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Access barriers to antiretroviral therapy (ART) in Zimbabwe, a case study of Chivhu Hospital.

A Mini-dissertation submitted to the University of Cape Town in line with the degree requirement of the Master of Public Health (MPH) specializing in Health Economics.

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Part 0: Preamble

Dedication

To the Almighty God for strength and grace, the loving memory of my dad and to my family, friends and mentors.

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Plagiarism Declaration

1. I know that plagiarism is wrong. Plagiarism is using another's work and pretend that it is one's own.
2. I have used the Havard style as the convention for citation and referencing for the protocol, literature review and the policy brief and the biomed central style for the journal manuscript. Each significant contribution to, and quotation in, this mini-dissertation from the work, or works of other people has been attributed and has been cited and referenced.
3. This mini-dissertation is my own work.
4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

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Thesis Abstract

Access to healthcare is one of the basic social goods which ensures that individuals lead healthy and long lives. There is an increased need towards ensuring access to health care for all, which has led to the question of how access is defined.

Access in this study is defined as the degree of fit between the health care system and patients. It involves an interaction between the system and patients in a way which removes access barriers to care. A comprehensive framework was used to measure access in this study. The framework allows for a systematic approach to the concept of access and measures access in three dimensions namely affordability, availability and acceptability. Using this framework, the study looked into the factors affecting access to antiretroviral therapy (ART) by patients at Chivhu Hospital in Zimbabwe. Chivhu was chosen because it has a mixed population of urban and rural patients which represents the typical Zimbabwean population. A cross sectional study design was adopted for this study.

Study findings revealed that the main barriers to access were financial barriers in the form of user fees and transport costs, as well as shortages of staff which result in long queues to see the doctor and increases the time spent by patients at the facility. Poor cleanliness of the facility was cited by users to be another deterrent for service use. It is hoped that the study results will guide in decision making and implementation of policies aimed at ensuring equal access to ART for all in need regardless of an individual's socio-economic status by removing the various access barriers faced by patients in seeking care.

Acknowledgements

I am grateful to God who has afforded me this opportunity and would like to thank every individual and institution who made this thesis a success. I would like to thank the Health Economics Unit and SIDA for funding my studies, the staff at Chivhu Hospital for being quite accommodative and understanding during the course of the study and most of all, my supervisor, A/Prof Susan Cleary for her guidance, patience and support. Many thanks also go to my family for their support and encouragement.

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Part A: Study Protocol

Synopsis

Purpose of the study

The purpose of this study is to perform an empirical investigation into the barriers associated with the use of antiretroviral treatment (ART) services in Zimbabwe using patients on ART in Chivhu as a case study. The study will look into the effects of socio-economic status on access and ascertain if different socio-economic groups face different access barriers. Access in this study was defined as the degree of fit between the health care system and patients. This fit will be measured along three dimensions namely acceptability (the fit between provider beliefs and attitudes and patient beliefs and attitudes), availability (the fit between the amount and quality of services provided and patient needs) and affordability (the fit between the full costs of care and patients' ability to pay) (McIntyre 2009).

Aim of the study

To explore the factors which affect access to ART in HIV positive patients who are using ART.

Objectives of the study

- To determine the access barriers or facilitators of the continued use of ART services and adherence to ARV medication by people on ART at Chivhu Hospital.
- To investigate the demographic and socio-economic correlates of differential access, and adherence to ART services.

Study Site

The study was carried out at Chivhu Hospital, which is located in the Mashonaland East province of Zimbabwe. Chivhu is the second largest town in the province and it was chosen for the study because it serves a population of mixed characteristics, that is, both urban and rural dwellers.

Study Design

Access was investigated through the use of an investigator-administered questionnaire. The questionnaire contained questions designed to collect demographic and socio-economic details from patients as well as questions about the "access" factors affecting continued adherence to ART. Exit interviews were conducted with patients as they came for their routine check-up visits or to collect medication. The sample size was 214 and written or verbal informed consent was sought before conducting the interview and participants were free to withdraw from the study if they were not

comfortable. The ethical practices of the study were guided by the Helsinki Declaration and permission to conduct the study was sought from the Hospital management, following ethical approval from the University of Cape Town Research Ethics Committee.

Study Population

The study focused on the users of ART services who had been on ART for more than 3 months. This is for two reasons. First, the initial period on ART is frequently characterised by higher morbidity and adverse events from medication. While patient coping strategies during this period are important, this research focuses on the barriers or enablers to on-going access to lifelong ART. For this reason, the focus is on patients that have had at least some experience on ART. However, limiting the sample to those who have been on treatment for more than a year, for example, would make the process of patient recruitment for interviews far more time consuming than can be accommodated by a master's level research project. A cut off of 3 months was therefore chosen to balance these considerations. In addition, patients were excluded if they were under 18 years of age given that interviewing minors imposes additional ethical implications.

- Inclusion criteria – Patients who have been on ART for at least 3 months and are judged sufficiently well by clinical staff to be interviewed.
- Exclusion criteria – Patients who do not consent; patients who have been on ART for less than 3 months; patients under 18 years of age.

Study Benefits

Participation in the study had no immediate benefits. However the results of the study will provide health managers and policy makers with information about how services can be aligned to meet the needs of the patients.

Study Protocol

Introduction

Zimbabwe's life expectancy at birth currently stands at 43, down from 62 in 1990, mainly due to the effects of HIV/AIDS (USAID 2010). The prevalence of HIV/AIDS has been reduced by implementation of widespread HIV campaigns which encouraged behavioural change, coupled with an active prevention of mother to child transmission program and a widespread roll out of antiretroviral therapy. The National Aids Council reported in 2010 that 56% of patients in need of ART were receiving it (UNAIDS website 2010, Avert website).

ART is the pharmacological management of HIV infection through the provision of antiretroviral drugs. The primary intent of ART is to prevent progression of AIDS. On initiation of ART, patients are given a combination of three first-line antiretrovirals drugs. In the event that there is drug resistance or adverse effects to the first line of drugs, a second line of drugs is initiated. ART in Zimbabwe includes both first and second line drugs. There is also third line antiretroviral therapy which has not yet been adopted by the public sector in Zimbabwe (WHO 2010).

Since the declaration of HIV/AIDS as a national emergency by the government in 2002, much emphasis has been placed on procurement and distribution of ARVs. As a result, the numbers of those on ART are increasing but more work should be done to ensure that patients are retained in ART programs.

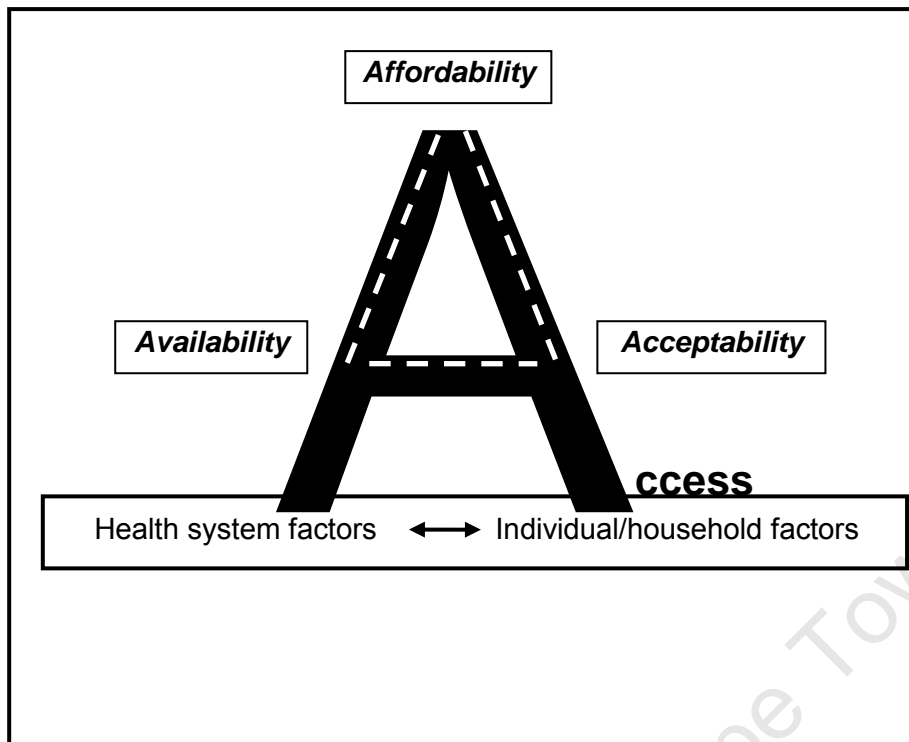
Study Site

Chivhu is the second largest town in the Mashonaland East province and unlike bigger cities and towns like Harare and Bulawayo, the town does not have a lot of satellite clinics capable of administering antiretrovirals. As a result patients in and around Chivhu have to come to Chivhu Hospital for reviews or collection of their medication. This study examines both patient level barriers and system level barriers to access and how they can be addressed in order to ensure continued use of services once ART is initiated. Studying the various aspects which determine access to ART will help to formulate solutions about how best the health care system can cater for the needs of the population within limited available resources.

Definition of access

Despite its complexity, the notion of access to health care has received much attention in health economics and policy. In this study, access is defined as the degree of fit between patient needs and system factors. Access refers to the relationship that exists between a health care system and the intended recipients and access determines whether or not those in need of health care have the opportunity to use the needed services (Penchansky and Thomas 1981). Given its complexity, a key to operationalizing this concept is to conceive of access as a number of distinct yet interrelated dimensions. Thiede and McIntyre (2008) came up with a framework of access comprising three dimensions: availability, acceptability and affordability, as illustrated in Figure 1. This access framework will guide the measurement of access in this study and data will be collected on each of the three dimensions, in addition to socio-demographic data in order to determine access.

