUT THE RESPONDENT, HIS/HER HOUSEHOLD AND HOUSEHOLD HEAD

READ OUT:
I am going to start by asking you a few questions about you and your household. A household is a social group of one or more individual members. The members are usually, but not always, related. They share in the joint household resources and know each other well enough to provide information about each other.

In each household, one of the members is considered to be the head of the household. This person is usually, but not always, a senior male member of the household.

1.1 Sex	Male	1
	Female	2

1.2 Note the race of the respondent. If you are not certain, ask: How would you describe yourself racially?	African/Black	1
	Coloured	2
	Asian/Indian	3
	White	4
	Other	5
	Other (specify)	

1.3 What was your age at your last birthday? Fill in one block only	Year born	Years

1.4 Who is the head of your household? This is the person who is considered by the other household members to be their head. Indicate relationship e.g. father, mother not name.	Relationship	**If respon-dent HHH, go to 1.9**

1.5 Code sex of HHH. If not clear ask: What is the sex of your HHH?	Male	1
	Female	2

1.6 Code position in HH of respondent. If unclear, ask: What is your position in the household, in relation to the household head such as **…**read out a few relevant options. Circle one only	Head/acting head	1
	Husband/wife/partner	2
	Son/daughter/stepchild/adopted child	3
	Brother/sister/step brother/step sister	4
	Father/mother/step father/step mother	5
	Grandparent/great grandparent	6
	Grandchild/great grandchild	7
	Other relative (e.g. in laws or aunt/uncle)	8
	Non-related persons (tenant, boarder, lodger)	9
	Don't know	99
	Other (specify)	

1.7 What was the age of your HHH i.e. husband / father / mother etc. at his/her last birthday? fill in one block only	Year born	Years

1.8 Does your HHH i.e. husband / father / mother etc. stay with you for at least 2 weeks each month?	Yes	1
	No	0

1.9 What is your current marital status? Circle one only		
	Married	1
	Living with partner	2
	Widow/widower	3
	Divorced or separated	4
	Never married (single)	5
	Other (specify)	

1.10 What is YOUR highest level of education? Circle one only If the person is NOT the HHH ask What is the highest level of education of your HHH i.e. husband / father / mother etc.	**Type of education**	**You**	**Your HHH**
	No schooling	0	0
	Highest grade passed in school (1-12)		
	Completed diploma/certificate	13	13
	Completed degree	14	14
	Other (specify)	**You**	**Your HHH**

1.11 Are you currently employed working or earning money? If the person is NOT the HHH ask Is your HHH i.e. husband / father / mother etc. currently employed?	**Type of employment**	**You**	**Your HHH**	
	Yes, full-time	1	1	**If no or don't know go to 1.13**
	Yes, part-time	2	2	
	No	3	3	←
	Don't know	99	99	←

1.12 If respondent employed ask: Are you self-employed or do you work for someone else? If HHH employed, ask Is your HHH i.e. husband / father / mother etc. self-employed or does HE/SHE work for someone else?	**Type of employment**	**You**	**Your HHH**	
	Self-employed	1	1	**Go to 1.14**
	Employee	2	2	
	Don't know	99	99	

1.13 If respondent not employed ask: What are the reasons that you are not employed? Circle "Yes" or "No" on every row.	**Reason**	**Yes**	**No**
	Studying	1	0
	Looking for work	1	0
	Retired or pensioner	1	0
	Sick or injured	1	0
	Pregnant or caring for own children	1	0
	Caring for other children	1	0
	Caring for sick/injured	1	0
	Retrenched	1	0
	Nothing	1	0
	Don't know	99	
	Other (specify)		

1.14 Including yourself, how many adults (18 years or older) live in your household? When I talk about your household, I am talking about people that share in the joint household resources and know each other well enough to provide information about each other.	

1.15 How many children younger than 18 years live in your household?	

1.16 Does anyone in your household receive a government grant OR income from the government such as…….read out each option and circle yes or no on every row. IF YES ask: How many of each type of grant is received (i.e. how many people receive each?)	**Type of grant**	**Yes**	**No**	**If yes, number received**
	Unemployment insurance (UIF)	1	0	
	Worker's compensation	1	0	
	State old age pension	1	0	
	Disability grant	1	0	
	Child support grant	1	0	
	Care dependency grant	1	0	
	Foster care grant	1	0	
	Grant in aid	1	0	
	Social relief	1	0	
	Other	1	0	
	Don't know	99		

If no DG go to 1.19

1.17 If someone in the household receives a disability grant, ask Is it you that receives the disability grant?	Yes	1
	No	0

If no go to 1.19

1.18 If YES ask: What is the reason that you receive this disability grant?	_____ _____ _____

1.19 If NO ask: Have you applied for a disability grant?	Yes	1
	No	0

1.20 Where were you born? READ OUT I know this is a sensitive question to ask at this stage, but we are asking because we want to see if health services treat South Africans differently to those who are not from South Africa.	South Africa	1
	Other (specify)	

If other go to 1.22

1.21 **If respondent born in South Africa, ask:** Which province were you born in? Use current province borders	Western Cape	1
	Eastern Cape	2
	Northern Cape	3
	Free State	4
	KwaZulu-Natal	5
	North West	6
	Gauteng	7
	Mpumalanga	8
	Limpopo	9
	Don't Know	99

Go to 1.23

1.22 If respondent not born in South Africa, ask: Do you have a South African ID document?	Yes	1
	No	0
1.23 Are you covered by a Medical Aid or any scheme that helps you pay for health-care services or medicines?	Yes	1
	No	0

SECTION 2: UTILISATION OF TB AND OTHER HEALTH SERVICES AND INDIRECT COSTS OF THE DISEASE

READ OUT: In this section we are asking you some questions about what health care you have used for your TB.

2.1 Is this the first time you have had TB?	Yes	1
	No	0
2.2 During this current episode, when did you start taking your TB treatment??	MM YYYY	
2.3 Where were you diagnosed with TB?	Facility name/mobile clinic	
	Province/city/village/township	
2.4 Have you been offered an HIV test (during this current treatment episode)	Yes	1
	No	0
	Don't know	99
2.5 How often do you collect your TB treatment here at the clinic?	Daily during the week	1
	Weekly	2
	Monthly	3
	Other (specify)	
2.6 Who checks that you have taken your TB treatment each day? i.e. what form of DOTS does the patient receive?	The TB DOTS sister or counsellor in the clinic (clinic DOTS)	1
	A community worker (community DOTS)	2
	Someone at my place of work (workplace DOTS)	3
	No-one	4
	Other (specify)	
2.7 During this current treatment episode, have you received TB treatment from a clinic other than this one?	Yes	1
	No	0
2.8 Besides TB, are you able to get the other health services you need in this facility?	Yes	1
	No	0
2.9 If NO ask: What services do you have to get elsewhere?		

If yes go to 2.10

READ OUT: Some people find it quite hard to stick to their TB treatment and might not always be able to make their appointments at the clinic. We are now going to ask you about whether you have had any of these sorts of problems and what the reasons might be.

2.10 Did you miss taking any of your TB tablets YESTERDAY?	Yes	1
	No	0
2.11 Did you miss taking any TB tablets the day before YESTERDAY?	Yes	1
	No	0
2.12 Did you miss taking any TB tablets 3 DAYS AGO? Specify the calendar day in relation to the day of the interview	Yes	1
	No	0
2.13 Apart from the last three days, have you ever missed taking any tablets?	Yes	1
	No	0

2.14 Have you missed any of the following since you started TB treatment for this current episode

Type of visit	**Yes**	**No**	**N/A**	If YES, how many?
Daily DOTS visit	1	0	98	
Nurse/doctor clinic visit	1	0	98	
TB treatment collection	1	0	98	

If all no or N/A go to 2.16

2.15 For the last appointment missed, what was your reason(s)?

Do not read the list aloud; probe respondent to give you up to three reasons

Circle up to three yes options and circle all others no

Reason	**Yes**	**No**
Lack of money	1	0
Lack of time	1	0
I felt better	1	0
I could not take time off from work	1	0
No transport	1	0
Too ill to travel	1	0
Other responsibilities	1	0
The treatment is not effective / does not make me feel better	1	0
The queues in the facility are too long	1	0
The staff are rude or uncaring	1	0
I have had bad experiences with staff in the past	1	0
Don't know	99	
Other 1 (specify)		
Other 2 (specify)		

2.16 Apart from visits to this clinic for your TB, have you used this clinic or any other health service in the last four weeks? Specify in relation to the calendar date Read out each option one at a time. IF YES ask: How many visits (or inpatient days) did you have? Then ask: How much did you have to pay the provider for each? Circle "Yes" or "No" on every row.	**Type of facility or service**	**Yes**	**No**	**If yes, times used**	**If yes, amount spent**
	Chemist/pharmacy	1	0		
	This clinic (not for TB)	1	0		
	A different public clinic	1	0		
	A private doctor	1	0		
	A traditional healer	1	0		
	A public hospital emergency/ outpatient department	1	0		
	Inpatient stay in a public hospital	1	0		
	A private hospital emergency/ outpatient department	1	0		
	Inpatient stay in a private hospital	1	0		
	ARV (HIV) clinic	1	0	**Leave blank**	
	Antenatal clinic [women only]	1	0		
	Other (Specify)				

2.17 Have you spent any other money on health care in the past month (e.g. traditional medicines, spaza shops, special food, etc). If YES, how much have you spent?	Yes	1
	No	0
	If Yes, specify amount _____ (Rand)	

SECTION 3: AFFORDABILITY

READ OUT: I am now going to ask you some questions about the financial difficulties you might face in seeking health care for your TB.

3.1 In the last month did you have to borrow money to pay for healthcare?	Yes	1	
	No	0	**If no go to 3.3**
3.2 If YES How much money did you borrow?	_____ (Rand)		
3.3 In the last month did you have to sell personal or household items in order to pay for healthcare?	Yes	1	
	No	0	
3.4 How much time did you spend at the clinic last time you came for DOTS	_____ hrs _____ minutes		
3.5 How much time did you spend at the clinic last time you came to see the doctor/nurse for your TB?	_____ hrs _____ minutes		

3.6
What would you have been doing if you weren't at the clinic today?

Circle "Yes" or "No" on every row.

Activity	Yes	No
Working for pay	1	0
Doing unpaid community work or volunteer work	1	0
Doing household chores such as cleaning, cooking, shopping for food, maintenance and repairs, working in the garden, gathering wood, gathering water, housework etc.	1	0
Taking care of children	1	0
Leisure activities (sport, watching TV, listening to music, reading, visiting friends and family, going to movies etc)	1	0
Attending school or other educational institution	1	0
Nothing	1	0
I don't know	99	
Other (specify)		

3.7
In coming to receive treatment today, how much did you pay for:

Read out each item. If no money spent, code as "0" for each item

Category	Rand
Transport (one way)	
Clinic fees	
Medicines	
Someone to take over your tasks while you are here including childcare	
Accommodation if you need to stay the night nearby	
Food during visit	
Phoning or sms'ing	
Other, specify:	

If no expense, go to 3.9

3.8
Did you find it easy or difficult to incur these expenses? Refer to expenses in 3.7

Easy	1
Difficult	2
Neither easy nor difficult	3
Don't know	99

3.9
If respondent is working
Did you lose money from the time you took from your job to come here today?

Yes	1
No	0

If no go to 3.11

3.10
If YES:
How much money did you lose?

_____(Rand)

3.11
Who has been helping you financially, i.e. with cash, buying food, providing transport etc, with your TB?

Circle "Yes" or "No" on every row.

Person	Yes	No
Husband/wife	1	0
Father/mother	1	0
Boyfriend/girlfriend	1	0
Other relatives	1	0
Friends	1	0
Nobody	1	0
Employer (over and above normal wages)	1	0
Don't know	99	
Other (specify)		

SECTION 4: AVAILABILITY

4.1 Is this the closest clinic to your home that offers TB treatment?	Yes	1	If yes go to 4.3
	No	0	
4.2 If NO ask: Why do you prefer this facility?	_____ _____ _____		
4.3 Are the opening hours of this clinic convenient for you?	Yes	1	
	No	0	
	Don't know	99	

4.4 How did you get here today?

Circle "Yes" or "No" on every row.

Transport mode	Yes	No
By foot	1	0
Bicycle	1	0
Minibus taxi	1	0
Bus / Train	1	0
Own private car	1	0
Other private car (can be meter taxi, hired car, catching a lift)	1	0
Ambulance / hospital transport	1	0
Other (specify)		

4.5 How long did it take you to get here? (one way only) time taken from leaving home to arriving at facility

_____ hrs _____ minutes

SECTION 5: ACCEPTABILITY

5.1 Have you told anyone besides the health care workers that you have TB?	Yes	1	If no go to 5.3
	No	0	
5.2 If YES Who have you told about your TB? Indicate relationship e.g. sister, friend etc not name.	_____ Relationship		
	_____ Relationship		
	_____ Relationship		
	_____ Relationship		

READ OUT: For the following three questions, please tell me whether you agree or disagree with the statements I make.		
5.3 "I have all the support from my partner that I need to cope with my illness"?	Agree	1
	Disagree	2
	Don't know	99
	Not applicable	98
5.4 "I have all the support that I need from my family"	Agree	1
	Disagree	2
	Don't know	99
	Not applicable	98
5.5 "I have all the support that I need from my friends"	Agree	1
	Disagree	2
	Don't know	99
	Not applicable	98
5.6 Do you feel that people in the community judge you negatively for attending this facility for your TB treatment?	Yes	1
	No	0
	Don't know	99
5.7 In general, when you need to seek healthcare, what do you prefer: a) To see a nurse in a nearby clinic or b) To travel further to see a doctor	Nurse	1
	Doctor	2
	Indifferent	3
	Don't know	99
5.8 In this clinic are you able to talk to the doctors or nurses in private?	Always	1
	Sometimes	2
	Never	3

READ OUT: Can you tell me whether you agree or disagree with these statements when thinking about your general experience in this clinic?		
5.9 The queues to see a doctor or nurse are too long at this facility	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.10 The doctors and nurses (*health workers)* discussed the treatment fully with me	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.11 It is a problem that the *health workers* DO NOT speak my language.	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.12 I find it easy to tell the *health workers* when I have missed taking my tablets	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
	Not applicable	98

5.13 The *health workers* are too busy to listen to my problems	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.14 Patient information is kept confidential in this clinic	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.15 Some staff DO NOT treat patients with sufficient respect	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.16 The health workers I see respect me	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.17 The facilities (including waiting area and toilets) are dirty	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.18 How satisfied were you with the service today?	Very satisfied/ Satisfied	1
	Neither satisfied nor dissatisfied	2
	Dissatisfied/ Very dissatisfied	3
	Don't know	99
5.19 Since you first started coming to this facility, have you ever left without being helped?	Yes	1
	No	0
5.20 IF YES Can you explain what happened?	_____ _____ _____	
5.21 Have you ever <u>not used</u> TB services when you needed them?	Yes	1
	No	0
5.22 If YES Why did you not use TB services? Include all factors – personal and facility-related	_____ _____ _____ _____	

If no go to 5.21

If no go to 5.23

5.23 How do you think the service in this clinic could be improved? Circle "Yes" or "No" on every row.	**Improvement**	**Yes**	**No**
	Shorter queues	1	0
	More health workers	1	0
	Cleaner facilities	1	0
	Better patient facilities (toilets, waiting room area etc)	1	0
	Don't know	99	
	Other (specify)		

SECTION 6: DWELLING CHARACTERISTICS, HOUSEHOLD INCOME, EXPENDITURE AND HOUSEHOLD ASSETS

READ OUT: Finally, we want to ask you some questions about the characteristics of the house where you live and type of facilities available within your household

6.1 Where do you live?	_____village or community _____area or township	
6.2 Which best describes the type of house in which you live? **Clarify answer** **Circle one only**	House or brick structure on a separate stand or yard or on farm	1
	Traditional dwelling/hut/structure made of traditional materials	2
	Flat	3
	Town/cluster/semi-detached house (simplex, duplex or triplex)	4
	Unit in retirement village	5
	Dwelling/house/flat/room in backyard	6
	Informal dwelling/shack IN the backyard of a formal house	7
	Informal dwelling/shack NOT in backyard e.g. in an informal/squatter settlement or on farm	8
	Room/flatlet not in backyard but on a shared property e.g granny flat	9
	Caravan/tent	10
	Worker's hostel	11
	Other (specify)	

6.3 What is the main material of your house's walls? **Clarify answer** **Circle one only**	Bricks & plaster/finished	1
	Bare brick/cement block	2
	Corrugated iron/zinc	3
	Wood	4
	Plastic	5
	Cardboard	6
	Mixture of mud and cement	7
	Wattle and daub	8
	Mud	9
	Other (specify)	

6.4 What is the main material of your house's roof? **Clarify answer** **Circle one only**	Tiles	1
	Corrugated iron/zinc	2
	Thatching	3
	Asbestos	4
	Plastic	5
	Cardboard	6
	Other (specify)	
6.5 How many rooms, including kitchens, does your house have? Interviewer, prove and exclude bathrooms, sheds, garages, stables, etc. from the total unless people are living in them.		
6.6 What is the main source of **drinking water** for members of your household? Clarify answer Circle one only	Piped (tap) water in dwelling	1
	Piped (tap) water on site or in yard	2
	Borehole on site	3
	Rain water tank on site	4
	Neighbour's tap	5
	Public/communal tap (either free or paid)	6
	Water carrier/tanker	7
	Borehole off site/communal	8
	Flowing water/stream/river	9
	Stagnant water/dam/pool	10
	Well	11
	Spring	12
	Other (specify)	
6.7 What type of toilet does your household use? Clarify answer Circle one only	Flush toilet (connected to sewer)	1
	Flush toilet (with septic tank)	2
	Chemical toilet	3
	Pit latrine with ventilation pipe	4
	Pit latrine without ventilation pipe	5
	Bucket toilet	6
	No facility/bush/field	7
	Other (specify)	
6.8 What is the main source of energy for cooking in your household? Clarify answer Circle one only	Electricity from mains	1
	Electricity from generator	2
	Gas	3
	Paraffin	4
	Wood	5
	Coal	6
	Animal dung	7
	Solar energy	8
	Other (specify)	

6.9 Does your household have any of the following items in good working order? Read out each item and circle "Yes" or "No" on every row.		**Yes**	**No**
	Telkom / landline phone	1	0
	Cell phone	1	0
	Radio	1	0
	Television	1	0
	Video recorder/DVD player	1	0
	Electric stove with oven	1	0
	Bicycle	1	0
	Personal computer at home	1	0
	Internet facilities at home	1	0
	Fridge	1	0
	Car/truck/bakkie	1	0
	Primus cooker, Sikeni	1	0
	Electric hot plate	1	0
	Gas cooker	1	0
	Electric kettle	1	0
	Sewing machine	1	0
	Block maker	1	0
	Motorcycle or scooter	1	0
	Kombi, lorry or tractor	1	0
	Bed	1	0
	Table and chairs	1	0
	Sofa or sofa set	1	0
	Kitchen sink	1	0
	Car battery for electricity	1	0
	Wheelbarrow	1	0
	Hoe, spade or garden fork	1	0
	Bed nets	1	0
	Cattle	1	0
	Other livestock (chickens etc)	1	0
6.10 Does your household own cattle, livestock or chickens?		Yes	1
		No	0

If no go to 6.16

6.11 **IF YES** How many cattle does the household own?	_____(Number of cattle)	
	None	0
	Don't know	99
6.12 **IF YES** How many goats does the household own?	_____(Number of goats)	
	None	0
	Don't know	99
6.13 **IF YES** How many chickens does the household own?	_____(Number of chickens)	
	None	0
	Don't know	99
6.14 **IF YES** How many pigs does the household own?	_____(Number of pigs)	
	None	0
	Don't know	99

6.15 **IF YES** Does the HH own any other farm animals? **IF YES** What are they How many [other] does the household own?	(Other, specify) (Number of other)	
	None	0
	Don't know	99
6.16 In general how much does your household usually spend in a month? If the respondent does not give you a precise estimate ask him/her In which of the following ranges, would you say your household EXPENDITURE generally falls? Circle one only	_____Rand	
	R0 – R399	1
	R400 – R799	2
	R800 – R1 199	3
	R1 200 - R1 799	4
	R1 800 - R2 499	5
	R2 500 - R4 999	6
	R5 000 - R9 999	7
	R10 000 or more	8
	Don't know	99
	Refuse	97
6.17 Do you have anything else that you would like to tell us about your experience of seeking or receiving care at this facility?	_____ _____ _____ _____ _____ _____ _____	
6.18 Note the end time of the interview	_____:_____ hour min	

Thank the interviewee and indicate that you would now like to ask his/her permission to examine his/her TB record (card).

HOUSEHOLD COSTS SEEKING CARE

- LINKAGE FORM -

Instructions

1. Record the patient's personal details on this page.
2. Write down the **Patient Study Number** on this page and also on the front page of the questionnaire (make sure they are the same).
3. This personal information is only for linking the data to the Africa Centre databases
4. Once quality control has been completed and data has been linked, this page will be detached and destroyed.

Patient details

Patient Study Number: |_____|

Patient South African ID number: |_____|

Patient name *(first name(s);surname)*: |_____|

Patient date of birth *(yyyy/mm/dd)*: |_____|

Place of interview *(Facility name)*: |_____|

HOUSEHOLD COSTS SEEKING CARE

- QUESTIONNAIRE –

Section 1 : Background questions

Patient Study Number:	I_____I	
Patient age *(as at last birthday in years)*:	I_____I	(1)
Patient sex *(M; F)*:	I_____I	(2)
Date of interview *(yyyy/mm/dd):*	I_____I	(3)
Place of interview *(Facility name)*:	I_____I	(4)
Interview conducted by:	I_____I	(5)
Interview checked by:	I_____I	(6)

Section 2: Utilisation of health services and costs of the disease

INSTRUCTIONS

Read out*: First I would like to ask you some general questions about the health care services that you have used and the financial difficulties you might face in seeking care.*

PART A

1. Apart from visits to this clinic, have you used this clinic or any other health service in the last four weeks? Specify in relation to the calendar date Read out each option one at a time. IF YES ask: How many visits (or inpatient days) did you have? **Then ask:** **How much did you have to pay the provider for each?** Circle all that apply "Yes" and others "No"	**Type of facility or service**	**Yes**	**No**	**If yes, times used**	**If yes, amount spent**
	Chemist/pharmacy	1	0		
	This clinic (not for ARVs)	1	0		
	A different public clinic	1	0		
	A private doctor	1	0		
	A traditional healer	1	0		
	A public hospital emergency/ outpatient department	1	0		
	Inpatient stay in a public hospital	1	0		
	A private hospital emergency/ outpatient department	1	0		
	Inpatient stay in a private hospital	1	0		
	TB clinic	1	0		
	Antenatal clinic [women only]	1	0		
	Other	1	0		
	If other, specify				

	Activity	Yes	No
2. What would you have been doing if you weren't at the clinic today? Circle "Yes" or "No" on every row.	Working for pay	1	0
	Doing unpaid community work or volunteer work	1	0
	Doing household chores such as cleaning, cooking, shopping for food, maintenance and repairs, working in the garden, gathering wood, gathering water, housework etc.	1	0
	Taking care of children	1	0
	Leisure activities (sport, watching TV, listening to music, reading, visiting friends and family, going to movies etc)	1	0
	Attending school or other educational institution	1	0
	Nothing	1	0
	I don't know	99	
	Other	97	
	If other, specify		

3. Have you spent any other money on health care in the past month (eg traditional medicines, spaza shops, special food, etc)?

