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Understanding Patterns of Health System Utilisation among People Living with HIV/AIDS Attending Rural HIV Services

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"It is often the health system itself that serves to limit the individual's capacity to engage with it" Mackian et al. 2004

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Declaration

I, **Matlagolo Mosa Moshabela**, declare that this research thesis is my own work. The thesis is being submitted for the degree of Doctor of Philosophy in the field of public health at the University of Witwatersrand, Johannesburg. The thesis has not been submitted before any degree or examination at this or any other University.



……

Matlagolo Mosa Moshabela

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Glossary of Terms

Access to Health Care	Described as the opportunity or freedom to use a health service (1), and reflects an individual's capacity to benefit from services given the individual's circumstances and experiences in relation to the health care systems (2).
Decentralisation of Health Care	For ART, the concept refers to a systematic process through which lower levels of care, largely primary health care clinics, are authorised to provide ART.
Delayed or Late Presentation	In this study, and for AIDS patient seeking care (testing and treatment), delay in presentation for health care is defined as later than one month after observation of AIDS-related symptoms, and to any part of health system.
Down-referral of Patients	A process of referring patients from centralised ART service points, such as major hospitals, where they are first initiated on ART, to local clinics nearest to their homes.
Health Care Pluralism	The diverse ways in which illness can be perceived, understood and treated (3). Implies in this study the use of multiple levels and types of health services available in local contexts, either sequentially or concurrently.
Health Care Services	Unless otherwise specified, health care service is used in this document to refer to the scientific Western-type formal health care and/or non-formal health care services. These include private, public and traditional health care services.
Health Care System	Used in this study to encompass all available forms of services intended for health care including formal health care (Western), African traditional health care and other alternative forms of health care.
Patient Retention in Care	Measures the proportion of patients remaining in care after enrolment into either pre-ART or ART care. The antonym is attrition from care.
Provider-Shopping	Borne from doctor-shopping (4), this is a practice of using multiple health care sources ranging from use of traditional and faith healers, medicines obtained from pharmacists and herbalists, to the use of private physicians and public health facilities in varying degrees.
Traditional Health Care	This service refers to traditional health care system including African traditional healing, herbalists, diviners, faith healers and other healers, who are often self-reliant and tend to accept largely out-of-pocket payments and payment-in-kind.
Uptake of ART	Measures the degree of new initiation onto ART relative to the proportion of AIDS patient meeting the criteria for initiation in a demarcated population.
Utilisation of Health Care	Actual use of health services for remedial actions to rectify ill-health, and represents the action of using health care undertaken by an empowered person after making an explicit and informed decision to exercise their freedom or opportunity to use health care (1).

Preface

In 2006, the Bushbuckridge homeland of South Africa's rural northeast had two sites accredited to provide antiretroviral therapy (ART) - one that opened in 2004 and the other in 2005. During this time, I formed part of a public health team at the University of Witwatersrand, which operated through a non-governmental organisation to support HIV and AIDS services delivered through the Department of Health's hospitals and clinics in this area. After several years of intensive activities, we observed with exasperation the low uptake of ART in our hospitals. With Bushbuckridge's antenatal HIV prevalence of 25%, and nearly 600 000 people, we estimated approximately 15 000 patients would require ART at any one time. However, only 2000 people were receiving ART, suggesting a coverage rate of just 13%.

There were clearly a number of different barriers to accessing services. First were low levels of HIV testing that characterized the stigma surrounding the epidemic which emerged in force in the region only in the early 2000's. Second were the long delays faced by patients in the period prior to commencement of therapy. Several initiatives were embarked upon to improve the supply-side factors, including human resources and administrative procedures such as registers, tracking of laboratory results, and improving the supply-chain for medications. The objective was to ensure that patients were mobilised for treatment and all those completing their ART preparation phase were initiated immediately without long waits. While uptake improved slightly, it was clear that many more patients needing ART were not receiving it.

Finally, we were also aware that the predicted load of patients associated with potential coverage gains would quickly overwhelm the two hospital-based ART sites. The decentralization of ART support services to the primary care level was critical. We initiated a training program for all primary health care (PHC) facilities in region, introducing both nurses and lay counsellors to

treatment and support guidelines in preparation for the eventual down-referral of stable ART-initiated patients.

As a clinical HIV care specialist, I spent more than five years living and working in the area and was heavily involved in all aspects of this program. While the narrative constructed around the research questions posed in this thesis pertains to the specific case of HIV care, the insights and lessons learned are a wider metaphor for the dynamics of a society and a health system immersed in unparalleled transition in post-apartheid South Africa.

The purpose of this doctoral research was to examine the access to and utilisation patterns in HIV and ART services, as well as factors influencing these, in a remote and resource-constrained rural South African setting. This thesis tells the story of how access and utilisation of AIDS treatment, care and support services evolved in the context of a partnership between the local department of health, academic institutions and a range of local non-governmental organisations – working together amidst a rapidly shifting national policy discourse.

Four scientific papers have been published based on this research, with one additional manuscript included in this narrative. All can be found at end of this document. This integrating narrative will attempt to highlight and summarize key themes emerging from these papers.

Abstract

Following the successful introduction of antiretroviral therapy (ART) in resource-limited settings, we have observed an unprecedented explosion in the expansion of ART programs throughout sub-Saharan Africa, resulting in a 13-fold increase in coverage since 2004. In spite of these achievements, uptake of ART remains low. The gap in treatment coverage is approximately 50% of those who need ART in South Africa, while the country boasts the largest ART program worldwide. Rural areas are particularly prone to lower ART coverage rates, largely a result of existing health care inequities. The ART coverage gap will widen given the recent introduction of new treatment guidelines, which allows for ART commencement at CD4 350 cells/mm^3. Furthermore, approximately one-third of ART patients are lost to follow up after two years of treatment initiation in sub-Saharan Africa. This study explores factors associated with ART access and utilisation in a rural area, in order to reduce the gap in knowledge on patient and health system factors. Unaddressed, these factors may continue to hinder adoption of rigorous interventions to improve ART uptake and retention.

This research employs the A-Framework to conceptualize access to health care, where dimensions of access include availability (physical access), affordability (financial access), and acceptability (cultural access). A data triangulation approach was adopted as very little was known on the utilization patterns of health care by HIV/AIDS patients. Quantitative research (2008-2010) employed a four-site rural-urban comparative analysis of 1266 participants, and was part of a 5-year project Researching Equity and Access to Health care (REACH).This was complemented by a more in-depth qualitative assessment (2006-2007) that followed the treatment experience of 32 patients before and after ART initiation in the rural Bushbuckridge site.

We found plural utilisation of health care to be a cross-cutting theme throughout this thesis. While the movement of patients between providers at various levels within the traditional and formal health sector may be a sign of agency, it may also result in excessive health costs that threaten the livelihoods of individuals and their households. We discuss a number of strategies to improve ART initiation and adherence including the need to incorporate metrics for pluralism into routine assessments; the importance of decentralized, humane and high quality care and support services; support for efforts to enhance patient self-efficacy through education, awareness and social support interventions; the incorporation and regulation of traditional healers

into the formal system; risk protection mechanisms that reduce financial barriers and consequences of HIV care including grants, subsidies and National Health Insurance, and support for wider efforts to reduce urban-rural inequalities.

Background

The development of the ART roll-out program in South Africa

In 2003, the cabinet in South Africa approved an Operational Plan for Comprehensive HIV /AIDS Care, Management and Treatment to implement the most ambitious antiretroviral treatment (ART) roll-out plan the world was yet to see. The operational plan had two strategic goals. The first was to deliver a comprehensive care package for people living with HIV/AIDS that includes a combination of three ART drugs. The second goal was to strengthen the health system in South Africa.

The above goals must be viewed alongside three clinical objectives of an ART treatment programme. First, the viral load has to be suppressed to levels below 400 copies/ml, and considered "undetectable". Second, the recovery of the immune system has to be demonstrated through sustained increase in CD4 count with levels above 200 cells/ul (5). Finally, patients should be clinically well and free from opportunistic infections (5).

The nation-wide ART roll-out program was implemented in April 2004, governed by the National Antiretroviral Treatment Guidelines (5). In addition to the medical criteria of a CD4 count below 200 or a WHO Stage 4 disease, these guidelines emphasised the need to obtain patients' informed consent to be initiated on and continue their ART. The operational plan also indicated the need to introduce ART through major hospitals, where the hub of medical expertise exists, and follow a cascade down to regional and district hospitals towards primary health care facilities. A rigorous time-intensive accreditation process for ART roll-out was followed through all levels of government including provincial and national departments of health (6). These activities were followed in 2007 by the release of the national strategic plan 2007-2011, seeking to reduce new HIV infections by 50% and increasing coverage of treatment to 80% of people in need (7). More recently, the national

treatment guidelines have been revised to initiate TB patients and pregnant women when CD4 count depletion reaches 350 cells/mm^3. Today, South Africa boasts the largest national ART roll-out programme in the world, with more than 1 000 000 patients initiated on ART by end of 2009 – covering an estimated 55% of those eligible according to the National Department of Health's 2010 report. However, these successes are not without challenges (8).

Inequitable health care and decentralised models of ART care in South Africa

Access to ART in the South African context is made more complex by the nature of inequalities in the co-existing public and private health care systems (9, 10). The public sector, said to be the custodian of health care, is hierarchically-layered in ascending order from primary care clinics to level 1 (district) hospitals, level 2 (provincial) hospitals and level 3 (tertiary) hospitals and serves over 80% of the population, largely the poor (10, 11). The affluent are mainly served through the private sector, which caters for approximately 16% of the population (11). The uneven distribution of private and public sector health care is a historical by-product of the racial segregation that characterized the apartheid era (10, 12). Therefore, as explained through the inverse care law (13), poor people who need health care do not receive it, while the rich receive care even when it is not necessarily indicated (9). This inequitable distribution of health care is a major source of concern for the current government, and a principal driver of the health reform initiatives currently underway (14, 15).

This rural-urban divide has the potential to influence ART access and utilisation. South Africa has a history of high levels of labour migration – with poor rural areas serving as cheap sources of labour for more affluent urban areas. In Bushbuckridge, approximately 60% of men and 25% of women are considered circular labour migrants. When these labour migrants fall sick and lose their jobs, they often return to rural areas for health care (16, 17), creating an added burden on already-strained rural health care systems (18, 19). The existence of such complex geographic and economic realities

makes the development of coordinated and comprehensive systems of care and support for chronic conditions such as HIV even more challenging (19, 20).

In light of the above, there has been a substantial body of recent research on the strategies to decentralise ART care and support. Decentralized models for ART initiation and support have been implemented in certain parts of South Africa, notably the Eastern Cape and Kwa-Zulu Natal Provinces (21, 22). The experience in Lusikisiki in the Eastern Cape was the first widely-known example of a successful initiative to scale up access to ART in a hard-to-reach setting. This Medecins sans Frontiers programme was among the first to deliver ART through rural primary health care clinics (6, 22). Their experience was an important 'proof-of-concept', and highlighted how quality of care and support systems, as opposed to characteristics of patients, were critical determinants of treatment access and adherence. Similar decentralized efforts in Kwa-Zulu Natal have achieved near universal coverage, with ART reaching above 80% of the population in need (23).

In spite of these pockets of progress, South Africa continues to chase the goals laid out in the Strategic Plan of 80% coverage. Our experience on the front-lines of HIV and ART care delivery in rural Bushbuckridge echoes the challenges of ART rollout experienced in many settings. Despite the successful supply-side achievements documented in Lusikisiki (6, 22), a more nuanced picture of the multiplicity of access challenges faced by these early ART initiators has also emerged. In his book 'three-letter Plague', Steinberg documents emergent tensions between sick patients and a health care system that clashed with their cultural beliefs and other day-to-day challenges. The book highlights the role of power relationships and their influence on decisions regarding whether or not to use a service, even when a health provider is ready to render it (24). These dynamics critically influence our understanding of care-seeking behaviour and the acceptability of care – both which will be explored in more detail in this thesis.

Demand and supply-side barriers to ART coverage

In 2008, ART coverage in South Africa was only 40% of those who needed treatment (25). A range of demand-side issues are important barriers to low ART uptake. First, large numbers of people living with HIV do not know their HIV status. In a South African national survey, about 75% of people infected with HIV did not know their status, and were therefore unlikely to seek care, monitor their immunological status and initiate ART (26). Reasons for not knowing one's HIV status are diverse, and may include lack of or missed testing opportunities, fear of stigma, lack of information, lack of motivation and low risk perception (27-29).

Second, people with full knowledge of their HIV status may fail to complete pre-ART care either due to personal reasons or access barriers (30). Personal reasons may include denial of HIV status, preference to seek alternative health care, or feelings of physical well-being (31, 32). Access barriers may include long distances to health facilities (33), excessive transport costs (30) and high opportunity costs (34). Whether people know their status or not, they may present for care in late stages of their disease, resulting in reduced chances of survival (35, 36). Recently, studies have demonstrated that attrition is high among patients waiting (therefore willing) to be initiated on ART, largely due to deaths and loss to follow up (37). These missed opportunities to provide a life-saving intervention represent a major failure in the health system.

The third category highlights barriers within the health system, such as poor referral channels and long waits between the various tiers of the system (38), inadequate staff training and human resource capacity, and the high costs of delivering HIV care (39). All these factors may result in low ART uptake and poor levels of coverage.

Similar barriers in accessing treatment have been seen previously in resource-limited contexts including South Africa, particularly with the tuberculosis (TB) program (40). There is much that HIV is learning from TB. TB services had to be decentralised in order to increase access, and case-finding initiatives were implemented to identify patients who were ill but not presenting for TB care (41). Drawing from this experience, the World Health Organisation's called for a public-health approach to delivery of ART, namely, decentralisation of services, task-shifting to lower cadres, simplified treatment regiments, cohort-style registers and standardised treatment guidelines to improve ART delivery and uptake in resource-limited settings (42).