Figure 1. The Access Framework



Adapted from Thiede, Akweongo and McIntyre (2007)

This framework will serve as the basis for analysing the various factors associated with access to ART in this study.

Methods and analysis

Study perspective

The study will be from the user's perspective.

The conceptual framework of access and objectives of the research guided the design of the data collection tool. The questionnaire will collect demographic details, socio-economic details, details of patient adherence as well as data on the access variables (acceptability, availability and affordability).

Interviewees will be selected using convenience sampling, and the study will employ a cross-sectional design. These choices were necessitated by the time and financial resources available to complete the study. The interviews are expected to last for 10 to 20 minutes and data will be recorded onto the questionnaire during the course of the interview. The interviews were carried out by the investigator in a private room. The investigator will familiarise with the system and routines at the facility before administering the questionnaire.

As of January 2011, there were 1 300 patients on the ART register at Chivhu Hospital. Using the procedure for determining sample size in survey research which was put forward by Bartlett in 2001

using Cochran's (1977) formulas, a sample size of 214 was found to be a representative sample for a population size of 1 500 at a 0.05 margin of error for categorical data (Bartlett J.E, 2001).

The questionnaire was divided into the following five sections,

- a) Socio-economic and demographic details
- b) Affordability of services
- c) Availability of services
- d) Acceptability of services
- e) Dwelling characteristics, household assets and expenditure

Table 1 shows the different variables included in the questionnaire.

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Table 1: Variables included in the questionnaire

<p>1.Socio-economic and demographic variables</p> <p>Sex of respondent Marital Status Age Level of Education Employment Status Monthly Expenditure Assets and dwelling characteristics</p>	<p>2. Affordability</p> <p>Borrowing money to pay for health care Amount borrowed to pay for health care Amount spent on one visit to the facility - transport, food, hospital fees etc Money spent on self-care - special food, herbal medicines etc</p>
<p>3.Acceptability</p> <p>Patients agree or disagree that the queue to see the doctor is too long. Patients feel that people in the community judge them negatively because they attend the ART facility. Patients agree or disagree that providers fully explain their illness and medication to them. Patients agree that providers undertake a thorough examination.</p>	<p>4.Availability</p> <p>Mode of transport Belonging to a support group Receiving visits from health care workers Time spent travelling to the facility Time taken to collect medicines Convenience of facility opening hours</p>
<p>5. Dwelling characteristics and household assets</p> <p>Type of dwelling eg traditional structure, house in backyard, flat Main material of the house's walls eg bricks, wood, corrugated iron Main source of household's drinking water Household's toilet type Household's main source of energy for cooking Ownership of the following assets – Cell phone, Radio, Television, DVD, Fridge, Car</p>	

A similar type of questionnaire was used on a similar study, the (Researching Equity on Access to Healthcare, (REACH) study hence the questionnaire will not be piloted since it has been well validated (Cleary et al 2010). However, the questionnaire will be translated into the local language, Shona to cater for participants speaking in Shona.

Data Management

Data will be entered into a database using Epi Info and stored in a code protected laptop machine used only by the investigator, backed up on a data CD then exported to STATA 11 for analysis. The questionnaires will be kept safe by the researcher to ensure integrity of the data as well as for future reference. STATA 11 was used to quantitatively analyse the data and produce the required statistical information.

The data will be cleaned to check for missing values or any errors during entering. This will be followed by an exploratory analysis, to check for the distribution patterns in the data, using tests such as the Shapiro-Wilk test for normality. For non- normally distributed data, non parametric tests such as the Wilcoxon ranksum test will be used for analysis. Variables such as age, gender, employment status and type of transportation used to get to the facility will be analysed using univariate analysis. Bivariate analysis will be done to check for associations between variables using the chi-squared test of association.

The data collection tool in this study includes questions on ownership of assets such as TVs, radios, cars, cell phones and landline phones. Dwelling characteristics such as type of house wall, type of roofing material, source of energy and source of drinking water were also recorded. These were then used to construct an asset index which is an indicator of the wealth status of an individual. The asset index was constructed by way of a Multiple Correspondence Analysis (MCA). Although the application of the Principal Component Analysis (PCA) on asset ownership data is commonly used for measuring socio-economic status, it may not be the best approach to measurement (Howe et al 2008). In this study data on asset ownership was mainly categorical, hence the use of the Multiple Correspondence Analysis (Booyesen et al 2005). PCA was mainly designed for continuous variables, and it assumes that data are normally distributed. Once the asset indices are obtained, patients will be classified as either rich or poor. The chi-squares test of association will be used to test for association between the socio-economic status and access variables such as being able to afford to pay for health care, missing appointments, and borrowing to pay for health care.

Ethics

The ethical practices of this study will be guided by the Helsinki Declaration. Ethical approval to conduct this study will be sought from the University of Cape Town's Research Ethics committee and the management of Chivhu General Hospital. Informed consent will be obtained from each of the study participants, after the provision of verbal and written information about the study to be undertaken. The interviews will be in English and/or Shona, whichever was preferred by the interviewee and participation will be voluntary. Permission to record information onto the data

collection tool without revealing identities will be sought from participants. The name of the institution will also be kept confidential in the event that the study findings are published.

This study could potentially cause some emotional distress to study participants arising from anxiety and fear of disclosing confidential information about themselves or their service providers if their true identity is discovered. This in turn could influence what the participants say to researchers. Participants will be assured of anonymity and confidentiality.

Dissemination

The results of this study will benefit the participants, Chivhu Hospital staff and management and the community at large. A final report of the study and a policy brief will be made available to the Health Economics Unit and if possible, the findings will be published in an academic journal.

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Part B: Literature Review

Literature Review

Introduction

Beyond the regularly reported figures about how many people are using various health care services, policymakers and the public have few regular reports on the problem of access to health care. The subject of access to healthcare is quite common and relevant in health economics research. However, there are still challenges involved in its conceptualization, measurement and operationalization. A number of definitions of access have therefore been proposed in literature. For example, some studies use utilisation as a proxy for access (Gulliford 2002, Waters 2000) while others argue that access and utilisation are two different and distinct concepts. For someone to utilise or use something, they must first have access to it. The use of utilisation as a proxy for access does not cover all the aspects of access (Gulliford 2002). Other studies also have looked at one or more aspect of access, leaving out the other aspects (Peters 2008). However, this may not be broad enough to capture all of the access barriers.

This chapter includes a review of the theoretical and conceptual literature associated with the concept of access. Where appropriate, conceptual arguments are supported with examples from empirical studies. The aim of the review is to defend a conceptualization of access that can be useful in studying access to ART in Chivhu. In addition, given the equity focus of this study, this chapter will review relevant literature on equitable access to health care. This review is not exhaustive on everything that has been written on the subject of access. It picks out key literature and key concepts on the subject.

The first section of this chapter discusses the various definitions of access found in literature and it is followed by a section on the various dimensions of access according to different authors, leading to the framework of access which will be used in this study. Each access dimension considered in this study will then be described, giving empirical examples. The last section discusses the important concept of equity in access.

What is access?

This section looks at how access is defined by various authors, firstly as a supply side concept, secondly as a demand side concept and finally as the degree of fit between the health care system and the recipients of care. This is followed by a discussion of these definitions and a proposed access definition for this study.

As a supply side phenomenon (that is, from the perspective of the health care system), access is defined as the provision of an adequate supply of health care services to the population in need by various authors (Goddard and Smith 2001, Gulliford 2002, Hoist et al 1997, Mooney 1983). More specifically, the health care system should have adequate and well trained staff, enough equipment and it should avail services conveniently to the community. The supply categorisation of access

however focuses on the health system and does not consider the patients (the demand side). This school of thought argues that having the right services available at an appropriate time reflects access (Goddard 2001). The services available must be relevant and effective if the targeted population is to 'gain access to satisfactory health outcomes' (Gulliford 2002; p187), although other factors such as financial, organisational and social or cultural barriers may limit the utilisation of services. Having the right services available is not sufficient on its own to ensure access, for example in a community where residents cannot afford to pay for the services, despite the service being available.

Another group of authors consider access as the possession of sufficient resources by the patient which enables them to seek care. This demand categorisation of access views the possession of financial resources or health insurance cover and other forms of ability to pay (White 2002, Falkingham 2004, Domenighetti 2009) as the determinants of access. The demand categorisation of access also considers other patient factors such as patient proximity to health care services and presence of social supporting networks which hinder or enable the patient's ability to access health services. From the affordability viewpoint, access to healthcare services is measured by considering whether people have insurance coverage or eligibility that allows them to obtain services when they need them (Savedoff 2009). In countries where social security institutions enrol formal sector workers or directly provide health care services to their members, rising enrolment might be taken as a measure of increasing access. Affordability on its own does not empower individuals with needs to use the services (McIntyre 2009). Services can only be utilised if they are availed at the right place and time and in a suitable manner.

This availability of services in the appropriate manner and quantity ushers us to another school of thought on the various access definitions proposed in literature. These authors define access as the degree of fit between the health care system and its recipients (Penchansky 1977, Thiede and McIntyre 2008). To have a full understanding of access, there should be an account of patient and health care system factors which enhance or act as barriers to care, thereby limiting the potential interaction between the health care system and recipients of care. The exchange of information plays a major role in determining access. The choices of care available to an individual are dependent on the amount of information they have on the existing services (Thiede 2005) and the characteristics of the health care system which make it conducive for patients to seek care.