1. Yes **2. No**

If yes, how much have you spent? **R**_____

4. In the last month, did you have to borrow money to pay for healthcare?

1. Yes **2. No**

If no, go to 6

5. If yes, how much money did you borrow? R_____

6. In the last month did you have to sell personal or household items in order to pay for healthcare? **1. Yes** **2. No**

7. How much time did you spend at the clinic last time you came?

_____**hours** _____**minutes**

8. How much time did you spend at the clinic last time you came to see the doctor/nurse?

_____**hours** _____**minutes**

	Category	Rand
9. In coming to receive treatment today, how much did you pay for: Read out each item. If no money spent, code as "0" for each item	Transport (one way)	
	Clinic/hospital fees	
	Medicines	
	Someone to take over your tasks while you are here including childcare	
	Accommodation if you need to stay the night nearby	
	Food during visit	
	Phoning or sms'ing	
	Other, specify:	

If no expenses go to 11

10. Did you find it easy or difficult to incur these expenses? (Refer to expenses in 9)

1. Easy **2. Difficult**

3. Neither easy nor difficult **99. Don't know**

11. If respondent is working for pay

Did you lose income from the time you took from your job to come here today?

1. Yes **2. No**

If no, go to 13

12. If YES:

How much money did you lose? **R**_____

13. **Who has been helping you financially, i.e. with cash, buying food, providing transport etc, with your HIV/AIDS?** Circle "Yes" or "No" on every row.	**Person**	**Yes**	**No**
	Husband/wife	1	0
	Father/mother	1	0
	Boyfriend/girlfriend	1	0
	Other relatives	1	0
	Friends	1	0
	Nobody	1	0
	Employer (over and above normal wages)	1	0
	Don't know	99	
	Other	97	

Section 3: Household Socioeconomic questions

***Read out*:** I would like to ask you some general questions about your family income.

PART B

		Note for interviewer	
14	What are the family income-generating activities of the head of your household?	See table below, and report number of activity (Write all that apply)	
		If other specify	
15	What is the monthly income of these activities?	Record amount in R. If zero, write 0.	
16	What is the income generating activities of the other family members?	See table below, and report number of activity (Write all that apply)	
		If other specify	
17	What is the monthly income of these activities?	Record amount in R. If zero, write 0.	

Activity	
1. Employed full-time	97. Other
2. Employed part-time	98. Not applicable
3. Self-employed	99. Don't know
4. Unemployed	

HEALTHCARE PROVIDER COMMUNICATION STUDY – FIELD DISCUSSION GUIDE

This is a guide for the feedback and discussion with ART healthcare providers (nurses-in-charge, ART nurses, counsellors) from the selected primary healthcare clinics in Hlabisa sub-district. Obtain all necessary ethical procedures at this point, explain the study, seek and obtain consent.

Background information

Clinic name…….....

Sex 1.Male…….. 2. Female…….....

Age ……years

Qualifications (nurse-in-charge – operations nurse, ART nurse – NIMART trained,

ART counsellor, enrolled nurse, professional nurse etc)…….……..…….....

How long have you been working as nurse-in-charge, ART nurse, ART counsellor?

At this clinic…….....

In your profession.....

Start time.....

Introduction

In 2009 we conducted a study called Researching Equity in ACcess to Healthcare (REACH) to examine barriers that patients utilizing ART treatment were facing at six selected primary healthcare clinics in Hlabisa sub-district. We now want to do a follow-up study to discuss these findings with you, and understand whether this discussion will have an effect on the operations in this primary healthcare clinic that improve the quality of care for ART patients and I also want to document your views on the barriers faced by ART patients.

Results presentation

Questions/prompts to guide discussion

Below are points/prompts to guide the discussion session with the healthcare providers (nurse-in-charge, ART nurse, ART counsellor), taking from the results presented.

1. **Can we now discuss the current barriers that <u>PATIENTS</u> are facing when utilizing ART treatment and care in this facility (over and above the ones already listed above)**

a. Can you tell me what problems you think your patients are facing when they come to get treatment at this clinic?
   (Probe: How the problems arise? How big the problems are? How often they occur?)
b. Which patients do you see as affected by the problems you mentioned? (age, sex, educated, poor etc)
c. Are there any problems that you have left out or not mentioned that patients face when they come to get their treatment?

2. **Can we now move on to discuss your role as a healthcare provider? Can you please tell me how you help your patients overcome the challenges they face when they come for their treatment?**
   a. Probe on the barriers they mentioned above
   b. Probe on the results you presented in the feedback (unless they have already mentioned) and recap so they remember.
      i. Patient satisfaction
      ii. Patient communication
      iii. Respect
      iv. Privacy and confidentiality
      v. Cleanliness
      vi. Waiting time
   c. Have you received any training that helps you manage to reduce the barriers patients face?
   d. Are the National Core Standards followed in this clinic? How do you ensure you are following them?
3. **Now I would like us to discuss about <u>YOUR</u> experiences as a healthcare provider in providing ART treatment and care to your patients. What are the challenges (probe for healthcare provider, patient and healthcare system related challenges) that <u>YOU</u> face in providing ART healthcare in this clinic?**
   a. How do these challenges arise? Explain
   b. How big are the challenges? Explain
   c. How frequent do they occur? Explain
   d. When do they usually occur? Explain

   e. How do the policies and regulations regarding quality healthcare provision for ART and the guidelines, affect the way you work in providing care to patients?
   f. How useful/relevant are they for you in providing care?

4. **Can we now discuss about the changes (structural, organizational, governance etc) that have occurred in this facility since 2009 (when the REACH study was done) that you think may have they affected healthcare provision?**
   a. How big were these changes
   b. How have these changes affected the way you work in providing care to patients?
5. **Thank you for your input in this discussion, before we finish, would you like to share with me any other issues that may be holding back provision of quality care for ART patients in this clinic for example from the patients' side, your side or the health system, or even the community?**
   a. Do you have any suggestions for how to improve the situation so that patients are able to successfully utilize good quality ART and you the healthcare providers are able to provide for it without challenges?

Notes: Brief notes of the circumstance in which the discussion was conducted

English proficiency, Weather, Busyness of clinic, Pay-days, Before or after public holidays etc.
Note the mood, attitude, body language of healthcare provider before and after the discussion
Note the healthcare providers' attitude, voice tone, and relation/interaction with patient(s) before you start the feedback/discussion if possible

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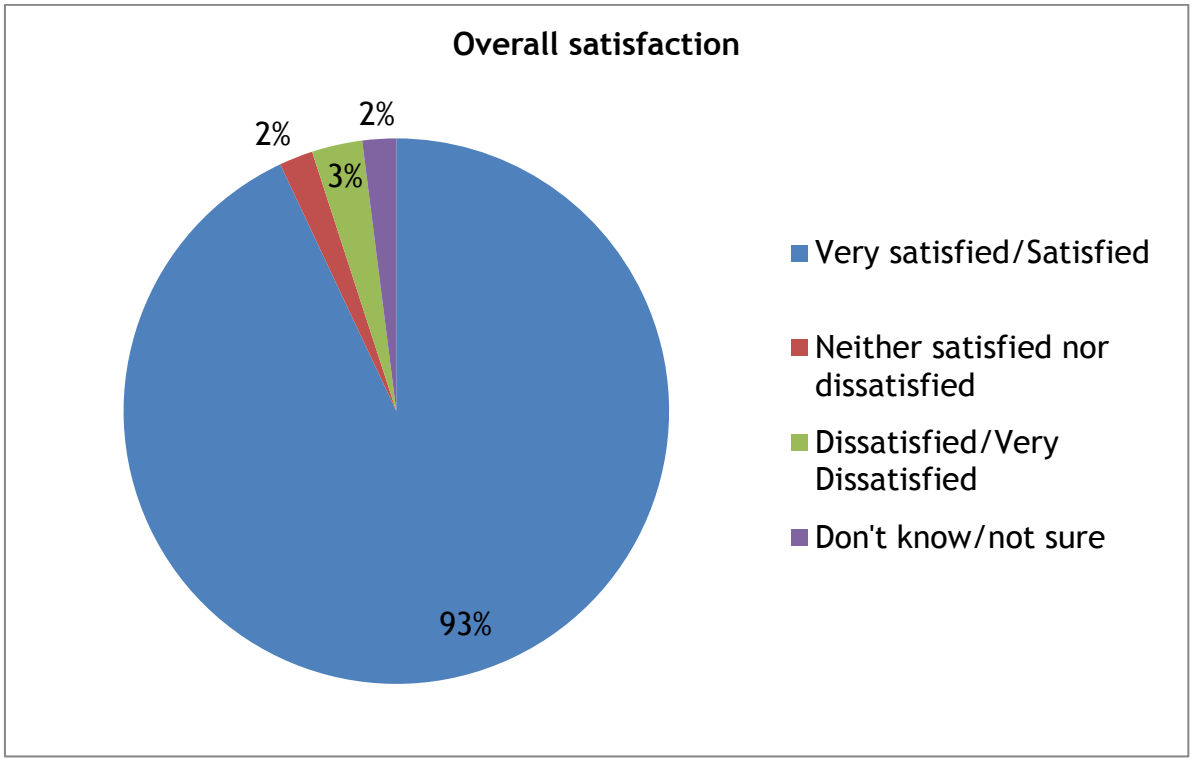
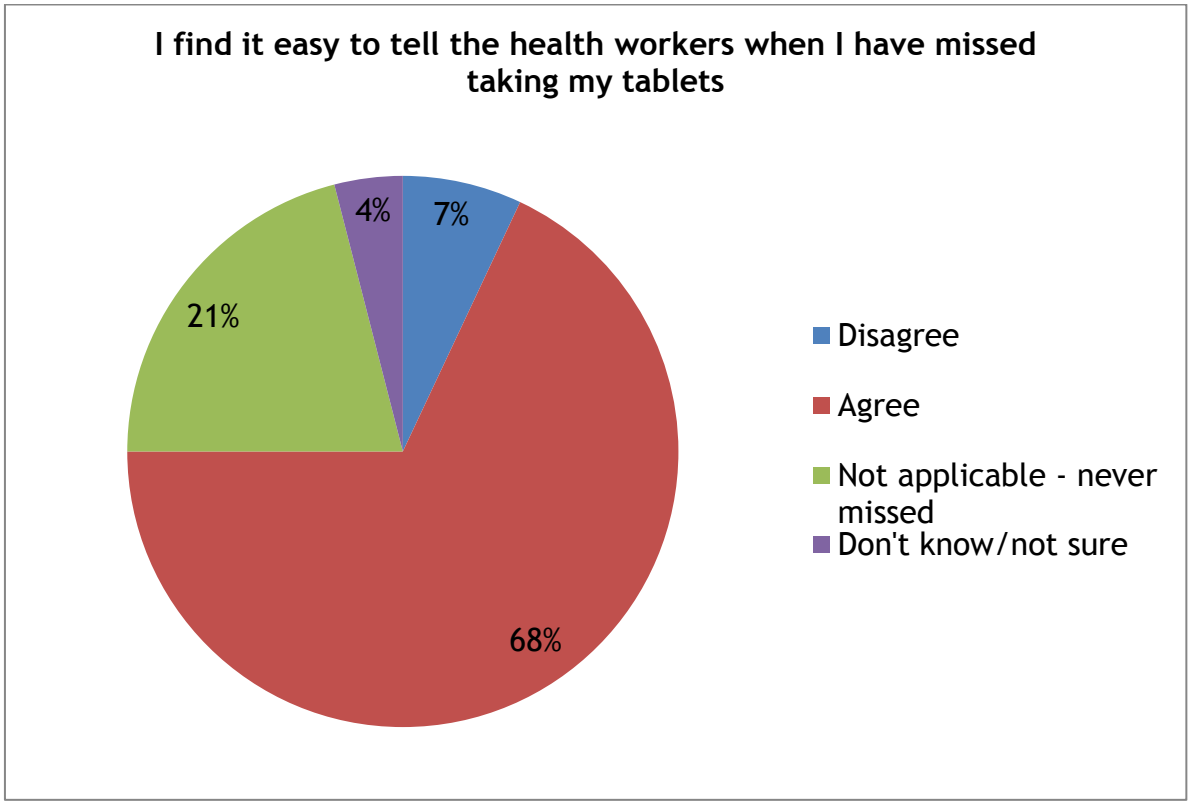
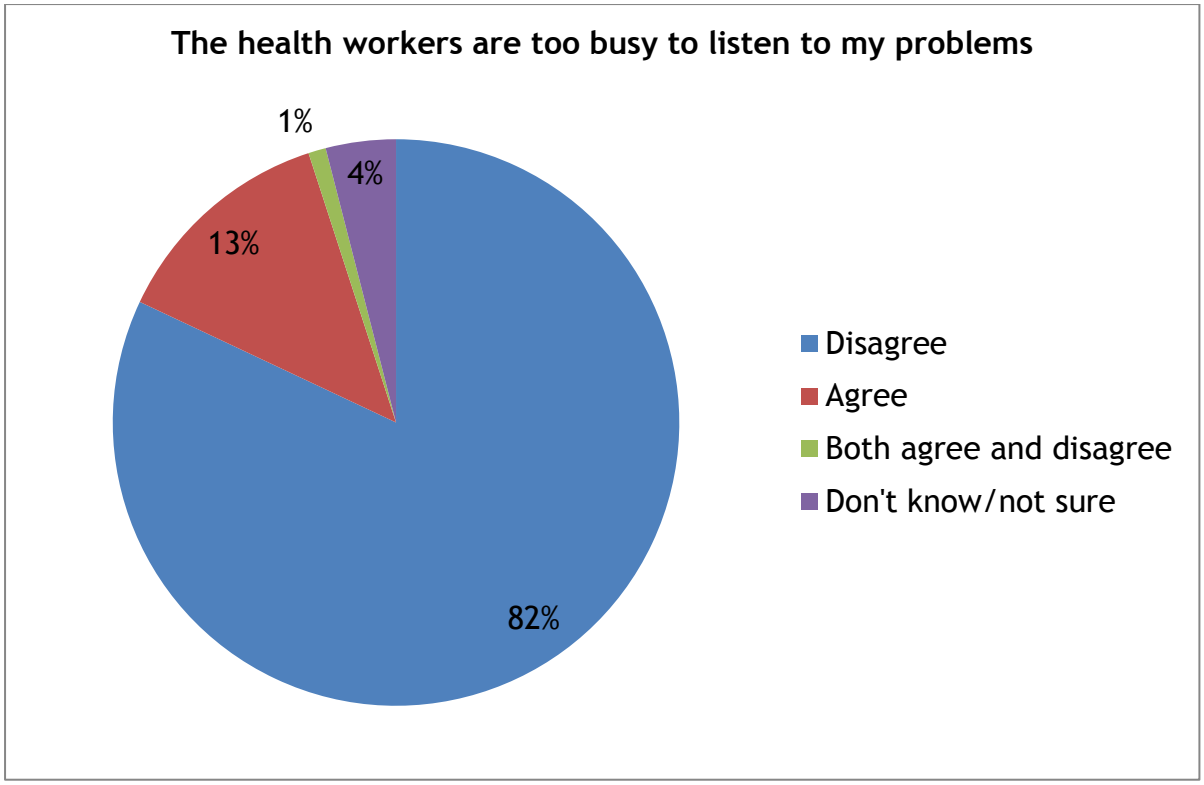
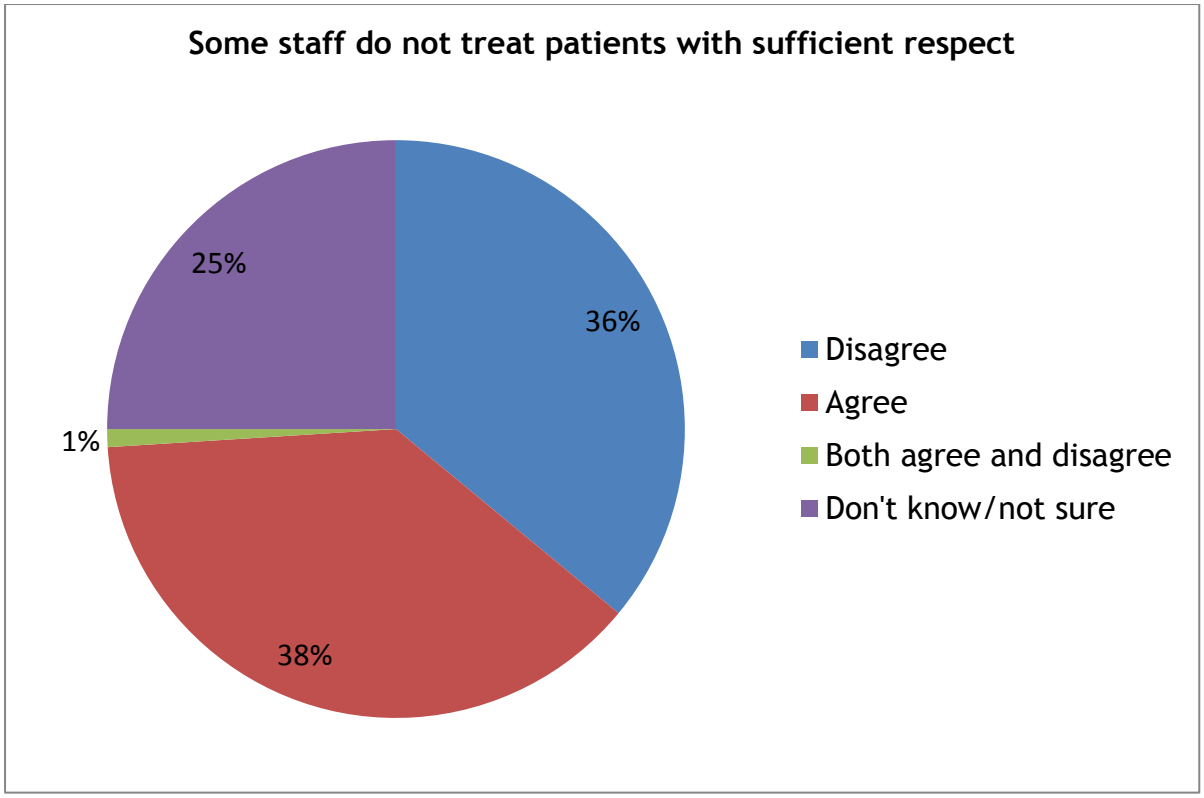
HEALTHCARE PROVIDER COMMUNICATION STUDY - RESULTS PRESENTATION

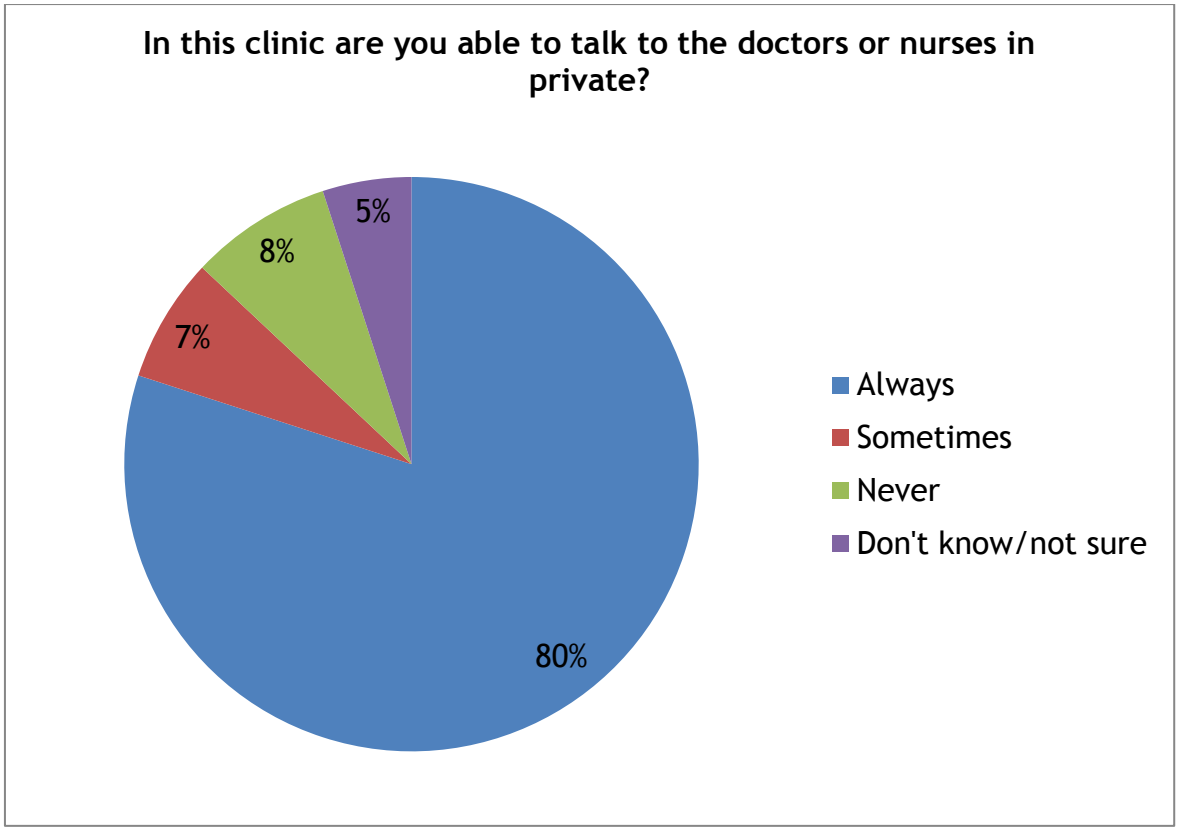
Researching Equity in ACcess to Healthcare (REACH) study - ART Patient-exit interviews results (N=300)