Retention and attrition among patients on ART

In low and middle-income countries, ART numbers have expanded 13-fold since 2004, with much of these gains taking place in sub-Saharan Africa (43). However, in 2007 a review of country-level experience suggested only 50-60% of patients initiated on ART on the continent remained on therapy after two years of follow up (44). Measuring loss to follow up is generally done through tracking clinic appointments (45). For instance, since patient using ART tend to be seen on monthly basis (sometimes two- or three- monthly), missing two or three appointments should alert providers to the possibility of patient default (45).

High levels of attrition are often the result of mortality and loss to follow up. Patients not returning for appointments may be traced either by phone or in person at their homes and brought back into care (46). Those that never return are regarded as lost to follow up or lost to care. Among those categorized as lost to care, studies have shown that their outcomes may include both death and self-transfer to other facilities (47-49). It is argued that the latter form of patient movement between health care providers may result in overestimation of losses to ART care (45). In the absence of national longitudinal tracking systems for ART-initiated patients as they move between health

facilities, accurately estimating the contribution of self-transfers and medical pluralism within the formal health system is extremely difficult (50).

Poor retention in care and low levels of adherence are associated with poor survival among ART users (51). ART adherence levels above 95% are necessary for treatment to achieve treatment goals (52). Poor ART adherence is negatively associated with low therapeutic drug levels, reduced effectiveness and higher rates of HIV-related mortality (53, 54). A number of patient-related factors that contribute to poor adherence have been identified and include depression (55), stigma and discrimination (56, 57), non-disclosure of HIV status (58), alcohol use (55), hunger (59), and forgetfulness (60). When low therapeutic levels are observed in patients, the risk of resistant mutations is high (61), and such strains are transmissible (42). Where mortality is concerned, several studies have attempted to explain patterns and causes of mortality in ART patients. In rural areas, mortality among ART initiators is largely a result of preventable conditions such as TB and diarrhoea (62). In better-resourced settings, preventable deaths among ART users are less common (63).

In summary, ART care and support programs in high prevalence countries such as South Africa face a range of challenges. For an HIV infected individual to live a long and productive life, they must be tested early, initiated on treatment appropriately, and provided with necessary support to foster good adherence. It is the goal of public health programs to enable these processes. High levels of HIV-related mortality may be the result of low levels of treatment initiation – a product of supply side issues of availability or more complex patient-related demand side dynamics that are closely linked to culture, stigma, power dynamics, and economic realities. Among those already initiated on ART, patient attrition with loss to follow-up, low levels of adherence and poor quality of care converge to undermine the effectiveness of treatment programs.

Aims and Objectives

Study Aim

The aim of this doctoral research is to generate a better understanding of the factors limiting uptake of anti-retroviral therapy and fuelling attrition from ART care services in rural South Africa.

Specific objectives

1. To identify sources of health care and examine patterns of utilisation (e.g. rates and sequencing of provider visits) among rural patients living with HIV/AIDS -exploring both formal and informal health care options.
2. To determine individual factors (e.g. sex, employment status, viral load and stigma) influencing health care utilisation among rural patients seeking and using antiretroviral therapy.
3. To investigate health system-related barriers and facilitators of access (e.g. provider attitudes, distance to health care and provider user fees) to ART care experienced by patients seeking and using ART in rural South Africa.

Review of Concepts

Study Rationale

This study was motivated by the need to find ways to improve uptake of ART and patient retention in ART care services within a rural South African setting. A 'patient perspective' was employed to inform our exploration - in an effort to document and describe what a health system may look like from a rural patient's perspective. The ***health system*** necessarily includes both formal and non-formal service providers, with emphasis on a demand-side perspective, as depicted on the left-side of Figure 1. The diagram in Figure 1, hand-drafted as part of the initial research question, acknowledges the potentially complex interaction between the context of health care on the left, the ART clinic on top, and the health outcomes on the right (See also Appendix 1). The ***question*** mark at the centre depicts the knowledge gap on how the various points interact to influence utilisation of health care among patients seeking and using ART, and the implications of access to health care for treatment uptake and patient retention. Notably, ***Access*** can be understood as the opportunity or freedom to use health care (62), whereas ***Utilisation*** occurs when an empowered person makes an explicit and informed decision to exercise their freedom to use health care (1). This conceptual distinction between access and utilisation is fundamental to this research.

Conceptual Framework

In an attempt to better understand the complexity outlined above, a theoretical framework for health care access was employed (2). Access is viewed as a multi-dimensional by-product of the interaction between health care systems and individuals, and reflects an individual's capacity to benefit from services given their life circumstances and experiences of the health care system (60). While views of access from developed countries tend to see access largely as a service delivery issue (63), anthropological research on medical systems in developing countries has called for the

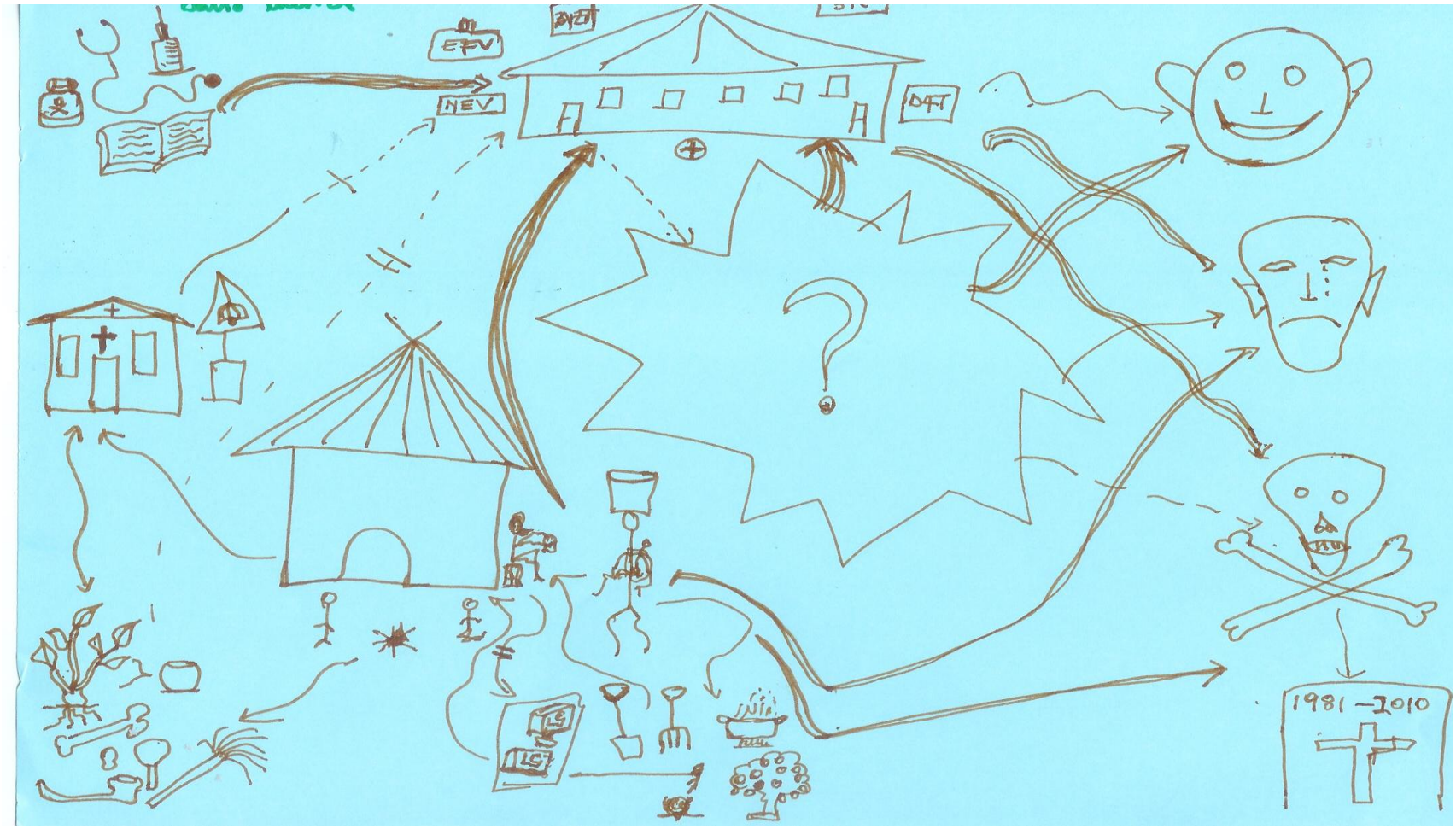


Figure 1: Depicts the knowledge gap in ART access and utilisation for rural patients in the context of formal and non-formal health care services

recognition and importance of socio-cultural factors as determinants of access to health care (64, 65). Important decisions about health care are therefore said to lie with the users and their social networks (64). Since each individual experiences health care differently, the degree of fit between the health system and the individuals could be measured across the dimensions of access (65).

This dissertation employs the A-Framework (Figure 2) where dimensions of access include availability (physical access), affordability (financial access), acceptability (cultural access) (66) and the interactions between them. 'Knowledge' (about health care and services) and 'trust' (usually between the patient and the provider) are seen as cross-cutting themes represented in all 3 dimensions.

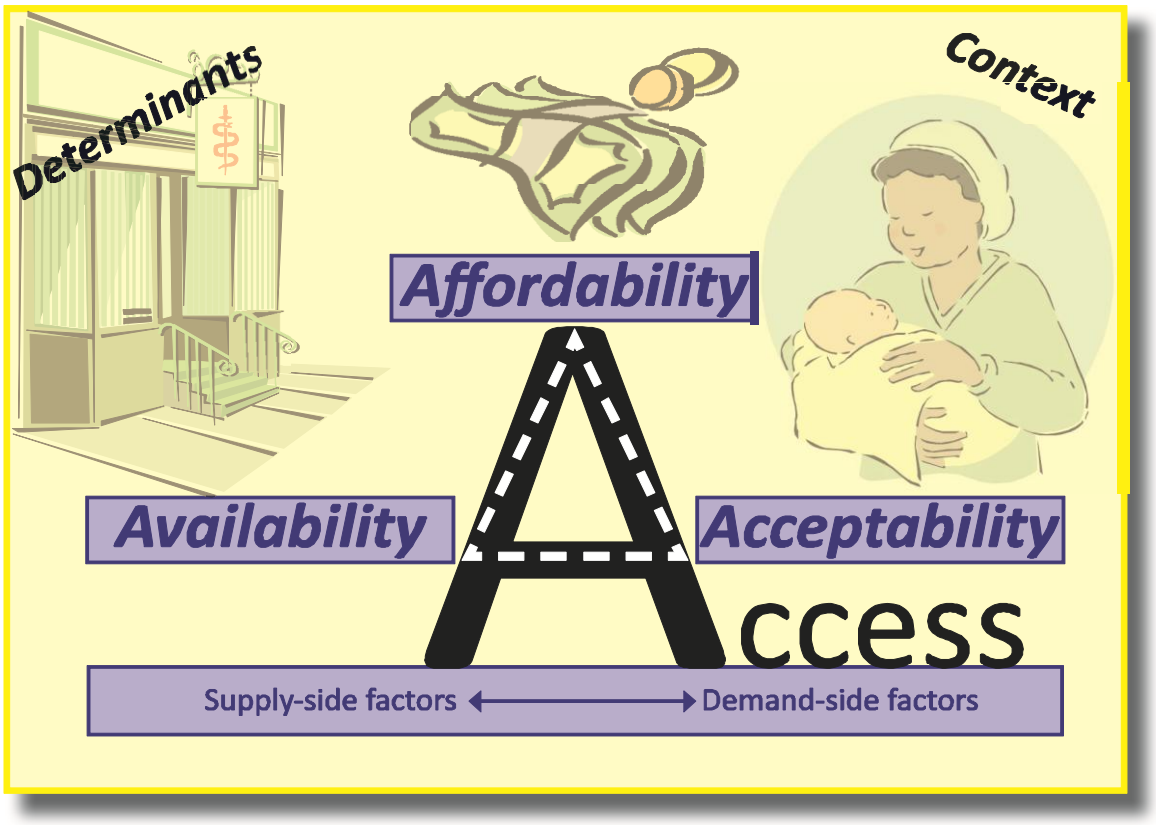


Figure 2: The A-Framework of access to health care with availability, affordability and acceptability dimensions

- ***Availability*** is conceptualised as 'the right health services being available in the right place at the right time' (66). The degree of fit has to be achieved between factors such as locations of users' homes and the health facilities or operating hours and users' times of health care needs.
- ***Affordability*** takes into account direct health costs, indirect health costs and opportunity costs to the user (66). Therefore, a degree of fit has to be achieved between all health costs and the user's ability to pay, taking into account disposable income, health insurance, other sources of material support and all other household and budgetary demands.
- ***Acceptability*** represents the social and cultural distance of the health care system (or providers) and its clients (1). The acceptability dimension considers the fit between provider and patient attitudes towards each other, as well their expectations. Therefore, the patients' perceived trust, quality of care, the responsiveness of the health care systems and provider attitudes are all included here. It is argued that even when migrants enter the developed world, they tend to combine health care with practices coming from their own countries of origin since they are 'not completely westernised' (67), thereby highlighting the importance of socio-cultural distance between users and health services.

The emphasis of the A-framework is that, whereas each dimension of access independently contributes to the measurement of access, each one of them cannot be addressed without affecting the other (2). ***Health information***, expressed as knowledge, can be regarded as goods that are supplied and demanded within the health care system (68). Furthermore, the information that empowers people to realise choice in the health care context is quite specific and different from other forms of general information (68). In this framework, broader policies, institutions, organisations and processes that govern health services and likely to influence access are not

considered. In addition, individual's health beliefs or perceived health needs are implied under acceptability (1).