Access to healthcare services is driven by a combination of demand-side and supply-side factors. On the one hand, access to healthcare, even when available and adequate, would be low if demand constraints are binding. On the other hand, if the quantity or quality of supply is inadequate or uncertain, access would remain limited even though households and individuals can afford the services (Ensor and Cooper, 2004). The need for fulfilment of demand and supply factors in order to achieve access makes it a dynamic concept as these factors change from time to time. This study defines access as the interaction (degree of fit) (Donabedian 1973, Penchansky 1977, McIntyre 2007) between supply side (health system) and demand factors (patient factors) through clear communication channels. The concept of access is further illustrated using a framework which describes the various interactive processes occurring between the health care system and its recipients. Having a framework of access enables a systematic approach to the concept, making it

easier to operationalize and measure. The next section explores the various access dimensions as proposed by various authors

Dimensions of access

The concept of access and how it is communicated becomes clearer if we think of access in terms of stages and dimensions. Access dimensions are useful for conceptualisation and measurement of access. A number of authors have proposed that access could be broken into a number of key dimensions (Aday and Andersen 1974, Penchansky and Thomas 1981, Obrist 2001, McIntyre 2007).

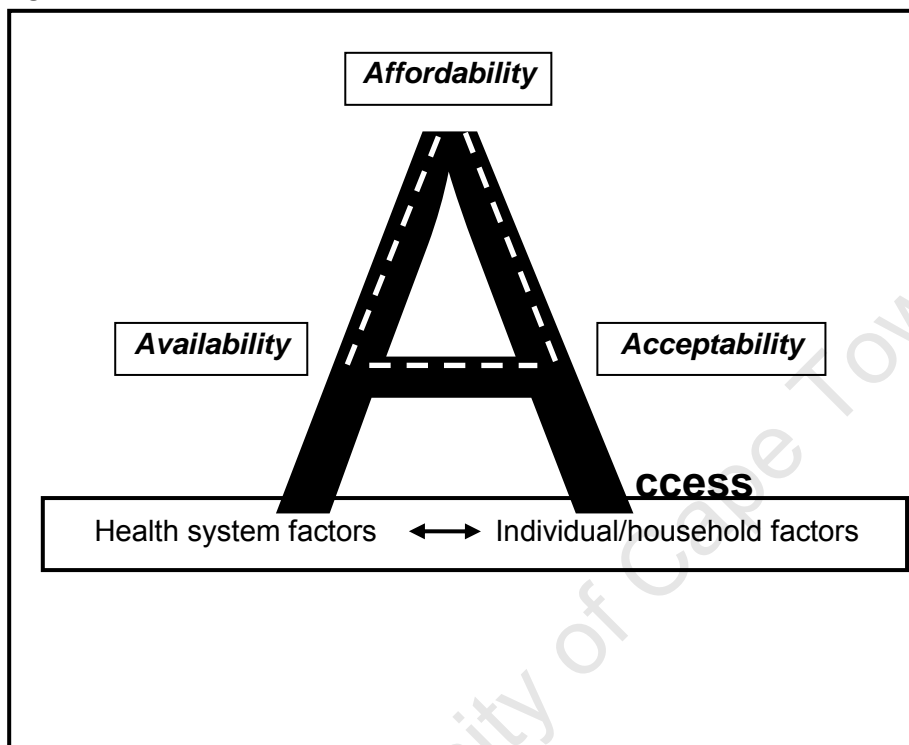
Penchansky and Thomas (1981) proposed that access comprises of five dimensions namely availability, accessibility, accommodation, affordability and acceptability, and they defined them as follows:

- Acceptability – the relationship of the volume and type of available services to the clients' volume and type of needs.
- Accessibility – the relationship between the location of the service provider and the location of clients. It is the distance or time between the patient and the service point.
- Accommodation – the relationship between the organisation of the health service and the client's perceptions and ability to accommodate such factors. Hours of operation, appointment systems and the presence or absence of walk-in services fall under accommodation.
- Availability – the relationship between the client's needs and the volume of existing types of services and resources. This refers to the number of local points of service from which a client can choose.
- Affordability – the relationship between the clients' income and ability to pay and the price of services and providers' deposit requirements. Issues such as the client's perception of the value of service and the possible credit arrangements are also covered under affordability.

In a similar fashion, Obrist (2001) argued for five dimensions of access namely availability, acceptability, adequacy, affordability and accessibility. The definitions of availability, accessibility, acceptability and affordability were similar to those put forward by Penchansky and Thomas. The new dimension of adequacy was related to whether the organization of health care services met the clients' expectations. This included the cleanliness of facilities and the convenience of opening hours to the population in need. This adequacy dimension is the equivalent of the accommodation dimension put forward by Penchansky and Thomas. According to Obrist, the degree of access attained depends on the interplay between (a) the health care services and the broader policies, institutions, organizations, and processes that govern the services, and (b) the livelihood assets people can mobilize in particular vulnerability contexts. This definition takes into consideration the fact that there should be an interaction between the health care system and the recipients of the services provided for access to occur.

More recently, McIntyre et al (2009) argued for a simpler model based on three dimensions of access. Given the conceptual similarities between accommodation, accessibility and availability, they argued that these ideas could be accommodated within a broader definition of availability. Their framework therefore includes only three dimensions namely **availability, affordability and acceptability**. Their notion of access is depicted in Figure 1.

Figure 1: The Access Framework



Adapted from Thiede, Akweongo and McIntyre (2007)

Although the access dimensions are distinct, they have a great deal of interaction between them. Availability for example, cannot be separated from affordability or acceptability issues. They might be distinct dimensions but they are interwoven to form an access frame as shown above. The framework by McIntyre emphasises the importance of the interaction between the three access dimensions. The following sections describe each of these three dimensions of access, with examples from the empirical literature.

Acceptability

This section looks at how various authors have defined acceptability in relation to access to health care and how this dimension of access relates to the other access dimensions, using relevant examples.

The provision of healthcare cannot be separated from the society in which patients and providers live and from the beliefs and perceptions governing the practices of patients and providers. The acceptability dimension is concerned with the degree of fit between the socio-cultural beliefs of

patients and providers. (Thiede et al 2007, McIntyre et al 2009). Thus, apart from the physical and cost barriers, acceptability should be taken seriously in policy debates on health care access. (Sen and Ostlin 2007, Goudge et al 2009)

It is defined as the social and cultural distance between the health care system and its users (Gilson 2007). This 'fit' or interaction is affected by patient variables such as age, gender, ethnicity, language, cultural beliefs and socio-economic status. The patient's attitude towards the provider on the other hand is shaped by provider characteristics which include age, gender, years of experience and degree of expertise, for example whether the provider is a nurse or a doctor. Acceptability varies from one instance to the other, depending on cultural beliefs and the nature and type of illness. As a result, health services should be oriented in a way that caters for the cultural needs and understanding of the targeted population. The Australian Aborigines for example have different cultural constructs and values from the rest of the Australian society. The greatest barrier for Aboriginal people in attending health services is the fact that most services are culturally alienating in their view (Mooney 2007). Involving the Aboriginal community in planning for its health will ensure that services are then directed towards the ends that Aboriginal people want, thereby being more likely both to improve accessibility and to maximise the benefit or the good from the resources available. Such a process will help to build self esteem of the Aborigines, leading to better health and well being.

Acceptability is in three elements namely; the relationship between lay and professional health beliefs, patient provider communication, and organisational arrangements of health care (Gilson 2007).

The first element of acceptability according to Gilson (2007) has to do with patient perceptions towards the treatment offered and its effectiveness. Issues such as the perceived importance of taking medication and the views of patients regarding the competence of their providers and availability of enough drugs and equipment contribute to lay health beliefs. In the same manner, health care providers have their views and perceptions towards patients. In order to have acceptable services, these perceptions, attitudes and beliefs of patients and the health care professionals should be aligned. Once there is a fit in the beliefs of both parties, barriers are removed resulting in access to care.

The second element of acceptability is the dialogue and engagement between patients and providers. It covers the patients' ability to have a say in the medical care they receive and the communication processes between patients and healthcare workers. Both parties should be able to communicate effectively in a way that encourages continuous dialogue and engagement. Effective communication has been shown to remove barriers to care (Thiede and McIntyre, 2008).

The third element focuses on the structure of the health services in relation to the needs of the population being served. These organisational arrangements include the range of services provided and measures put in place to guarantee provision of such services. The British National Health Service (NHS) recommends governments to focus on the relationship between patients and health

care providers through monitoring of care, using patients and consumer groups and the involvement of lay people at different levels of health systems. This may improve both quality of care and the accountability of the system as a whole (Donabedian 1973). Improvement will occur when patients know what they are entitled to by establishing well-publicised minimum standards which are continuously revised over time. The organisation of health services in relation to patient needs is quite similar to the access dimension of availability, reflecting the close relation between the three access dimensions.

Acceptability of services is quite crucial in the provision of lifelong antiretroviral treatment. To ensure that patients stay on treatment, healthcare services should be tailored towards patient needs, in addition to having clear communication channels between patients and providers. This ensures removal of barriers and ensures access to care. Various acceptability barriers have been cited in literature and these include stigma (Grant et al 2008, Foreman 2006, Duff et al 2010), lack of information about ART and the procedures involved in ART (Ochuole, 2010), dirty facilities (Muchedzi et al 2010), poor patient provider interactions (Goudge 2009), lack of confidentiality and language barriers (Duff et al 2010).