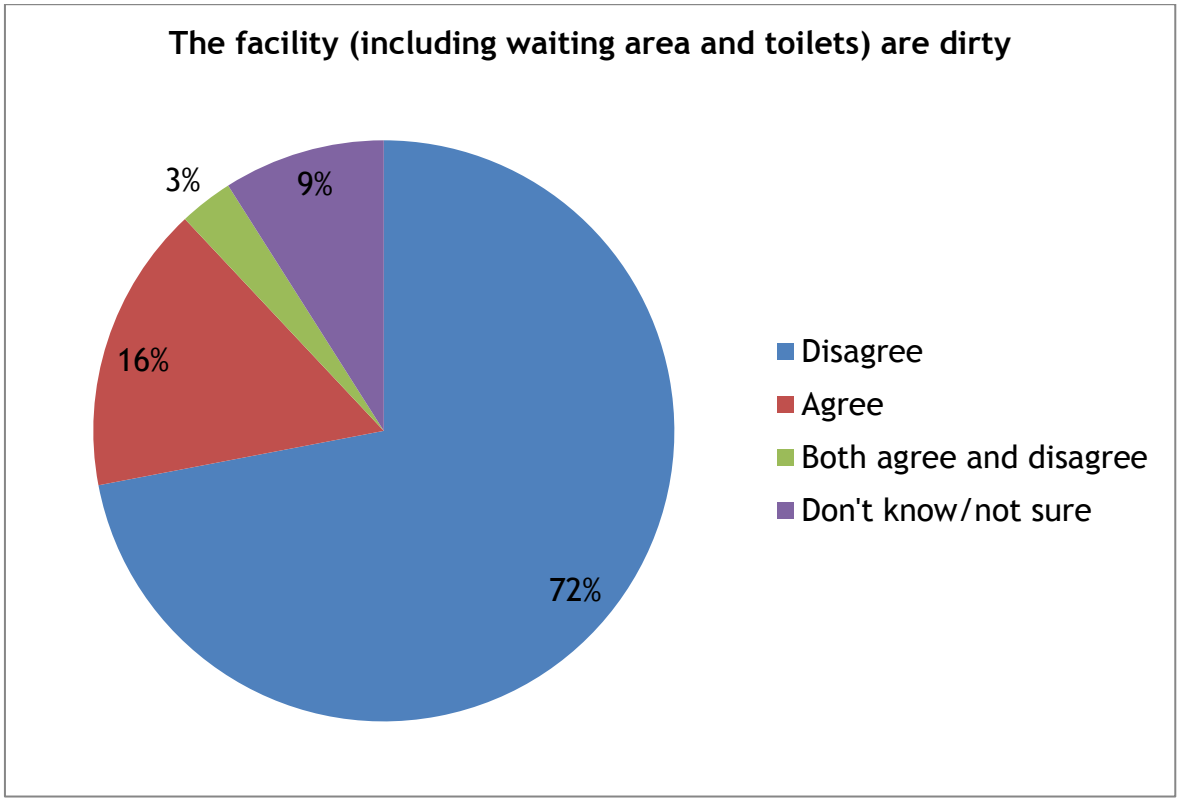


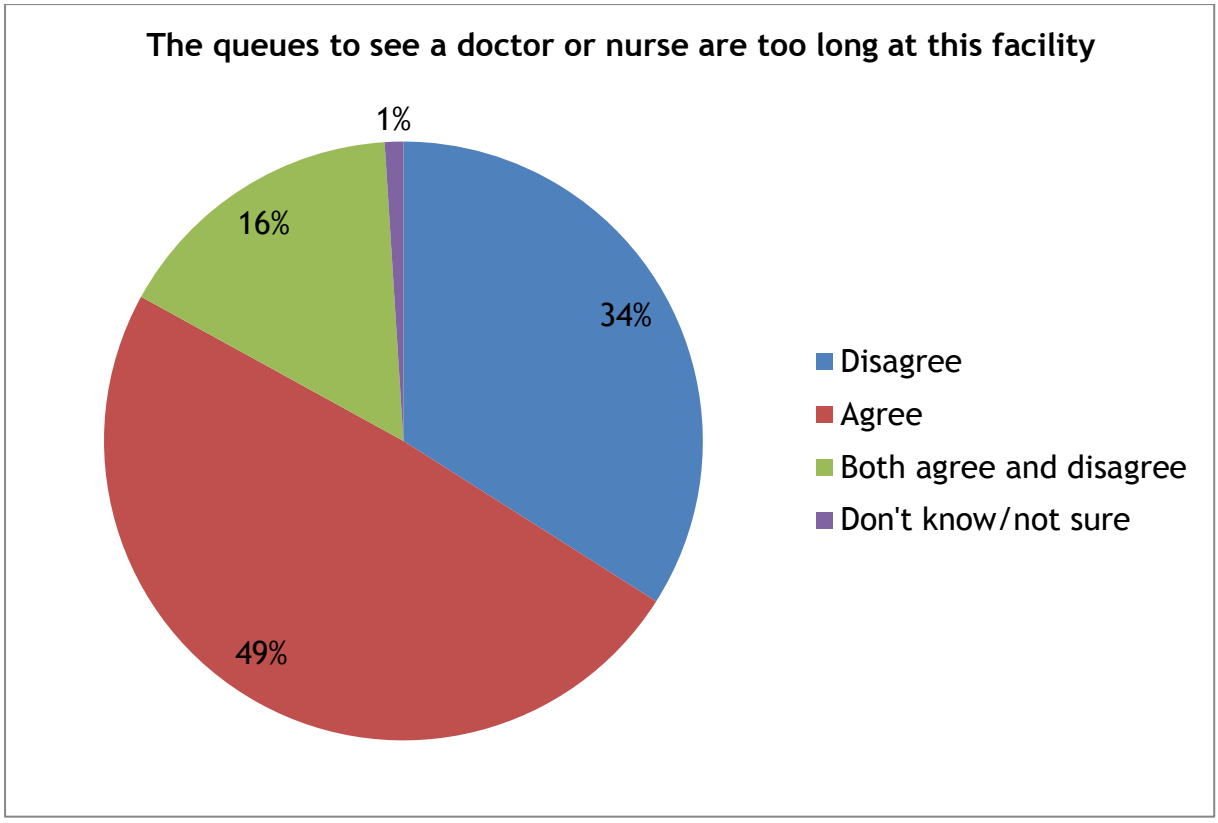



The health workers are too busy to listen to my problems
1%
4%
13%
82%
Disagree
Agree
Both agree and disagree
Don't know/not sure


Some staff do not treat patients with sufficient respect
25%
36%
1%
38%
Disagree
Agree
Both agree and disagree
Don't know/not sure


In this clinic are you able to talk to the doctors or nurses in private?
5%
8%
7%
80%
Always
Sometimes
Never
Don't know/not sure


The facility (including waiting area and toilets) are dirty
3%
9%
16%
72%
Disagree
Agree
Both agree and disagree
Don't know/not sure


The queues to see a doctor or nurse are too long at this facility
1%
16%
34%
49%
Disagree
Agree
Both agree and disagree
Don't know/not sure

Patient satisfaction with HIV treatment and care services in Hlabisa sub-district

N. Chimbindi*, T. Bärnighausen, M-L Newell

BACKGROUND

The healthcare delivery system should aim to provide good quality standards of basic care including HIV treatment and care in order to improve patient satisfaction with the healthcare services provided.

Patient satisfaction is an indicator of subjective quality of care that can be used to evaluate health worker performance, the responsiveness of the health system processes to patient demands, or quality of the healthcare infrastructure.

Patient satisfaction can be an important determinant of treatment uptake, adherence and retention, which are crucial for optimum treatment outcome for HIV patients.

In 2009, we conducted a study called Researching Equity in Access to Health care (REACH) in six primary health care clinics in the Hlabisa sub-district. We interviewed 300 patients aged 18 years and above to examine barriers that patients utilizing ART treatment were facing.

IMPLICATIONS OF FINDINGS

1. Although general acceptability and satisfaction with healthcare services provided seemed high as shown by high overall patient satisfaction, patients expressed some dissatisfaction with particular dimensions of quality of care, including respect and long queues.

2. Improved health worker attitudes towards patients in terms respect is likely to make clinics patient-friendly thereby motivating patients to continue utilizing care.

3. Health workers should be trained on how to engage with and attend to the needs of patients utilizing ART care.

4. Privacy and confidentiality is especially crucial in our setting where most patients receive treatment from their nearest clinic.

5. Long queues to see the health worker often result in longer waiting times, and this has been found to reduce patient satisfaction.

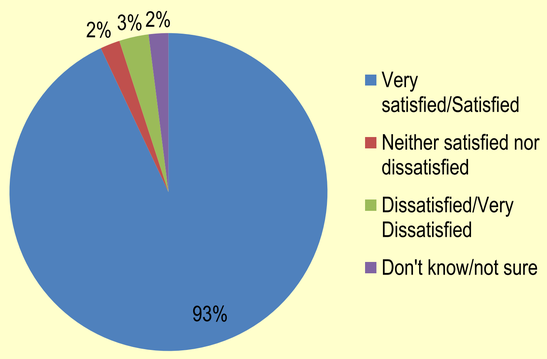
6. Poor staff communication skills, including not listening to patient problems, can affect patient satisfaction. Health workers need to show concern, empathy and understanding to patients to encourage continued utilization of healthcare services.

7. The National Core Standards of Health Establishments patient rights domain includes providing dignified attention to patients in an acceptable and hygienic environment, therefore it is imperative to improve the standard of facility cleanliness in the sub-district.

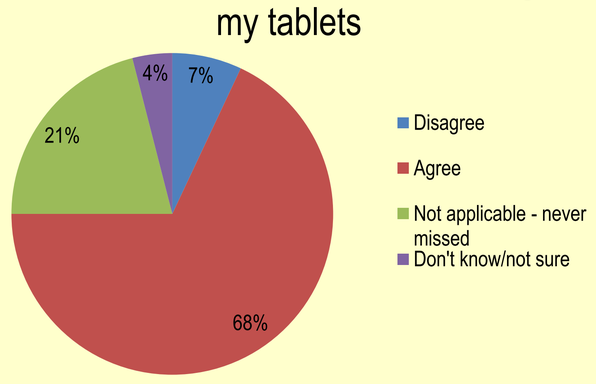
8. Policy makers should take note of patients' suggestions on how to improve the quality of service in the clinics such as provision of better facilities, shorter queues and increased health workers to improve efficiency and reduce patient waiting times.

FINDINGS

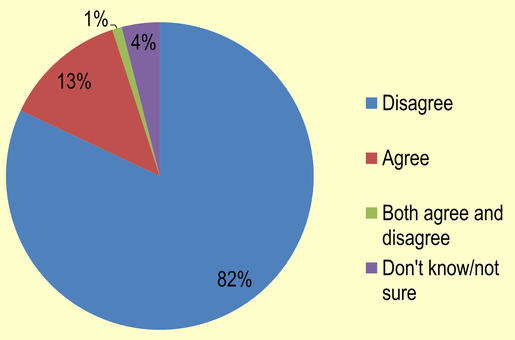
Overall satisfaction



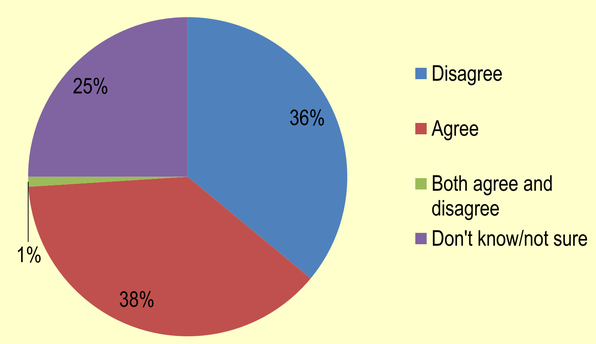
I find it easy to tell the health workers when I have missed taking my tablets



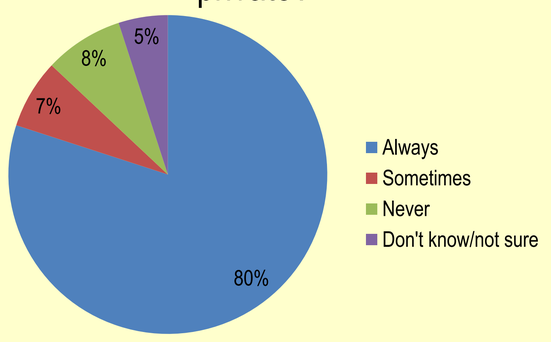
The health workers are too busy to listen to my problems



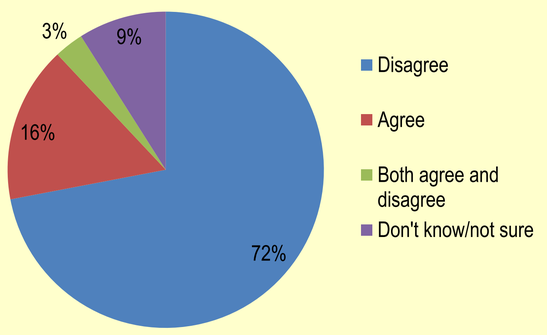
Some staff do not treat patients with sufficient respect



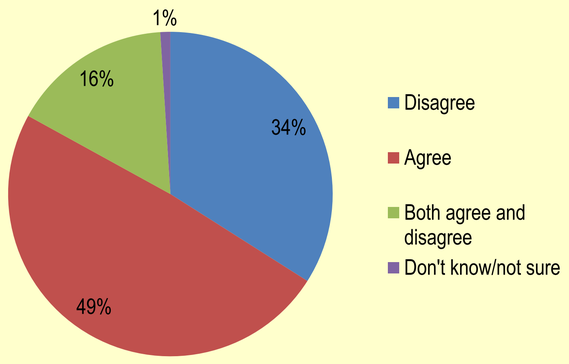
In this clinic are you able to talk to the doctors or nurses in private?



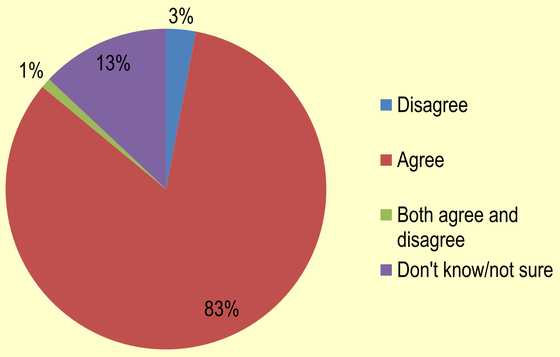
The facility (including waiting area and toilets) are dirty



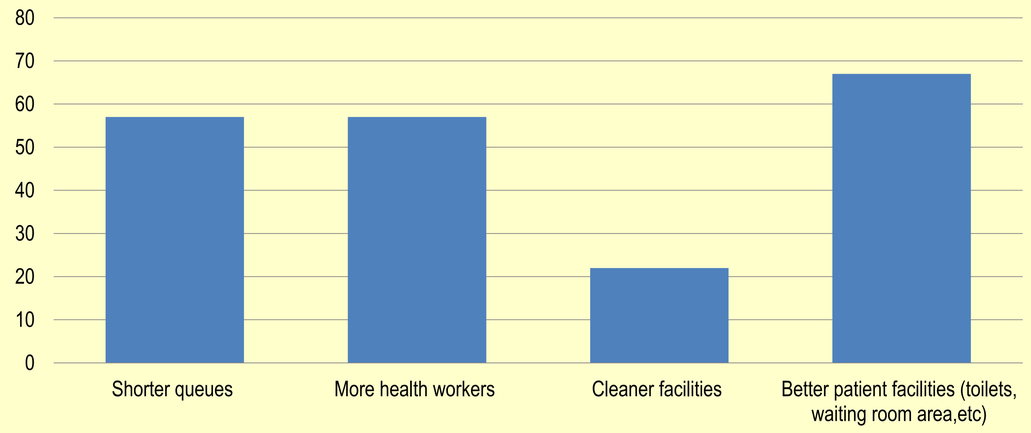
The queues to see a doctor or nurse are too long at this facility



Patient information is kept confidential in this clinic



How do you think the service in this clinic could be improved? Yes (%)



* For more information contact – Natsayi at 035 550 7500 or nchimbindi@africacentre.ac.za

wellcome trust

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INYUVESI
YAKWAZULU-NATALI

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Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx

10 March 2016

Dr Till Barnighausen
Africa Centre for Health and Population Studies
P O Box 198, Mtubatuba
3935

Dear Dr Barnighausen

PROTOCOL: Researching Equity in Access to Health Care (REACH). Dr T Barnighausen. REF: BE174/08.

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 20 February 2016
Expiration of Ethical Approval: 19 February 2017

I wish to advise you that your application for Recertification dated 22 February 2016 for the above protocol has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee (BREC) for another approval period. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

This approval will be ratified at the next full meeting to be held on 12 April 2016.

Yours sincerely

Mrs A Marimuthu
Senior Administrative Officer
Biomedical Research Ethics Committee

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Email: BREC@ukzn.ac.za
Website http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

21 October 2016

Dr Till Barnighausen
Africa Centre for Health and Population Studies
PO Box 198
Mtubatuba
3935

Dear Dr Barnighausen

PROTOCOL: The impact on antiretroviral therapy on HIV epidemic dynamics. Dr Till Barnighhausen. Ref: BF072/09.

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved: 18 June 2016
Expiration of Ethical Approval: 17 June 2017

I wish to advise you that your application for Recertification dated 08 September 2016 for the above protocol has been noted and approved by the Biomedical Research Ethics Committee (BREC) at a meeting held on 11 October 2016. The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

Yours sincerely

Ms A Marimuthu
Senior Administrator: Biomedical Research Ethics

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24 October 2012

Dr Till Barnighausen
Africa Centre for Health and Population Studies
P O Box 198, Mtubatuba
3935

Dear Dr Barnighausen

PROTOCOL: Researching Equity in Access to Health Care (REACH). Dr T Barnighausen. REF:BE174/08.

We wish to advise you that your application for amendments dated 19 July 2012 requesting approval of Dr Natsayi Chimbindi as one of the investigators of the original REACH study has been noted and approved by the sub-committee of the Biomedical Research Ethics Committee.

This approval will be ratified at the next full Committee meeting to be held on 13 November 2012.

Yours sincerely

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Natsayi Z Chimbindi

CLEARANCE CERTIFICATE	M111136
PROJECT	Implications of Human Immuno-Deficiency Virus (HIV), Tuberculosis (TB) and Co-Infection on Utilization of Healthcare Services in KwaZulu Natal
INVESTIGATORS	Ms Natsayi Z Chimbindi.
DEPARTMENT	School of Public Health
DATE CONSIDERED	28/10/2011
M1111360DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 28/10/2011 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Till Barnighausen

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

An integrated approach to improving the availability and utilisation of tuberculosis healthcare in rural South Africa

N Chimbindi, T Bärnighausen, M-L Newell

Africa Centre for Health and Population Studies, University of KwaZulu-Natal, Durban, and School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa
N Chimbindi, MSc

Africa Centre for Health and Population Studies, University of KwaZulu-Natal, Durban, and Department of Global Health and Population, Harvard School of Public Health, Boston, MA, USA
T Bärnighausen, MD, ScD

Africa Centre for Health and Population Studies, University of KwaZulu-Natal, Durban, and Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health, University College London, UK
M-L Newell, PhD

Corresponding author: *N Chimbindi (nchimbindi@africacentre.ac.za)*

Background. Patients with tuberculosis (TB) face several challenges in accessing care, and an integrated service that includes HIV testing could be preferable for them and ensure timely HIV treatment initiation and optimal TB care.
Objectives. To investigate factors, including uptake of HIV testing, associated with availability and utilisation of healthcare by TB patients in a rural programme devolved to primary care in Hlabisa sub-district, KwaZulu-Natal.
Methods. Three hundred TB patients were randomly selected in a two-stage-sampling scheme with five primary healthcare clinic (PHC) sampling units selected with probability proportional to size. Data were collected using a structured questionnaire. We describe key availability and utilisation factors and analyse factors associated with being offered an HIV test in multiple regressions controlling for sex, age, education, employment and marital status.
Results. Most patients (75.2%) received care for a first episode of TB, mainly pulmonary. Nearly all (94.3%) were offered an HIV test during their current TB treatment episode, patients using their closest clinic being substantially more likely to have been offered HIV testing than those not using their closest clinic (adjusted odds ratio 12.79, p=0.05). About one-fifth (20.3%) of patients did not take medication under observation, and 3.4% reported missing taking their tablets at some stage. Average travelling time to the clinic and back was 2 hours, most patients (56.8%) using minibus taxis.
Conclusion. We demonstrate high HIV testing rates among TB patients in a rural public programme, suggesting appropriate management of HIV-TB co-infected patients. We describe healthcare availability and utilisation factors that can inform the proposed district management teams for PHC re-engineering on areas needing improvement.

S Afr Med J 2013;103(4):237-240. DOI:10.7196/SAMJ.6423

The human immunodeficiency virus (HIV) continues to be a leading cause of death in sub-Saharan Africa, with South Africa (SA) having the highest number of people living with HIV. Countries with a high prevalence of HIV, mainly those in sub-Saharan Africa, have witnessed an increase in tuberculosis (TB) cases. High TB and HIV co-infection rates have been reported in SA. In 2009, more than 60% of TB patients in SA were reported to be co-infected with HIV,[1] the figure reaching nearly 80% in Hlabisa sub-district.[2] HIV in TB patients increases mortality, promotes progression of latent and recently acquired TB to active TB, and increases TB recurrence rates.[1]

TB patients face several challenges in accessing care, and an integrated service that includes HIV testing is most likely to ensure timely initiation of HIV treatment and optimal TB care. The need to integrate TB and HIV programmes was highlighted in 2004 by the World Health Organization (WHO)'s HIV and Stop TB departments, and from 2009 onwards WHO guidelines recommended that all HIV-positive patients with active TB start antiretroviral therapy (ART) immediately.[3] Integrated TB/HIV activities, including HIV testing of all TB patients, can help ensure that HIV-positive TB patients are identified and treated appropriately and help prevent TB in HIV-positive patients,[1] thereby accelerating universal access to comprehensive TB and HIV prevention, treatment and care.[4] HIV testing rates among TB patients differ according to approaches used (voluntary or provider-initiated testing) and the setting, with higher rates being reported in integrated as opposed to vertical programmes.[5,6]

Vertical models are those in which HIV or TB services stand alone and cross-refer patients to the other service for testing and treatment. Programmes can be integrated in respect of funding, management, service delivery, and monitoring and evaluation of health systems.[7,8] From the patient's perspective it is most important

that TB and HIV services are provided in the same facility.[6,9,10] Facility-level integration in the delivery of TB and HIV services has been adopted in the primary healthcare clinics (PHCs) in the Hlabisa sub-district of KwaZulu-Natal.[6] Benefits of such integration include increased satisfaction and reduced time and financial costs for patients receiving care for both diseases.

Understanding factors that influence availability and utilisation of healthcare is essential in providing comprehensive healthcare services. Multiple factors potentially affect healthcare utilisation among TB patients, including HIV testing uptake; some of these are patient socio-demographic characteristics, availability of services (e.g. directly observed treatment, short course (DOTS)), physical/geographical variables (e.g. travel time, mode of transport), and organisational issues (e.g. opening times of clinics). The aim of this study was to investigate factors affecting healthcare availability and utilisation, including uptake of HIV testing, in TB patients in a programme devolved to rural PHCs in the Hlabisa sub-district.

Methodology

Setting

The Department of Health TB (DoH-TB) control programme operates at the Hlabisa district hospital (DH) and 17 PHCs. The programme is integrated with the Hlabisa HIV Treatment and Care Programme (ART programme), which receives additional staff support and database management from the Africa Centre for Health and Population Studies (www.africacentre.com).[6,11] The ART programme utilises a decentralised approach with integration of TB and HIV services to primary healthcare, linking treatment, care and prevention services.[11]

TB nurses at each PHC identify TB suspects and collect sputum, which is sent to the National Health Laboratory Service (NHLS) for acid-fast bacilli smear testing. All smear-positive patients are initiated onto the first-line standard TB regimen, and patients with negative smears (most of whom are HIV-infected) who remain symptomatic are referred to the DH for further clinical assessment and X-rays.[2,6] The DoH-TB control programme adheres to national guidelines on the diagnosis, treatment and care of TB patients. All TB patients requiring inpatient services or those with complications, as well as those with multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB, are referred to the DH. After completing their hospitalisation (typically 1 month), patients are treated daily on an outpatient basis, with monthly clinic follow-up.

Since the end of 2009, a routine opt-out provider-initiated approach for HIV testing and counselling (PITC) has been in place at all PHCs in the sub-district, in addition to established voluntary counselling and testing.[11,12] A rapid HIV test is performed in patients who agree to be tested, and blood samples from HIV-positive patients are sent to the NHLS for CD4 cell counts. Results are available within 2 days and patients are requested to return to the clinic for their CD4 count results within a week of sample collection. Individuals who are not yet eligible for ART are monitored and followed up regularly. Prior to ART initiation, patients are screened for TB and other opportunistic infections, which are treated appropriately when diagnosed. ART initiation, treatment and care are offered according to the national guidelines.