Care-Seeking Behaviour and Medical Pluralism

Health-seeking behaviour can be conceptualised in two different ways (69, 70). First, a distinction can be made between care-seeking and the more general health-seeking behaviour. The former is concerned with remedial actions to rectify ill-health, or the actual utilisation of services, and the latter emphasizes mainly health-promoting behaviours, wherein the Health-Belief Model stands out (69, 70). Second, the body of health-seeking behaviour literature considers both the determinants and pathways of care. Determinants of health care utilisation (71) are on the whole the same as those of access, except where specific triggers to use health care are considered (72). Pathways models tend to logically arrange a sequence of steps in utilisation of health care followed by care-seeking patients, and two examples are provided here: first, a model of 11 stages of care-seeking behaviour from the point of recognizing symptoms until care is sought (73), and second, pathways pertaining to decision-making around seeking care and the factors that may hinder the initial decision to seek care (74).

Since the main goal of our study is to identify potential strategies to optimize ART care services such that patient retention can be improved and treatment uptake promoted, we focus largely on actual utilisation or care-seeking behaviour. Insights are drawn from both determinants and pathways of care to ART access based on the experiences of those who have already had the opportunity to use HIV and ART services. For chronically-ill patients, the need to return to care on regular basis may trigger further opportunities to use health care leading to experiences of quality during encounter with health services that may affect future use of health care (1, 2, 75). Furthermore, chronic illness also means that an on-going relationship is formed with the health care system, and therefore, the

socio-cultural distance has to be reduced as much as possible for trust to form and patient-doctor relationships to be healthy (1).

Worth noting is the study of chronically-ill people sampled from their households within the Bushbuckridge area, called the South Africa Costs and Coping (SACOCO) study. Using the A-framework of access, the SACOCO study provided 3 essential messages. Firstly, patients who lived in vulnerable households were not able to sustain the financial burden of chronic health care, such that these households were at risk of deteriorating livelihoods (9, 76). Secondly, patients tended to use and spend money on other providers, including traditional healers, private practitioners and private pharmacists (77), displaying medical pluralism (3). ***Medical pluralism*** is defined as the diverse ways in which illness can be perceived, understood or treated (3, 78, 79). Lastly, although patients overcame barriers in order to successfully use services, poor patient-provider relationships lead patients to withdrawal from care, contributing to healer-shopping (77). These 'shopping' patterns of care-seeking behaviour have also been described among chronically-ill diabetic patients (80).

Healer-shopping, or ***provider-shopping*** as used in this study, is a form of care-seeking behaviour whereby patients obtain care from multiple providers for the same illnesses, and largely without proper referral (4). These concepts are conceived as unhealthy patient practices in the literature, and generally discouraged. Healer-shopping indicates that the provider is not necessarily a doctor, but can also be a traditional or another form of an alternative healer. Also, the use of alternative healers is generally discouraged by the mainstream or formal health providers. As a result, patients are often less likely to disclose their use of non-formal health care services to practitioners in the formal sector (81). In South Africa, traditional healers are not considered part of the health system, and often referred to as members of the informal health sector (82). However, the government in South Africa has recently recognised these practitioners through the Traditional Health Practitioners

Act 22 of 2007 (83), and more recent policy to more formally integrate them into the current health system (84).

Health care pluralism or use of multiple sources of health care has been documented for other medical conditions such as malaria (85). Such care-seeking patterns are likely to be compounded in chronic illnesses such as HIV/AIDS. Patients have already been said to transfer themselves between providers for collection or ART (49). Recently, literature on patient retention in ART was reviewed, and the study identified the current focus of many studies on single specialised ART clinics as one of the major gaps (50). Such studies were unable to account for movement of patients between ART facilities (50). In Sub-Saharan Africa, failure to understand how HIV/AIDS patients seeking ART move in the broader health system, which most probably includes both formal and informal systems of health care (82), may limit our understanding of ART uptake and patient losses. In the South African context, given the co-existence of modern and traditional forms of care and support, medical pluralism may represent another challenge to ART initiation, adherence, and ultimately survival.

Overview of Scientific Papers

The goal of this integrating narrative is to examine factors that can potentially influence ART uptake of and loss-to-follow-up within a rural health system, with specific emphasis on access and the pathways, determinants and patterns of health care use. The synthesis draws data from 5 manuscripts written to systematically address the study objectives, themes of which are presented in Table 2 in line with the thesis objectives. The main research questions, methods and major findings of each paper are briefly summarized below.

Paper I: Patterns and implications of medical pluralism among HIV/AIDS patients in rural South Africa

AIDS and Behavior 15 (4): 842-852, 2011.

- Questions- Among rural HIV/AIDS patients, what are the sources of healthcare, patterns of health care use and triggers of care-seeking behaviour before and after ART initiation?
- Methods- A longitudinal qualitative study of patients seeking and using ART was conducted through in-depth interviews carried out on monthly intervals
- Findings- Multiple health care modalities identified before ART initiation can lead to delayed HIV testing and ART initiation. Efforts to better integrate care and support services could mitigate against the consequences of medical pluralism

Paper II: Factors associated with patterns of plural health care utilisation among patients taking antiretroviral therapy in rural and urban South Africa: a cross-sectional study

BMC Health Services, forthcoming 2012.

- Questions- What are the factors, determinants and consequences, associated with patterns of plural health care utilisation among patients using antiretroviral therapy?

- Methods- A cross-sectional study of 1266 patients using ART in both rural and urban settings, taking into account a broad access framework inclusive of availability, affordability and acceptability
- Findings- Plural health care provider utilisation was more common in urban than rural areas, whereas self-care pluralism was higher in rural areas. Major determinants of pluralism included higher socioeconomic status, better ability to finance health care and poor quality of ART care in clinics and hospitals.

Paper III: Does access to antiretroviral therapy improve following 'down-referral' of patients from hospitals to health centres in rural South Africa?

African Journal of AIDS Research 2011, 10(4): 393–401

- Questions- What are the differences in measures of access between down-referred clinic-based and hospital-based ART patients, and what factors characterise the two groups?
- Methods- An evaluation of ART care access and utilisation was conducted through a cross-sectional study of down-referred clinic-based patients with a comparison group of hospital-based patients, with both groups on ART for a minimum duration of six months
- Findings- Down-referred patients save time and money, feel more respected, perceive lower stigma and show better adherence levels. However, there is evidence of unintended consequences as shown by increased utilisation rates and costs of both private physicians and self-care practices among the down-referred group

Paper IV: Unequal access to ART: exploratory results from rural and urban case studies of ART use

British Medical Journal Sex Transm Infect, 2012, 88: 141-146.

- Questions- What are the barriers to ART access in rural and urban South Africa among adults, and how can these be used to improve health equity between geographic locations?
- Methods- A cross-sectional study of ART users across two rural and two urban sub-districts were investigated for access barriers employing a framework of access that includes availability, affordability and acceptability

- Findings- Inequitable access to ART among rural relative to urban users was found. Rural users were more likely to be older, male, unemployed, poorer, and walk longer distances. Minimizing access barriers requires an understanding of their context-specific and multi-dimensional nature

Paper V: Dedicated HIV/AIDS clinics can alleviate access barriers to antiretroviral therapy in rural South Africa: a longitudinal qualitative study

Manuscript to be submitted to AIDS Care in 2012

- Questions- What are bottlenecks to ART access in a dedicated rural HIV/AIDS clinic?
- Methods- A longitudinal qualitative study of patients seeking and using ART was conducted through in-depth interviews carried out on monthly intervals over a 10-month period
- Findings- Patients can employ tactics, such as concealing stigmatising records, to minimise health system barriers, and providers can cooperate with patients by providing patient-tailored care to reduce the impact of both patient factors and health system barriers.

Methods

Study Design

The methods employed for the papers contained in this dissertation combine qualitative and quantitative approaches, and are summarised in Table 1. Triangulation of methods was adopted as very little was known on the utilization patterns of health care by HIV/AIDS patients – thus allowing for exploratory and explanatory assessments. The main qualitative study involved an in-depth longitudinal design, explored experiences of patients before and after ART initiation, and took place only in the Bushbuckridge site. The main quantitative research employed a four-site rural-urban comparative analysis and was part of a 5-year project Researching Equity and Access to Health care (REACH). REACH was designed to measure access using the A-Framework for 3 tracers, including ART-initiated care, emergency obstetric care and TB care in four provinces of South Africa; Mpumalanga (Bushbuckridge), Gauteng (Soweto), Western Cape (Mitchell's Plain) and Kwa-Zulu Natal (Hlabisa) to allow for urban-rural comparisons of inequities (See Table 2).

Study Setting

Mitchell's Plain is an urban setting in the outskirts of Cape Town, with a population of 290 000 people, and a decentralised delivery system for ART. Soweto, Region D, is also an urban settlement located outside the Johannesburg City Metro, with a population of approximately 1 million people, and the ART delivery was mainly hospital-based at the time of the study. Hlabisa, a rural setting with an on-going demographic surveillance, is situated 250km north of the City of Durban and inhabits about 228 000 people. Bushbuckridge (Figure 3) is a remote and rural sub-district of Mpumalanga Province in South Africa. It is a densely-settled area home to approximately 600 000 inhabitants, and many households in the area rely on remittance income from migrant labour.

Table 1: Summary of methods for the integrating narrative

	Qualitative Study	Quantitative Study
Papers	Paper I: Patterns and implications of medical pluralism Paper V: Dedicated HIV/AIDS clinics can alleviate access barriers	Paper II: Factors associated with patterns of plural health care utilisation Paper III: Does access to ART improve following 'down-referral' of patients? Paper IV: Unequal access to ART in urban and rural South Africa
Design	Longitudinal in-depth interviews	Cross-sectional study using A-Framework of Access to health care
Setting	Bushbuckridge (Rural)	Bushbuckridge (Rural), Hlabisa (Rural), Mitchell's Plain (Urban) and Soweto (Urban)
Population	Adult HIV/AIDS patients attending specialised HIV Clinic with and/or without ART	Adult HIV/AIDS patients on ART for at least two weeks, sampled from specialised HIV clinics including down-referral sites for ART
Sample Size	32 participants in one rural HIV clinic	1266 participants in four sub-districts (two rural and two urban) across four provinces
Study period	June 2006 to March 2007	April 2008 to February 2010
Tools and methods	In-depth face-to-face interviews with monthly follow-up	Structured questionnaire in exit interviews combined with clinic record reviews
Research topics	1. Socio-demographic factors and circumstances 2. Experiences of HIV illness over time 3. Experiences of and circumstances around HIV testing 4. Experiences of ART initiation and treatment 5. Experiences of non-formal health care related to illness 6. Social support, HIV disclosure and HIV knowledge and perceptions 7. Satisfaction with health care services	1. Socio-demographic data 2. Utilisation of HIV and ART services 3. Availability of ART care services 4. Affordability of ART care services 5. Acceptability of ART care services 6. Assets and livelihoods data
Data analysis	Pathway of care analysis, thematic analysis and direct and indirect content analysis	Descriptive statistics, multiple regression analysis and multiple correspondence analysis

Table 2: Study sites and sampling methods presented under elected provinces and sub-districts.

Province	Western Cape	Gauteng	Mpumalanga	Kwa-Zulu Natal
Site (Sub-district) selected	Mitchell's Plain	Soweto	Bushbuckridge	Hlabisa
Classification	Urban	Urban	Rural	Rural
Population	290000	1100000	620000	228000
ART facilities	03	07	02	16
Facility sampling method	All	Self-weighting Stratified	All	Probability Proportional to Size
Facilities sampled	03	03	02	05
Participants sampled	323	331	312	300
Participants sampling method	Systematic	Systematic	Systematic	Systematic

The population is largely poor, with 60% and 25% of men and women respectively declared circular labour migrants (16). The area is designated as one of the 13 most rural nodes of poverty and in need of development and densely-settled. Bushbuckridge is surrounded by the Kruger National Park, and many other private game reserves, and the tourism industry is key source of employment in the area. High levels of labour migration characterize the area, resulting in large numbers of female-headed households (86). HIV/AIDS-sick circular labour migrants are known to 'return home to die' (16). Low education and high unemployment rates are typical characteristics. Half of households live on less than ZAR 800 ($USD110) per month (87). The antenatal HIV prevalence is estimated to be 34% (88). The area is served by 3 hospitals, 2 health centres and 37 PHC clinics. Two hospitals were accredited to initiate ART in September 2004 and October 2005, and the 2 health centres were permitted to serve as nurse-driven ART sites for down-referral in May 2007.

Qualitative Methods

Data Collection

Data collection for the qualitative component took place over 10 months from June 2006-March 2007. A support group at a hospital-based rural HIV clinic was used to recruit patients for participation in qualitative research. For a month prior to data collection, a qualitative researcher and a trained assistant observed daily HIV support groups to identify potential participants.