Stigma and discrimination against HIV / AIDS continue to exist despite the various efforts in place to fight them (Zamberia et al 2011). People on ART at times are seen as if they do not fit into the social norm, leading to their exclusion in society, which restricts their chances of accessing ART services. Stigma has got an array of consequences. Firstly, patients are afraid of seeking care at the clinic (Mshana et al 2006, Grant et al 2008) for fear of discrimination, resulting in them not accessing care and treatment. Stigma affects adherence to ART as patients become reluctant to take medication at the right place at the right time (Foreman 2006), when they are in the presence of people who do not want to know about their condition. Although there is increasing use of ART, stigma still exists and plays a role in the decision making process around ART uptake. Overcoming stigma means that more patients will be free to access ART services. The dissemination of correct information about ART and provision of services which respect patient confidentiality are some of the effective methods for fighting stigma and encouraging access to ART.

The exchange of information between health care providers and patients creates trust and improves access to care (Thiede 2005). Lack of information about treatment procedures involved in ART and the drugs used was considered a barrier to access amongst HIV positive women in Uganda (Duff et al 2010). Knowledge about the presence of a service increases their chances of accessing care and gives the patient the freedom to choose. Information should be conveyed in a simple manner and it should be easy to understand, especially in the provision of ART where there are various regimens and procedures of therapy.

In addition to fighting stigma, confidentiality and trust between the patient and the provider are another set of access barriers. Patients may only approach a provider who they know will respect them and treat them in confidence. Lack of confidentiality was found to be a barrier to access in Nigeria (Ochuole 2010), resulting in patients travelling for long periods to distant clinics and shunning local clinics. This also serves as an example of the effect of poor provider-patient interactions on access to care. Lack of confidentiality results in patients giving the wrong clinical and demographic information, thereby making diagnosis and follow up visits difficult.

Patients' beliefs, perceptions and understandings on the causes of the disease and the effectiveness of therapy affect their health seeking behaviour. Some patients prefer to self medicate or consult faith healers in line with their beliefs. Presence of traditional medicines and drug stores give patients a wide range of options in terms of where to seek help. This presence of alternative forms of care can be a barrier to care if the other forms of care are perceived to be better.

Muchedzi (2010) identified poor referral systems as an access barrier to care which results in patients being lost along the referral chain. Other studies acknowledged the lack of coordination between ART and other health care services as a barrier to access. The successful integration of ART into primary health care in Mozambique increased access to ART by increasing geographical coverage of ART, reducing loss to follow ups, filling of workforce gaps and an improved flow of patients between services and facilities (Pfeiffer et al 2010).

The organisation of the health care system plays a vital role in shaping patient perceptions. Patients should have the perception that health care workers will act in the best of their interests (Gilson, 2007). Negative staff attitudes such as being rude to patients (Ochuole 2010, Zamberia 2011) were found to be barriers to ART. Dirty facilities and old structures hindered access to care as patients did not feel comfortable under such unhygienic conditions.

The provision of ART has various acceptability issues which hinder access to care as mentioned above. To ensure access to care, ART programs should not be culturally alienating and they should be relevant to the society being served. Any policies or interventions to enhance access or address equity of access to care should take into consideration the social context, in which the policy or intervention will be implemented.

Affordability

Affordability is concerned with the 'degree of fit' between the full costs to the individual of using the service and the individual's ability to pay in the context of the household budget and other demands on that budget (McIntyre et al 2009).

The full costs of service include user fees charged for the services at the point of delivery, direct costs such as transportation and food costs and indirect costs such as lost income or productivity while using the service. Affordability is dependent on the form of payment required by the health care provider and it extends beyond the ability to pay by considering the potential impact on a particular household of seeking health care (Goudge 2003, McIntyre 2009). The opportunity cost of making a payment to get health care determines whether or not health care is affordable. If a household has to sacrifice basic needs in order to pay for health care, the cost of health care will be regarded as unaffordable.

In terms of the required form of payment, affordability is influenced by whether an immediate cash payment is required or whether an account will be sent at a later stage or a credit facility provided, and in low-income contexts whether payment in kind (e.g. livestock or some grain, or provision of a

reciprocal service) is acceptable. The available payment mechanisms must be agreeable to both the provider and the potential user.

People's ability to pay (ATP) for health care, or the affordability of health care, has become a critical policy issue in developing countries, and a particularly urgent issue where households face combined user fee burdens from various essential service sectors such as health, education and water (Russel 2005). The cost of accessing health care (both direct and indirect) can be said to be 'affordable' when utilisation is not hindered by financial reasons. Participation or indirect costs in seeking health care such as transport, accommodation, food and loss of potential income have been shown to be major obstacles to care especially to poor households (Lambert-Evans et al 2009, Goudge 2003). Other than direct costs of illness, prolonged or lifelong illnesses are associated with income losses that undermine the household's command over essential goods and services. In the case of ART, there is potential loss of productive time as patients come to the health care facility to get treatment and medication.

Direct and indirect costs of seeking care have been shown to be access barriers to care (Ensor and Cooper 2004). Although ART is offered free of charge, patients still faced financial barriers in the form of transport costs (Hardon et al 2007, Mukherjee et al 2006), costs of other medicines to be taken alongside their usual ART medicines and consultation fees. In addition patients also cited costs which had no attached monetary value such as missing work and having to find child minders (Ensor and Cooper 2004). The cost of travelling is also high, resulting in patients running out of supplies between hospital visits. Medical expenses can push households in low and middle income countries into poverty. In the case of HIV infected individuals, the indirect costs of ART can be high. It should also be noted that some patients on ART are economically active and this lost productive time does not only affect the household but the nation as a whole as it affects the workforce.

Another factor covered under affordability is the issue of informal fees where some poor households make such payments in order to get favours from health care workers. As a result of limited financial access to health facilities, many poor households then tend to forego treatment or use unregulated facilities (Russel 2005). Affordability is an important element of the study as it has been shown elsewhere that medical expenses can push households in low and middle income countries into poverty (McIntyre et al 2005).

Although countries such as Ghana, South Africa, Uganda and Zambia have abolished user charges at primary care level in the public sector, informal or 'under-the-counter' payments still remain. This creates a financial barrier, especially in rural communities where income is low.

As long as out of pockets payments still exist, disparities in provision and access to health care will remain. For 5.6 billion people reported to live in low- to middle-income countries as of 2008, half of all health expenditure was through out-of-pocket payments (World Health Report 2010). These payments have been shown to be associated with exclusion from health facilities, resulting in some households ignoring illness symptoms at an early stage. Poor households tend to respond to illness at an advanced stage and in the process incur 'catastrophic' health expenditure which affects the long term household prosperity (Cuyler 1993). Research has shown that any health care expenditure ranging from 5% to 40% of total household expenditure can impoverish a household (Onoka C.A et al

2010). Under affordability, this study will assess the extent of catastrophic health care expenditure incurred by a household as a result of seeking antiretroviral therapy.

Although there is growing literature on affordability of health care (Chuma et al 2007) and the impact of illness and death as a result of catastrophic diseases such as HIV (Russel 2004, WHO 2005), there are few studies on the cost burden of recurring chronic care. A review of studies on the economic costs of TB, HIV and malaria in low and middle income countries showed that the largest costs from HIV were those costs associated with death, indicating that regular treatment was not commonly available (Matwa 2010). In Nigeria for instance, it was found that nearly 25% of households in the poorest one-fifth of the population spent more than 40% of their total non food expenditure on health care costs (Hanson 2010). Such margins of expenditure suggest that affordability issues should be included in access studies.

Given demands for care and constrained resources, the aspect of affordability should not be left out in access studies

Availability

Availability is the relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs (Penchansky and Thomas 1981). This access dimension deals with the question of whether or not the appropriate health services are available in the right place and at the right time that they are needed.

It refers to the supply of doctors, nurses, counsellors and other providers; the adequacy of facilities and equipment as well as specialised programs such as home visits and nutritional education. Availability encompasses system and individual factors which affect access. System factors include the location of the facilities and their orientation towards the needs of the population, including their opening hours, and the range, quality and quantity of services (McIntyre, Thiede and Birch 2009). Individual factors include the location of recipients of the service, type and severity of disease conditions in the population and the time of day at which the individuals need the service. Availability encompasses the convenience of getting care from a service provider. This includes the opening times of the facility, the willingness of providers to reach out to the community they serve, the attitude of staff, their experience and qualifications and the range and quality of services they provide.

Availability means that there is an adequate supply of well trained staff, effective drug supply and management (avert.org), convenient opening hours and presence of patient support networks such as treatment partners and support groups (Muchedzi et al 2010). However, in terms of availability of staff, it has been shown that countries with higher HIV prevalence have lower health staff-to-patient ratios compared to more developed countries. In Malawi, for example, there is just one doctor per 50,000 people compared to the United States with one per 390 people (UNAIDS 2008). On average, there are 15 times the numbers of doctors and 8 times the number of nurses in Europe compared to Africa (WHO 2007). In order to cater for these staff shortages, lesser-qualified health workers were

trained and allowed to perform tasks which they were previously unqualified to do. This is known as 'task-shifting'. Allowing nurses to perform some of the tasks of doctors, and community workers to take up some of the roles of nurses could facilitate access to ART and improve adherence and management of therapy. Studies suggest that quality of care would not be compromised and that this could be more cost-effective than the present division of labour (WHO 2007). Task-shifting was implemented in Zambia in 2004, (Morris et al 2009) and it was shown to be quite beneficial.

A study carried out in the copperbelt of Zambia revealed that availability of medication in health facilities did not automatically ensure access to those in need (Grant et al 2008). Once within the system of care, further barriers can also hinder access to receiving treatment. Such barriers include staff attitudes, overcrowded systems, cost of seeking care, cost of food, cost of further medical tests, and discrimination by family and society and staff attitudes towards patients among others. Although they faced such barriers, patients on ART were adherent to therapy. The Zambian study recommended that ART should be incorporated into the main stream health service.