As part of a larger multisite cross-sectional study called Researching Equity in ACcess to Healthcare (REACH), which was conducted in four sub-districts in SA in 2009 to examine barriers to healthcare access, we collected data on factors affecting healthcare availability and utilisation, including uptake of HIV testing in adults with TB attending PHCs in Hlabisa sub-district.

Sampling and sample size

We randomly selected patients in a two-stage-sampling scheme, with five PHC sampling units selected with probability proportional to size, and collected data through exit interviews with 300 patients utilising TB treatment at the selected PHCs. Three clinics that had some ongoing research activities were excluded from the sampling frame of the then 16 PHCs in the sub-district, to avoid over-burdening staff and patients.

Data collection

A structured questionnaire was administered to patients in *isiZulu* by four trained fieldworkers. Written consent was obtained from patients aged 18 years and above who volunteered to participate and had been on TB treatment for at least 2 months (by which time they would be expected to have completed the intensive phase of treatment). Those patients with MDR/XDR TB and who received treatment in hospital for the first 2 months were therefore also captured for this study, having been referred for follow-up treatment at the PHC. The study received ethical clearance from the University of KwaZulu-Natal (BE174/08).

Statistical methods

Summary statistics on the variables collected are set out in Table 1. Further, we regressed the binary variable indicating whether an HIV test was offered on a range of independent variables in multivariable logistic regression to gain insights on the predictors of HIV testing in this patient population. All analyses were done using STATA (Release Version 11, Stata Corporation, College Station, TX) and values of $p<0.05$ were considered significant.

Results

Table 1 shows the socio-demographic profile of patients utilising TB healthcare at the PHCs, as well as summary statistics on aspects of TB-related care. The majority of patients (75.2%) were receiving care for a first episode of TB, in most cases pulmonary. Almost all patients (94.3%) reported having been offered an HIV test during the current TB treatment episode, most had been diagnosed with TB at the same clinic at which they were receiving their TB treatment, and almost all (95.8%) stated that they were able to access other healthcare services at the same facilities they utilised for their TB treatment. Although most patients were supported by DOTS, 20.3% did not take their TB medication under observation.

Almost all patients (97.0%) were accessing the clinic closest to their home for TB treatment. Self-reported reasons for not using the closest clinic were that the clinic they attended was closer to their workplace (n=2), that they were offered good service at the present clinic (n=1), that the nearest clinic did not give correct treatment (n=1) or had too many patients and long queues (n=1), lack of knowledge on how to change clinics (n=1), treatment course almost completed and therefore no need to change clinics (n=1), and changes in place of residence after initiating TB treatment at the present clinic (n=2). More than a tenth of patients receiving TB care asserted that people in the community judged them negatively for attending for TB treatment.

Among the 9 patients who were not using their closest clinic, 2 (22.2%) were female, the median age was 39 years (interquartile range (IQR) 35 - 48 years), 5 (55.6%) had little or no education, 6 had never married (66.7%) and 7 (77.8%) were unemployed. Controlling for age, sex, education, marital status, employment and other factors associated with being offered an HIV test, patients using their closest clinic were substantially more likely to have been offered HIV testing than those not using their closest clinic (adjusted odds ratio 12.79, p=0.05).

Table 1. Availability and utilisation of TB treatment and care services in primary healthcare clinics (*N*=296)

Patient socio-demographic characteristics	
Gender, *n* (%)	
Female	156 (52.7)
Age (years), *n* (%)	
Mean (95% CI)	38 (37 - 39)
<20 - 29	73 (24.7)
30 - 39	102 (34.5)
40 - 49	77 (26.0)
≥50	44 (14.9)
Education, *n* (%)	
None	50 (16.9)
Primary	92 (31.1)
Secondary	101 (34.1)
Matric and higher	53 (17.9)
Employed (*n*=295), *n* (%)	
Yes	28 (9.5)
Marital status, *n* (%)	
Never married	249 (84.1)
TB healthcare-related factors	
Is this the first time you have had TB? (*N*=294), *n* (%)	
Yes	221 (75.2)
Have you been offered an HIV test (during this current treatment episode), *n* (%)	
Yes	279 (94.3)
Besides TB care, are you able to get the other health services you need in this facility? (*N*=286), *n* (%)	
Yes	274 (95.8)
Who checks that you have taken your TB treatment each day? *n* (%)	
The TB DOTS sister or counsellor	102 (34.5)
A community worker (community DOTS)	12 (4.1)
Someone at my place of work (workplace DOTS)	4 (1.4)
No one	60 (20.3)
Family members/partners/neighbours	118 (40.0)
Do you feel that people in the community judge you negatively for attending this facility for your TB treatment? (*N*=257), *n* (%)	
Yes	31 (12.1)
Since you first started coming to this facility, have you ever left without being helped? (*N*=296), *n* (%)	
Yes	38 (12.8)
During this current treatment episode, have you received treatment from a clinic other than this one? (*N*=293), *n* (%)	
Yes	40 (13.7)
Apart from the past 3 days, have you ever missed taking any tablets? (*N*=293), *n* (%)	
Yes	10 (3.4)

Table 1 (continued). Availability and utilisation of TB treatment and care services in primary healthcare clinics (*N*=296)

TB healthcare-related factors	
Are the opening hours of this clinic convenient for you? *n* (%)	
Yes	291 (99.3)
Is this the closest clinic to your home that offers TB treatment? *n* (%)	
Yes	287 (97.0)
How long does it take you to get here (clinic) and return? (minutes), mean (95% CI)	120 (109.6 - 129.9)

CI = confidence interval.

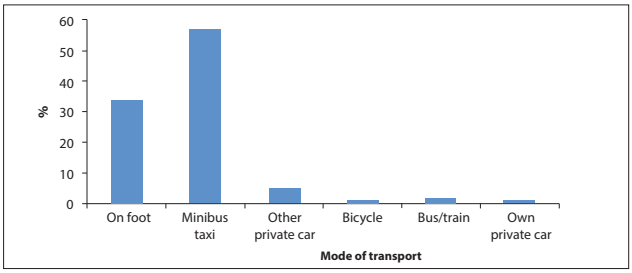

Fig. 1. Modes of transport used by patients (%) to travel to the primary healthcare clinics to receive TB treatment (N=296).

The average travel time for patients attending a clinic was 2 hours for a return trip, and most of them used a minibus taxi (Fig. 1). The median time taken to travel (return trip) to the clinic on foot or by public transport was 90 minutes (IQR 60 - 180 minutes), by own car 60 minutes (IQR 40 - 75 minutes) and by other private car (a hired car or catching a lift) 120 minutes (IQR 60 - 120 minutes). ('Other private car' refers to a personal car that usually transports people from typically inaccessible areas where there is no public transport. Individuals hire these cars, or wait for them at pick-up points, or obtain lifts on their way to the destination point.)

We analysed the 17 patients who were not offered HIV testing according to socio-demographic characteristics, and found that 10 (58.8%) were female and the median age was 33 years (IQR 30 - 49 years). A high proportion had never been married (13, 76.5%) and were unemployed (16, 94.1%), and 3 (17.7%) had no formal education. There was no statistically significant difference in the socio-demographic profile of those offered and not offered HIV testing, but statistical power to detect such differences was low due to the study sample size.

Discussion and conclusion

In an area with a high burden of TB and HIV, we found near-universal HIV testing among TB patients attending PHCs in a rural programme devolved to primary care level. Few people refused the offer of HIV testing once they had received counselling on the importance of knowing their HIV status for optimal general medical care and TB treatment. The HIV testing rate had risen to 94%[13] from the previously reported 88%,[6,11] with an age-sex profile comparable to previous studies in the area.[2,6] There was no significant difference in terms of socio-demographic characteristics between patients not offered an HIV test and those offered one, indicating that health workers were following the TB guidelines on HIV screening satisfactorily and have adopted a successful PITC approach.

Integration of TB and HIV services with primary healthcare services ensures patient accessibility to comprehensive healthcare and also strengthens health systems, in turn achieving improved universal access to health.[4,6,14] Almost all patients in our study confirmed their ability to utilise the other healthcare services they required from the same facility at which they obtained their TB treatment. Joint delivery of TB and HIV in PHCs serves to support good accessibility (encompassing availability and utilisation of services) to comprehensive healthcare. However, some TB healthcare services need to be improved in respect of DOTS delivery to ensure sustained adherence to treatment.[4,14] While the TB programme has not received the same level of support as the ART programme,[6] further research is needed to understand the imperfections in TB DOTS coverage identified in this study. Significantly, the gap in the DOTS delivery system creates an opportunity to strengthen the current TB programme, e.g. through community-based linkages and DOTS support on the part of policymakers and district management teams, as proposed in efforts to reform the SA health system.

Patients generally use the clinic closest to their homes for TB treatment and HIV testing, implying that fear of stigma appears not to play a major role in their decision where to seek health care. This conclusion is supported by the fact that reasons for not using the clinic closest to home included better quality of care, shorter waiting time and queues, and closeness to place of work. The few patients who did not test for HIV at their closest clinic may have been diagnosed with resistant TB and hospitalised; they would have been offered HIV testing while treatment was initiated, and their results sent to the nearest clinic from the hospital. Our study area has experienced sustained high levels of both HIV and TB, as well achieving high coverage of treatment of both diseases; in 2010, 25% of people in the area shared a household with someone receiving ART.[15] Social exposure to people receiving treatment may have normalised attitudes and behaviours towards HIV and TB. Integration of HIV and TB services in PHCs, as well as PITC, is also likely to have reduced stigma.

The average travelling time for TB patients attending PHCs in Hlabisa sub-district was 2 hours for a return trip, and most used minibus taxis. The time losses arising from TB treatment are a potential threat to treatment uptake and retention. In this context, the time saved in utilising combined TB and HIV treatment at the same PHC, instead of in geographically separate locations, is likely to have had a positive impact on healthcare access by co-infected patients. Policymakers could consider providing subsidised transport for patients, and increasing the geographical density of PHCs in rural areas where possible.

In conclusion, this study demonstrates that in a devolved integrated public sector programme, TB and HIV services can be integrated successfully at the level of the rural PHC. The high HIV testing rates among TB patients indicate that patients co-infected with the two diseases are clearing the first hurdle to adequate treatment of HIV infection, and that service integration has the potential subsequently to ensure their appropriate management. However, research is needed on whether TB patients who test positive for HIV do indeed return for their CD4 count results and ART. Findings on factors affecting healthcare utilisation, such as DOTS, adherence and patient accessibility to clinics, could further inform activities deserving the focus of the district management teams proposed as part of the SA health system reform.

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Almost universal coverage: HIV testing among TB patients in a rural public programme

With many tuberculosis (TB) patients also human immunodeficiency virus (HIV) infected, testing all TB patients for HIV is important so that HIV treatment can be initiated promptly. HIV testing in TB patients is one important route into combined HIV and TB treatment and care.[1]

We collected data as part of a multi-site cross-sectional study, Researching Equity in Access to Healthcare (REACH), to examine HIV testing coverage in TB patients, administering a structured questionnaire to 300 patients accessing TB treatment in five primary health care clinics in Hlabisa subdistrict, KwaZulu-Natal, South Africa. These clinics operate within the Hlabisa HIV Treatment and Care Programme, with separate, vertically structured TB and HIV services devolved to the primary health care level.[2] In 2009, the TB notification rate in the area was approximately 928 per 100 000 population and HIV prevalence among adults in 2010 was 24%; the rate of co-infection was 76%.[3]

Fifty-three per cent of patients accessing TB care were female; the median age of the patients was 37 years. The majority (75%) were receiving care for a first TB episode, mostly pulmonary TB. Although most patients were on DOTS, a substantial proportion (20%) did not take their medication under observation. Almost all patients (94%) reported that they had been offered HIV testing during their current TB treatment episode. The majority (97%) used the clinic closest to their homes; those who did were more likely to be offered HIV testing than those using a clinic further away (aOR 16.22, $P < 0.01$).* Among the 17 patients not offered HIV testing, 10 (59%) were female, and the median age was 33 years (18–75 years). There was no statistically significant difference in age and sex between those offered and those not offered HIV testing, but the limited sample size would have reduced statistical power.

We demonstrate high HIV testing rates among TB patients in a rural public programme in a high TB and HIV burden area, suggesting that TB-HIV co-infected patients can be managed appropriately for treatment of both infections.[4] The decentralised programme appears largely successful in attaining universal HIV testing in TB patients[5] in this resource-limited setting. Our testing rate of 94% was slightly higher than the 88% seen previously in the area.[3] However, there is scope for further improvement such as in DOTS delivery, a sustainable and effective way of ensuring good adherence to TB treatment. Patients mostly use the closest clinic for both TB treatment and HIV testing, suggesting a receding fear of stigma of HIV. However, the small number of patients not using the closest clinic are far less likely to undergo HIV testing, possibly indicating vulnerability expressed both in the location of seeking TB treatment and HIV testing uptake. Policy makers should encourage integration of services and cross-testing in HIV-TB facilities.

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A presentation of Poncet's disease identified following immunosuppressive steroid therapy

We present a case of Poncet's disease, a rare extrapulmonary manifestation of tuberculosis (TB), first described in 1897.[1] Poncet's disease is a non-suppurative reactive polyarthritis arising secondary to infection with *Mycobacterium tuberculosis*, with only a small number of cases reported in the literature.[2]

* Controlling for age, sex, education, marital status, employment, whether it was the patient's first episode of TB and the distance between the clinic and the patient's home.

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RESEARCH ARTICLE Open Access

Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews

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Abstract

Background: Patient satisfaction is a determinant of treatment uptake, adherence and retention, and an important health systems outcome. Queues, health worker-patient contact time, staff attitudes, and facility cleanliness may affect patient satisfaction. We quantified dimensions of patient satisfaction among HIV and TB patients in a rural sub-district of KwaZulu-Natal, South Africa, and identified underlying satisfaction factors that explained the data.

Methods: We conducted patient-exit interviews with 300 HIV and 300 TB patients who were randomly selected using a two-stage cluster random sampling approach with primary sampling units (primary healthcare clinics) selected with probability-proportional-to-size sampling. We performed factor analysis to investigate underlying patient satisfaction factors. We compared the satisfaction with HIV and TB services and examined the relationships between patient satisfaction and patients' socio-demographic characteristics in multivariable regression.

Results: Almost all patients (95% HIV, 97% TB) reported to be globally satisfied with the healthcare services received on the day of the interview. However, patient satisfaction with specific concrete aspects of the health services was substantially lower: 52% of HIV and 40% of TB patients agreed that some staff did not treat patients with sufficient respect ($p = 0.02$ for difference between the two patient groups); 65% of HIV and 40% of TB patients agreed that health worker queues were too long ($p < 0.001$). Based on factor analysis, we identified five factors underlying the HIV data and the TB data (availability, accommodation, acceptability and communication for HIV and TB patients; health worker preference for HIV patients only; and global satisfaction for TB patients only). The level of satisfaction did not vary significantly with patients' socio-demographic characteristics.

Conclusions: In this rural area, HIV and TB patients' evaluations of specific aspects of health services delivery revealed substantial dissatisfaction hidden in the global assessments of satisfaction. A wide range of patient satisfaction variables could be reduced to a few underlying factors that align broadly with concepts previously identified in the literature as affecting access to healthcare. Increases in health systems resources for HIV and TB, but also improvements in facility maintenance, staff attitudes and communication, are likely to substantially improve HIV and TB patients' satisfaction with the care they receive in public-sector treatment programmes in rural communities in South Africa.

Keywords: Patient satisfaction, Factor analysis, HIV, TB, Health systems

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Background

The epidemics of HIV and TB in sub-Saharan Africa are closely related and particularly persistent. Currently, approximately 33 million people are HIV infected globally, with South Africa having the greatest absolute number of HIV-infected individuals in the world [1]. Globally, the World Health Organization (WHO) estimates that 8.7million new cases of TB were reported in 2011 (13% of these being co-infected with HIV) [2]. South Africa contributes a substantial proportion of the global burden of TB, for example in 2010, 490 000 cases of TB were recorded in the country [3,4]. In rural Hlabisa sub-district of KwaZulu-Natal, both HIV and TB remain major causes of morbidity and mortality, despite the recent impact of ART on mortality and HIV incidence [5-9]. HIV prevalence among resident adults in 2010 was 29% and TB prevalence was almost 25% among those initiated on ART in 2006 [10,11]. While TB treatment has been widely available in this area for more than three decades [12], ART only became available in public services in South Africa in 2004 [13]. Since then, the Hlabisa HIV Treatment and Care Programme (ART programme) has provided HIV treatment and care at an increasing number of primary healthcare (PHC) clinics (16 at the time of the study). By 2011, 37% of all HIV infected people in the study area had been initiated on ART [6].

Patient satisfaction is an important outcome of health systems [14]. It can be defined as the perceived fulfillment of patients' needs and desires through the delivery of healthcare [15,16]. Patient satisfaction with HIV and TB treatment is important for two main reasons. First, it is an important outcome in its own right as a health systems goal. Many of the well-known frameworks to structure health systems thinking, such as WHO's building blocks [17] and the "control knobs" framework [14], include a measure of patients' subjective evaluation of health services, such as "patient satisfaction" [14] or "responsiveness" [17] as one of the main health systems outcomes. Second, patients who are satisfied with the healthcare received in the healthcare facility were less likely to face barriers to access and challenges to treatment adherence [18,19]. Quantifying and understanding HIV and TB patients' satisfaction with public-sector treatment programmes is thus important for developing strategies to ensure that both health systems goals are attained. Understanding the level, dimensions and determinants of patient satisfaction is particularly topical in the South African context, for informing the current efforts at reforming the national health system [20].

While in Hlabisa sub-district in recent years HIV and TB services have been increasingly integrated at the level of front-line delivery [21,22], HIV and TB treatment and care services are still largely vertically administered regarding planning, funding, and monitoring and evaluation, despite the highly overlapping patient clientele. The two programmes have very different histories and lengths of operation; the TB Directly Observed Treatment Short-Course (DOTS) strategy was introduced in KwaZulu-Natal in 1996 through the National TB control programme to improve cure rates and reduce drug resistance [12,21,23], while HIV treatment only became available through the public-sector health system in KwaZulu-Natal in 2004 and has since then been progressively scaled up [13,22,24-27]. It is thus plausible that patient satisfaction differs substantially across the two programmes. The TB programme has had more than three decades to learn how to best accommodate and respond to patients' demands. On the other hand, the HIV programme is relatively young and structures and processes are likely to be less well-adapted to patients' needs and desires.

In this paper we quantified dimensions of patient satisfaction among HIV and TB patients attending public-sector PHC clinics in rural KwaZulu-Natal. We further identified underlying satisfaction factors that explained the data, compared satisfaction between HIV and TB patients and determined the extent to which socio-demographic patient characteristics are related to the different patient satisfaction factors.

Methods

Study area

Hlabisa sub-district located in the uMkhanyakude district in northern KwaZulu-Natal is predominately rural with a population of approximately 228 000. The Hlabisa HIV Treatment and Care Programme is a Department of Health (DoH) programme which has received operational support from the Wellcome Trust Africa Centre for Health and Population Sciences, (Africa Centre) and financial support from the Presidential Emergency Fund for AIDS Relief (PEPFAR) [27]. (www.africacentre.com) The DoH TB programme does not directly receive external donor support, but the externally-supported HIV treatment programme has supported the integration of the TB and the HIV treatment programmes. Both programmes utilize a decentralized model of healthcare delivery and were available at all 16 PHC clinics at the time of this study [27], but HIV and TB treatment services are delivered by different front-line health workers [21,22].

The HIV and TB treatment programmes operate according to the South African DoH guidelines [12,27,28]. All the PHC clinics in the sub-district offer HIV counseling and testing (both provider-initiated and through standard voluntary counseling and testing (VCT) centres) [27,29,30]. HIV patients visit the clinic monthly in the first year of treatment and two-monthly thereafter if they are stable on treatment, for counselling, assessment and drug collection. TB nurses identify TB suspects at each PHC clinic and collect sputum which is sent to the

Hlabisa National Health Laboratory Services (NHLS) for acid-fast bacilli (AFS) smear testing. All smear-positive patients are initiated onto first-line standard TB regimens and patients with negative smear who remain symptomatic are referred to the district hospital for further assessment [11,21]. TB patients visit the clinic once every month for review and to collect their TB medication; patients with multi-drug resistant (MDR) and extensively-drug resistant (XDR) TB are hospitalized at the district hospital for one to two months with further follow-up at the PHC clinic. TB treatment is six months for routine TB cases and up to 24 months for MDR and XDR patients.

Data sources and sampling

In 2009 we collected data in a survey that was part of a larger multi-site study called Researching Equity in ACcess to Health Care (REACH) [31,32]. For the study presented here, we used data from patient-exit interviews that were part of the REACH study to examine patient satisfaction with different aspects of treatment delivery among patients utilizing HIV and TB treatment and care services. The sample size for the final sampling unit (300 HIV and 300 TB patients) was established through a formal power calculation to ensure a sufficiently large sample to detect significant differences in several key indicators, including patient satisfaction, while accounting for the expected clustering of indicator values at the level of the PHC clinics where we approached patients for the interviews [33]. We used a two-stage cluster random sampling approach, first selecting a random sample of PHC clinics within the sub-district (with replacement) and then randomly sampling the same number of patients (60) in each facility in the second sampling stage [34]. The number of patients (i.e., the second-stage sampling units) was determined in the power calculation, given the number of clinics we decided to visit based on operational feasibility of this research work.

In the first sampling stage, we randomly drew five PHC clinics with probability-proportional-to-size – i.e., larger facilities had a larger probability of being selected into the sample. Because we sampled with replacement, it was possible for one clinic to be selected multiple times. The initial first-stage sampling frame comprised of the 16 PHC clinics in the district, which delivered both HIV and TB treatment. In three clinics other research projects were ongoing and these three clinics were removed from the initial first-stage sampling frame to avoid participant fatigue and over-researching; furthermore, the four clinics which had a patient load of fewer than 60 ART or 60 TB patients were excluded, leaving a final first-stage sampling frame of nine clinics. According to the HIV treatment programme statistics, the number of patients per clinic who were on ART by 2008 in the 16 PHC clinics in the initial sampling frame, ranged from 34 to 1006, and the number of patients on ART who were in the four clinics that were selected in the first sampling stage was 213, 260, 381 and 635 respectively. Based on the DoH statistics for Hlabisa subdistrict, by 2008 the number of TB patients in the 16 PHC clinics ranged from 12 to 250, and the number of TB patients who were in the five clinics selected in the first sampling stage was 100, 100, 133, 160 and 250. Four trained fieldworkers conducted the patient-exit interviews using the local language in the study area, *isiZulu*, with 60 patients randomly selected from three clinics each and 120 patients from one clinic that was sampled twice (HIV patients) and with 60 patients selected from each of five clinics (TB patients). We received ethical clearance for the study from University of KwaZulu-Natal (BE174/08).

Figure 1 shows a map of Hlabisa sub-district (in grey) and the location of the clinics in which the study was conducted. The primary healthcare (PHC) clinics are shown as red crosses; the square with a red cross indicates the location of the PHC clinic located on the premises of the district hospital. The Africa Centre is shown as a yellow triangle. TB patients were interviewed in all of the five clinics shown; ART patients were interviewed in all of the clinics shown with the exception of the clinic that is located lowest on this map.