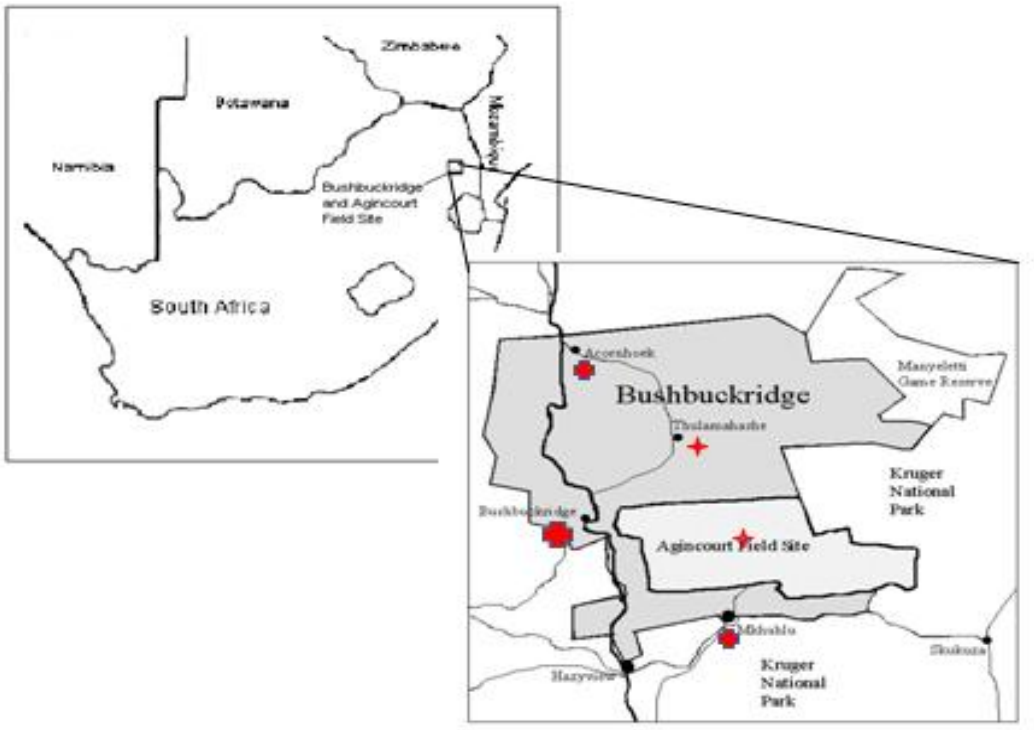


Figure 3: The map of Bushbuckridge indicating the major formal health service points

Verbal informed consent for the research team to attend support groups was obtained prior to each session. Criteria for selection included a representative mix of age and gender, ART-initiated and non-initiated, and those likely to provide information-rich interviews. Selected participants were invited to attend an interview session in a secluded area. Written informed consent was obtained from each respondent, and it was emphasized that refusal to participate at any stage would not affect services they received. Interviews were conducted, with the aid of an interpreter, in the preferred language of the participant.

The themes explored in this study are presented in Table 1, and include experiences with illness preceding HIV diagnosis, HIV testing, ART initiation, use of non-formal health care. After an initial interview, follow-up interviews were conducted once per month to capture the continuum of the HIV illness experience. At follow up, missing information was completed, new information was obtained, and member-checking or respondent validation (89) was done to increase reliability and validity. On average, four interviews were conducted per participant. The number of interviews ranged from three to seven when loss to follow up (1/32) and death (1/32) were excluded. The duration of interviews ranged from 20 minutes to 2 hours. Interviews were conducted in private within the premises of the hospital. Alternate meeting times and locations were arranged based on participant preferences, while still ensuring participant anonymity and confidentiality.

Data Analysis

Text files were managed using N6 (NUD*IST: QSR International, Doncaster, Australia). Analysis was conducted in two stages. Thematic content analysis was used throughout data collection to achieve familiarization and allow validation by respondents during follow-up interviews. Additionally, we conducted a pathway of care analysis for each participant by tracking their experiences of illness and health care service utilization (69, 70). We summarized the illness experience of individual participants from their onset of AIDS-related symptoms to the day of their final interview. Using participants' pathways of care, the various sources of health care within the broader health system were retrospectively mapped out for each of the 32 participants, and later categorized by health sector type. Furthermore, inductive content analysis method was used to identify applicable codes (90). The codes were later grouped into sub-categories and broader categories, which were tested and where necessary recoded using directed content analysis (90). This coding scheme was applied consistently to all participants included in the study. Codes were identified through immersion and repeated reading of the text to achieve data familiarity, and documentation was achieved through

multiple stages of free-writing and crafting of thematic outputs. Supporting quotes and descriptive summaries are presented as evidence to support thematic interpretation of study findings. Six case summaries considered representative of thematic outputs are presented in text boxes for reference. Pseudonyms were used in all case summaries.

Quantitative Methods

Data Collection

Data collection for the REACH parent study occurred between 2008 and 2010. Data were collected through ART patient exit interviews within health facilities, including both closed and open-ended questions, and clinic records were reviewed to retrieve CD4 count and viral load data. Table 1 outlines the key topics included in the questionnaire, largely availability, affordability, utilisation and acceptability of ART services. At the time of the study, a total of 120 patients in Bushbuckridge were receiving ART at the PHC level following initiation and down-referral from the hospital level, while approximately 3500 ART patients were hospital-based. In both settings, patients were excluded from interviews if they were less than 18 years of age, had been on ART for less than 2 weeks or were not prepared to give informed consent to participate. At the hospitals, patients were selected for the interview through a systematic random sampling method, using their daily patient numbers assigned for purposes of clinic patient flow. Interviews continued until a minimum of 300 patients had been interviewed. At the health centres, all adult patients were included in the study. Participants were interviewed by trained research assistants in XiTsonga, Sepedi or English depending on the participant's language preference on the day of the participant's clinic visit to the ART service point. Record reviews were conducted on the same day as the interview.

Data Analysis

Data were double-entered into purpose designed database in EpiData v3.1 and imported into STATA v10 (Statacorp, College Station, Texas) for analysis. Descriptive statistics stratified by type of facility were generated, student t-tests were used for continuous variables, and bivariate analyses were conducted with the chi-squared test and logistic regression. Simple and multiple logistic regressions were used to unpack differential access experiences, health care utilisation, outcomes (increase in CD4 count from baseline, and viral load suppression) and adherence for down referred patients (where a binary dependent variable takes a value of 1 for PHC-based users, or 0 for hospital-based users). An index of socio-economic status was constructed as part of the broader REACH study, using multiple correspondence analysis, and described elsewhere (91). Catastrophic healthcare expenditure was defined as mean monthly health care-related expenditure of greater than 10% of mean monthly household expenditure.

Ethical Considerations

Ethical approval was obtained from the University of Witwatersrand, Johannesburg, University of Kwa-Zulu Natal, University of Cape Town and the Mpumalanga, Gauteng, Western Cape and Kwa-Zulu Natal Provincial Health Research and Ethics Committees. For the quantitative study, written informed consent was obtained separately for the interview and for the HIV clinic record review. Anonymity of participants was maintained during data collection, management, analysis, and reporting. For the qualitative study, verbal consent was obtained for researcher attendance at the support groups, and all participants signed a written informed consent before the first interview began. All interviews were conducted in private locations agreed to by both the interviewers and the participants. Some participants agreed to be interviewed in their homes or at convenient locations near their homes at follow-up. In reporting findings, we removed all identifying data, and have used pseudonyms instead of real names.

Table 3: Themes across scientific papers

Themes	**Paper 1**: Patterns and implications of medical pluralism	**Paper 2**: Plural health care utilisation in urban and rural South Africa	**Paper 3**: Down-referral from hospitals to health centres in rural South Africa	**Paper 4**: Poor quality of care in the ART clinic is a threat to patient retention and treatment adherence	**Paper 5**: Urban-rural differences in access to ART care
1. Patterns of Health care Utilisation among HIV Patients	-Multiple transitions in illness progression -Multiple health provider usage -Complex pathways of health care usage	-Urban and rural differences in plural health care -Socioeconomic distribution -Plural provider usage and self-care practices	-Formalised referral of patients for ART care -Perceived stigma -Preference for doctors over nurses in PHC -Poor ART-related knowledge	-Patient-patient socialisation -Passive patient provider but active patient health system -Role of non-clinical team members -Seeking symptomatic improvement	-Urban and rural inequities -Plural health care context -Socioeconomic inequities
2. Patient Factors influencing access to HIV and ART Care	-Delayed health care -Sequential and concurrent health care -Switching of health care providers -Social support systems	-Ability to pay for health care -Social support and networks -Perceptions of quality in health care	-Acceptability of down-referral to PHC -Self-referral to seek additional health care -Ability to pay for health care	-Ability to pay for health care -Values of respect and proper behaviour by staff or perceived quality of care -Tactic employ to overcome barriers	-Perceived respect by health workers -High cost barriers among rural patients -Ability to pay for health care options
3. Health System Factors influencing access to HIV and ART Care	-Multiple sources of health care -Formal and non-formal providers -Costly private and non-formal sectors	-Multiple providers of health care -Differences in costs between providers -Communication of health information -Perceived disrespect by staff and lack of privacy	-Private physician usage and self-care practices -Poor quality of ART care -Long distances to ART services -Excessive costs of health care	-Complementary alternative healing and divine intervention -Comprehensive multidisciplinary ART care team -Multiple layers of influence in the health facility	-Decentralised ART models in rural areas -Availability of self-care medicines and their high costs -Availability and use of additional private providers
4. Breaking down barriers to care and treatment-seeking in ART clinics	-Initial delays in health care (home visits) -Triggers of health care use -Access to and utilisation of primary health care services	-Negative experiences in health care (quality) -Catastrophic health care expenditures -Borrowing to finance health care -Poor quality of ART care	-Decentralisation of health care systems -Saving time and money for patients using ART care -Catastrophic health care expenditures	-Resourcefulness, agency and self-efficacy by ART patients -Lack of explanation and information -Implicit contracts between providers and patients -Poor quality of ART services	-Catastrophic health care expenditure -Borrowing to finance health care

Results

In this section, we draw from the data triangulation approach to address the study objectives by presenting patterns of health care utilisation, as well as patient and health system factors that appear to influence health care-seeking behaviour in the quest for HIV and ART care. The final subsection focuses on the interaction between users and the health system, reflecting both the demand and supply perspectives on minimising access barriers to ART care. The results of this research are summarised thematically by papers in Table 3, supplemented by Appendix 2.

Socio-demographic Characteristics of Rural and Urban users

The results of this research can be better understood with a background understanding of the socio-demographic inequities between rural and urban contexts in health care access, presented in Paper IV. Essential socio-demographic rural-urban differences are presented in Table 4. Rural users were more likely to be older, male, unemployed, and poorer with a lower socio-economic status (SES).

Table 4: Socio-demographic urban-rural inequities

	Rural	Urban
Total Sample (%)	612/1266 (48%)	654/1266 (52%)
Mean Age (Years)	39	36
Sex (Male)	31.1%	21.9%
Marital Status (Single)	48.0%	62.1%
Mean Education (Years)	6.9	9.3
Employment (No)	85.3%	70.5%
Disability Grant (Yes)	46.6%	27.2%
Socio-economic Status (Poorer Half)	77.4%	24.2%

Patient factors, pathways and patterns influencing access to HIV and ART Care

The use of multiple sources of health care by HIV/AIDS patients can be tracked from the point at which AIDS-related illnesses begin to warrant entry into the health system. This section tracks users seeking and using ART through their health system encounter to map out the movements and interactions. We draw data from all papers to highlight the pathways, determinants and implications related to plural health care utilisation.

Transitions in Illness Progression

In rural South Africa, patients living with HIV/AIDS and seeking ART experienced three major phases in the course of their illness experiences and use of services as demonstrated in paper I i.e. initial Consultation ('Leaving home'), Diagnosis with HIV ('Finding the problem'), and ART Commencement ('Taking treatment'). These three phases highlight key transitions related to HIV-related care for these patients.

- First, there was a transition from a state of well-being to physically-evident disease when patients progressed into the AIDS stage. The illness progression manifested physical symptoms that necessitated a consultation with a health provider, and thereby leading up to the initial contact with the health system for AIDS-related symptoms.
- Second, at some point during their interaction with the health system, users were diagnosed with HIV infection and ultimately with immunosuppression, determined by their clinical stage or CD4 count. Following this diagnosis, patients responded in various ways including denial, disclosure, divorce, acceptance etc. Many of them consulted multiple times with health providers in an attempt to find solutions to their persisting or recurrent medical problems.

- Third, patients eventually received ART prescribed by providers working in dedicated HIV clinics. The preparation period building up to initiation of ART was almost always intense for patients, involving multiple frequent visits for treatment literacy and adherence training, as shown in paper V.

Initial contact with health care

Two-thirds of users enter the health system less than one month upon recognising the need for care, as presented in paper I. Amongst those who delayed initial care, an average of seven months was observed in our study, ranging from two to 24 months. In almost all users, 29/32 in paper I, having AIDS-related symptoms was their main trigger to initiate contact with the health system. HIV testing was delayed by two years on average. Although HIV test was offered earlier upon entering the health system, the use of traditional healers and prophets delayed return to the HIV-testing facility. Therefore, use of multiple sources of health care by HIV users, many of which may not be offering HIV-specific care, may result in delayed uptake of definitive care.

In total, it took Mabuti four years to finally receive an HIV test, and another year before receiving ART services, depicted in Figure 4. ART commencement was also delayed by about 15 months on average. The exclusive use of the public sector resulted in early access to HIV testing in 70% of cases. However, combinations with traditional healers and private sector both delayed HIV testing in more than 3/4 of cases. Notably, proportions of users walking to their ART clinic in this research were 25.8% and 18.7% in urban and rural users respectively, and the mean travel was respectively 28.5 and 71.4 minutes. Therefore, rural people walked longer distances to reach their HIV care, an observation with consequences for uptake of ART and retention in care made in other rural settings (23).

Pathways of Health Care Utilisation

In visiting plural health care providers, users follow both sequential and concurrent pathways equally, as shown in paper I. However, mixed and poorly-defined patterns were also observed, also suggested by Mackian et al. (70). Once started in a certain health sector, be it public, private or informal, most users remain in the same sector when switching providers. Switches between sectors are also discussed in Paper I. When inter-sector switching occurred, it largely involved users moving out of the informal and private sectors into the public sector.