Some researchers have separated issues such as opening times into a dimension referred to as accommodation and geographic location into an aspect termed accessibility. It appears appropriate, however, to incorporate in one dimension the aspects that refer to the physical 'ease of use' of health services or the degree of fit between the health system and its clients around space and time (Thiede, Akweongo and McIntyre 2007).

An important factor under availability is geographic accessibility of facilities. It refers to the physical distance and travel time between the health care facility and the catchment community. Geographic accessibility focuses on geographic features such as mountains and rivers and the existence of infrastructure such as settlements, roads, schools etc. An inverse relationship between distance or travel time to health facilities and utilisation of health services has been demonstrated as an important barrier to access in low income countries (Peters 2008). Good infrastructure such as roads, bridges and communication systems are required for efficient health care delivery. With good roads, patients can commute to health care centres with ease and the distribution of drugs and other supplies is made easy. A good road network reduces the time spent travelling to the health care facility.

Keeping people on treatment programmes is an important factor after the numbers enrolled have been boosted. In order to retain patients the required services should be available to the patients in a manner that suits the patient's needs. This means that a specified volume and type of service should be at the patient's disposal. In order to maintain patients on the ART programme, they want to have a sense of belonging which can be established by way of good support networks. Patients may require moral support from family, friends and their HIV positive associates to stay on therapy. Success stories of other people on ARVs can encourage patients to continue with their therapy (Roura et al 2009). In Kenya it was shown that the use of mobile phone texts by nurses to check on patients is effective in improving adherence (Lester et al 2010). Patients felt 'highly satisfied' by the service and wanted it to continue was because they felt "like someone cares. Adherence is however dependant on the information possessed by an individual and their level of motivation (Ware et al 2008). In addition to individual factors, availability of resources has been cited as an obstacle to

adherence, especially in resource poor settings. Over time, patients may face economic challenges, with some of the implications being the non-availability of money for purchase of food which is critically needed when one is on treatment and failure to meet appointments due to lack of bus fare. Some studies in resource limited settings have shown increased loss to follow up as time progresses (Boulle et al 2008), mainly due to the reasons stated above. The importance of adherence should be emphasised both to the patient and to the service providers.

Health care users should be educated on the type and range of services at their disposal. This form of education is important in provision of a service like ART where patients are prone to adverse effects of drugs and they should know that support services are available if they encounter any problems with their medication. Patients should be aware of the full range of services at their disposal so that they are fully empowered.

The various studies reviewed bring out the importance of equity in access to health care. Besides, being affordable, acceptable and available, health care should be equitably distributed, that is, there should be equal access for equal need.

Equity in health care

The concept of equity, like access, is quite common in the literature but there is little consensus on its meaning (Mooney 1983, Braveman 2003, Braveman 2006). The lack of clarity on the definition of equity has led to difficulties in its conceptualization, measurement and interpretation. The Oxford dictionary defines equity as the quality of being fair and impartial (Oxford Dictionaries website). Whether or not something is fair involves a moral judgement. As a result the definition of equity depends on the context. In order to describe a situation as unjust or unfair, the cause has to be examined and judged in relation to what is going on in the rest of the society (Whitehead 1992). Judgements on which situations are unfair vary from one place to another but the commonly used judgement criterion is the degree of choice involved. Where people have no choice in living and working conditions, the differences are likely to be unjust as compared to cases where health differences are due to voluntarily chosen health risks. The concept of equity is based on value judgement, hence its interpretation in many ways.

Equity in health care is often defined in terms of equal access to health services for equal need (Thiede et al 2007, McIntyre et al 2005, Whitehead 1992). Clearly stated and clearly understood principles of equal access can serve as an ideal for which societies committed to equal opportunity and respect for persons can strive (Gutman 1981). Equal access requires that every person who shares the same type and degree of health need must be given an equally effective chance of receiving appropriate treatment of equal quality. If anyone in society has an opportunity to receive a good or a service that meets a health need, then everyone who shares the same type and degree of health need should have an equally effective chance of receiving that service or good. The principle of equal access does not guarantee equal results, although it aims at moving the society in that direction.

If access to care is to be equitable, then people's needs rather than their social privileges will guide the distribution of opportunities for well being (Murray 1994, Braveman 1996). Health care is therefore equitable when access to care and the allocation of resources is driven by need (Aday 1984). Differences relevant to equitable access are in most instances systematic and not random or occasional. Equitable access should not permit discrimination based upon characteristics of people which they did not freely choose. These characteristics include sex, race, genetic disposition, wealth and place of residence. The rural-urban distribution of services is important when considering equity of access to health care. Where a person lives should not determine the ease with which one acquires health care. Similarly, differences in family income, race or gender should not result in differential access. In other words, inequity exists when there are trends in population groups such that it becomes possible to predict the health of individuals based on their social positions. For example Whitehead (WHO 2006) highlighted how disadvantaged groups do not only have higher mortality rates, but also suffer a heavier burden of illness than others and also experience the onset of chronic illness and disability at younger ages.

In considering equity of access it should be assumed that; health care is a right, resources for allocating health care are finite and 'just or fair' mechanisms should be designed to allocate scarce health care resources (Aday and Andersen 1981). Most studies reveal that lower socioeconomic classes face greater access constraints compared to richer groups (Gulliford et al 2002, Kristiansson et al 2009). Equity of access to health care should aim at removing the socio-economic barriers to care. Equity of access determines whether there are systematic differences in access to health care among various population groups and whether these differences are due to financial constraints, availability barriers or barriers related to acceptability of services. In relating to the health care system, recipients of health care should afford the services, they should find the services acceptable within their context and the system should be able to accommodate them, implying that all the aspects of access are covered. Pursuing equity in health means reducing the avoidable gaps between groups with different levels of social privilege (Braveman 1996).

Ensuring access to health care will involve removing obstacles for groups such as the poor and disadvantaged racial/ethnic groups who historically have faced obstacles to realising their rights to health (Braveman 1996). Such measures were adopted in the United States in the 1950s, and access profiles showed that there was improvement in access to medical care for traditionally disadvantaged groups (Aday 1975, Andersen et al 1976). These improvements were attributed to the advent of large scale financing programs, Medicare and Medicaid, which were specifically targeted to low income populations.

Problems in access to antiretrovirals and retention in treatment programs are leading to disparities in HIV-related mortality among specific population groups. These groups have traditionally been at risk of inferior access to health care and they include, for example, people of lower socio-economic status, minority ethnic groups and injection drug users (Fein 1995, Montgomery 1996, Pappas 1993). Pursuing equity in access for these groups means removing the barriers faced by patients in accessing care. Studies have shown that households with low income tend to have higher catastrophic health expenditures (Kim 2011, Onoka 2011). This is a significant barrier to access which should be addressed as it threatens the livelihood of the household. Antiretroviral therapy is a

lifelong procedure and as such health care policies should be aimed at reducing access barriers to recipients, regardless of their socio-economic status. This will ensure that patients will not drop out of treatment programs. A higher proportion of defaulters are most likely to come from poorer patients who have no other options of therapy since they cannot afford to purchase drugs elsewhere if they are not available or to seek services elsewhere if they are not satisfied with the services rendered. Such scenarios result in both poor health outcomes and they increase inequity in health. This is avoidable through pro-poor policies aimed at ensuring that for the same type of need, everyone gets similar treatment. The equity focus of this study is to assess whether access barriers to care differ by groups of lower or higher socio-economic status.

This chapter has reviewed the access definitions proposed by various authors and came up with a definition of access for this study. The access framework for analysing access was described and its application in this study was shown. In addition to being affordable, acceptable and available, health care services should be distributed according to need, regardless of one's position in society, gender or other attributes.

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Part C Journal Manuscript

Access barriers to antiretroviral treatment in Zimbabwe, a case study of Chivhu Hospital.

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Proposed Journal: **BMC Health Services Research**

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Abstract

Introduction

Geographical access to antiretroviral therapy (ART) in Zimbabwe has increased over the years due to decentralisation and implementation of outreach programs. In addition, ART is offered free of charge. However, increased geographical coverage and the offering of services for free do not necessarily remove all of the access barriers to care. The constraints faced by patients in accessing treatment are not known. This case study investigates the various access barriers faced by ART users at Chivhu Hospital and looks at how access barriers differ by the socio-economic status of an individual.

Methods

The study sought to investigate the access barriers faced by patients in the continued use of antiretroviral therapy (ART) services at Chivhu Hospital. Access in this study was defined as the degree of fit between patients' needs, attitudes, ability to pay and the characteristics and of the health system. It was measured in three dimensions namely acceptability, availability and affordability of ART services. Exit interviews were conducted with 214 users of ART at Chivhu Hospital between January and February 2011 using a questionnaire designed to collect demographic and socio-economic information as well as data on each of the access dimensions. The data were analysed using Stata version 11. Descriptive statistics were generated and differences between groups were tested using the chi-squared test.

Results

Under affordability, it was found that there were significant differences in expenditure between the rich and the poor ($p < 0.01$). Furthermore, patients in both socio-economic groups faced financial barriers in the form of user fees, transport costs and paying for other drugs. The opening hours of the facility were convenient and patients adhered to their treatment schedule. However patients felt that more staff and services such as CD4 checks should be made available to improve on availability of services. Furthermore, sixty-one percent of the respondents said the queues to the doctor were long. To make the services at the facility more acceptable, ninety-five percent of the patients felt that the cleanliness of facilities had to be improved and they also expressed concerns over whether staff kept their sensitive information confidential. Despite this, patients felt comfortable to come to the facility for assistance.