Data collection instrument and variables

We used a structured patient-exit interview questionnaire, which included multiple questions on patient satisfaction. The same questionnaire was used for HIV and TB treatment patients [33]. Patient satisfaction is a multidimensional construct, which focuses on patient perceptions and evaluation of the treatment and care they receive [35]. Several questions to collect information on patient satisfaction have been used in multiple studies in sub-Saharan Africa, and have been validated and subjected to reliability analysis. We used such established questions about patient satisfaction for this study to elicit patient satisfaction with the overall (or global) experience during the treatment visit, staff respect, privacy and confidentiality, staff attitudes, communication, staff competency, and physical environment [36-43]. The responses for satisfaction outcomes were categorical ("always", "sometimes" or "never"; or "agree", "disagree", "both agree and disagree") or binary ("yes" or "no") (see Table 1). For the analyses (see below), the categorical responses were coded into binary variables ("always" vs. "not always" and "agree" vs. "not agree"). In total we used 13 questions from the multisite study questionnaire (Table 1) for this analysis of patient satisfaction.

Patients who agreed to participate in the study were asked to sign a consent form by the fieldworkers. Consent

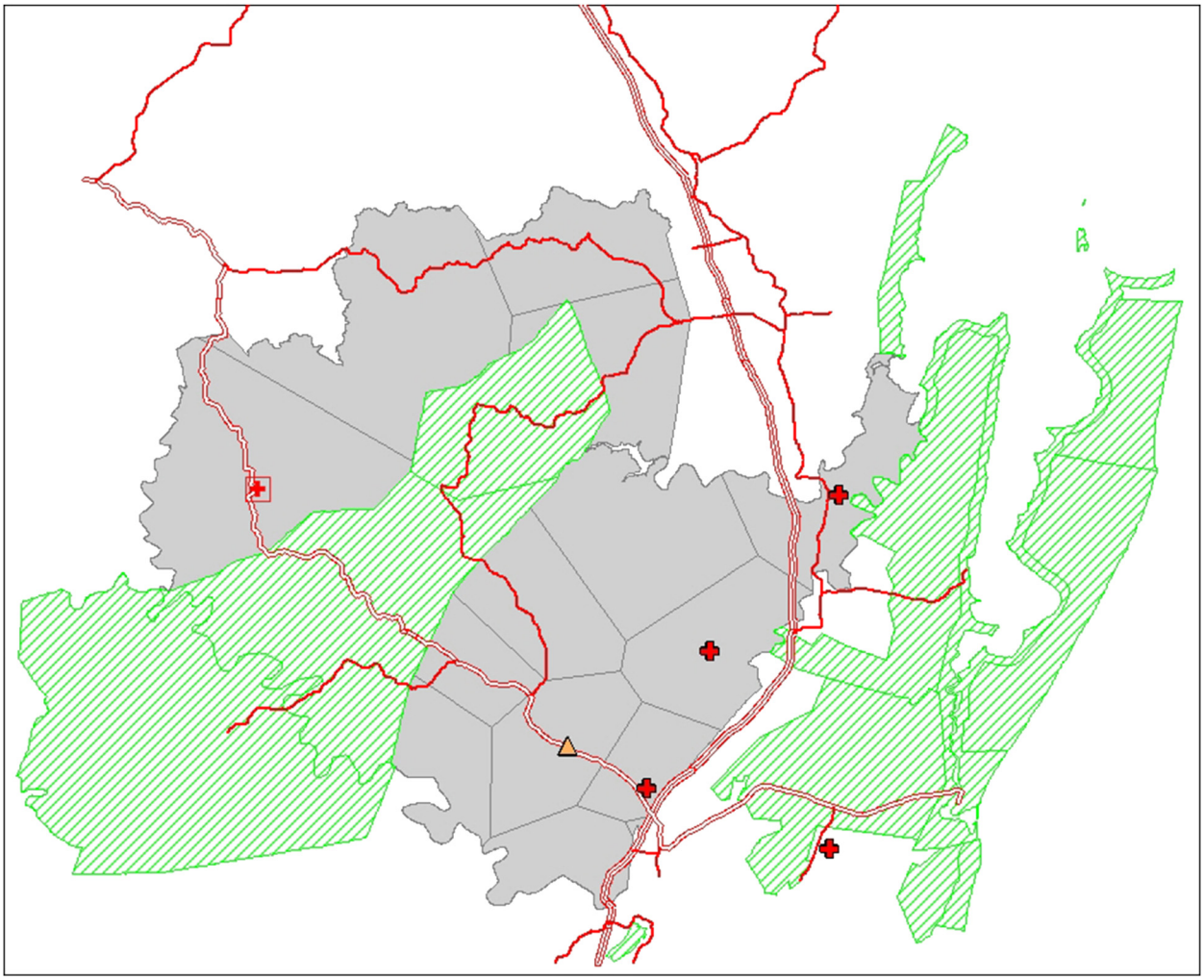

Figure 1 Map of Hlabisa sub-district. Figure 1 shows a map of Hlabisa sub-district (in grey) and the location of the clinics in which the study was conducted. The primary healthcare (PHC) clinics are shown as red crosses; the square with a red cross indicates the location of the PHC clinic located on the premises of the district hospital. The Africa Centre is shown as a yellow triangle.

to participate was obtained from all patients who were at least 18 years of age and, for HIV patients, who had been receiving ART for at least two weeks or for TB patients, who were on TB treatment for at least two months. The treatment duration criterion for HIV patients was used to exclude patients who had just been initiated on ART, because initiation visits are very different from the follow-up visits and we intended to focus on the patient satisfaction with routine visits rather than with ART initiations. Since the first visit following ART initiation occurs two weeks after initiation in this setting (unlike the routine visits thereafter), this inclusion criterion ensures that patients had completed at least two ART visits. We chose this criterion to ensure that the experience represented by the patients in our sample was as wide regarding their time on ART as possible. However, the vast majority of patients in the sample had been on treatment for much longer than two weeks: 99% of the patients in the sample of ART patients had been on ART one month or longer and 95% of patients had been on ART for two months or longer. The treatment duration criterion for TB patients was used, because after two months the intensive phase of treatment for patients with drug-resistant TB, which usually occurs in a hospital, would be completed. The intention here is to restrict the sample to patients who are receiving routine care.

Analysis

We used standard descriptive statistics to present the findings on different indicators of patient satisfaction. Next, we performed a factor analysis with oblique rotation (oblimin rotation) to identify the latent variables, or factors, that generated the patient satisfaction data [44]. Oblique rotation was used because on theoretical grounds it

Table 1 Measures of the indicators of patient satisfaction with healthcare

Statement/question	Response categories
1. How satisfied were you with the service today?	Very satisfied/satisfied; neither satisfied nor dissatisfied; dissatisfied/very dissatisfied; don't know
2. The doctors and nurses (health workers) discussed the treatment fully with me	
3. I find it easy to tell the health workers when I have missed taking my tablets	(Statement/question 2-10) Agree; disagree; both agree and disagree; don't know/not sure
4. It is a problem that health workers do not speak my language	
5. The health workers are too busy to listen to my problems	
6. Some staff do not treat patients with sufficient respect	
7. The health workers I see respect me	
8. Patient information is kept confidential in this clinic	
9. The facilities (including waiting area and toilets) are dirty	
10. The queues to see a doctor or nurse are too long at this facility	
11. In this clinic are you able to talk to the doctors or nurses in private?	Always; sometimes; never
12. For your ARV treatment (TB care) what would you prefer:	Nurse; doctor; indifferent; don't know
a) To see a nurse in a nearby clinic or	
b) To travel further to see doctor	
13. How do you think the service in this clinic could be improved?	Yes; no
a) Shorter queues	
b) More health workers	
c) Cleaner facilities	
d) Better patient facilities (toilets, waiting room area etc)	
e) Don't know	
f) Other specify	

is likely that different patient satisfaction factors are related to each other; e.g. a factor capturing global satisfaction is likely related to several of the factors capturing more specific satisfaction dimensions. The Kaiser criterion (eigenvalue > 1.00) was used to guide decisions regarding which factors to retain and inspection of the factor loadings was used to determine which aspects of patient satisfaction the identified factors capture [38,45,46]. To assess whether socio-demographic characteristics were associated with different patient satisfaction factors, we regressed the five factors identified in the factor analysis on sex, age, marital status, employment status and education level. All these variables have previously been found to influence patient satisfaction levels [42,47]. We controlled for clustering at the clinic level in the regressions. All analyses were done using STATA IC, version 11. We further extracted responses from the open-ended, qualitative questions to aid the interpretation of the quantitative findings. Responses to the open-ended question *"How do you think the service in this clinic could be improved?"* were coded manually into themes and a thematic analysis of the responses was done by one of the authors (NC) through identifying and analyzing common ideas and patterns in the responses from the data.

Results

Table 2 shows the socio-demographic profile of patients utilizing HIV and TB treatment. More women (62% HIV and 53% TB) than men utilized treatment. Almost all patients were globally satisfied with the service they received on the day of the interview; Table 3 shows that 95% of HIV patients and 97% of TB patients reported being either very satisfied or satisfied with the service they had just received. However, satisfaction levels were substantially lower for some specific dimensions of quality of care particularly among patients utilizing HIV treatment.

a. Staff-patient communication

The majority of patients (96% TB and all 100% HIV) agreed that health workers discussed treatment fully with them. However, 10% of HIV patients and 5% of TB patients did not find it easy to tell the health worker when they had missed taking tablets. Although nearly all patients disagreed that it was a problem that some health workers do not speak the patients' language, more than a tenth of the patients (15%) utilizing either HIV or TB treatment agreed that health workers were too busy to listen to their problems anyway.

Table 2 Socio-demographic characteristics of HIV (N = 300) and TB (N = 296) patients

Variable		Types of care		p-value
		HIV	TB	
Sex	Female	186 (62%)	156 (53%)	p = 0.03
Age (years)*		Mean (40) 95% CI (39-41) Median (39)	Mean (38) 95% CI (37-39) Median (37)	p = 0.07
		range (21-89)	range (18-82)	
	Less than 20-29†	45 (15%)	73 (25%)	p = 0.04
	30-39	113 (38%)	102 (34%)	
	40-49	91 (31%)	77 (26%)	
	> = 50	49 (16%)	44 (15%)	
Education				p = 0.43
	None	55 (18%)	50 (17%)	
	Primary	104 (35%)	92 (31%)	
	Secondary	101 (34%)	101 (34%)	
	Matric‡ and higher	40 (13%)	53 (18%)	
Employed*	Yes	36 (12%)	28 (9%)	p = 0.36
Marital status*§	Never married	238 (80%)	249 (84%)	p = 0.15

*Information on age was missing two HIV patients and marital status was missing in one HIV patient. Information on employment status was missing in one TB patient.
†12 people receiving TB treatment and care were less than 20 years old.
‡Matric is the final year of high school in South Africa.
§Ever married: currently married, divorced or separated, widowed.
The p-values indicate the significance of the difference between values among HIV and TB patients.

b. Staff attitudes
Level of dissatisfaction with staff attitudes was greater among HIV than TB patients. A significantly higher proportion of HIV (52%) than TB (40%) patients agreed with the statement that some staff do not treat patients with sufficient respect. However, when asked whether they themselves were treated with respect by their healthcare worker, the majority of patients (93% HIV and 96% TB) agreed that they were treated with respect.

c. Privacy and confidentiality
16% of HIV patients and 11% of TB patients reported that they had either sometimes or never been able to talk in private to their doctors and nurses in their past clinic visits. However, a high proportion of patients (96% HIV and 94% TB) agreed that patient information is kept confidential at the clinic.

d. Staffing and amenities
Nurse-based care for HIV and TB treatment and care was highly acceptable to respondents (100% for HIV and 99% for TB). Slightly more than a fifth (21%) of patients utilizing either HIV or TB care agreed that the facilities (including waiting area and toilets) were dirty. Data from open-ended responses provided some indications of the precise sources of dissatisfaction (lack of a water dispenser and cups to drink, shortage of seats in the waiting area, and lack of shelter from rain and sun in the waiting area, which is outside the clinics).
A significantly higher proportion of HIV (65%) than TB (40%) patients agreed that the queues to see a doctor or nurse were too long. Regarding means of improving services in the clinic, a significantly higher proportion of HIV than TB patients reported shorter queues (57% v 35%); having more health workers (57% v 45%) and having better patient facilities (67% v 54%), respectively, as ways of improving the services at the facilities. One TB patient highlighted that "doctors must always be available" while another suggested that "the staff need to work shifts" as a means of improving services in the clinics.

e. Food provision and patient support
One HIV patient suggested food hand-outs at the clinics because patients have to wait very long to fetch their treatment; another patient suggested patient support in the form of clinic patient groups. Patients in both the HIV and TB programmes emphasized that transport could substantially improve their satisfaction with the treatment experience ("they have to transport us because we are far from the hospital", or "they need to take us from home with the hospital cars").

f. Staff efficiency and easy access to medication
A few patients told the interviewers during the open-ended part of the interviews that they hoped

Table 3 Indicators of reported satisfaction of patients utilizing HIV (N = 300) and TB (N = 296) treatment

Variable	Types of care		
	HIV	TB	p-value
Global satisfaction	n = 293	n = 296	
How satisfied were you with the service today?			
Very satisfied/satisfied	278 (95%)	286 (97%)	p = 0.31
Staff-patient communication	n = 300	n = 294	
The doctors and nurses (health workers) discussed treatment fully with me			
Agree	300 (100%)	283 (96%)	p ≤ 0.001
	n = 226	n = 205	
I find it easy to tell the health worker when I have missed taking my tablets			
Agree	204 (90%)	194 (95%)	p = 0.09
	n = 300	n = 294	
It is a problem that health workers do not speak my language			
Agree	4 (1%)	4 (1%)	p = 0.63
	n = 288	n = 290	
The health workers are too busy to listen to my problems			
Agree	42 (15%)	43 (15%)	p = 0.93
Staff attitudes	n = 226	n = 191	
Some staff do not treat patients with sufficient respect			
Agree	118 (52%)	77 (40%)	p = 0.02
	n = 300	n = 294	
The health workers I see respect me			
Agree	279 (93%)	282 (96%)	p = 0.15
Privacy and confidentiality	n = 286	n = 295	
In this clinic are you able to talk to the doctors or nurses in private?			
Always	241 (84%)	262 (89%)	p = 0.12
	n = 262	n = 230	
Patient information is kept confidential in this clinic			
Agree	251 (96%)	217 (94%)	p = 0.43
Staffing and amenities	n = 300	n = 296	
For your ARV (TB) treatment what would you prefer:			
To see a nurse in a nearby clinic or	299 (100%)	291 (99%)	p = 0.21
To travel further to see doctor	1 (0%)	4 (1%)	
	n = 275	n = 276	
The facilities (including waiting area and toilets) are dirty			
Agree	58 (21%)	58 (21%)	p = 0.98
	n = 298	n = 288	
The queues to see a doctor or nurse are too long at this facility			
Agree	195 (65%)	115 (40%)	p ≤ 0.001
	n = 299	n = 296	
How do you think the service in this clinic could be improved?			
Shorter queues: Yes	170 (57%)	104 (35%)	p ≤ 0.001
More health workers: Yes	171 (57%)	132 (45%)	p ≤ 0.001
Cleaner facilities: Yes	65 (22%)	68 (23%)	p = 0.72
Better patient facilities (toilets, waiting room area): Yes	201 (67%)	161 (54%)	p ≤ 0.001

The p-values indicate the significance of the difference of values among HIV and TB patients.

the health delivery system would make it easier for them to access needed services. Nine TB patients expressed the hope that medicines could be delivered to patients' homes or to collection points nearer to their homes than the PHC clinics. One HIV patient requested that healthcare providers provide a faster service.

g. Factors underlying the patient satisfaction data

We retained five factors in factor analysis of the patient satisfaction data for both HIV and TB patients with eigenvalues > 1.00. The five factors accounted for 58% of the variance in satisfaction for HIV patients and 60% for TB patients. Table 4 shows the factor loadings for each of the variables. Based on the factor loadings, we labeled the five factors underlying the HIV data and the TB data (availability, accommodation, acceptability, and communication for both HIV and TB, and health worker preference for HIV and global satisfaction for TB). The labels capture the content of the different variables that load heavily on the individual factors.

Generally, patient demographic characteristics were not significantly associated with the satisfaction factors in multivariable analysis for both HIV and TB patients (Table 5). However, male HIV patients were less likely to be satisfied with the availability of resources than females, while among TB patients male patients and patients who had ever been married were less satisfied than female patients or patients who had never been married with the degree to which the health systems structures and processes accommodated their demands. TB patients with secondary and higher level of education were more likely to be satisfied with the quality of communication than those with no education.

Discussion

The subjective concept of patient satisfaction is an important intrinsic outcome of healthcare delivery, and it can instrumentally affect health outcomes because it determines long-term retention in care as well as adherence. In scaling-up HIV and TB treatment in sub-Saharan Africa, programme managers should thus not only focus on increasing the number of patients on treatment to decrease HIV-related mortality [9], but also on aspects of treatment delivery that could affect patient satisfaction.

Patients attending HIV and TB treatment services in this typical rural South African community reported high levels of overall satisfaction with their experience. However, as has been found in other studies [16,36,43,48], the high overall satisfaction level masked substantial dissatisfaction with particular aspects of the services, including the availability of health workers, the respect health workers showed patients, waiting times, and cleanliness of facilities.

HIV patients reported being less satisfied with some aspects of quality of care than TB patients (in particular, respectfulness of treatment, waiting times, and availability of

Table 4 Factor loadings for indicator variables for assessing patient satisfaction for HIV (n = 265) and TB (n = 259) patients

Variable	HIV					TB				
	1	2	3	4	5	1	2	3	4	5
	AV	AD	AC	CN	HW	AV	AD	AC	CN	GS
How satisfied were you with the service today?	−0.14	−0.17	0.77	−0.02	0.09	−0.12	−0.02	0.03	−0.06	0.84
The doctors and nurses (health workers) discussed treatment fully with me‡	-	-	-	-	-	0.07	−0.01	0.01	0.54	0.51
It is a problem that health workers do not speak my language	0.02	−0.02	0.08	0.83	0.02	−0.09	−0.06	0.08	−0.77	0.12
The health workers are too busy to listen to my problems	−0.04	0.42	0.35	−0.47	0.09	−0.14	−0.18	0.47	0.42	−0.04
The health workers I see respect me	0.08	0.20	0.66	0.15	−0.15	−0.42	0.49	−0.03	0.13	−0.20
In this clinic are you able to talk to the doctors or nurses in private?	−0.04	0.48	0.09	0.34	0.14	−0.10	−0.21	0.76	−0.06	0.22
For your ARV (TB) treatment what would you prefer: to see a nurse in a nearby clinic or to travel further to see doctor	0.02	0.02	−0.00	0.01	0.94	0.09	−0.27	−0.75	0.02	0.16
The facilities (including waiting area and toilets) are dirty	−0.17	0.76	−0.10	−0.09	0.03	−0.21	−0.49	0.14	0.39	0.12
The queues to see a doctor or nurse are too long at this facility	−0.73	0.02	0.06	0.01	−0.12	−0.77	0.06	0.03	−0.13	0.21
How do you think the service in this clinic could be improved? Shorter queues	0.80	−0.24	0.03	0.06	0.08	0.84	0.06	−0.12	−0.05	−0.01
More health workers	0.72	−0.06	−0.13	−0.00	−0.24	0.69	0.33	−0.04	0.06	0.08
Cleaner facilities	0.16	−0.74	−0.01	0.00	0.04	0.40	0.65	−0.01	−0.16	−0.10
Better patient facilities (toilets, waiting room area)	0.46	−0.02	0.11	−0.21	0.10	0.06	0.74	0.05	0.13	0.12

AV, Availability; *AD,* Accommodation; *AC,* Acceptability; *CN,* Communication; *HW,* Health worker preference; *GS,* Global satisfaction.
‡For HIV patients, this variable was dropped from the factor analysis, because there was no variation in the variable (see Table 3).

Table 5 Factors associated with patient satisfaction for patients utilizing HIV (n = 265) and TB (n = 259) treatment

Patient demographic characteristics	HIV coefficient (95% CI) p-value*					TB coefficient (95% CI) p-value*				
	1	2	3	4	5	1	2	3	4	5
	AV	AD	AC	CN	HW	AV	AD	AC	CN	GS
Sex: Male	**−0.21**	0.13	0.05	0.05	0.10	−0.22	**−0.20**	−0.31	−0.06	−0.11
	(−0.35– -0.07)	(−0.41–0.67)	(−0.37–0.47)	(−0.25–0.35)	(−0.33–0.54)	(−0.60–0.15)	(−0.39– -0.00)	(−0.39–0.33)	(−0.32–0.20)	(−0.53–0.32)
	0.02	0.51	0.74	0.63	0.50	0.17	0.05	0.82	0.55	0.53
Age	0.01	0.01	0.01	−0.01	−0.02	−0.01	0.00	0.01	0.02	−0.01
	(−0.03–0.04)	(−0.03–0.46)	(−0.02–0.03)	(−0.03–0.02)	(−0.08–0.04)	(−0.03–0.02)	(-0.01–0.02)	(−0.00–0.02)	(−0.00–0.04)	(−0.02–0.01)
	0.56	0.49	0.53	0.47	0.45	0.36	0.53	0.06	0.10	0.28
Education: Primary	0.05	0.18	0.04	0.24	0.15	0.10	0.37	0.29	0.37	0.01
	(−0.57–0.67)	(−0.50–0.87)	(−0.16–0.25)	(−0.25–0.72)	(−0.12–0.43)	(−0.25–0.44)	(−0.23–0.97)	(−0.37–0.95)	(−0.07–0.82)	(−0.11–0.13)
	0.80	0.45	0.57	0.22	0.17	0.48	0.16	0.29	0.08	0.77
Secondary and higher	0.10	0.58	0.09	−0.09	−0.18	−0.12	0.02	0.22	**0.56**	−0.38
	(−0.47–0.67)	(−0.17–1.33)	(−0.19–0.36)	(−0.62–0.43)	(−1.06–0.70)	(−0.77–0.54)	(−0.86–0.90)	(−0.32–0.76)	(0.32–0.79)	(−0.90–0.14)
	0.62	0.09	0.39	0.62	0.57	0.64	0.96	0.32	0.00	0.11
Employed: Yes	0.27	−0.30	−0.08	0.20	−0.05	0.14	0.21	−0.17	0.06	0.22
	(−0.36–0.91)	(−1.01–0.40)	(−0.36–0.19)	(−0.97–1.36)	(−0.19–0.09)	(−0.34–0.62)	(−0.22–0.64)	(−1.19–0.85)	(−0.55–0.68)	(−0.36–0.79)
	0.27	0.26	0.41	0.63	0.33	0.46	0.25	0.67	0.79	0.35
Marital status: Ever married	−0.04	−0.03	0.10	−0.04	0.04	0.01	**−0.43**	−0.15	0.06	−0.08
	(−0.22–0.14)	(−8.88–0.83)	(−0.30–0.51)	(−0.22–0.13)	(−0.28–0.36)	(−0.36–0.38)	(−0.71– -0.14)	(−0.66–0.37)	(−0.17–0.2)	(−0.52–0.35)
	0.57	0.93	0.48	0.49	0.73	0.94	0.01	0.48	0.50	0.62

*Coefficients that are statistically significant at the 0.05 level are shown in bold font.
AV, Availability; *AD,* Accommodation; *AC,* Acceptability; *CN,* Communication; *HW*, Health worker preference; *GS,* Global satisfaction.

waiting areas and toilets). These differentials in satisfaction levels between HIV and TB patients are likely due to historical differences in the organizations of healthcare delivery – the HIV treatment programme is much younger and still learning how to best organize service delivery – and differences in the speed of increase of patient load – unlike the TB treatment programme, the HIV treatment programme experienced an extremely rapid increase in patient load, which is likely to have led to temporary mismatches between human and physical resources for service delivery and patient demands. However, most satisfaction indicators were similar in HIV and TB patients except for two indicators, suggesting that in general treatment structures and processes do not differ significantly across the two programmes.