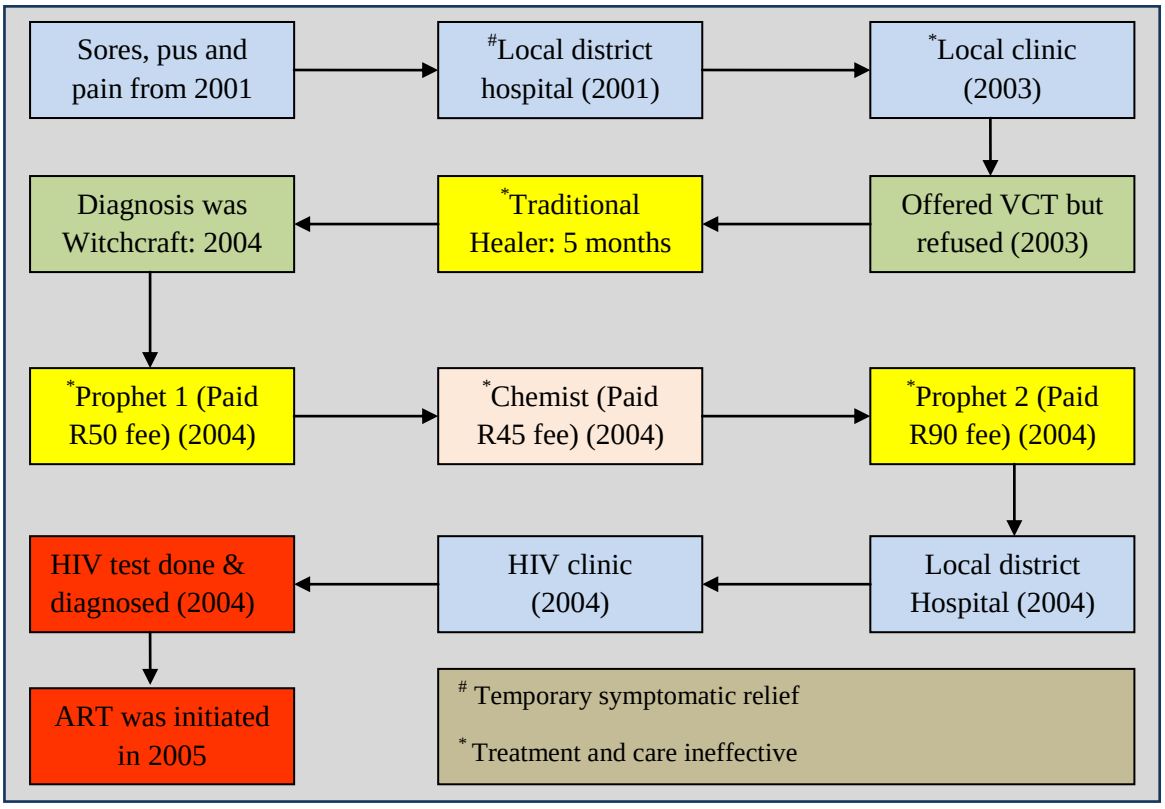


Figure 4: Mabuti's Pathway to ART care

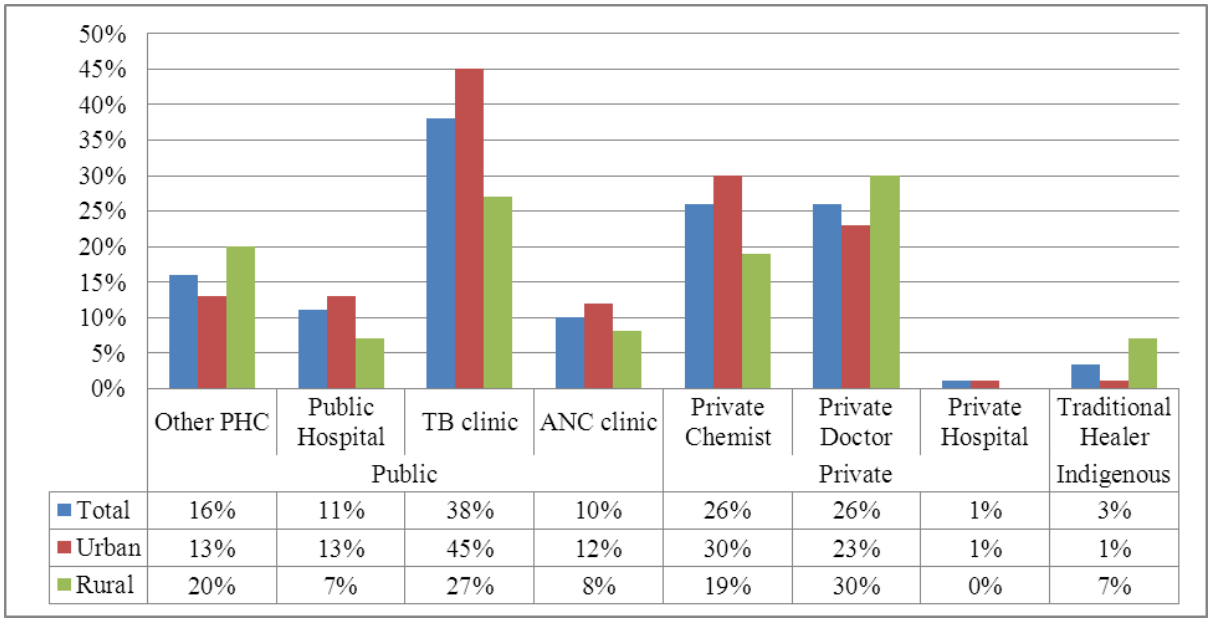
The public sector remained the primary and main source of health care for our study population. As demonstrated in papers I and II, pluralistic patterns involving private doctors, private pharmacists, PHC clinics and public hospitals are common among users of ART services. Paper II suggests that one

third of patients on ART have engaged in some form of formal or non-formal sector plural health care utilisation within the four weeks prior to their regular clinic visit. . Furthermore, the purchase of medical products for purposes of health care, also termed self-care, was common.

Multiple sources of health care

As shown in Figure 4 and Paper I, several providers were visited by the user before finally receiving an HIV test. When testing was finally done, triggers for testing ranged from health education and medical referrals to referral by partners, neighbours and employers, information from the Radio, pregnancy and sexual assault. Only a third of the users waited more than one month before entering a health system. However, these users do not necessarily visit the specialised HIV clinic where they are likely to receive ART, instead they present to any provider likely to address their symptoms. These providers may range from PHC clinics, hospitals and private doctors to traditional and faith healers. Figure 4 demonstrates the pathway followed by Mabuti in his quest for ART care. The range of health providers used by this user is diverse, highlighting the nature of a plural health care system from a patient's perspective.

In this study, the use of traditional healers was higher in the period prior to ART commencement, during which half of the users had at some point seen a traditional healer, whereas only 6.3% participants had visited a traditional healer since commencing ART. The reduced rate of traditional healer usage following ART initiation is also confirmed in paper II, where only 7.0% of users in the rural areas had visited traditional healers in the four weeks prior to their clinic visits, shown in Figure 5. This is in-keeping with existing literature indicating low rates of traditional medicine use with ART (92, 93). Rural residents made greater use of traditional healers, while urban users were more likely to use private pharmacists.



	Other PHC	Public Hospital	TB clinic	ANC clinic	Private Chemist	Private Doctor	Private Hospital	Traditional Healer
	Public				Private			Indigenous
Total	16%	11%	38%	10%	26%	26%	1%	3%
Urban	13%	13%	45%	12%	30%	23%	1%	1%
Rural	20%	7%	27%	8%	19%	30%	0%	7%

Figure 5: Urban-rural differences among HAART users consulting an additional provider in prior month (N=335)

Self-care behaviour in addition to multiple providers

Self-care pluralism, defined as reported self-help products purchased by participants and used concurrently with ART in the four weeks prior to their clinic visit, was six times more likely to occur among rural-dwellers than urban residents, extensively discussed in Paper II. Self-care, identified in the older anthropology literature as one form of patient-driven medical systems (64), was also strongly associated with patients who were receiving a temporary disability grant. Those reporting self-care were 2.4 times more likely to borrow money, reported lack of privacy during consultations, perceived disrespect by clinic staff, and preferred to be seen by a doctor rather than a nurse provider. Higher socio-economic status and access to medical insurance were predictors of provider pluralism. Ability to pay has been associated with the increasing use of traditional, complementary and alternative medicines (92), as well as social influence (94). Leaving the ART clinic without receiving the needed help and perceptions of disrespect were also associated with provider pluralism. These variables are associated with quality of care, which has been shown to result in low patient satisfaction with HIV care when poor (95).

Social Networks and Support

Paper I, II and V further demonstrates the important role played by friends, family members and relatives of health care users. This role manifests as social support, assisting the user in arriving at the point of care and adhering to treatment instructions. Worth noting is the role of several social networks in influencing decisions by users to test for HIV. However, the role of treatment supporters and persons conducting HIV-related home visits can potentially influence patterns of using health care services among HIV/AIDS users is noted in paper II. The presence of a treatment supporter, a form of social support, was higher by 58% among those with self-care pluralism. Therefore, social influence appears to be an important driver of care-seeking behaviour in these populations (94). Since HIV/AIDS users differ by their possession of disability grants, medical aid insurance and socio-economic status as shown in paper II and III, and therefore their ability to pay for health care, they tend to draw from their social networks and support system for financial support. Ware et al. demonstrated that overcoming health care cost barriers involves borrowing from within the social networks (54).

Affordability implications of pluralism

Ultimately, the use of multiple sources of health care leads to increased health care expenditure from direct user fees, with the consequence of increased need to borrow money and also associated with difficulties incurring health care costs. In total, nearly one third of rural users had to borrow money to finance user fees for obtaining additional health care, compared to only 6.4% of urban users. Although borrowing money was more common among all plural health care users, rural users were 6.8 times more likely to borrow than urban users. Borrowing can be seen as a way of overcoming costs barriers in health care, particularly in cases of high out-of-pocket payments (54).

Amongst those borrowing, plural care users (63.0%) were more likely to report increased difficulty incurring health care costs, compared to 37.0% of non-plural users.

The socio-economic distribution of plural care users showed opposing trends in rural and urban areas, as shown in paper II. In rural areas, plural health care utilisation declined with increasing SES, whereas in urban areas, increasing SES led to increased plural health care use. The high SES urban trends of plural health care utilisation are in-keeping with the picture seen in complementary and alternative medicine usage in developed countries, used largely by the well-off (96). Interestingly, catastrophic levels of health care expenditure above 15% of the total household expenditure were higher among plural health care users (34.8%), as opposed to only 6.9% of non-plural users. In addition, catastrophic levels of health care expenditure were identified in 77.2% of plural health care users with rural origin compared to only 22.8% of urban residents. Borrowing money was associated with catastrophic health care expenditure. In paper III, we demonstrated the problem of increased levels of catastrophic health care expenditure in patients who are receiving ART care from PHC clinics closer to their homes (29/109, 26.6%) compared to those using hospitals (24/220, 10.9%).

Health System Factors influencing access to HIV and ART Care

The papers all highlight a range of health systems-related factors, with a heavy emphasis on pluralism, that shape ART initiation and retention in care.

<u>The elements of the plural health care system</u>

Paper I identified the public sector primary health care clinic as the most popular first point of contact with health care among rural HIV/AIDS patients. Paper II notes that only 3% of ART users had visited traditional healers in the previous month. However, users of traditional healers incurred the highest amounts of user fees (ZAR 1000=USD125) in comparison to other forms of health providers,

as shown in Figure 6. Worth noting is the self-reliant nature of traditional health care system, which depends largely on out-of-pocket payments, and has no state subsidy or health insurance system as may be seen with the formal sector (97). Private practitioners were consulted by 26% of ART users, with clients incurring up to ZAR 904 (USD113). Use of primary health care facilities was relatively cheap, with users incurring only up to ZAR 56 (USD7). Worth noting was the increased difficulty among 63% of plural health care users to incur costs of health care when compared with 37% non-plural users.

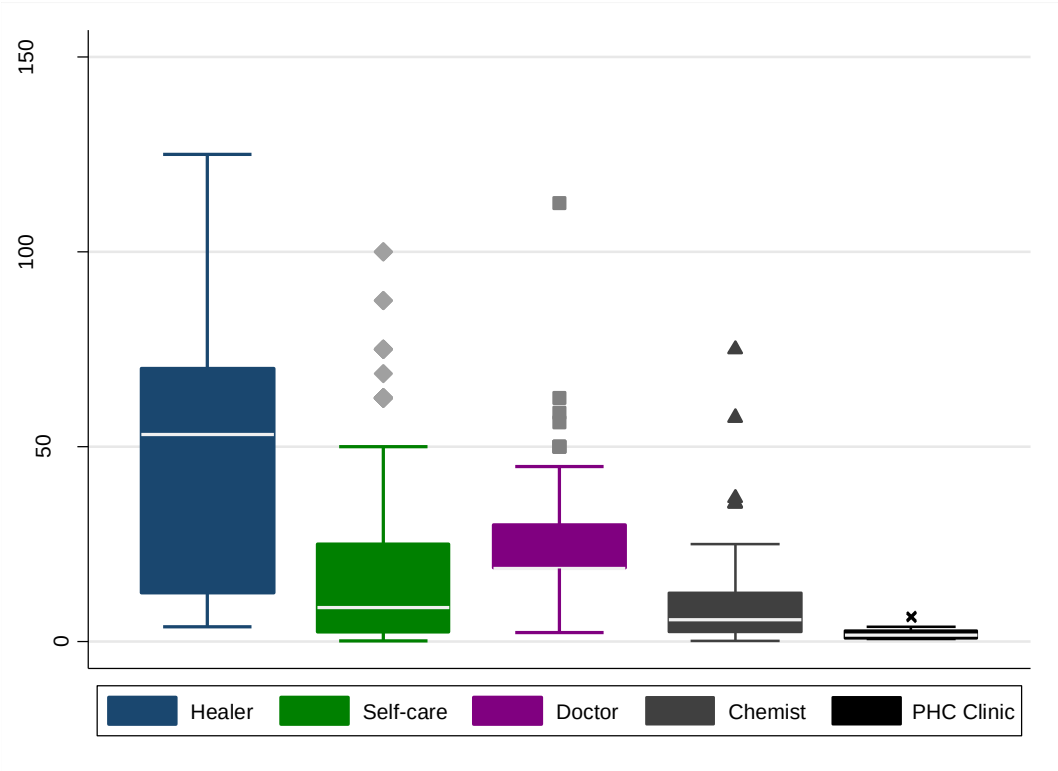


Figure 6: Provider costs incurred by users in USD (N=392)

Levels and forms of patient-system interaction in the public health system

The dedicated HIV clinic is made up of a comprehensive team of doctors, nurse clinicians, pharmacists, dieticians, administrators, lay health workers and other allied workers. In addition, users in the HIV clinic may also be linked through referrals to other providers within the health system, such as eye clinicians and physiotherapists. Upon entering the premises of the health facility

within which a dedicated ART clinic is located, users engage different actors of the health facility in stages.