Conclusion

Although ART is free of charge in Zimbabwe, patients face prohibitive financial barriers to care at Chivhu Hospital. In terms of availability, more doctors are needed at the facility; meaning that in addition to spending too much time travelling to the facility, patients also wait for long before they are attended to. The main acceptability barriers faced were cleanliness of facilities and issues of trust between health care workers and patients. Using such findings, access can systematically be tackled from a policy perspective to ensure that barriers are removed.

Key words- Access, antiretroviral therapy, availability, acceptability, affordability, equity.

Introduction

Around two thirds of the global HIV/AIDS burden is found in Sub Saharan Africa [1, 2], translating to 22.5 million people living with HIV/AIDS [1]. HIV incidence and prevalence rates vary between Sub Saharan African countries, with West Africa being the least affected by the pandemic while Southern Africa is the worst affected. According to UNAIDS and WHO estimates, 47% (6.6 million) of the estimated 14.2 million people eligible for treatment in low and middle-income countries were accessing lifesaving antiretroviral therapy (ART) in 2010, an increase of 1.35 million since 2009 [1,3]. The 2010 edition of the UNAIDS report revealed that while some progress has been made in halting new HIV infections, more could still be done in terms of reaching out to those in need of ART [3].

As of 2010, 14.3% of Zimbabweans were living with HIV/AIDS [3]. Zimbabwe is a signatory to a number of international and regional conventions on fighting the HIV/AIDS pandemic which include the Millennium Development Goals and has responded positively in its efforts to curb the HIV/AIDS epidemic. In December 1999, the government created a coordinating body for various HIV services, the National AIDS Council (NAC), which falls under the Ministry of Health [4]. In May 2002, HIV/AIDS was declared a national emergency [4, 5], thereby setting the stage for the country to import low-cost generic antiretroviral drugs. The government, with assistance from the Global Fund and other non-governmental organisations has been on a drive to ensure availability of antiretroviral therapy to those eligible and this has resulted in increased geographical coverage of ART within the country. This coverage has been largely driven by a number of factors such as decentralisation of ART as well as implementation and expansion of outreach programs. Although considerable strides were made in increasing coverage, the number of people on ART still falls short of the required numbers for universal access. As of December 2010, 59% of those in need of ART were receiving treatment [6, 7] and at the time of the study there were four nurses at the ART clinic in Chivhu and one doctor at the hospital.

Despite the increasing burden of illness in low and middle income countries due to TB/HIV and non-communicable diseases, few health systems are organised to meet the needs of chronically ill patients [8], including those on ART. The implications are that patients might face sizeable access barriers to both initiating and remaining in care. This study uses a comprehensive framework of access to systematically examine the affordability, availability and acceptability issues faced by patients as they use ART services, using Chivhu Hospital, in the Mashonaland province, as a case study. In addition to examining the barriers in general, the study also examines whether, and how these barriers might differ for patients of higher or lower socioeconomic status. Access in this study is defined as the interaction between patients and the health care system [9, 10], and the extent to which this interaction facilitates or results in an opportunity to use health care services. In other instances, access has been measured as the ability to secure a set of services [11]; while such an approach may facilitate quantification, it does not capture many of the potential access barriers that can occur even if a service is available. Other studies define access as being able to afford to pay for health care [12, 13]. Ensuring access to healthcare however entails the removal of obstacles for groups such as the poor and disadvantaged racial/ethnic groups who historically have faced difficulties in realising their rights to health [14]. The results of the study will provide policy makers with information about how ART programs can be more accessible and ultimately more effective. The results are also useful for planning how best the health system can align itself to accommodate

the diverse needs of patients. In addition, the study adds to the body of knowledge and makes way for other detailed studies on the multi-faceted issue of access.

Methods

The aim of this study was to explore the availability, affordability and acceptability barriers to the continued use of ART services by patients at Chivhu Hospital. Chivhu is the second largest town in the Mashonaland East province and is a small farming town. The ART clinic at Chivhu Hospital is a service centre for people living in and around Chivhu. Data were collected from participants using a semi-structured questionnaire which contained sections to collect demographic details, affordability, availability, acceptability of ART services as well as socio-economic indicators. The data were collected from January to February 2011. Exit interviews were carried out by the investigator with those patients who were on ART for more than 3 months and were above 18 years of age after they gave oral or written informed consent. Some patients did not want to write on anything for fear of disclosure of personal details and they opted for verbal consent. To control for researcher bias, the researcher was also involved in the day to day activities at the facility. As a result the researcher was considered as part of team of health care providers at the facility, making it easier for respondents to open up.

The questionnaire was divided into the following five sections:

- a) Socio-economic and demographic details
- b) Affordability of services
- c) Availability of services
- d) Acceptability of services
- e) Dwelling characteristics, household expenditure and assets

Each of the sections had questions designed to bring out the various aspects of access, in line with the study objectives.

To measure *affordability*, quantitative categorical questions and quantitative numerical responses were given by respondents, as illustrated in table 1. In addition to giving the breakdown of costs incurred in seeking treatment, respondents also answered questions about whether or not they could afford to pay for the needed healthcare. Respondents also gave information on other sources of financing health care such as borrowing from friends and relatives or selling household items.

Acceptability was measured by asking patients about their feelings and perceptions on the service they receive. Patients were asked if they could trust the providers with sensitive information and whether or not the health care workers undertook thorough examinations as well as explain fully to patients about the medication they were giving them. Other important variables under acceptability of the service were cleanliness of facilities and whether or not patients had to wait in long queues to see the nurse or the doctor.

Availability variables included time spent travelling to the facility, form of transport used, convenience of opening hours and whether or not patients ever got visits from their health care

workers. Patients were also asked if they were part of treatment support networks such as support groups and if they had treatment buddies.

Table 1 - Summary of data needed to meet study objectives.

<i>Objective</i>	<i>Data Needed</i>
<i>To determine the demographic characteristics of the study population.</i>	<i>Socio-demographic details including the age, sex, marital status and educational levels of study participants.</i>
<i>To determine the availability of ART at Chivhu Hospital.</i>	<i>Distance of the facility in relation to where patients live.</i> <i>Mode of transport to the hospital.</i> <i>Convenience of opening hours.</i> <i>Availability of support systems (home visits by hospital staff, treatment buddies, and support groups).</i> <i>Availability of other health services which are not related to ART.</i> <i>Time spent when collecting ARVs and time spent when one sees a doctor or nurse for a check up.</i>
<i>To determine the affordability of ART at Chivhu Hospital and assess how patients are able to finance their treatment.</i>	<i>Direct costs of care (transport, food, user fees etc).</i> <i>Patients' ability to meet the costs (whether or not it is easy for them).</i> <i>Whether or not patients borrow or sell household items to finance their health care and health seeking related expenditure.</i>
<i>To determine the acceptability of ART at Chivhu Hospital.</i>	<i>Patients' perceptions on discrimination by society because they are on ART.</i> <i>Patients' preferences on how they would want to be treated.</i> <i>Patients' views of how they are treated by hospital staff.</i> <i>Maintenance of confidentiality and privacy by staff.</i> <i>Respect for patients by providers.</i> <i>Cleanliness of premises.</i>

To measure the socio-economic status of the individual, data on respondents' dwelling characteristics including their source of drinking water and their main energy source were collected. In addition, respondents were asked if they possess household assets such as radios, televisions, cars, bicycle and cell phones which are indicators of wealth. The data were used to construct an asset index through performing a Multiple Correspondence Analysis (MCA). While the Principal Component Analysis (PCA) is normally used for constructing the asset index, the MCA was used in this case because it is appropriate for categorical data [15], compared to the PCA which is for discrete and normally distributed data [16,17]. The data collected for developing the asset index were mainly categorical. For purposes of this study, respondents were divided into two wealth groupings, the poor and the rich. These are however not absolute terms as the definition of rich and poor varies from one setting to another. The extent to which one is rich or poor cannot be quantified but is a relative term used to compare two groups.

Finally, adherence was measured through asking patients to self-report whether they had missed taking any of their ARV medication.

Sampling and study design

Study participants were selected using convenience sampling within a cross-sectional study design. While panel data might be more appropriate for capturing changing access and adherence, a cross sectional design allowed for collection of data within the confines of the available time and financial resources of this study. As of January 2011, there were 1 300 patients on the ART register at Chivhu Hospital and 214 patients were interviewed. This sample size was found to be representative of the population size with a 0.05 margin of error. Given that the questionnaire used in this study was adapted from a previous research project where it was validated, no piloting was carried out. The questionnaire was however translated into the local language, Shona.

Study participants were conveniently selected as they came to the facility for medication refills and/or checkups. The exit interviews were carried out by the investigator daily between January and February 2011. Only five patients declined to participate in the study, their chief reason being lack of time, giving a 98% response rate. Gender of the respondent did not serve as a criterion for participating in the study and all participants, whether male or female had an equal chance of participating in the study. Following written or verbal informed consent, interviews were conducted in English or Shona, and responses were entered on paper questionnaires. Institutional approval was given by the Chikomba District Medical Officer and ethical approval granted by the University of Cape Town Research Ethics Committee. The ethical practices of this study were guided by the Helsinki Declaration.

Data Management and Analysis

Data were entered into a database using Epi Info and safely stored in a code protected laptop machine then exported to STATA 11 for analysis. The questionnaires were kept safe by the researcher to ensure integrity of the data as well as for future reference. The analysis of data consisted of computing descriptive statistics for the demographic variables which included age, sex, marital status, educational level of respondent and household head and employment status.