The HIV and TB programmes in the study area are supposed to follow the national guidelines for HIV and TB treatment and care, which are intended to be appropriate for nurse-led treatment and lay-out in detail which aspects of treatment should be discussed with patients [49,50]. Our findings that almost all patients reported that treatment was discussed fully with them and that the nurse-based care was highly acceptable can thus be interpreted as an indicator that the nurse-led and guideline-based HIV and TB treatment strategies are successful. However, healthcare providers may sometimes feel pressured to see many patients in a short space of time because of the high patient load leading to concerns by some patients that the health workers were too busy to listen to their problems. A study in Ethiopia found poor staff communication skills and lack of empathy to be factors affecting patient satisfaction [51]. Patients' ability to freely talk about missed doses or their problems with their healthcare provider is important for improving treatment outcomes and adherence which are essential for the full treatment benefits for both HIV and TB to be realized [52,53].

Whereas overall relatively large proportions of HIV (52%) and TB (40%) patients reported that some healthcare staff did not treat patients with sufficient respect, the vast majority of patients in both groups (HIV 93%, TB 96%) agreed that they were personally treated with respect by the health worker who attended to them. This could be an indicator that patients have a higher tolerability for treatment lacking respect in their own encounters with health workers rather than in observed encounters of other patients. It is also plausible that patients wrongly report that they have been treated respectfully because of fear of negative consequences when complaining about their own health workers or because they feel such an answer is generally socially desirable. In developed countries, perception about staff respect has been found to be related to race and language, with minority groups reporting highest levels of disrespect [54]. In our setting all participants and health workers were from the same race and shared the same primary language (*isiZulu*). Future studies need to explore in more detail how health workers communication skills and attitudes can be improved to ensure that patients feel respected and understood in this community.

Both HIV and TB patients reported they were not able to always speak to healthcare providers in private. Privacy and confidentiality have been found to be strong predictors of patient satisfaction when seeking and utilizing care [55]. Patients need to be treated in private and their information should be seen to be kept confidential, so that they continue utilizing care. This is especially relevant in our study area where most patients received treatment from the clinic that was nearest to their homes [56-58]. Patient lack of trust with their healthcare provider has negative effects on patient satisfaction, treatment adherence and ultimately improved health status [59].

As in our study, several previous studies have found waiting times due to queues to be a main determinant of patient satisfaction [36,41,60]. HIV patients were significantly more dissatisfied with the length of the queues than TB patients. Indeed, based on observation and practice in both programmes, it is clear that queuing times for TB treatment are usually shorter than for HIV patients. This difference arises because TB patients join one queue to collect their treatment; the data clerk and TB nurse are in the same room to provide the patient clinic file and offer counselling before giving out treatment. In contrast, HIV patients normally have to join two queues – first to see a counsellor and then to see a nurse for clinical assessment and medication. HIV patient queues are even longer on days when the doctor visits the clinics for patient examination and initiation of patients on ART – this was before nurse-initiated ART was introduced in 2011. At present, ART initiation does not happen on specific days when the doctor is available but it can happen on any day. Additionally, there are generally more patients on ART than TB treatment in the study area. Patients offered interesting suggestions to improve the queuing system – health workers should work in shifts and that doctors should always be available at the clinics – and to make queuing a more pleasant experience – by providing food rations, and to reduce travel times to and from the clinics – by providing transport.

Patient satisfaction is the perceived fulfillment of patients' needs and desires through the delivery of healthcare. As such, it will depend not only on the objective quality of care provided but also on patients' expectations [15,51]. These expectations are known to vary with patient socio-demographic characteristics, with time and by context. Some studies of patient satisfaction thus attempt to 'anchor' the patient evaluations through the

use of 'anchoring vignettes', i.e., short descriptions of experiences of other patients in utilizing healthcare, which participants in patient satisfaction surveys are asked to evaluate. Such anchoring approaches will provide an important improvement in our ability to compare patient satisfaction in this setting compared to other settings in the Southern African region and globally. However, for the comparison in satisfaction between HIV and TB patients in this study, it is unlikely that anchoring of patient responses would have substantially changed our findings, since HIV and TB treatment are delivered in very similar contexts, in close proximity to each other and within the same general PHC clinics.

Five factors were found to be underlying both the HIV and the TB patient satisfaction data. Four of these factors – which captured availability, accommodation, and acceptability of services, and the quality of communication – were similar in their representation of specific variables in the HIV and TB programme, pointing towards general constructs of patient satisfaction rather than disease-specific constructs. It is interesting to note that three of these underlying factors resemble closely three of the five dimensions of healthcare access identified by Penchansky and Thomas (1981) in their conception of access as the degree of fit between the health system and patient needs and wants [61]. In as far as patient satisfaction reports determine access; our findings thus partially validate this conception. A relationship between patient satisfaction and healthcare utilization is likely to arise – patient satisfaction will determine future access; we expect more highly satisfied patients to be more likely to utilize treatment in the same clinic again. Furthermore, patients can share their experience with others, which in turn can influence their access to care when the need arises. The different underlying factors were regarding global satisfaction for TB patients and health worker preference for HIV patients. This finding could possibly indicate that although these patients utilize care at PHC clinics integrated at facility level; experiences, expectations and quality of care needs for HIV and TB patients may not be identical but may vary by the type of healthcare a patient is utilizing – the issue of health worker preference is more crucial for HIV patients probably because of the nature of the disease and its demands in healthcare provision.

Some studies have found that patient characteristics such as age and sex influence patient satisfaction probably because of lower expectations of healthcare and reluctance to articulate their dissatisfaction particularly among men and older patients [16,42]. In some studies in sub-Saharan Africa, patients with higher education were less satisfied with the level of privacy received at public sector HIV services [60], while women reported low levels of confidentiality with patient HIV test results [41]. However, in this study patient characteristics generally did not significantly influence patient satisfaction, indicating that the health systems structures and processes affected all patients roughly equally. However, we found that men receiving ART were more likely to complain about availability of services than women, possibly because they are more likely to work in the formal sector, where absenteeism is more likely to have negative consequences than in the informal sector and home production. We also found that those with a higher level of education were more likely to be satisfied in general with the level of health worker communication compared to those with no education. Patients with a higher level of education are likely to express greater dissatisfaction with the service received because they are more assertive and more aware of their patient rights and information needs than less educated patients.

Conclusions

HIV and TB patients' evaluations of specific healthcare delivery aspects revealed substantial dissatisfaction hidden in the global assessment of satisfaction. A wide range of patient satisfaction variables could be reduced to a few underlying factors that align broadly with concepts previously identified in the literature as affecting access to healthcare. Although patients reported high levels of general patient satisfaction, dissatisfaction with specific dimensions of care – in particular, health worker respect, queuing times, and availability and cleanliness of facilities – point towards possible interventions to improve patient satisfaction. Such improvements will be critical to maintain and further improve the performance of both the HIV and the TB programme in this typical rural South African community.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

The authors NC, MLN and TB contributed to the conception and design of the article and revising it critically. NC did the acquisition of data and drafted the article, NC and TB did the analysis and interpretation of data. All authors have read and approved the final manuscript.

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Time and Money: The True Costs of Health Care Utilization for Patients Receiving "Free" HIV/Tuberculosis Care and Treatment in Rural KwaZulu-Natal

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Background: HIV and tuberculosis (TB) services are provided free of charge in many sub-Saharan African countries, but patients still incur costs.

Methods: Patient-exit interviews were conducted in primary health care clinics in rural South Africa with representative samples of 200 HIV-infected patients enrolled in a pre-antiretroviral treatment (pre-ART) program, 300 patients receiving antiretroviral treatment (ART), and 300 patients receiving TB treatment. For each group, we calculated health expenditures across different spending categories, time spent traveling to and using services, and how patients financed their spending. Associations between patient group and costs were assessed in multivariate regression models.

Results: Total monthly health expenditures [1 USD = 7.3 South African Rand (ZAR)] were ZAR 171 [95% confidence interval (CI): 134 to 207] for pre-ART, ZAR 164 (95% CI: 141 to 187) for ART, and ZAR 122 (95% CI: 105 to 140) for TB patients ($P = 0.01$). Total monthly time costs (in hours) were 3.4 (95% CI: 3.3 to 3.5) for pre-ART, 5.0 (95% CI: 4.7 to 5.3) for ART, and 3.2 (95% CI: 2.9 to 3.4) for TB patients ($P < 0.01$). Although overall patient costs were similar across groups, pre-ART patients spent on average ZAR 29.2 more on traditional healers and ZAR 25.9 more on chemists and private doctors than ART patients, whereas ART patients spent ZAR 34.0 more than pre-ART patients on transport to clinics ($P < 0.05$ for all results). Thirty-one percent of pre-ART, 39% of ART, and 41% of TB patients borrowed money or sold assets to finance health care.

Conclusions: Patients receiving nominally free care for HIV/TB face large private costs, commonly leading to financial distress. Subsidized transport, fewer clinic visits, and drug pick-up points closer to home could reduce costs for ART patients, potentially improving retention and adherence. Large expenditure on alternative care among pre-ART patients suggests that transitioning patients to ART earlier, as under HIV treatment-as-prevention policies, may not substantially increase patients' financial burden.

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Key Words: borrowing, selling assets, financial distress, health care costs, HIV, TB, out-of-pocket, health expenditure, time use, South Africa, ART, pre-ART, retention, costs

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INTRODUCTION

South Africa has the largest number of people infected with HIV worldwide[1] and the largest public antiretroviral therapy (ART) program in the world.[2,3] Tuberculosis (TB) is among the leading causes of morbidity and mortality in South Africa and a common opportunistic infection in HIV patients.[1,4]

The South African Department of Health (DoH) has made both TB treatment and HIV care and treatment free of charge in public health care facilities to increase treatment accessibility.[5,6] However, HIV and TB patients may still face financial hardships due to other health care–related expenditures, such as transport to and from the clinic, food and in some cases overnight accommodation near the clinic, expenditure on alternative sources of care including private doctors, pharmacies, and traditional healers, and income losses due to time spent seeking care.[7,8] In this study, we aim to establish the true costs of health care utilization for patients receiving "free" HIV/TB care and treatment in rural KwaZulu-Natal.

Previous research suggests that patients bear costs—in both time and money—not captured in clinic fees. Routine surveillance data collected annually in the study area shows that the median time taken to travel to the nearest clinic is 81 minutes and the common mode of transport for most patients is by minibus taxis.[9,10] These expenditures can lead to financial distress for patients already living in poverty. People may forego essential consumption to pay for health care by borrowing money from relatives or friends or resort to selling of assets, contributing to longer-term impoverishment.[11–15] For HIV care and treatment in particular, time losses and out-of-pocket payments could amount cumulatively to very large sums, as treatment is life long.[13,14]

A key contribution of this study is the ability to compare health expenditures across both pre-ART and ART patients. Research focused on the health expenditures of pre-ART patients is scarce, yet it is important because it can provide insight into the barriers to retention during the pre-ART stage[3] and patients' willingness and ability to transition to ART initiation when eligible.[7] If ART initiation is associated with higher patient costs, eg, due to the higher frequency of clinic visits, then this may discourage pre-ART patients from remaining in care and lead to later-than-optimal initiation of ART. However, if patients experience high out-of-pocket expenditures in pre-ART care, eg, due to treatment of opportunistic infections, then ART initiation could be a financially attractive option and demand for earlier initiation could be high.[3,16] The relative costs to patients of pre-ART vs. ART have significant implications for the successful rollout of treatment-as-prevention programs.

To provide insight into the true costs of health care seeking for public-sector patients, we set out to measure the financial and time-related costs of health care utilization among patients receiving "free" pre-ART, ART, and TB services in primary health care (PHC) clinics in rural South Africa. We assessed costs associated both with accessing public-sector care and with complementary utilization of traditional healers and private providers. Finally, we assessed whether these expenditures led to financial distress, as indicated by borrowing money or selling assets to finance care.

METHODS

Study Area and Health Systems Context

We performed the study within the public-sector ART program of Hlabisa subdistrict, situated in northern KwaZulu-Natal, South Africa. HIV prevalence among adults in the rural Hlabisa subdistrict of KwaZulu-Natal in 2010 was 29%[17] with incidence remaining high despite recent reductions in mortality and HIV acquisition due to the scale-up of ART.[18–22] TB prevalence was almost 25% among those initiated on ART in 2006, and the population TB notification rate was approximately 928 cases per 100,000 in 2009, with evidence of emerging drug resistance.[23]

Since 2004, the Hlabisa HIV Treatment and Care Program (ART program) has provided free HIV treatment and care in 17 (16 at the time of the study) PHC clinics in the subdistrict; the program works in partnership with the DoH-TB program to provide free TB treatment in the same PHC clinics.[24] The subdistrict is predominantly rural, about 90% of the population of approximately 228,000 individuals live in rural areas, with pockets of urban and peri-urban areas. All PHC clinics within the ART program (www.africacentre.ac.za)[24] operate in accordance with the current South African DoH guidelines on HIV and TB management.[5,23–26]

Both HIV and TB care and treatment require repeated clinic visits to diagnose and manage these infections; ART and TB treatment can be collected on the same visit for coinfected patients. All PHC clinics offer HIV counseling and testing.[24,27,28] When a patient tests HIV-positive, blood samples are sent to the National Health Laboratory Services at Hlabisa district hospital for CD4 cell count measurement, and patients return to the clinic for their results within a week from sample collection. Individuals who are not yet eligible for ART are instructed to return to the clinic every 6 or 12 months, depending on CD4 count.[29] ART eligible patients attend 3 adherence counseling sessions and then initiate therapy. Patients initiated on ART are instructed to visit the clinic monthly to refill medications and for clinical observation.

Sputum from patients with suspected TB is sent to the National Health Laboratory Services for acid-fast bacilli smear testing.[25,26] All smear-positive patients are initiated onto first-line standard TB regimen, and patients with negative smear who remain symptomatic are referred to Hlabisa district hospital for further assessment. TB patients collect treatment monthly from the PHC clinic; multidrug (MDR) and extensively drug (XDR) resistant TB cases are hospitalized for 1-2 months with further follow-up at PHC clinics.

Data Sources and Sampling

We measured the financial and time-related costs of health care utilization among patients using free pre-ART, ART, and TB services and other private health care services. Data were collected through exit interviews with 800 HIV and TB patients, with patients sampled to be representative of the patient population in the Hlabisa subdistrict public-sector health system. Data were collected on a wide range of health-related expenditures and time spent seeking clinical care. To assess whether these expenditures led to financial distress, we collected information on whether patients reported either borrowing money or selling assets to finance health care utilization.

We collected data in patient-exit interviews at the HIV and TB facilities from 2 cross-sectional surveys in the subdistrict. The first of these two surveys was the Hlabisa subdistrict component of a multisite study called Researching Equity in ACcess to Health care (REACH)[15], which was conducted in 2009 and focused on patients using ART and TB services in PHC clinics. The ART and TB questionnaires for this survey were constructed using questions on access to health care that have been used, validated, and subjected to reliability analyses in multiple studies in sub-Saharan Africa (www.wits.ac.za/pdf/10500/10500_chp_10500_reach.pdf).[15,30–32] We used the questions about patient affordability to establish the direct and indirect health care utilization expenditures in the study populations. The questionnaires were structured such that we started with simple and nonthreatening questions and ended with questions that were more sensitive or more difficult to answer.

Second, we extended the study to HIV-infected people not yet eligible for ART within the same PHC clinics in 2010 in Hlabisa subdistrict. We used a 2-stage cluster random sampling approach, first selecting a random sample of PHC clinics within the subdistrict drawn (with replacement) with probability proportional to size and then randomly sampling 60 patients in each facility in the second stage. The sample size for the final sampling unit (300 ART and 300 TB patients) was established through a formal power calculation to ensure a sufficiently large sample to detect significant differences in cost components while accounting for the expected clustering at the level of the PHC clinics where we approached patients for the interviews. Pre-ART patients (sample size 200) were randomly selected from the clinics included in the REACH study. To be included in the ART group, patients had to be on ART for at least 2 weeks; to be included in the TB group, patients had to have been on TB treatment for at least 2 months; pre-ART patients had to be ART naive. Four trained fieldworkers conducted the patient-exit interviews using the local language in the study area, isiZulu. The questionnaires were translated from English to Zulu and back-translated to English by certified translators to ensure that meaning and consistency were maintained in the translation. All 4 fieldworkers were native Zulu speakers, and all 4 had previously been trained and worked as fieldworkers in the population-based surveillance at the Africa Centre for Health and Population Studies. During the fieldwork, the study coordinator debriefed and discussed challenges with the fieldworkers. The study coordinator also continuously checked the interview forms for completeness and quality and provided feedback on interview issues to the fieldworkers once per week.

Ethics Approval

We received ethical clearance for this study from the University of KwaZulu-Natal (BF072/09 and BE174/08). We obtained written informed consent from all participants. Interviews were performed within the clinic premises but in a separate space outside the health care facility to ensure privacy and confidentiality for all participants.

Measures

Data were collected on different health-related financial expenditures, time spent traveling to and using clinical services, and indicators of financial distress due to health care expenditures.

Financial Expenditures

We collected data on expenditures on 3 broad categories: costs of visits to the clinic, costs of other health care services, and costs associated with self care, each of which had a number of subcategories. Expenditures associated with clinic visits were assessed on a per-visit basis. Patients were asked: "In coming to receive treatment today, how much did you pay for: transport (one way), clinic/hospital fees, medicines, someone to take over your tasks while you are here including childcare, accommodation if you need to stay the night nearby, food during the visit, telephone, other, specify." In addition patients were asked "Did you find it easy or difficult to incur these expenses?" Since most ART and TB patients had 1 visit per month, these single episode costs were taken to be monthly costs of seeking care at the clinic. To allow for the different visit schedules, we translated pre-ART patients' financial and time costs per clinic visit to monthly costs by dividing the financial and time costs by 3 (on average pre-ART patients are expected to make 4 clinic visits per year for CD4 count testing and clinical monitoring).[5,29] Costs associated with other health care services and self care were assessed with reference to the past 4 weeks. With respect to other health care services, patients were asked about utilization and expenditure on "chemist/pharmacy, private doctor, traditional healer, other public or private hospital/clinics—inpatient stay or emergency/outpatient department." To capture the costs of self care, we asked patients to report expenditure on "any other health care in the past month [eg, traditional medicines, spaza shops, special food, etc]." Spaza shops are informal convenience stores in South Africa, which sell a wide variety of food and health-related goods.[33] The above health expenditures were aggregated to calculate "total expenditures in the last 4 weeks." All expenditures were reported in South African Rand (USD 1 = ZAR 7.3, at the time of the study in 2010). We standardized the ART and TB patients' costs to 2010 for comparability with pre-ART patient costs taking into account inflation.[34,35]

Time Costs

Data were also collected on time-related costs associated with clinic visits. Data were collected on time (in hours)

spent traveling to the clinic and time spent at the clinic, using the questions: "How much time did you spend at the clinic last time you came to collect your ARV or TB treatment?" and "How long did it take you to get here? (one way only i.e., time taken from leaving home to arriving at facility?)" Round-trip transit and utilization times were aggregated to calculate "total time costs" associated with clinic visits. As with financial costs, we divided pre-ART time costs by 3 to adjust for the different visit schedules.[5,29]

To enable comparisons between time and financial costs, we converted time spent in hours into equivalent monetary expenditure using an estimate of the opportunity cost of time. We calculated the rate of income per hour worked by dividing the Gross Domestic Product per capita for KwaZulu-Natal with the working hours per year and obtained an average hourly wage of ZAR 17.49.[36,37] Evidence from the study setting finds 90% recovery of baseline employment levels among patients established on ART.[38] To obtain time costs in Rand, we multiplied the monthly time spent during clinic visits and the travel times to the facility for pre-ART, ART, and TB patients by ZAR 17.49. We note that estimating the value of time in settings with very high unemployment is difficult, and therefore, we present time costs in hours as our main results.

Financial Distress

Patients were asked how they paid for health care using the questions "In the last month, did you have to borrow money to pay for health care?" and "In the last month, did you have to sell personal or household items in order to pay for health care?" We constructed an indicator of "financial distress," which took the value of 1 if individuals reported either borrowing money or selling personal or household items to pay for health care in the last month and 0 otherwise.[13,15] We also elicited data on the disability grants that many ART and TB patients are eligible to receive to compensate for disease- and disability-related employment loss; most pre-ART patients are not eligible (and are not encouraged to apply) for the disability grants under the inability to work due to illness criteria unless they meet the criteria for reasons unrelated to their HIV infection. The question on disability grants was thus omitted for this group.[39,40]

Analysis

The analysis proceeded in 3 steps. First, we used standard descriptive statistics to summarize the patient sociodemographic characteristics and time-related costs, financial costs, and financial distress indicators for pre-ART, ART, and TB patients. Second, to investigate whether patient type (pre-ART vs. ART vs. TB) was associated with differences in patient costs, we estimated multivariate regression models controlling for socioeconomic covariates and clustering standard errors at the clinic level. Third, we assessed the association between patient costs and financial distress in multivariate logistic regression models, controlling for sociodemographic characteristics and accounting for clustering at clinic level. We estimated separate logistic regression models for pre-ART, ART, and TB patients and a pooled model for all 3 groups, and we obtained predicted marginal effects after each model. When modeled as exposures, costs were expressed per ZAR 100. All analyses were performed using STATA version 11,[41] and values of $P < 0.05$ were considered significant.

RESULTS

Patients' Characteristics

Pre-ART patients were more likely to be female (79% pre-ART, 62% ART, and 53% TB) and were significantly younger than ART and TB patients (Table 1). ART patients had been on treatment for more than a year, on average 19 months [95% confidence interval (CI): 17.3 to 20.5], and the average most recent CD4 count was 347.9 cells per cubic millimeter (95% CI: 321 to 375). Most TB patients (75%) reported that it was their first episode of TB; 83% had pulmonary TB and 17% had extrapulmonary TB. Most households of ART patients (92%) and TB patients (89%) were receiving social grants from the government; households with ART patients received a significantly higher average grant amount than households with TB patients (Table 1).

Patient Expenditures and Time Costs Associated With Clinic Visits

Financial Expenditures

For all groups, transport was the largest expense associated with clinic visits, with a monthly cost of pre-ART (ZAR 5; 95% CI: 4 to 6), ART (ZAR 37; 95% CI: 29 to 45), and TB patients (ZAR 24; 95% CI: 21 to 28) (Table 2). Sixty-three percent of ART and 57% of TB patients

TABLE 1. Characteristics of Pre-ART, ART, and TB Patients

Characteristics	Pre-ART (N = 200)	ART (N = 300)	TB (N = 296)	*P*
Sex (male), %	21	38	47	<0.001*
Age, mean (SD), yrs	33 (10)	40 (10)	38 (12)	<0.001†
Head of household employment status (unemployed), %	73	86	81	0.002*
Households receiving grants‡ (yes), %	—	92	89	0.113*
Household grant value,‡ mean in ZAR (SD)	—	1503 (974)	1198 (922)	<0.001†

*P-value based on Pearson's χ^2 test for differences in proportions across patient groups.
†P-value based on F statistic test for differences in means across patient groups.
‡Data on grants was not available for pre-ART patients.