Three levels of interaction were identified, each with its own dynamic. The first level is the patient-provider relationship; the second level, the wider HIV clinic team and; the third level, consisting of additional members within the broader health facility. In addition, users interact with fellow patients while awaiting their consultations, and significantly influencing their perceptions on matters pertaining to health care in the HIV clinic. Users often asked other patients for information, such as the reasons for the blood collection. The different interactions seem to carry potential to independently obstruct or facilitate utilisation of ART care, as shall be shown next. Interestingly, patients knew the names of the providers in the HIV clinic, but were often not able to distinguish their professional roles. For example, it was not uncommon for users to ask administrators and dieticians about laboratory-based clinical data in their files, suggesting a lack of fit between the provision of care in the HIV clinic and patient knowledge of this care.

Quality of care for ART patients

Papers II and III highlight the importance of quality of care experienced by ART users in their regular clinics. We demonstrated in paper V the role of the health system in influencing health care experiences and behaviour among HIV/AIDS users, as shown in Table 5. Users of rural HIV services found barriers to utilisation of care to involve firstly, relationships with providers, secondly, clarity of health messaging and care-related information, and thirdly, processes and procedures in the health facility. Some administrators and clinicians were singled out by users as consistently portraying rude behaviour. Rude behaviour displayed by health providers and other members of the health team was identified by users as the most unwanted behaviour that was also demonstrated to affect utilisation of care. Likewise, disrespect by health staff was also shown to act as a push factor

Table 5: Barriers to and Facilitators of HIV care utilisation

Barriers and Facilitators	
Barriers	
Inability to afford care	Thuli purchased treatment through a private physician recommended by her family, but interrupted for two months because she ran out of money.
Stifling clinic environment	On her first appointment to the HIV clinic, Helen was also collecting TB treatment for her daughter. However, she was confused and did not know whether to report at the HIV clinic or TB ward.
Long waiting times	Lindy had been at the clinic until afternoon, and the pharmacist had not arrived. Patients were told another pharmacist would be coming to fill in for the missing one.
Inadequate information	Thandi consulted for a problem she was having with her leg, and was referred to a physiotherapist because of difficulty in walking. She had not seen the physiotherapist yet, and this was because she feared they will put in metal rods that might immobilize her even more.
Rudeness	Johnny identified, by description, a particular clinician who was not friendly. He asked the clinician two questions and she yelled at him both times 'You don't listen to people!' He always finds a way to avoid going into her consulting room.
Facilitators	
Implied contract	Mary asked the clinician at the time of treatment initiation whether the treatment will boost her body, and the clinician confirmed that it will boost her immune system. The clinician wanted to know whether Mary would be able to take treatment regularly, she had disclosed her status to anyone else, she was contraception, and she accepted her status. She confirmed that she knew how to take treatment.
Effort and Responsiveness	"There used to be a woman who would personally follow up missing results of blood tests. Now clinicians cannot answer my questions when results are missing."
Patient-to-patient socialization	One participant failed to understand reasons for blood collection. He asked other clients in the clinic about why clinicians are collecting blood, and they all responded that it was to 'check the blood'. He was satisfied that 'if it is done to everyone, then it must be the norm'.

increasing plural health care usage. Inadequate or lack of relevant information limited users' ability to maximise use of HIV services. A much higher proportion of urban users (87.7%) were able to state their most recent CD4 count, as opposed to only 56.0% of rural users. While this may be explained by lower literacy levels among rural participants, retention of such essential information may be impaired by inadequate provision.

Uncoordinated clinic procedures and processes were also found to be a hindrance, along with constraints in infrastructure. Apparent shortage, absenteeism and late-arrival were repeatedly linked to doctors and pharmacists, resulting in long waiting periods and poor coordination of clinic queues. Several variables related to the quality of care experienced by participants in the ART clinic showed association with use of plural healthcare. Perceived lack of privacy in the ART consultation rooms and disrespect by ART providers was associated with plural healthcare use, whereas participants who encountered language barriers with ART providers had 43% reduced usage of plural healthcare as opposed to those who did not. Participants who on any previous occasion had to leave the ART clinic without receiving help were 2.7 times more likely to use additional providers. Participants who preferred to be seen by a nurse provider on their regular clinic visit were less likely to engage in self-care pluralism, as opposed to those who preferred a doctor.

Breaking down barriers to care- and treatment-seeking in ART clinics

Efforts to overcome access barriers were observed at both patient and health system levels. Papers III and V are used here to demonstrate various efforts undertaken to reduce access barriers, as well as existing gaps that may serve to provide lessons, direction and possible avenues for future improvements of access to ART care without compromising other essential elements of health care and livelihoods of users.

Patient tactics to overcome barriers to ART care

In light of barriers to care, some patients devised means to circumvent barriers in the ART clinic, highlighted in Table 6. For example, it was not uncommon for users to purposefully avoid a consultation room known to be occupied by a 'rude clinician'. Furthermore, users would often tap into their own personal resources in order to close the gap between services expected and those actually provided. When Mkhonto, also presented in paper V, realised that clinicians were not able to recognise his previously prescribed medication, he called his wife at home to help identify the names of the pills. If this user had not been so resourceful and creative in acquiring his medication, very likely the supply-side may have failed him. However, some users were not able to archive a similar level of resourcefulness. A degree of helplessness or disempowerment may be detected from a perception that, "It might not be good to ask questions of clinicians, as it might appear as though you are telling them how to do their jobs.", or perhaps based on trust as Songeni said, "…clinicians know what they are doing".

The users' ability to source ways of overcoming barriers in the health system was observed beyond the HIV clinic, as demonstrated by the encounter Thomas had with the security guards at the entrance to the hospital. Thomas found that the need to display consultation cards at the gate ran the risk of being identified as HIV-infected by the security personnel, and as a result, he hid his HIV clinic card and displayed an out-patient one. His efforts to conceal a potentially stigmatising card may have reduced the potential for security personnel to 'spread rumours' about him back in the community.

At the community-level, users encounter and have to overcome several barriers before arriving at the health facility. The most prominent is the cost of transport. In paper V, we demonstrate that two

Table 6: HIV/AIDS patients' strategies to overcome health system barriers

Employed Strategies	
Telling Lies	The traditional healer that he was consulting did not want him to get an HIV test, so he lied he was going to have a tooth removed, but instead went to attend voluntary counseling and testing for HIV.
Generating Capital	Marumbu had difficulties getting to the HIV clinic. He normally sold spinach to collect money for transport, but sometimes he borrowed money.
'Beating' the queue	Some experienced patients contrived by using non-authentic clinic attendance numbers and lies to get ahead in the queue so as to finish early, while others employed genuine measures such as Memory's usual early arrival at the clinic by 5am.
Concealment of records	Thomas had to present clinic identification at the main entrance, but this was problematic because the HIV clinic patient-carried cards are green, so the security guards would know that he was going to the HIV clinic. Instead, he showed his white out-patient department card to avoid being stigmatized by the health system.
Resourcefulness	"They had no recollection of pills I got previously for my leg pains, and did not even look up my previous prescriptions. I had to call my wife."
Exonerating rude behavior	"There are some administration people who yell at patients when sitting in wrong places. It is obvious that people like [named administrator] get tired and irritable."
Avoiding confrontation	"It might not be good to ask questions of the clinicians, because I might appear like I was telling them how to do their jobs."

users having to pay the same amount of money to get to the health facility may cope differently with the costs needed. Susan failed to attend her clinic visits, but although Thembi did not have the money either, she was able to raise the necessary transport cost in time for her next visit. Marumbu had to sell spinach or borrow money so that he can be able to pay for transport. Other barriers

included those caused by difficult employers or other authorities such as traditional healers. In all these cases, users found ways to overcome their hurdles so that they can eventually receive the HIV care the needed. However, some users found solutions to barriers to be beyond their control, and have had to either abandon their jobs completely or relocate to villages nearest to HIV service points where they were able to receive care.

Health system level interventions to ART care barriers

In addition to the agency shown by the demand-side, users in this study were able to reveal the capacity of the providers to reduce barriers to HIV care amidst all the difficulties. According to Mkhonto, “There used to be a woman (nurse clinician) who would personally follow-up missing results of blood tests. Now clinicians don’t know anything and cannot answer my questions when results are missing”.

Users and providers in the HIV clinic form relationships and partnerships, as demonstrated elsewhere (54, 98), such as shown in the example of Thomas who was requested by a provider to sell Mopani worms in the support groups, but also to trace patients in the community when lost to follow up from the HIV clinic. These partnerships carry the potential to influence the therapeutic alliance and possibly minimise barriers to access.

In recognition of the limitations caused by long distances between users’ residences and the location of the HIV service point, the down-referral strategy is implemented with the intention of moving ART-using patients to facilities closer to their homes. In paper III, we demonstrate how this strategy successfully improved dimensions of access ART care in rural South Africa, as shown in Figure 7. However, these ART care-related access improvements were threatened by plural health care system utilisation behaviour among down-referred users, resulting in excessive costs on health care. Relative to hospital-based users, those down-referred had fewer access barriers to their ART care, as

demonstrated by lower levels of expenditure on meals and transport, and 75% reduced perceived stigma when receiving their ART in a primary care-setting. Levels of adherence to ART were also higher among the down-referred.

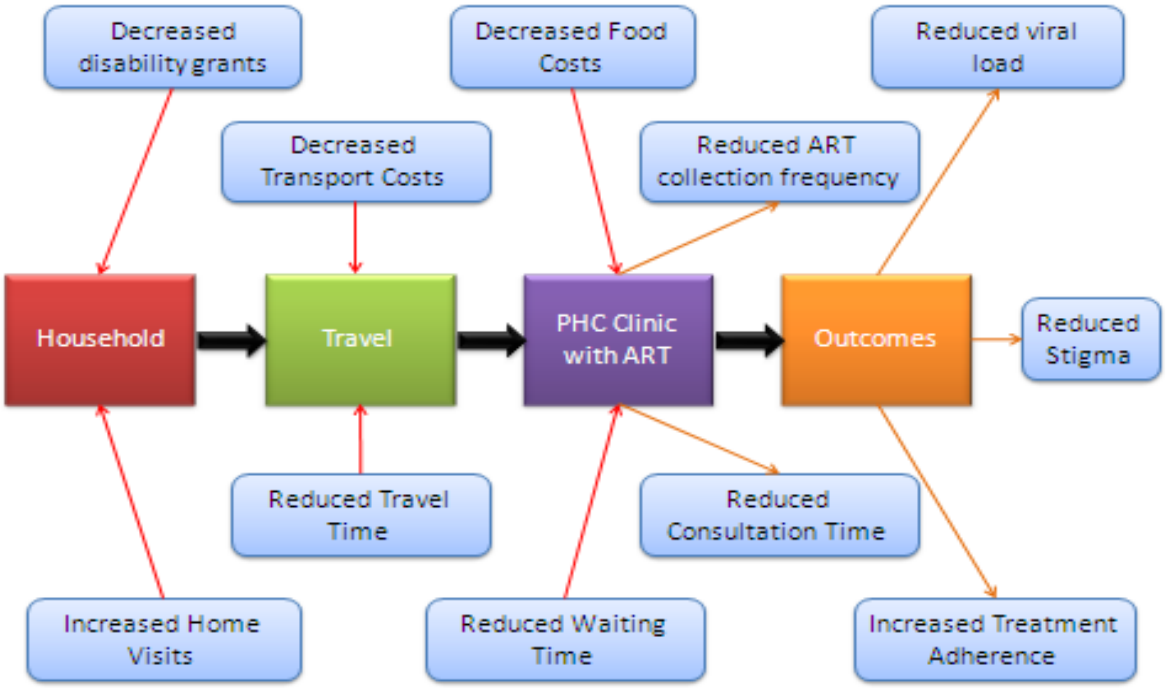


Figure 7: Schematic representation of gains associated with down-referral for ART care services

There was, however, increased utilisation of private doctors and self-care practices by the down-referred in comparison to hospital-based users. The costs incurred from the complementary use of private doctors and self-care practices, as shown in Figure 7, resulted in much higher rates of catastrophic health care expenditure, 15% of total household expenditure, among down-referred users. The increased use of private doctors occurs in the context of a predominantly nurse-driven PHC clinic system and parallel concerns regarding the quality of care rendered. There was an overwhelming preference by down-referred users to travel further to be seen by a doctor rather than consult a nurse clinician nearby when compared with hospital-based users. Furthermore, those

who were down-referred also had poorer knowledge of their most recent CD4 count and their education level was also lower.

Discussion

This doctoral research draws from the perspectives and experiences of HIV infected patients regarding their care-seeking behaviours with the intent of generating lessons to improve care and support interventions. In the context of the pressing needs of HIV positive patients in high prevalence settings, the goals are to increase testing, treatment uptake and reduce patient attrition. However, in the context of a country in rapid transition, the wider goal is to examine ways through which these perspectives might improve health systems more broadly.