Participants living in the town of Chivhu, were considered as the urban population while those living outside the town of Chivhu were classified as the rural population. The rural dwellers mostly had to use public transport to get to the facility and their households did not have electricity and running water. For availability of services the following continuous variables were analysed: time spent travelling to the facility, time spent collecting medication and time spent waiting for the doctor or nurses. The continuous variables were not normally distributed so both mean and median times were presented in the results. The following categorical variables were collected and analysed under availability: mode of transport, whether or not patients ever got visits from the health care workers, and whether or not the patient had a treatment buddy or belonged to a support group. Data for household expenditure were collected as categorical data; these categorical responses were converted into a continuous variable using the geometric mean from within each category. Under affordability, patients were asked if they had borrowed to pay for healthcare, and whether or not it was easy for them to meet their healthcare expenses. The amounts paid for hospital fees, medicine, transport and food were recorded as continuous variables. The threshold for catastrophic health care expenditure in the study was set at 20% of total household expenditure. The threshold in past studies has varied from 5% to 20% [34, 35]. The Shapiro-Wilk test was used to determine if data were normally distributed and the Wilcoxon rank sum test was used for analysis of categorical data and non-normally distributed data. Acceptability variables, which investigated patient perceptions and feelings regarding the service rendered, were recorded and analysed in stata.

Results

Demographic Data

Data were collected from 214 participants. Table 2 presents the demographic data collected from the participants.

Table 2: Socio-demographic profile of the study population

Characteristics		N (%)
Sex	Male	77 (36%)
	Female	137 (64%)
Marital Status	Married	106 (49.5%)
	Widow/(er)	75 (35.0%)
	Divorced	26(12.1%)
	Single	7(3.4%)
Education Level	Degree	6 (2.80%)
	Diploma/Certificate	6 (2.80%)
	High School	116 (54.4%)
	Primary School	80 (37.2%)
	No Education	6 (2.80%)
Employment Status	Employed	88(41%)
	Unemployed	125(59%)

The age range of the study population was from 18 years to 74 years, with a median age of 41years.

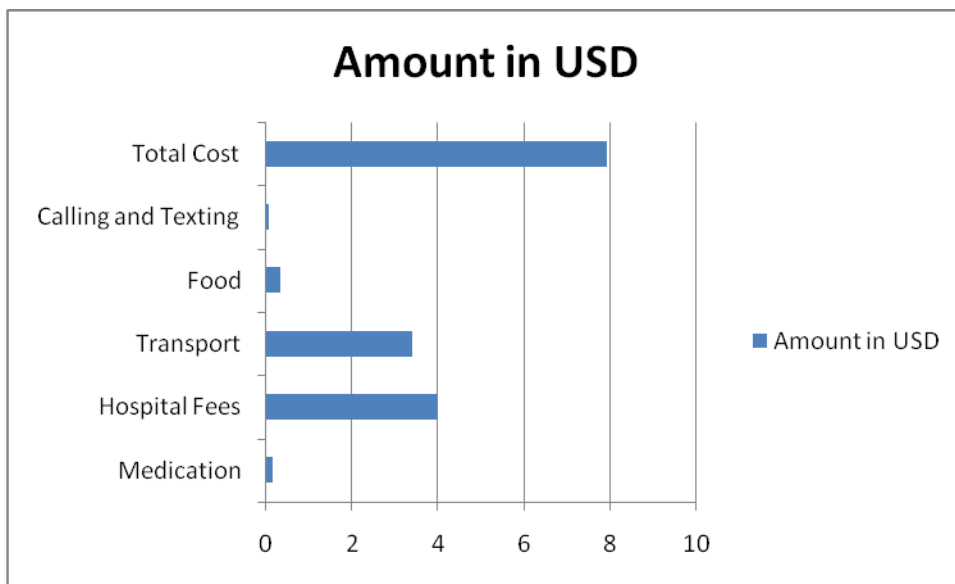
Affordability of services

Although the results revealed similar mean amounts of health care expenditure by the rich and the poor, the non-parametric Wilcoxon ranksum test, showed that the poor socio-economic group incurred higher health expenses than the rich ($p < 0.01$). Mean health care expenditure by the poorer group was \$9.02, compared to \$9.80 for the richer patients. Health care expenditure per month amongst the poor ranged from \$4 to \$54 and health care expenditure amongst the rich ranged from \$2 to \$124. Fifty four percent of the respondents incurred catastrophic health expenditure as a result of seeking care at the facility, and this proportion was higher amongst the poorer patients (77%) compared to the rich (31%) ($p = 0.0000$).

The results show that 76% of the poor patients had to borrow to cover their health care costs ($p = 0.000$), in comparison to 47% of the richer group. Selling items to finance health care was found to be higher in the lower socio-economic group ($p = 0.000$), with a greater proportion of the poor (9%) having to sell their household items to fund health care costs as compared to the higher socio-economic class (3%). The poorer also found it more difficult to meet health care expenses (87%) as compared to their richer counterparts (69%) ($p = 0.003$). Affordability of food was reported to be difficult by 88% of the poor as compared to the 75% of the rich ($p = 0.02$).

The mean cost for transport was \$3.40, while hospital fees were an average of \$4. Although the basic user fee is \$1.50, in addition to this, fees are charged for patients if they are admitted or if they need to buy drugs other than ARVs. Patients spent an average of \$0.15 on medication, mainly because antiretrovirals are free and patients only have to pay for any other drugs which are not ARVs. There was no accommodation cost for any respondent as they reported that they commuted to and from their homes on the day they were due for a prescription refill, an appointment with the doctor or when they come in for consultation if they are not feeling well. The average amount spent on food was \$0.32 and an average of \$0.05 was spent on calling and texting during these health care visits. Figure 1 gives a graphical presentation of the direct monetary costs incurred in coming to receive treatment in one episode.

Figure 1 – Costs incurred in coming to receive treatment



Patients at Chivhu Hospital pay a user fee of \$1.50 at the outpatient department even when they are using ART services. As a result, 25% of respondents said that the user fee was a deterrent to accessing services as many people were unemployed and could not afford it. 63% of the unemployed found it difficult to meet the health care expenses in comparison to 36% of the employed ($p=0.018$). In addition to being unaffordable, the \$1.50 user fee was also giving challenges to the cashiers because they had no change. Three respondents reported that they had to go back into town or wait for some time in order to get change so that they could pay the exact \$1.50 required by the hospital.

Mean household expenditure in a month was found to be \$75.54 with a standard deviation of \$104.30. Therefore the study population consisted of a wide variation in expenditure per household.

Availability of services

The results show that 75% of the respondents reported that Chivhu Hospital was the closest facility to them offering antiretroviral therapy. Most respondents, (46%) were local residents of Chivhu and 39% of the respondents walked to the hospital.

Both socio-economic classes in the study seemed to agree that the opening hours of the facility were convenient. The chi-squared test results indicated no statistically significant difference between convenience of opening hours and socio-economic status ($p=0.526$). In terms of the form of transport used to get to the facility, the poorer patients (82%) reported that they travelled to the facility by public transport or other private cars while the richer ones (62%) mainly travelled by foot or bicycle ($p=0.000$). This trend is attributable to the fact that most of the richer respondents live close to the facility and the hospital is in walking distance from their homes.

There was no statistically significant difference between socio-economic class and belonging to a support group ($p=0.471$). Having a pillbox was also not shown to be related to wealth grouping

($p=0.400$). In order to improve service availability, 23% of patients highlighted that ARVs should be available at the nearest primary care clinic, and 11% said that the clerks at the accounts department where payments are made should start work at the stipulated time. Only 3% of respondents ever got home visits from health care workers and there was no significant difference by socio-economic status ($p=0.701$). Of those who did not get visits, 80% of them ($N=168$) said they would have valued a visit at their homes by health care workers.

The following were the chief reasons for patients valuing home visits by health care workers:

- To aid patients with food – 38%
- To give advice to patients on a one on one basis – 42%
- To assess living conditions and diet of the patient – 3%
- To discuss personal issues – 3%
- To show they care – 4%
- To see where we live – 2%

Some of the patients reported that if they were to be visited, then it could be one way of convincing their partners to get tested and that it was just good to get visits. One patient was quoted saying, “It would be quite encouraging to get a visit from our health care workers as it would be a sign that you are not fighting the battle alone”. Another patient also cited that they would value being visited so that they could get financial assistance.

Both the richer group and the poorer one were comfortable to come and seek assistance at the hospital without an appointment ($p=0.190$). The main reason was that the staff were viewed to be very helpful (65%) and that patients know the importance of consulting their health care providers when in need and they also feel welcome and get good services at the hospital. The time spent travelling to the health care centre was not normally distributed using the Shapiro-Wilk test ($p=0.000$). Time taken to travel to the facility had a median of 120 minutes and a mean of 128 minutes, with 38% of respondents taking less than an hour to get to the facility. This means that most patients took up to 120 minutes to travel to the facility, with very few of them taking a shorter period than that. The median time taken to collect medicines at the facility was 60 minutes and there was no statistically significant difference in the time taken to collect medication between the poor and the rich, or between men and women. 61% of the patients reported that the queue to see a doctor at the facility was long. In terms of knowledge, the majority of patients knew that ARVs do not cure AIDS (85%) and this knowledge was not associated with sex ($p=0.656$) or socio-economic status ($p=0.088$). Furthermore, 94% of respondents also said that they should still turn up for checkups even if they feel well and 75% of respondents said antiretrovirals should not be stopped even when one has gained weight. In addition to assessing the various access variables, the study also looked at adherence issues which are closely related to access.