TABLE 2. Descriptive Table of Financial Costs, Time Costs, Total Costs and Financial Distress*†

Financial and Time Costs (Per month)	Pre-ART (N = 200), Mean (SD)	ART (N = 300), Mean (SD)	TB (N = 296), Mean (SD)	P‡
Costs associated with visits to HIV/TB clinic (ZAR/month)				
Transport costs (return trip)	5.0 (6.8)	36.9 (67.4)	24.4 (29.4)	<0.001
Nontransport costs	2.7 (3.8)	9.4 (11.7)	8.2 (36.1)	0.004
Subtotal	7.6 (8.5)	46.4 (71.8)	32.7 (52.0)	<0.001
Costs incurred for use of other health care services (ZAR/month)				
Chemist or pharmacy	17.4 (81.9)	0.8 (4.7)	2.0 (16.6)	<0.001
Public clinic	0.8 (10.6)	0.7 (8.1)	0.7 (10.8)	0.999
A private doctor	30.2 (77.7)	23.4 (82.8)	15.5 (55.3)	0.081
A traditional healer	29.1 (117.1)	0.2 (3.0)	1.5 (14.9)	<0.001
Public hospital	1.0 (7.8)	0.4 (4.0)	0.0 (0.0)	0.053
Private hospital	0.1 (1.4)	0.0 (0.0)	0.1 (1.2)	0.520
Self care (including spending on traditional medicines, health related-spending at spaza shops, and special foods)	84.5 (141.2)	91.7 (153.0)	69.8 (118.5)	0.145
Subtotal	163.1 (262.5)	117.3 (181.3)	89.5 (139.8)	<0.001
Total financial costs	170.7 (262.9)	163.7 (204.0)	122.2 (154.7)	0.012
Time costs (hours/month)				
Time spent at clinic	1.2 (0.7)	2.8 (2.0)	1.1 (1.3)	<0.001
Time spent travelling	2.2 (1.8)	2.2 (1.8)	2.0 (1.5)	0.105
Total (hours/month)	3.4 (0.7)	5.0 (2.8)	3.1 (2.0)	<0.001
Total monetized time costs (ZAR/month)	59.2 (12.7)	87.1 (49.4)	54.7 (35.2)	<0.001
Total financial + monetized time costs (ZAR)	230.2 (262.7)	250.7 (218.5)	177.0 (158.5)	<0.001
Financing health expenditure (yes), %				
Borrowed money	29 (22–35)	36 (31–42)	39 (33–45)	0.054§
Sold assets‖	5 (2–7)	8 (5–11)	6 (3–9)	0.365§
Borrowed money or sold assets to pay for health care¶	31 (24–37)	39 (34–45)	41 (35–47)	0.051§

*To estimate monthly costs for pre-ART patients we divided the costs per clinic visit reported by pre-ART patients by 3, because the patients are instructed to make 4 clinic visits per year for CD4 count testing and monitoring of ART eligibility.

†Time costs were calculated by multiplying the reported times (in hours) by ZAR 17.49, the average hourly wage for the province of KwaZulu-Natal.

‡*P*-value based on F statistic test for differences in means across patient groups.

§*P*-value based on Pearson's χ^2 test for differences in proportions across patient groups.

‖Sample was 282 for ART patients due to missing data.

¶Sample was 296 for ART patients due to missing data.

reported using public transportation to and from the clinic (mode of transport data were unavailable for pre-ART patients). Food costs during the clinic visit also contributed to monthly expenditures associated with clinic visits: pre-ART (ZAR 2; 95% CI: 2 to 3), ART (ZAR 9; 95% CI: 8 to 10), and TB patients (ZAR 6; 95% CI: 5 to 8). None of the patients paid for medicines, and small amounts were reported to have been spent on childcare, overnight accommodation, cell phone airtime, and on clinic/hospital fees. Total monthly costs of clinic visits (excluding time costs) were higher for ART patients (ZAR 46; 95% CI: 38 to 55) and TB patients (ZAR 33; 95% CI: 27 to 39) than for pre-ART (ZAR 8; 95% CI: 6 to 9), largely due to the frequency of visits (Table 2). Most patients indicated that it was difficult to bear these expenses [pre-ART: 135 (81%), ART: 203 (86%), and TB: 185 (92%) $P = 0.01$].

Patients in the 3 groups spent about the same amount of money per month on health care (clinic visit costs combined with expenditures on other health care services)—ZAR 171 (95% CI: 134 to 207) for pre-ART patients, ZAR 164 (95% CI: 140 to 187) for ART patients, and ZAR 122 (95% CI: 104 to 140) for TB patients (Table 2). However, the 3 patient groups differed widely in the composition of their financial expenditures: pre-ART patients spent more on traditional healers, chemists, and private doctors (Fig. 1; Table 2) compared with their counterparts; although they spent less on transport. All 3 groups reported large expenditures on self care (Table 2). These results held up in multivariate regression, after controlling for sociodemographic characteristics (Table 3). Pre-ART patients spent less on transport costs (−34.0; 95% CI: −57.0 to −11.0) than ART patients. However, pre-ART patients spent significantly more on traditional healers (29.2; 95% CI: 12.2 to 46.2) and private chemists/private doctors (25.9; 95% CI: 10.3 to 41.6) than ART patients, who spent very little on traditional, complementary, or alternative sources of care.

Financing Patient Expenditures

For a single clinic visit, pre-ART patients reported spending significantly more hours at the clinic (3.5; 95% CI:

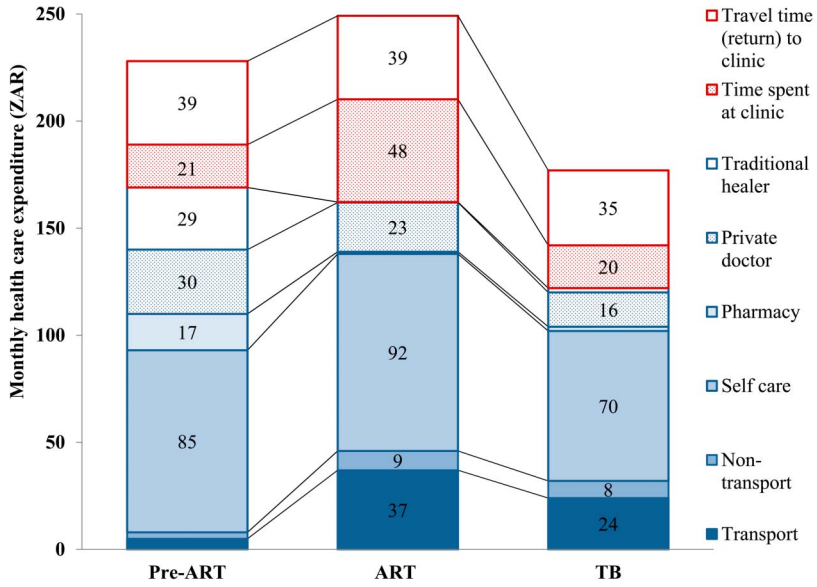

FIGURE 1. Average monthly direct and indirect health care expenditures (ZAR) incurred by pre-ART, HIV, and TB patients. Self care, use of traditional medicine, spaza shops, and special foods; Chemist/Pharmacy, use of the chemist/pharmacy; Private doctor, use of the private doctor; Traditional healer, use of the traditional healer; Transport, transport cost for a return trip to clinic; Nontransport, costs of clinic/hospital fees, childcare, overnight accommodation, food, cell phone airtime; Indirect costs, time spent at the clinic; Indirect costs, travel time (return) to the clinic. *Labels for expenditure categories <5 ZAR are suppressed for clarity; see Table 2 for the underlying numbers. Indirect costs are presented using the average hourly wage in the province of KwaZulu-Natal as monetary value of time.

3.2 to 3.8) than both TB (1.1; 95% CI: 1.0 to 1.3) and ART patients (2.8; 95% CI: 2.5 to 3.0); ART patients spend significantly more time at clinics per month than either pre-ART or TB patients. There was no significant difference in average travel time across the groups (Table 2).

Financial Distress

About one-third of patients borrowed money in the last month to pay for health care: 39% of TB patients, 29% of pre-ART patients, and 36% of ART patients. Fewer than one tenth of patients had sold personal or household items to finance health expenditures (Table 2). There was no difference in the average amount borrowed across all patient groups: pre-ART patients [ZAR 178; 95% CI: 128 to 229; median 100; interquartile range (IQR) 50–200], ART patients (ZAR 177; 95% CI: 97 to 256; median 104; IQR 42–209), and TB patients (ZAR 154; 95% CI: 108 to 201; median 94; IQR 31–209). Financial distress (as indicated by either borrowing money or selling assets) was high in all groups: TB patients (41%), pre-ART (31%), and ART (39%) (Table 2).

Factors Associated With financial Distress Due to Using Healthcare

Being male or having an unemployed head of household among pre-ART patients was associated with more than twice the odds of being financially distressed (Table 4). Computing marginal effects, for each ZAR 100 in financial expenditure, the probability of reporting financial distress increased by 6.6% points (95% CI: 4.9 to 8.3). For every hour

TABLE 3. Crude and Covariate-Adjusted Differences in Health Expenditures by Patient Type and Spending Category

	Total Financial Health Expenditure Mean (95% CI) *P*	**Expenditure on Transport** Mean (95% CI) *P*	**Expenditure on Traditional Healers** Mean (95% CI) *P*
Crude difference			
Pre-ART minus ART	7.1 (−46.2 to 60.4) 0.747	−32.0 (−54.1 to 9.8) 0.014	28.9 (12.4 to 45.3) 0.006
TB minus ART	−41.5 (−106.8 to 23.9) 0.164	−12.5 (−35.8 to 10.8) 0.227	1.2 (−0.7 to 3.2) 0.158
Adjusted difference*			
Pre-ART minus ART	1.3 (−57.0 to 59.7) 0.955	−34.0 (−57.0 to 11.0) 0.013	29.2 (12.2 to 46.2) 0.007
TB minus ART	−41.2 (−103.2 to 20.7) 0.148	−12.6 (−34.7 to 9.5) 0.203	1.2 (−1.8 to 4.2) 0.340

	Expenditure on Self Care Mean (95% CI) *P*	**Expenditure on Pharmacies and Private Doctors** Mean (95% CI) *P*	**Time Costs (Monetized)** Mean (95% CI) *P*
Crude difference			
Pre-ART minus ART	−7.2 (−37.9 to 23.5) 0.572	23.4 (6.7 to 40.1) 0.016	−27.9 (−38.8 to −17.1) 0.001
TB minus ART	−22.0 (−58.9 to 15.0) 0.187	−6.7 (−11.7 to 1.7) 0.018	−32.4 (−52.5 to −12.3) 0.009
Adjusted difference*			
Pre-ART minus ART	−13.2 (−46.0 to 19.7) 0.350	25.9 (10.3 to 41.6) 0.008	−26.7 (−38.0 to −15.3) 0.002
TB minus ART	−23.8 (−59.2 to 11.7) 0.145	−4.9 (−9.0 to −0.8) 0.029	−31.5 (−51.4 to −11.6) 0.010

*Controlling for age, sex, head of household employment status, and adjusted for clustering at the clinic level. All values are in ZAR.

TABLE 4. Factors Associated With Financial Distress Due to Health Care among Pre-ART, ART, and TB Patients

Patient Either Borrowed Money or Sold Assets to Pay for Health Care	Pre-ART (N = 200)		ART (N = 294)		TB (N = 295)		All Patient Groups (N = 789)	
	aOR	95% CI*	aOR	95% CI*	aOR	95% CI*	aOR	95% CI*
Male sex	2.40	1.14 to 5.05	1.09	0.63 to 1.88	1.15	0.54 to 2.45	1.29	0.92 to 1.79
Age (in years)	0.99	0.97 to 1.02	0.98	0.96 to 1.01	1.01	0.97 to 1.04	1.00	0.98 to 1.01
Head of household unemployed	1.97	1.21 to 3.22	1.49	0.52 to 4.27	2.31	0.78 to 6.87	1.86	1.22 to 2.85
Total monthly costs of using health care (per ZAR 100)	1.40	1.19 to 1.65	1.32	1.18 to 1.47	1.54	1.25 to 1.90	1.38	1.26 to 1.51
Time spent during clinic visit per month (in hours)	1.04	0.92 to 1.17	1.21	1.05 to 1.40	1.65	1.22 to 2.24	1.31	1.17 to 1.45
Pre-ART	—	—	—	—	—	—	1.10	0.69 to 1.73
TB	—	—	—	—	—	—	1.92	1.29 to 2.87

*Adjusted for clustering at the clinic level. Hosmer–Lemeshow goodness-of-fit test for pre-ART model $P = 0.46$; ART model $P = 0.35$; and TB model $P = 0.06$.

Marginal effects of the regression with all patient groups: change in total monthly costs of using health care per ZAR 100 = 6.6% points (P-value < 0.001, 95% CI: 4.9 to 8.3); change in time spent during clinic visit per month (in hours) = 5.5% points (P-value < 0.001, 95% CI: 3.4 to 7.6).

aOR, adjusted odds ratio.

spent at the clinic using health care, the probability of reporting financial distress increased by 5.5% points (95% CI: 3.4 to 7.6).

DISCUSSION

We show evidence of high health care–related financial expenditures and time costs among adults using public-sector HIV and TB services, although these services are provided free at point of service. Monthly private health expenditures were estimated at ZAR 171 for pre-ART patients, ZAR 164 for ART patients, and ZAR 122 for TB patients. From the patient perspective, these expenditures are very large, especially in a study area with high unemployment rates and dependency on social grants, representing over one third of median per capita income (ZAR 401) among Zulu-speaking South Africans.[42] In this light, it is not surprising that 31%–41% of our samples reported that health expenditures led to financial distress, with many patients driven into debt by health expenditures. Furthermore, and contrary to popular perception, patients' private contributions are a significant component of total spending for public-sector health care. Including the public-sector contribution to ART treatment—estimated at $682 (ZAR 4979) per patient per year at the facility level[43]—ART patients' private health expenditures represent over a quarter of the full cost of a patient being on ART. In addition to financial expenditures, patients face substantial time costs associated with care seeking, primarily due to the time required to travel to clinic visits. These patient costs are very likely large enough to influence ART and TB treatment uptake, adherence, and retention. Interventions to reduce the private costs of care could increase early treatment initiation and sustained viral suppression with benefits for patients and potentially large spillover effects in reducing onward transmission.

A critical gap in the HIV cascade of care has been the transition from pre-ART to ART, with high attrition from pre-ART care,[3,44,45] and many patients are still initiating ART at low CD4 counts.[3,45] One common explanation for this gap is the perception that the patient-borne costs of ART are significantly higher than the costs during pre-ART due to the burden of frequent and lengthy clinic visits to pick up medicines and that these costs discourage patients from initiating as early as they might. This theory is not supported by the data in this setting. Costs for ART patients were indeed large. However, expenditures were as high for pre-ART patients, who spent significant private resources on traditional healers, pharmacies, and private doctors. Use of alternative health care providers is common in South Africa and can result in hidden costs of illness that are not captured in facility-based costing studies.[7,15,46,47] We find that HIV patients, if not yet eligible for ART, tend to seek alternative (and likely less efficacious) forms of therapy implying that the demand for treatment for HIV is high among HIV patients.[47,48]

Much has been made of the pattern in which HIV patients use both ART and traditional, complementary, and alternative medicines simultaneously.[47] Interestingly, private expenditures on alternative sources of care all but disappeared for patients who had initiated ART, suggesting that in fact ART and alternative medicines may be substitutes rather than complements in this population.[7,15,46,47] A likely explanation is that once patients initiated ART, they no longer had the symptoms for which they were seeking alternate sources of care. These findings have powerful implications for the rollout of HIV treatment-as-prevention programs, suggesting that demand for early ART may be higher than previously thought and that initiating ART may not impose large financial burdens on patients, but rather relieve them from other health expenditures on less efficacious therapies. Reports of financial distress, although common, did not differ significantly between pre-ART and ART patients, alleviating concerns that HIV treatment-as-prevention strategies may increase the financial burden of health care for patients and lead to low uptake.

Transport was the single largest cost component for all patients groups, similar to what has been reported elsewhere, and contributed to high expenditures among ART and TB patients who have frequent clinic visits.[8,14,15,49] Many patients use public transport to visit the clinic,[7,10] but road networks are poor in most rural areas making it costly to access some clinics.[50] Three in five patients walked to the clinic, while two in five used public transport.[9] Both TB and ART patients are

instructed to make monthly clinic visits to collect their medicines, whereas those not yet eligible for ART are instructed to make about 4 clinic visits per year. Two of these 4 visits in pre-ART care are for physical examination and blood taking for CD4 counts; the other 2 are to receive the CD4 count results and to decide on treatment eligibility. Interventions to reduce transport costs, eg, a medicine delivery service, less frequent clinic visits for stable patients, or transport vouchers for poor households, could substantially improve patient welfare and lead to better treatment outcomes.[51,52] Importantly, because ART patients have more frequent clinic visits than pre-ART patients, any reductions in transport costs associated with clinic visits will lower the relative cost of ART from the patient perspective and could lead to even greater demand for early ART.

Our study has several limitations. First, due to the nature of the clinic-based sampling strategy, we excluded people in need of health care who did not access health care, including those who did not access health care because they could not afford it. In previous research, we found that distance to the nearest clinic strongly predicts ART initiation, suggesting that transport costs may discourage some HIV patients from seeking care.[53] The long run costs of forgoing care may be substantial but are excluded from this analysis. Second, it is possible that our cross-sectional comparisons across patient types—pre-ART, ART, and TB—were confounded by unobserved factors. We controlled for employment status of household head and basic demographics; furthermore, by design, all 3 groups are patients who have sought clinical care for HIV or TB. However, as in most observational studies, unmeasured factors could influence our effect estimates. Third, time costs associated with care seeking outside the clinic were not assessed in the survey and could not be included in the analysis. Given the higher utilization of alternative care among pre-ART patients, this omission would bias pre-ART patient costs downward, implying that one of our main conclusions—that patients do not pay more for ART than for pre-ART would still be valid in this case. Fourth, in this study, we have assessed the costs of health care utilization from the perspective of individual patients. An important additional perspective is the costs of patients' health care utilization to their households. Although our study focused on the individual, our findings that large proportions of patients reported that they had to borrow money or sell assets to pay for health care is likely to imply substantial household financial burdens due to patients' health care utilization for pre-ART, ART, and TB. In particular, assets, such as livestock, bicycles, tables or televisions, are commonly shared among household and even community members, and their sale thus likely affects people who are socially linked to the patients we have interviewed here. The spillover effects of health care utilization to household and community members are an important area for future research, including the broader impacts on household activities, time use, and economic status. Finally, we report data for only one rural district in South Africa. However, we note that the study setting has many characteristics common to rural areas in South Africa and neighboring countries: extensive use of traditional healers, a socioeconomic context of high cyclical migration and unemployment, and a very high HIV burden. Further research will be needed to demonstrate generalizability to other settings.

HIV and TB patients receiving nominally free care, nevertheless, face considerable costs due to health care expenditures and the time costs of seeking care. Interventions to reduce patient costs could improve progression through the HIV cascade of care.[54,55] ART patients have much lower expenditures than pre-ART patients on traditional healers, private doctors, and pharmacies, suggesting that ART serves as a substitute for alternative treatments. These findings imply high demand for some form of HIV treatment among HIV patients and that initiating patients earlier onto ART could be cost saving for patients, in addition to yielding health benefits for patients[56] and for society at large.[22,57]

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TITLE PAGE:

Title of manuscript: Engaging ART healthcare providers: A qualitative study on providers' responses and perspectives towards patient satisfaction and healthcare delivery in an ART programme in rural KwaZulu-Natal

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Abstract

Background: Healthcare providers play an important role in healthcare delivery and their behaviour likely influences the success of antiretroviral therapy (ART) scale-up and quality care provision. This study seeks to understand the ART healthcare provider's perspectives regarding patient care and provision of quality care; and how healthcare providers respond to patient satisfaction feedback and whether such feedback enables them to identify potentially modifiable problem areas that could influence quality of care.

Methods: In 2012 we carried out a qualitative study with 25 frontline ART healthcare providers in eight (of 17) randomly selected primary healthcare (PHC) clinics in a rural district in KwaZulu-Natal, South Africa. These clinics operate within the ART programme which utilises a decentralised approach with integration of HIV services to PHC, linking treatment, care and prevention services. ART healthcare providers were engaged in in-depth discussions about challenges faced by them and their patients, to inform understanding of healthcare providers' perceptions of factors affecting provision of quality care. In-depth discussions were structured around aspects of satisfaction reported by patients in a previous survey in the same setting in 2009 (overall satisfaction, communication, contact time, respect, privacy, cleanliness, and waiting times). Data were managed using Nvivo 10 and thematic content analysis used to identify emerging themes and patterns within the data.

Results: Two broad theoretical constructs emerged from the in-depth discussions: feelings of helplessness to address structural barriers within the health system; and empathy and responsiveness to individual patient's challenges. With regard to staff attitude, respect and the long waiting times for individuals, healthcare providers felt they were unable to respond within a health system that did not support delivery of quality care. Healthcare providers described their adopted solutions to deal with these issues including use of personal vehicles to collect antiretroviral drugs from the district hospital pharmacy and working longer hours.

Conclusion: The issues raised are salient in HIV programmes in light of universal test and treat, potentially affecting patient's engagement in care. The healthcare providers' responses show a commitment to providing quality care and to their profession. The healthcare system has to be strengthened to support healthcare provider's efforts.

Keywords: healthcare providers, healthcare delivery, patient satisfaction, antiretroviral therapy, quality of care

Background

Antiretroviral therapy (ART) coverage in sub-Saharan Africa has increased rapidly since 2004, particularly in South Africa (SA).(1) With increasing numbers of people surviving on ART, HIV prevalence in SA has remained high.(2) In the study area in rural KwaZulu-Natal, HIV prevalence increased steadily, reaching 29% overall in 2011.(3) The expansion of ART programmes has led to increased demands on the health system for accessible and quality healthcare services, which will face further challenges with the new World Health Organisation (WHO) guidelines recommending treatment initiation for all HIV positive individuals.(4, 5)

The healthcare workforce is crucial for healthcare delivery and a major building block in the WHO health system framework that affects access and quality of care for improved health.(6) In South Africa, the Batho Pele "People First" principles and the National Health Insurance (NHI) primary healthcare re-engineering reforms have been developed to guide service providers in improving patient relations, satisfaction and service delivery(7, 8); these principles also apply to ART scale-up and quality care provision.(9-12) ART programmes in sub-Saharan Africa face challenges with patients' uptake of treatment, adherence and retention in care.(13-17) However, for ART programmes to be sustainable and patients to receive the full benefits of treatment, there is need for adequate human resources, drugs, equipment, infrastructure and a health system that supports both patients and healthcare providers effectively.(18-20)

Patient satisfaction surveys have been used to improve communication with patients, evaluate health workers' performance and to inform quality improvement in healthcare organizations.(21-23) However, there is need to complement patients' opinions with providers' perspectives in order to develop effective policies to address identified gaps. In 2009, we undertook a HIV/Tuberculosis (TB) users' survey in this study area - the Researching Equity

in ACcess to Healthcare (REACH) study, and we now present the companion survey of ART healthcare providers in the same setting. In the context of an expanding ART programme in a high HIV prevalence rural setting, this study seeks to answer the following questions: What are the ART healthcare providers perspectives regarding ART patient care and provision of quality care? How do ART healthcare providers respond to patient satisfaction feedback and does such feedback enable them to identify potentially modifiable problem areas that could influence quality of care?