We argue in this thesis that, in order to improve uptake of ART and patient retention, efforts to shape utilisation behaviour are necessary. In addition, just as behaviour relating to ART adherence and ART clinic attendance is measured, plural health care utilisation behaviour among patients seeking and using ART should be measured. Plural utilisation of health care is a cross-cutting theme throughout this thesis. On the one hand, the pluralistic use of health care is determined by the quality of HIV and ART services and patients' ability to pay for additional health care. On the other hand, the predominant consequence of plural health care utilisation is catastrophic expenditure on health care.

Therefore, this thesis notes that while plural options and their usage may provide alternative channels from poor quality HIV services for patients who may seemingly afford financially, the result may be excessive health costs that may threaten risk protection by depleting resources and livelihoods of individuals and their households. The thesis also notes that some of the negative consequences of pluralism may be minimised in two ways. First, proactive, evidence-based and patient-informed efforts to improve the quality of health care in the ART clinics may reduce the degree of 'push' factors. A lot less palatable to confront is options to deal with 'pull' factors towards

plural options, particularly with regards to African traditional medicine and healer use. More integrated care may offer a viable solution. Second, promotion of patient agency and self-sufficiency may serve to reduce the negative impact of barriers to ART care. Thus, synthesis of this triangulated research aimed at understanding both the patterns and the drivers of health system utilisation among HIV/AIDS patients is summed up in five distinct but interrelated themes, each one presented in some detail below.

- HIV/AIDS care and plural health care utilisation behaviour
- Catastrophic health care expenditure and the quest for ART
- The poor quality of care in HIV/AIDS and ART services
- Improving the service delivery capacity of HIV/AIDS and ART clinics
- The promise offered by resourcefulness among service users

Pathways of people with HIV/AIDS seeking health care in the era of ART

In eliciting pathways followed by patients seeking HIV-related health care, multiple sources of health care were identified, which were used either singularly or in pluralistic patterns. When plural health care utilisation patterns were followed, self-treatment practices were observed, as well as 'shopping' and switching of providers. Movements of patients between multiple health providers could be classified into sequential or concurrent. In addition, plural utilisation patterns were associated with delayed arrival at the point of definitive HIV/AIDS-related health care.

'Provider-Shopping'

One fifth of respondents reported use of additional health care providers over and above their regular ART visits in the prior month. There was a wide range of providers available to people with HIV/AIDS, which diversifies our understanding of a health care system. Currently, a health system is

only understood to consist of the formal system of health care, which is made up of the public and the private sectors (10). This policy perspective is reinforced by the current medical training, as well as medical and other health professional bodies and institutions nationally and internationally (3). However, the recognition of the informal health care system utilisation by patients in general is not new, and has been recognised for the past 30 to 40 years more by scholars in anthropology (64, 78), than by the wider medical fraternity for what appears to be reasons of power and control (3). Regardless, the persistent use of traditional health care in the developing world and the growing use of complementary and alternative medicines in the developed countries have both stimulated growing openness to practices of healing beyond formal Western Medicine, and the possibility of recognising non-formal health care systems (99).

With respect to HIV-related care, failure to achieve universal coverage (25), challenges in retaining patients in care (45, 50), and ultimately, acknowledgement of HIV as a social phenomenon (100), have all led to renewed interest in the notion of health care systems, and the role of non-formal sectors in particular. Previous research in sub-Saharan have shown that HIV-infected patients look to traditional healers for health care (82). However, surveys of patients using ART care demonstrated very low levels of traditional medicine use or complementary and alternative medicine (92, 93). In this study, we add to this body of knowledge by charting pathways followed by HIV/AIDS patients, revealing the vivid involvement of multiple providers over time and changing patterns before and after the introduction of ART as presented in Paper I. In addition, we demonstrate how these patients switch between providers, a notion that has been introduced by Nyamongo among Malaria patients (85). However, shopping has also been shown among other chronically-ill patients such as those with diabetes mellitus (80), psychiatric disorders (101) and tuberculosis (102) within sub-Saharan Africa. Notably, the pathways of health care differ between patients attending the same HIV

clinic, and in addition, the patterns of using health care sources may change over time in the same person visiting an HIV clinic.

Self-Treatment

Among persons attending an HIV clinic and using ART, 14.5% had purchased substances and products for purposes of health care within 4 weeks of their clinic visit. Paper II introduces the concept of self- treatment as represented by purchased products, and does not account for non-purchased but used products, such as self-made home remedies, which have been shown to be common in the context of self-treatment (81, 103). Nevertheless, self-treatment forms a considerable part of health care among ART-using patients, particularly rural residents. Future research may need to distinguish between self-treating products supplied by recognizable health providers and non-health providers, those received from formal or non-formal providers, and those purchased or self-made. Most importantly, self-administration of health care products supplied by other providers should be distinguished from self-treatment, as we did in Paper I.

According to Kleinman, self-treatment in the context of the popular sector can be facilitated by the index patient, family members, friends or other members of the social network (64). This so-called popular sector constitutes an important part of social support, and thus contributes immensely to social influence with regards to health care (94). Treatment supporters, used to increase ART adherence among patients and thus often educated with regards to treatment use and requirements (5), were found to be associated with increased plural use of health care by fold. The promotion of plural utilisation patterns by the social network suggests that plural health care utilisation by people with HIV may be perceived to be beneficial for the patient within the popular sector. Therefore, future interventions to manage plural health care utilisation behaviours will need to involve the social network of patients, particularly treatment supporters.

Treatment Delay

A third of patients presented for care after one month of experiencing symptoms, and late testing for HIV as well ART initiation were not uncommon. Delays occurred at the different milestones faced by HIV/AIDS patients with regards to care-seeking behaviour and the pathways of care. The late presentation for HIV care (36), care which should be initiated prior to the onset of AIDS-related illness and opportunistic diseases, is indicated by the predominant role of illness as a trigger for the initial use of health care in this study. However, when a broad definition a health care system that is inclusive of both formal and non-formal sectors is adopted, then only one-third of patients could be considered late presenters after onset of symptoms.

However, HIV testing was delayed in the majority of patients, implying the failure in the broader health system to detect HIV early. This is also confirmed by the pathways of care shown in Figure 5, wherein Mabuti refuses an HIV test, drops the formal sector, and enters the non-formal services, only to be tested 4 years after the onset of his symptoms. Social influence was also found to play an important role in Paper I as a trigger to milestones in the utilisation of health care among patients with HIV/AIDS. One may therefore argue that cooperation in detecting HIV between formal and non-formal sectors may have assisted Mabuti to a test much earlier. This integration of formal and non-formal health care systems remains a thorny challenge for South Africa and many parts of sub-Saharan Africa.

However, integrated care (104) will have to be achieved if increased uptake of HIV services is promoted with the aim of serving the best interest of the patient rather than perpetuate the political and historic dogma surrounding the domination of the formal sector. In this study, the private sector in rural areas did not fare well in terms of HIV care when compared with the

traditional healers and the public sector. The central role of the public sector, the primary health care level in particular, is demonstrated in paper I. Therefore, improving the detection capacity of HIV in the health care system with relevance to rural people will involve the following; first, the competition existing between formal (and between public and private) and non-formal systems will have to be confronted, second, effective cooperation of the traditional sector as well as the private sector will have to be sought, and lastly, patient-centred referral systems between all these sectors will have to be established. In addition, education, involvement and cooperation of the social networks for the patient will have to be sought in a proactive manner. All these can largely be achieved if the patient's interests are put first before all others with the aim of achieving the best health outcomes for the index patient (105).

Catastrophic health care expenditure and the quest for ART

The quest for therapy, as was put by Janzen (78), can be a difficult experience not only for the patients, but also their households. Oftentimes, health outcomes following therapy are measured in terms of improvement in the perceived symptoms and laboratory-based technological indices. However, as already established in previous studies of help-seeking behaviour, health care occurs in the context of the patient's home, work, and other meaningful social networks (94). In this study we identified perhaps the most important reason for health providers and policies to focus in the first instance on the needs and best interests of the patient (and their households) rather than a predominant pursuit of the health care delivery agenda. Presented in papers II and III, people living with HIV and using ART were found to incur excessive amounts of health care-related costs while seeking care from additional sources of health care. These costs were found to constitute large proportions of total household expenditures, over 15%, regarded as catastrophic (106), for many of the patients. These excessive costs were seen even after patients were down-referred to primary health care clinics closest to their homes.

In paper V, it was established that the expectation of having their hunger and poverty relieved form an important part of patient's care-seeking behaviour at an HIV clinic in rural South Africa. Paying for additional health care impacted negatively on rural users more than urban users, and rural HIV/AIDS patients are therefore particularly vulnerable to catastrophic health care expenditure, as shown in paper II. In line with the principle of vertical equity, the poorer one is, the more severe is the 'hurt' of out-of-pocket payments (107). Therefore, risk protection, at both individual and household levels, should form an important measure of health outcome among people living chronically with HIV and seeking or receiving ART. Failing which, efforts to improve health outcomes with ART may be defeated by the perpetuation of poverty and hunger, which are well-known risk factors for both disease and failure to use health care (108). Additionally, crippling health care expenditure is currently the worst outcome associated with plural health care utilisation among HIV/AIDS and ART-using patients, as identified in both papers II and III. This negative outcome occurs in the context of free or low-cost public sector services, as well as prohibitive user fees in the private sector and some non-formal services such as the traditional sector.

Based on the findings of this research, excessive costs may be the main reason, in addition to delayed definitive care, to label plural health care utilisation as a negative or unwanted pattern of care-seeking behaviour among people living with HIV. However, the existence of plural usage in itself, the willingness among patients to incur these costs, as well as their determination to incur the costs, as implied by their efforts to incur costs despite perceived difficulty to raise the money, including having to borrow from within their social networks, all suggest that the motivation to use plural providers and sources may be high. Therefore, attempting to stop patients from plural practices may be a futile exercise. However, embracing pull factors and minimising push factors that lead patients to plural health care use may serve the much-needed purpose of protecting them from

catastrophic health care expenditures and thus, reducing risk to and protecting livelihoods of people living with HIV/AIDS and using ART as well as their households (75, 77).

The poor quality of care in HIV/AIDS and ART services

A recent review of qualitative studies (98), as this study also points out, suggested that poor quality of care in the HIV clinic may explain the high rates of poor patient retention, including public-sector ART clinics in South Africa where supply-chain problems have been seen (109). This thesis is not looking to suggest that the quality of care in the HIV clinic is worse or better off than other parts of the public-sector health care facilities and institutions, as this was not the scope of the study. In paper II and III, we highlight the role of poor quality of care in the HIV clinic as perceived by people already using ART, acting as negative experiences that contribute to 'push' factors driving the high rates of plural health care utilisation. For example, when clinicians in the ART clinic were perceived to lack respect for patients, the use of multiple providers and self-care practices tended to rise. In addition to respect, leaving without receiving the needed help and perceived lack of privacy in the consultation rooms were also found to explain plural health care utilisation patterns. Therefore, poor quality of care experienced by patients in the ART clinic is associated with concurrent use of multiple providers and self-treatment practices among these patients.

The notion of respect towards patients as exhibited by providers was found to be more important among rural than urban patients in paper IV. This may be because rural people have a higher expectation of respect within the context of local cultural norms than their urban counterparts. Perhaps providers in rural ART clinics tend to be a lot less respectful than in urban ART clinics. Alternatively, urban dwellers may be either more tolerant or able to cope better with disrespect. Regardless, it remains clear that perceived respect is an important variable making up the construct of quality in the ART clinic. Other studies have also found respect to be important when related to

patient satisfaction in the HIV clinic (95). In addition, perceived respect is said to have implications for trust between patients and providers, and therefore the therapeutic alliance, particularly in cases of chronic illness care (1, 77). Furthermore, respect for privacy is an important indicator of respect for human dignity. Promoting such practices of humane care will likely increase retention of patients in care, and minimise attrition or use of additional providers.

Paper V goes further in an attempt to closely examine the experiences of rural patients in the HIV clinic with relevance to access barriers and facilitators. Rude behaviour exhibited by different members of staff in the ART clinic stands out as a barrier to care. Although other ART clinic based studies have not shown this problem, studies on other chronic illnesses have previously reported rude provider behaviour as an important barrier to care (110). In fact, rude staff behaviour has been reported to reduce trust between patients and their providers (1). In paper III, it was shown that patients down-referred from hospitals to primary health care clinics, found the quality of care, humane care in particular, to be more acceptable compared to hospital-based patients. While hospitals are centralised institutions far removed from the communities, PHC clinics are often nested within communities, and this may explain the perceived greater effort at PHC level to offer better humane care. Furthermore, patients are able to appreciate circumstances in which providers make additional efforts to assist with care-related matters. The next section discusses in some detail ways in which the supply-side can increase utilisation by proactively minimising barriers.

Improving the service delivery capacity of HIV/AIDS and ART clinics

In paper V, patients' experiences demonstrate that ART clinics have the capacity to increase the standard of service rendered to patients to acceptable levels. Providers in the ART clinic were able to accommodate extenuating circumstances necessitating special kinds of responsiveness, and thereby delivering a form of personalised care. Patients were able to recognise when providers make extra

effort to find their laboratory results for example, suggesting that patients place providers under some form of evaluation or scrutiny based on their previous experiences and expectations. Based on our findings, the capacity to provide targeted care tailored to patients' needs exists.

Health providers have to take responsibility for tailored care to be realised, which will certainly amount to patient-centred care and lead to responsiveness in the health service (111). The question then is: how should this be achieved? Measuring and ensuring humane care and added effort on the part of providers, is best ensured by the patients themselves (112). For this to happen, conditions have to be created for patients to inform policies needing redress, and for implementation to occur without consequences for the patients. Health providers will have to shed some power over to promote patient empowerment (113), and allow for open communication and information-sharing, participatory decision-making and appropriate forums for patients to provide feedback on their service delivery experiences (68). In addition and contrary to common understanding, health providers have to make a commitment to human development as a whole, recognising that assisting patients to overcome social factors that may hinder chronic health care or aggravate chronic illness is not an inconvenience but a part of their central responsibility (114).

The promise offered by resourcefulness among service users

While the balance of power may be unequal, a lesson in this study is that empowered patients are able to negotiate the system so as to get the best care that can be delivered. Self-efficacy, defined as the individual's ability to influence their environment (115), has been shown to increase adherence to ART treatment (116). The observation that some patients are able to manoeuvre through the ART clinic in order to overcome access barriers means that there is room to promote this patient-driven behaviour, which can ultimately improve access even in cases where health system factors are not modified (117). Therefore, self-sufficiency or patient agency may contribute a great deal in holding

the health service delivery system of care accountable to patients (117). However, as shown in papers III and V, an increase in knowledge will be an essential ingredient for patient empowerment. This knowledge will have to be enhanced by the health providers themselves, or else through change agents or patient advocates (118).

Structural interventions may be necessary to promote formal education known to be associated with HIV infection (119). Formal education has been previously, and in this study, shown to be correlated to patients' knowledge regarding their health, illness and care (120). In addition, since resourcefulness shown by patients in attempting to overcome barriers may require for them to tap into their own personal resources, this means patients may need to have some economic resilience through better ability to pay for health care (54). This may also allow them to use alternative resources when barriers are not able to be overcome. However, as shown previously, this may deplete patients' personal resources. For patients who are already vulnerable financially, as most rural patients in this study were already victims of extreme poverty, they may be driven further into a downward spiral of poverty and destitution. While patients may also mobilise their social support and networks in cases of illness and care, chronic illness such as seen with HIV may stretch these resources (54). Furthermore, stigma when prevalent and still is, may hinder patients' success in mobilising social capital (56). In advocating for patient agency and empowerment, it will be necessary to guard against burdening of patients through a shift of responsibility from health care systems to patients, as well as negative impacts on the livelihoods of their households. However, it remains clear that the successful utilisation of health care for patients seeking and using ART will not only depend on efforts made from the supply-side only, but also the resourcefulness shown by the users.

Limitations

The research presented here uses experiences of service users, often viewed as successful users. Understandably, essential lessons can be learned from people who are unable to access health care, including reasons for their failed access such as poor referral systems (38). Patients needing ART but having failed to access care would have been an important study population, and knowing their reasons for not using care would be valuable for designing interventions to improve initial uptake of ART. However, the stigma surrounding HIV would render any attempt at active case-finding somewhat unethical and logistically challenging. Furthermore, such cases do not provide any insight into the ways through which patients overcome access barriers (117). In addition, as was apparent in the research, existing barriers among successful users may continue to threaten access to care that is chronic in nature, and could potentially lead to drop out from care in future (38).

Furthermore, this dissertation uses plural health care in a particular way, focusing on it as a single phenomenon of health care use, and not disaggregating by formal and non-formal health care providers. This approach may mask factors associated with each one of the provider types. However, the investigation was about the concept of plural health care as defined from a patient perspective in a particular context where the reality of use is complex and fluid, and where the distinctions between forms and providers are not that clear cut. These results may not be generalizable to contexts where patterns of pluralism differ from those observed in the context of this study. In addition, this study does not segregate participants according to their reasons for using specific providers. A value-based system may have been employed to judge whether visits to providers were warranted, justified or beneficial. However, this was not the question the study sought to address. An assumption was made that, through the eyes of a patient any visit undertook is warranted and justified, and their perceptions of service utilisation were sought as part of study questions. Future

studies may address the above issues, and perhaps also employ longitudinal study designs, to reduce the limitations of cross-sectional quantitative design.

Longitudinal designs, such as cohorts, may also help integrate questions related clinical or psychosocial factors and health systems or access factors. This study could have provided further exposition of access by mapping out relationships between clinical and access factors. Therefore, not all individual factors likely to influence access and utilisation of health care were addressed in this piece of research. Likewise, not all health systems factors were included in the covariates studied in this work. For example, health system frameworks may include financing, governance, supply-chain and health information systems that may certainly influence access directly or indirectly. However, not all these factors were adequately addressed. Therefore, future research has a long way to go in deducing factors likely to reduce access among ART patients and the chronically-ill in general, and proposing complete frameworks and packages of intervention informed by rigorous research.

Conclusions

In summary, this doctoral research puts forth a number of points regarding the structure of the health systems and movements within it:

- A health system is made up of a multiplicity of formal and non-formal services and providers (public, private, community, lay and self-care), and thus a plural health care context
- Movements of patients connect the different forms of health care and their providers (self-determined or formally/informally referred)
- The order of relative importance, as opposed to size of individual components of plural health care systems or services changes depending on the experiences and perceptions of patients
- Patient perception of or experience with one form or sector of care or provider influences future use of that provider (pull or push)
- Patient perception of or experience with one provider or form or sector of care influences how other providers or forms of care are used or avoided (push or pull)

We can further conclude that ART usage in a plural health care context has several determinants:

- Patients located in rural areas suffer most from socioeconomic inequities and the burden of paying for health care compared to their urban counterparts
- Patients' ability to pay, their perceptions of quality of care and available social networks affect their utilisation behaviour of health services
- Referral of patients to their local clinics, and decentralised models of ART care, results in improved access and should be promoted in rural areas particularly.

Finally, we suggest that ART usage in a plural health care context carries several implications:

- Limited financial resilience results in the need to borrow money to finance health care, particularly among rural patients
- Catastrophic health care expenditures, affecting largely rural residents, may result in reduced livelihoods and financial risk for patients and their households.

Utilisation behaviour research intended to improve the quality of health care and outcomes, should recognise the care sources and pathways followed by patients, and begin to identify determinants and consequences thereof, so that interventions can be designed that are appropriate and relevant to the particular users. The patient perspective adopted in this study was instrumental in revealing the limitations of a hierarchical or simplistic view of health systems, and instead suggests a complex 'maze-like' structure of plural health system utilisation. Particular movements and pathways displayed by patients in their shopping and switching practices deserve more attention, and perhaps responsiveness on the side of the health providers, program implementers and policy-makers. This is not to imply that different parts of a health system, be it sectors, levels, facilities or providers, perform equally (whether from an objective or subjective point of view), but rather the value of understanding the organic pathways and general patterns created by users as they move through various parts of the health system. The observation in this study that patients can draw on their own resources to overcome health system barriers is essential to note for the future design of health care services, particularly in strengthening the role of the demand-side. In addition, it is encouraging to observe that health providers, when efforts are made, can reduce or minimise barriers experienced by patients. One can draw on these latter two observations to enhance a process of health system strengthening for patients seeking and using ART services, particularly in rural settings. In dealing with access factors and utilisation behaviour geared at improvement of uptake of and retention in ART services, the fundamental differences between provider and patient roles have to be acknowledged, and a shift be adopted to recognise the contribution of both actors in the interaction

of the supply and demand sides. Thus, the complexities, determinants and consequences that come with availability and utilisation of multiple sources of health care by ART seekers and users, or plural health care utilisation, form an integral part of a health system according to this research study.

Recommendations

The results and conclusions of this study suggest a need for a shift in the paradigm of health systems through which chronic diseases, such as HIV/AIDS, are managed for people in rural South Africa, and perhaps much of sub-Saharan Africa. For a setting like Bushbuckridge, the following are recommendations to optimise the delivery of such health services:

- An inclusive patient view of health care services, limited in its discrimination between formal and non-formal sectors, suggests a need for a firm recognition of a plural health care context within which illness and health care occurs among rural, and to some degree urban patients.
- Extension of the health system for chronic care to include non-formal services will necessitate regulatory systems, such as already proposed by the Government in South Africa in an attempt to formalise traditional healers as recognised health providers and well-integrated into the health system.
- The benefit to such integration in health care services will likely improve access to health care by bringing about better coordination of patient movement and referrals, and thereby promoting earlier access to appropriate health care and consistency in health messaging across sectors and providers.
- The costs of the private sector, traditional healers and self-care practices are high. Risk protection mechanisms to offset costs are needed, specifically targeted at rural patients also likely to be poor. These may involve efforts to eliminate extreme poverty and promote income generation for them to afford health care, or provision of cross-subsidies to reduce the costs of health care such as the National Health Insurance currently under development in South Africa.
- Since not all patients engage in plural health care practices at any given moment, and still recognizing that this is a transient situation that may change over time, it seems necessary

to include in all patient assessment an indicator measuring the use of additional health care just as much as treatment adherence is measured. Failing to do so, the health system will expose rural patients to catastrophic health expenditures.

- The evidence of tangible benefits emerging from this study supports the decentralisation of services to the margins of the health system through primary health care facilities. However, packages and quality level of health care have to be maintained or improved to minimise need for additional health care or attrition.
- Providers within the health system can minimise 'shopping' and 'switching' patient behaviours by providing high quality services that offer humane and effective care, as well as personalised care accommodating the unique circumstances of patients. This level of cooperation between patients and providers, also referred to as patient-centred care, is essential for successful patient retention.
- Mechanisms are needed from both patient and health system perspectives to cultivate or enhance patient self-efficacy or agency. Empowerment of patients with knowledge and freedom to make decisions in an adaptive and a supportive environment that promotes self-efficacy will very likely strengthen utilisation of chronic health care services.
- Social support benefits rural HIV patients seeking and using ART care in a number of ways. Interventions promoting social bonding and bridging may result in increased social capital, and therefore maximise patients' benefit from social support and networking systems.
- Structural interventions to reduce urban-rural inequities can also serve to increase access to health care in places like Bushbuckridge. These may include promotion of formal education, creation of job opportunities for rural and remote areas, and social security. Efficient and perhaps subsidised transport systems for chronic patients may also be of benefit.

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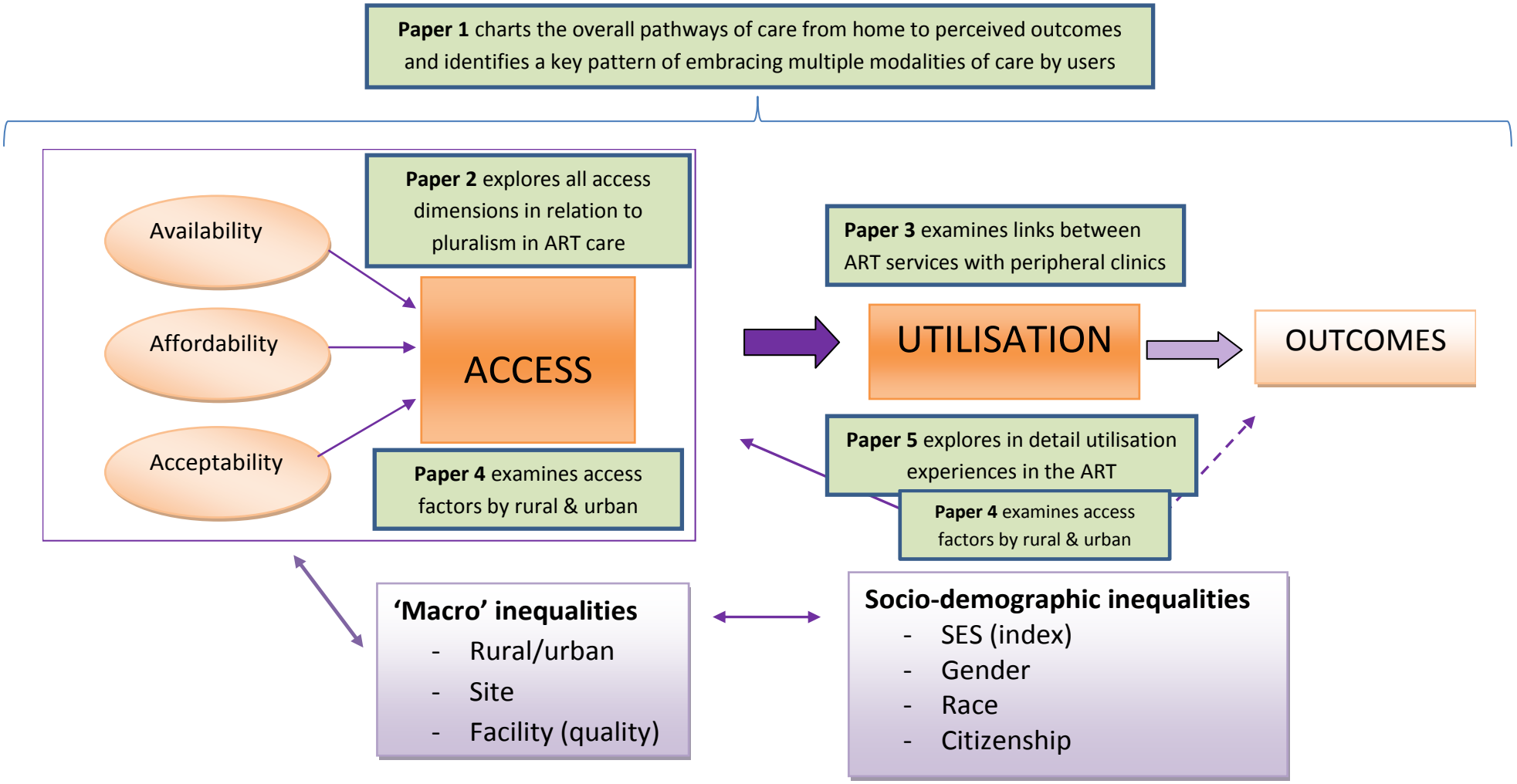
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Appendix 1: A descriptive depiction of study rationale and analysis plan, supplement to Figure 1.



Appendix 2: Synthesizing framework for research results of all scientific papers