Methods

The study was situated in the Hlabisa sub-district uMkhanyakude, northern KwaZulu-Natal with a population of approximately 228 000. This setting is typical of rural South Africa. Since 2004, the SA Department of Health (DoH) has delivered HIV treatment and care through a decentralised, primary healthcare programme at 17 primary healthcare (PHC) clinics and one district hospital. Between 2005 and 2012, the DoH programme was partially supported by the former Africa Centre for Population Health (Africa Centre) now Africa Health Research Institute (AHRI) through funding from the President's Emergency Plan for AIDS Relief (PEPFAR) via the United States Agency for International Development (USAID).(24) The AHRI support provided additional HIV counsellors and nurses, training, and infrastructure; an ART patient database was developed and maintained at AHRI. In early 2013, the programme became the sole responsibility of the DoH. The healthcare providers' survey was conducted from November 2012 to January 2013, coinciding with this transition period.

In 2012, eight of 17 PHC clinics in the study area were randomly selected for a qualitative study with ART healthcare providers. Twenty-five frontline ART healthcare providers directly involved in providing HIV care (nurses, counsellors and operational managers – the senior

nurse in charge of the PHC clinic) were purposively selected to participate in in-depth discussion about challenges faced by them and their patients, to inform understanding of healthcare providers' perceptions of factors affecting provision of quality care. Interviews were structured around the results from the patient exit surveys carried out in 2009, in particular around aspects of satisfaction in the same setting. The initial plan for the study was to hold focus group discussions with staff but this was not possible because the clinics were often busy and focus group discussions would have been disruptive and delay patients even longer. Appointments with healthcare staff were set prior to the discussions. Each clinic was visited no more than three times to identify participants and healthcare providers were approached once – if they declined they were replaced and if they were too busy but willing to participate the researcher would wait for them until convenient. None of the healthcare providers approached declined to participate. From each clinic, we selected the operational manager responsible for the clinic and at least one ART counsellor and one ART nurse, the number of nurses and counsellors selected per clinic is shown in Table 1.

The patient load per clinic end of 2012, ranged from 409 to 9056 patients utilizing ART, with clinics with a smaller patient load being fairly new and some started initiating ART patients at a later stage than the older bigger clinics; the number of ART nurses ranged from none to four and of counsellors from one to 11, proportional to patient load and size of clinic. (Table 1)

Table 1: Patient load and ART staff complement by clinics end of 2012 and ART healthcare providers interviewed

All the clinics are nurse-led and the nurses have been trained to initiate patients on treatment hence no doctors or pharmacists were included in the study. Healthcare providers were not selected on age, sex or years of experience – however, this information was collected at the beginning of each discussion and presented in Table 2.

Table 2: Characteristics of healthcare providers (N=25)

Seven of 13 patient satisfaction findings (including aspects of overall satisfaction, communication, contact time, respect, privacy, cleanliness, and waiting times) from the 2009 users' survey (25) were selected to structure the interviews (Table 3). These variables were selected because they covered the common aspects of patient satisfaction (26-28) and responses showed some variance. A topic guide with broader issues than patient satisfaction was developed by the researchers based on general quality of care framework to stimulate discussion and assess possible challenges/facilitators ART healthcare providers face when providing care (Table 3). Discussions were led by an experienced qualitative researcher (NC) and took place in the consultation rooms when no clinical sessions were ongoing.

All discussions were recorded (the average discussion duration was 37 minutes (range 26 – 54 minutes)) and transcribed. Data were managed using Nvivo 10 (29) and thematic content analysis used to identify emerging themes and patterns within the data. (30, 31) Clinic or healthcare provider identifiers were removed and replaced with pseudonyms.

Results

Most healthcare providers were female (n=23); median age for all ART healthcare providers was 42.5 (interquartile range Q1-Q3 37-50) years, median duration of employment at the

current clinic was three (Q1-Q3 1 - 5) years and median duration of employment in their profession was five (Q1-Q3 1 - 6) years (Table 2).

Two broad theoretical constructs(31) emerged: first, healthcare providers' feelings of helplessness to address structural barriers within the health system and second, their empathy and responsiveness to individual patients' challenges, despite the limitations of the healthcare system. Emerging sub-themes pointed to the challenges related to understaffing and increased workload, resulting in overwork, fatigue and burn-out. Further challenges related to lack of essential equipment and ART, leading to longer queues and increased waiting times, delayed treatment initiation, more frequent patient clinic visits, and emotional frustration for both patients and staff. Despite the health system constraints, providers described how they devised ways to provide the best care possible, e.g by using personal vehicles to collect ART from the hospital pharmacy or by working longer hours. Table 3 summarises the ART healthcare providers' responses and resolutions to feedback on patient satisfaction and also points out gaps for possible policy interventions.

Table 3: Indicators of patient satisfaction with service and the topics explored during feedback discussion with healthcare providers and their perspectives

1. **Understaffing and increased workload - "I see too many patients"**

In response to individuals' comments about long queues, poor contact time and lack of respect, healthcare providers pointed to the fact that they were short-staffed, overworked, fatigued and emotionally and mentally tired most of the time. They admitted that their stress may be taken out on patients, but blamed their full workload.

"…we are short-staffed, sometimes when you are seeing more patients and you are tired physically and mentally you end up taking it to the client and the client won't understand that you are tired and overworked." (Clinic G, Nurse)

Lack of sufficient nurses trained in Nurse Initiated Management of ART (NIMART) (during the REACH study, only doctors initiated patients on ART) limited staff adaptability in times of shortages compromising the quality of patient care. At times temporary ART nurses, not NIMART trained (Clinic D), stood in for ART nurses because of such shortages.

Staff shortages contributed to long patient queues and waiting times, although healthcare providers reported sacrificing lunch breaks until they finished the queue; and while they were not happy with the situation, they felt "there was no alternative". Conversely, patients were said to be always in a hurry and healthcare providers had to rush through consultations.

Healthcare providers indicated that patient selection of which facility to use was based on location, fear of being known or issues of stigma and disclosure. Facilities located in urban settings were overcrowded because of ease and lower costs for individuals who combined work, shopping and treatment pick-up.

"…people like to come in town, so the queues are too much, too much…If the appointment date is 29, so on the 29th they do both grocery and clinic." (Clinic A, Counsellor)

2. **Equipment and Infrastructure - "I motivate for equipment but no one is helping me"**

Lack of essential equipment such as HIV testing kits (Clinic C) and haemoglobin meter strips (Clinic F) needed for ART initiation of pregnant women hindered provision of quality care. Lack of domestic fridges for nurses resulted in compromised cold chain system as staff used vaccine fridges for their personal food.

Healthcare providers (Clinic E) motivated for repairs and equipment to the district hospital but there was no response.

"We always write letters and they say they are coming and help us with cupboards. We do not have medicine trolleys…we wait for them to come and help us…we don't have wheelchairs, and our stretcher is broken." (Clinic E, manager)

Space for filing patient records was increasingly problematic with increased patient load and paperwork (Clinic A, Clinic D). Water shortages and electricity power cuts were major challenges in most clinics. However, some clinics were making the effort to provide clean drinking water in the waiting area and for washing hands after toilet use.

3. **Cleanliness and hygiene - "The clinic is dirty"**

In response to patient comments on facilities' cleanliness, healthcare providers (Clinic B, Clinic D, Clinic G) reported water shortages, old buildings, portable toilets or pit latrines rather than flush toilets as the major drawbacks to their efforts to keep the facilities clean. Cleanliness was not only viewed as hygienic and essential for infection control but as a basic patient right.

"While we still talking about the rights of patients, really the toilets here are not enough. Gents and ladies use one toilet. These toilets are dirty and there is no water at all." (Clinic D, Nurse2)

In one clinic (Clinic E), community women helped with cleaning; while in other clinics healthcare providers opted to clean themselves (Clinic C).

4. **Policies and guidelines - "They are useful but no one cares to explain what they mean"**

There were mixed feelings concerning the relevance of HIV treatment policies and guidelines and the National Core Standards for Health Establishments in South Africa (32) in facilitating provision of quality care to patients. Most nurses indicated that the policies were useful because they could now initiate patients on ART and the guidelines provided direction.

Some clinics discussed the National Core Standards during in-house meetings but with no follow-up supervision, while other clinics (Clinic F) conducted in-service training of all nurses on ART issues so that staff could be flexible when short-staffed.

However, other healthcare providers, particularly counsellors and those from remote clinics, felt there was need for on-going guidelines training, as their clinics were inaccessible due to bad roads and they were sometimes left out from trainings and workshops (Clinic E). Despite the frustrations, healthcare providers responded by "making a plan" they thought practical and helpful for them and their patients.

"They just give us those packet of papers…we keep 'your' papers on the wall, we do things that will help our patients… making decisions what to prioritize in the guidelines given the time constraints due to staff-shortages or resources" (Clinic B, Counsellor2)

Healthcare providers felt national ART guidelines were general and "instructions from higher order" which did not apply to specific facility situations e.g. they did not have facilities for point-of-care CD4 count tests for same-day patient initiations.

5. **Drug stock-outs and healthcare providers responsiveness - "I'm frustrated, and the patients are also frustrated with ART shortages"**

Healthcare providers indicated that working in a resource-limited setting was frustrating and made them and their patients feel helpless. At the time of study, there were temporary ART shortages and people due to start treatment were either sent home or referred to the district hospital.

"Tenovifir, almost all of them are in short supply. We keep on phoning [the district hospital] and they say they are coming. So we send back our patients to come back tomorrow" (Clinic D, Nurse 2)

In response to drug shortages, some healthcare providers delayed initiating people on treatment, or used paediatric formulations for adults; this approach may result in poor treatment response, poor health outcomes and reduced patient confidence in the health system. Healthcare providers 'borrowed' treatment from other clinics and sometimes used their own cars to collect patients' treatment.

"I leave the patients and go to other clinic and ask for it and I have to use my own transport…It is because I want to assist the patients, so that the patient does not have to stay without treatment" (Clinic G, Nurse)

6. **Need for food support and social grant**

Healthcare providers reported that some people in the study area were poor and healthcare providers found it difficult to counsel them about adhering to treatment, with people unable to afford clinic visit costs or food

"They don't have food but they also have to take treatment, so it is something that bothers me...Some of them ask for porridge from Sister." (Clinic F, Counsellor)

Some healthcare providers reported their patients needed a social disability grant for money for transport and food to help them continue to utilize care. However, others reported (Clinic E) that patients were deliberately throwing away treatment so they would remain sick and be entitled to a grant.

7. **Health versus wealth - Healthcare providers support**

Healthcare providers reported that working patients (Clinic F, Clinic B, Clinic A, Clinic G, Clinic D) had specific challenges accessing treatment and highlighted that employers, particularly farmers, were reluctant to give time off to workers for initiation sessions and picking up treatment (Clinic G), resulting in some people being lost before they could start treatment.

Most people were paid hourly rates and time spent travelling and utilizing care meant lost income. Some healthcare providers (Clinic A) were sympathetic, "my conscience would haunt me" and delivered treatment disguised as take-away foods to patients' workplaces within town or left treatment in the clinic for collection after work.

In other clinics (Clinic F, Clinic B, Clinic A) priority was given to working patients and they were allowed to send their relatives to pick-up their treatment. However, sometimes patients needed to be seen and assessed in person.

Discussion

We identified two broad theoretical constructs – feelings of helplessness and inability to address structural barriers within the system and healthcare providers' empathy towards patients and responsiveness to individual patient's challenges. Some healthcare providers felt their attitude towards patients was sometimes out of their control and due to deeper structural and systemic problems within the healthcare system, indicating a limited capacity to bring about change. However, in line with elsewhere in South Africa, healthcare providers showed resilience, endurance and coping mechanisms within limited resources to provide quality care to patients,(33) such as using their personal cars to collect ART from the district hospital pharmacy and borrowing from neighbouring clinics. At the time of the study, there were intermittent drug stock-outs which resulted in longer queues, waiting times, and more frequent clinic trips for individuals, delayed ART initiation and reduced confidence in the health system to deliver treatment for life. Interrupted treatment may result in unsuppressed viral loads, drug resistance and poor treatment outcomes.(34)

There is a need to strengthen the health systems in terms of human resources and availability of drugs, especially in light of the new WHO ART initiation guidelines(5) for universal treatment with likely further increasing numbers of HIV positive people on treatment. Although there is no evidence that patient satisfaction directly improves clinical outcomes, patients' disengagement in care has been suggested to be associated with quality of services, implying an indirect relationship between patient satisfaction and retention in care.(13, 35, 36)

The South African healthcare delivery system is overburdened by a multiple disease burden including HIV, now a chronic condition,(37, 38) and rural health systems struggle due to inequities in resource allocation including human resources.(39, 40) Most clinics in our study were rural and patient load relative to the staff complement was high. Uncertainty regarding

staffing and funding of the ART programme at the time of the study may have destabilized working teams in facilities, which may have affected morale, as well as other factors such as training, remuneration/incentives, management and leadership at facility level.(10, 41)

South Africa DoH guidelines for ART eligibility have changed in line with WHO guidelines.(42, 43) Consequently, on-going training of staff on the new ART policies and treatment guidelines is required to ensure that they are implemented well. We found some staff improvised the guidelines, prioritising what was practical for their facilities given the limited resources. However, we cannot ascertain if such innovation is beneficial in retaining patients in care in the long run.(44)

Discussions sometimes became a means through which health workers could express their frustrations about the health system. In particular in the three years between the patient survey and this study, changes in the system included the introduction of NIMART, increased patient load, and changes in the local programme with resulting job insecurity and temporary drug shortages.

This study presents opportunities for intervention for policymakers such as provision of on-going training for healthcare providers, and introducing middle-level cadres in primary care facilities to assist nurses with the high-patient load to reduce the queues and probably impact on respect for patients. Establishing adherence clubs from the clinics or communities can help support the patients with their uptake of treatment despite transport costs as there will be limited trips to the clinics per year. Workplace ART clinics or support buddies could assist the working patients.

Conclusion

In conclusion, we show challenges healthcare providers face in providing HIV care in a resource-limited setting, taking into account the structural and systemic limitations they face. Healthcare providers' response towards patients shows a commitment to providing quality care and to their profession. The issues raised in this study are salient to HIV care and may affect patient's engagement in care. Engaging healthcare providers in a regular discussion may empower staff to be active agents of change and provide the ability to deal with the reality of constraints within a quality improvement framework.

Declarations

Ethics approval and consent to participate

Participation was voluntary and written consent was obtained from healthcare providers willing to participate. We obtained ethical clearance for the study from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BE174/08).

Consent for publication

The healthcare providers consented to participating in the study and providing data for research purposes which can be published.

Availability of data and material

The data that supports the findings of this study are available from the corresponding author upon reasonable request.

List of abbreviations

AHRI	Africa Health Research Institute
ART	Antiretroviral therapy
DoH	Department of Health
HIV	Human Immunodeficiency Virus
NHI	National Health Insurance

NIMART	Nurse Initiated Management of ART
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary healthcare
SA	South Africa
TB	Tuberculosis
USAID	United States Agency for International Development
WHO	World Health Organisation
REACH	Researching Equity in ACcess to Healthcare

Competing interests

The authors have no conflicts of interest to disclose.

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Authors' contributions

NC collected the data and did the initial coding, with TB and LR reviewing the codes. NC, ML and TB conceptualised the paper and NC drafted the paper and results. ML, TB, LR and RL

critically reviewed the manuscript; LR provided input with regards the health care system. All authors read and approved the final manuscript.

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Tables

Table 1: Patient load and ART staff complement by clinics end of 2012 and ART healthcare providers interviewed

Clinics and their description	Patient load (number of patients active on ART end of 2012)	*Number of nurses delivering HIV care end of 2012	*Number of HIV counsellors end of 2012	Number of §HIV nurses interviewed	Number of HIV counsellors interviewed
A Urban, big clinic and very busy	6077	2	7	2	1
B Urban, big clinic and very busy	9056	4	11	3	2
C Rural, small clinic and very busy	3200	2	5	1	1
D Rural, big clinic and very busy	4001	1	3	3	1
E Very rural, small clinic and less busy	409	0	1	1	1
F Rural, medium new clinic and busy	2444	2	3	2	1
G Rural, medium clinic and busy clinic	2231	1	3	2	1
H Rural, small clinic and not so busy	1176	1	2	2	1

* In this sub-district clinics still allocated specific nurses and counsellors to cover HIV services including counsellors doing HIV testing and counselling only

§ This includes the operational manager

Table 2: Characteristics of healthcare providers (N=25)

Characteristics of respondents	**N=25 n(%)**
Healthcare providers cadre	
Nurses	9 (36)
Operational managers*	7 (28)
Counsellors	9 (36)
Employer	
Department of Health	19 (76)
Africa Centre	6 (24)
Sex	
Female	23 (92)
Male	2 (8)
[§]**Age** Median (Q1-Q3) years	42.5 (37 – 50)
Length in employment at current clinic Median (Q1-Q3) (years)	3.0 (1-5)
Time in profession Median (Q1-Q3) (years)	5.0 (1-6)

*Operational managers are the senior nurse in charge of the primary healthcare clinic

[§]3 healthcare providers refused with their age

Table 3: Indicators of patient satisfaction with service and the topics explored during feedback discussion with healthcare providers and their perspectives

Statement/question in REACH study (n=300) that were included in the feedback discussion	**Healthcare responses/emerging themes/resolutions from ART healthcare provider**
1. How satisfied were you with the service today? (%) *93 Very satisfied/satisfied* *2 Neither satisfied nor dissatisfied* *3 Dissatisfied/very dissatisfied* *2 Don't know*	Most patients reported being generally satisfied with the service received, and thus the healthcare providers responded on causes for dissatisfaction
2. I find it easy to tell the health workers when I have missed taking my tablets (%) *63 Agree* *7 Disagree* *21 Never missed* *4 Don't know/not sure*	Most patients reported being generally adherent to treatment, and thus the healthcare providers responded on causes for dissatisfaction
3. The health workers are too busy to listen to my problems (%) *13 Agree* *82 Disagree* *1 Both agree and disagree* *4 Don't know/not sure*	Response: (1) Patients were said to be always in a hurry (2) Healthcare providers were short-staffed and overworked Resolution: Healthcare providers had to rush through consultations
4. Some staff do not treat patients with sufficient respect (%) *38 Agree* *36 Disagree* *1 Both agree and disagree* *25 Don't know/not sure*	Response: Healthcare providers had a full- workload but short-staffed, overworked, fatigued and emotionally and mentally tired most of the time Resolution: None - this is an opportunity for intervention
5. The facilities (including waiting area and toilets) are dirty (%) *16 Agree* *72 Disagree* *3 Both agree and disagree* *9 Don't know/not sure*	Response: Water shortages, old buildings, portable toilets or pit latrines rather than flush toilets were reported as the major drawbacks to efforts to keeping the facilities clean Resolution: (1) Healthcare providers acknowledged this was a breach of a basic patient right (2) Community women helped with cleaning or the healthcare providers opted to clean themselves (3) Healthcare providers provided clean drinking water in the waiting area and for washing hands after toilet use.
6. The queues to see a doctor or nurse are too long at this facility (%) *49 Agree* *34 Disagree* *16 Both agree and disagree* *1 Don't know/not sure*	Response: (1) Short-staffing (2) Overcrowding of clinics because of their location – patients not using their closest clinics for fear of stigma and disclosure (3) Intermittent drug shortages Resolution: (1) Healthcare providers reported sacrificing lunch breaks until they finished the queue (2) Limited power for healthcare providers to intervene - opportunity for policymakers to intervene
7. In this clinic are you able to talk to the doctors or nurses in private? (%)	Most patients were generally happy, the healthcare providers responded on causes for dissatisfaction

80 Always *7 Sometimes* *8 Never* *5 Don't know/not sure*	
Topics explored in the topic guide used in the feedback discussion	
Current patient utilization barriers	Emerging/identified themes: Poverty – patients were reported unable to afford transport to the clinic and food to adhere on treatment Response: Healthcare providers suggested a need for support and social disability grant Emerging/identified themes: Working patients fear of losing income during clinic visits Response: (1) Healthcare providers were sympathetic and delivered treatment disguised as take-away foods to patients' workplaces within town or left treatment in the clinic for collection after work. (2) Priority queuing was given to working patients and they were allowed to send their relatives to pick-up their treatment This is also an opportunity for intervention – through educating employees or establishing workplace ART clinics and adherence clubs for patients to reduce clinic visits
Healthcare provider's role and how they help patients overcome their utilization challenges	Emerging/identified themes: Drug stock-outs Response/Resolution: (1) Healthcare providers delayed initiating people on treatment, (2) Healthcare providers used paediatric formulations for adults (3) Healthcare providers 'borrowed' treatment from other clinics (4) Healthcare providers sometimes used their own cars to collect patients' treatment This is an opportunity for intervention to ensure drugs are always available and reduced patient clinic visits for those who are stable
Healthcare provider's experiences and challenges in providing ART treatment and care to patients	Need for on-going training on HIV treatment policies and guidelines and the National Core Standards for Health Establishments in South Africa Resource limited setting: staffing, equipment, facilities Response: Opportunity for intervention
Changes (structural, organizational, governance etc) that have occurred in the facility since 2009 (when the REACH study was done) that you think may have they affected healthcare provision	Introduction of NIMART Slow roll-out of NHI Africa Centre/AHRI handover of ART programme to DoH
Any other issues that may be holding back provision of quality care for ART patients in this clinic for example from the patients' side, your side or the health system, or even the community).	Response: (1) Lack of essential equipment (2) Lack of domestic fridges for maintaining the cold chain system (3) Lack of space for filing patient records (4) Water shortages and electricity power cuts

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Ms NZ Chimbindi
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Dear Ms Chimbindi

Doctor of Philosophy: Change of title of research

I am pleased to inform you that the following change in the title of your Thesis for the degree of **Doctor of Philosophy** has been approved:

From:

To: **HIV and TB care and treatment: patients utilization and provider perspectives in rural KwaZulu-Natal**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

NatsayiChimbindiThesis04October2016final.docx

ORIGINALITY REPORT

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SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Chimbindi, Natsayi, Jacob Bor, Marie-Louise Newell, Frank Tanser, Rob Baltusen, Jan Hontelez, Sake de Vlas, Mark Lurie, Deenan Pillay, and Till Bärnighausen. "Time and money : the true costs of health care utilization for patients receiving 'free' HIV/TB care and treatment in rural KwaZulu-Natal", JAIDS Journal of Acquired Immune Deficiency Syndromes, 2015. Publication	%6
2	www.biomedcentral.com Internet Source	%4
3	Natsayi Chimbindi, Till Bärnighausen, Marie-Louise Newell. "Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews", BMC Health Services Research, 2014 Publication	%3
4	www.samj.org.za Internet Source	%3

Marie-Louise Newell 26 Oct 2016