There was no relationship found between self-reporting missing medication and socio-economic status ($p=0.788$) and missing medication and sex of respondent ($p=0.658$). However those who were married were less likely to miss taking their medication ($P=0.024$). When asked about what should

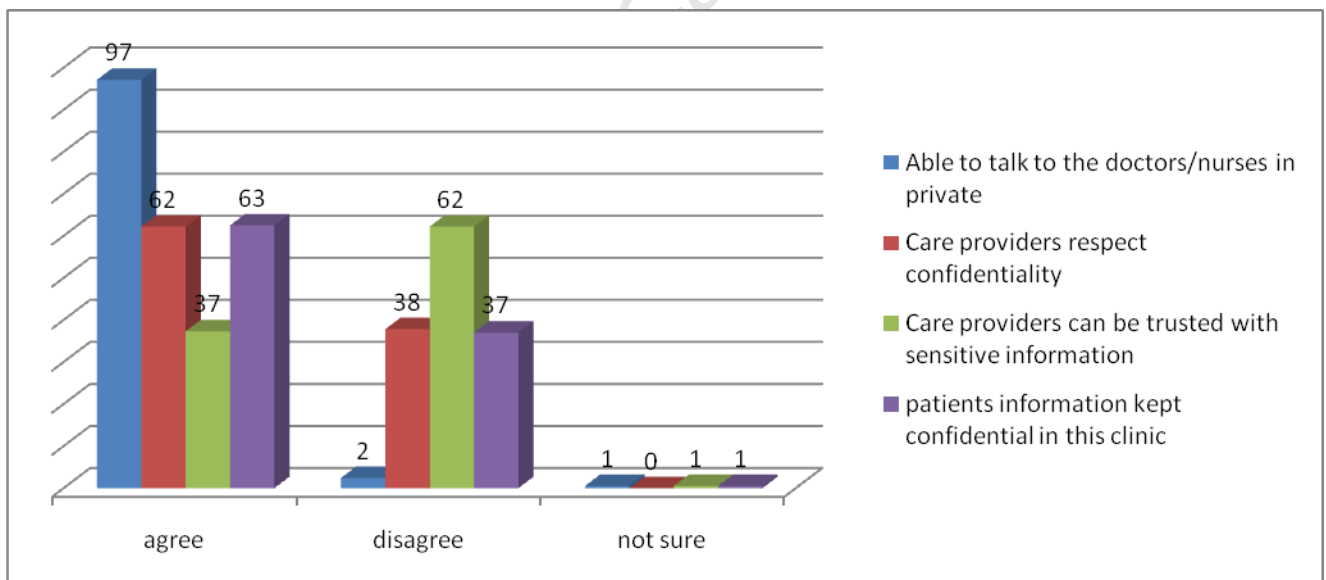
be done to improve the service at the hospital, 23% of the patients said that antiretroviral treatment should be made available at local clinics to reduce commuting by patients and 20% of the respondents said the service was good.

Acceptability of services

This section analyses the expectations and attitudes of patients to providers as well as patient perceptions of the ART service. Acceptability responses were not found to differ significantly by socioeconomic status, and so these results are presented for the full sample of patients. Most respondents (97%) agreed that they were able to talk to the doctors and nurses in private and that the care providers fully explained the medication and illness to their patients. However when it came to being examined thoroughly, a lower proportion of patients (61%) felt that they were being given thorough examinations by health care workers.

It was found that 95% of the respondents were comfortable to seek assistance from the clinic. Furthermore, 97% of the patients disclosed their status to their families and 84% of them said they were not being stigmatised in the society because they were on ART. Trust plays a very important role in the acceptability component of access to health care [18-20] and trust barriers in this study are presented in the following graph. Figure 2 below shows a graphical presentation of the various trust and confidentiality issues brought out in the study.

Figure 2- Patient responses on trust and confidentiality



Although 97% of the patients agreed that they were able to talk to the doctors and nurses in private, only 62% of them said care providers respect confidentiality and 63% agreed that information was kept confidential at the clinic. The majority of patients (62%) did not agree that the care providers could be trusted with sensitive information and 54.30% of the patients did not feel that the health care workers were respectful in their conduct.

Cleanliness of the facilities was found to be a major acceptability barrier with 95% of the respondents agreeing that the facilities, especially the toilets, were dirty. One patient was quoted saying, 'Something has to be done concerning the cleanliness of the toilets. Although they are

hospital toilets they actually pose a health hazard'. The queues to see the doctor were said to be long by 61% of respondents.

Patients did not mind being treated by a male or a female health care worker. Furthermore, language was not an issue which patients complained about since most of them (90%) shared the same language with health care providers. Given the affordability barriers outlined above, it is unsurprising that patients wanted to reduce the number of visits to the clinic as much as possible (98%).

Discussion

The discussion of findings will be carried out under each of the sections presented in the results namely the demographic details of respondents, affordability, availability and acceptability and of services.

This study shows that uptake of ART is higher in females (64%) compared to males (36%). Similar findings were reported in the neighbouring Mashonaland West province where 65% of the people on ART are females and 35% are males [21]. The unemployment rate was at 59% and only 6% were educated beyond high school. Being employed potentially translates to economic empowerment and results in one being able to afford health care. With such levels of unemployment in the study population, it is unsurprising that 78% of respondents said that it was difficult for them to meet their health care costs. The results of the study show that even the employed (66%) were facing difficulties in affording health care.

Affordability

The expenditure incurred to get treatment was quite high considering that the mean household expenditure was \$75.54. With such a total monthly household expenditure, spending \$7.92 which was the total average cost of seeking care would significantly compromise the already strained household budget. Some households, especially in rural areas do not readily have cash [22-26] therefore getting the money required for monthly consultations would be difficult for them [23, 26]. As a result patients end up borrowing, selling household items [25] or skipping their appointments because they cannot afford to attend clinics. It is for such reason that 30% of patients suggested that user fees at the hospital should be removed; 15% said that outreach programs should be widespread to cut down on transport and others said that patients should get financial assistance. Affordability of care has been shown to be one of the deterrents of access in the literature [23, 24, 27, 28].

In coming to receive treatment, patients on ART first have to pay a user fee of \$1.50 at the outpatients department. This amount has been said to be unaffordable by many and in addition even when one has the money the cashiers do not have change for such an amount. Patients bring in \$5 and \$10 notes and the cashiers cannot change them. The main reason for shortage of change is that there is a shortage of coins in circulation since Zimbabwe uses multiple currencies, the main ones being the South African Rand and the United States dollar. As a result patients spend more time at the facility as they have to find the change themselves or pay as a group then split the money later. Scrapping the user fee of \$1.50 and making the ART patients attend the facility free of charge will significantly reduce the financial access barriers faced by patients in seeking treatment.

Studies carried out in Zambia [28] and Uganda [26] revealed that user fees, transport costs and the costs of medication were barriers to access. The provision of free medical care in Haiti was shown to overcome access these barriers [23], resulting in increased uptake of antiretroviral therapy.

Availability

Queues to see a doctor or nurse were reported to be long by 61% of respondents which led to some of the respondents suggesting that the staff complement should be increased and a doctor should be available at all times. At the moment, the patients' first port of call is the outpatients' department where they pay the user fee and get their card stamped so that they can proceed to the ART clinic for collecting medication or for a review. This results in patients spending more time at the hospital and can be avoided by allowing ART patients to come directly to their clinic. In order not to inconvenience patients and reduce congestion at the facility, the nurses screened and attended to those who came in for checkups and only those considered to have a serious conditions needing the doctors' attention were told to wait. Despite the opening hours of the facility being convenient, patients dedicated a lot of time to seeking care. Firstly, the median travel time was found to be 120 minutes. After that, patients had to wait for up to four hours if they had to see a doctor or nurse for a checkup or two hours if they were just collecting medication. Studies conducted elsewhere cited the opportunity cost of time spent seeking care as a significant barrier to access [23, 29]. An increased network of outreach services will reduce congestion at the facility and reduce queues. Such an intervention also reduces cost barriers to accessing health care as patients no longer have to pay for transport.

Acceptability

The major acceptability barriers were cleanliness of facilities, especially the toilets; presence of long queues to see the doctor and patients' lack of trust in the health care workers. Most respondents (95% N=198), said that toilets were dirty and had to be improved upon. Others also suggested that the general cleanliness of facilities needed to improve. Despite patients being able to talk to the nurses in private (97%), 62% of the patients reported that they did not trust the health care workers with sensitive information. Although patients did not feel that the health care workers were respectful in their conduct (54%), they agreed that health care workers fully explained to patients about their condition and the medication (97%). To improve on acceptability of services, staff should receive training on patient care, in addition to the implementation of regular staff audits and supervisory visits from both the local managing authorities and the Ministry of Health.

Presence of social support networks were quite beneficial in ensuring adherence as those who were married were less likely to miss taking their medication ($P=0.024$). With fewer married patients reporting ever missing their medication, measures to enhance adherence should be targeted towards patients who are likely to default such as the divorced and single patients.

Recommendations and limitations of the study

It should be borne in mind that this study has unpacked barriers to access from the perspective of the users of ART services: results are therefore not necessarily applicable to those in need of ART who have been unable to overcome the access barriers to use or who have become lost to follow-up. These results may also fail to apply in others settings where the context is different.

Building upon this study, the acceptability section can be improved by carrying out a qualitative study so that patients' perceptions and feelings are fully recorded. Qualitative studies could be critical in understanding why patients eligible for ART do not initiate or continue with ART [30]. From an equity perspective, several issues need to be addressed if equitable access to ART is to be achieved at Chivhu Hospital. Firstly, transport cost barriers faced by the poorer patients coming from rural areas should be minimised by increasing coverage of outreach programs. Implementing more outreach removes availability barriers in the form of time spent travelling to the facility. A case in point is the implementation of home based ART in Uganda [31] and directly observed ART in Haiti [32]. As a result of such initiatives, poor households from remote rural areas have an equal chance of getting medication in comparison to those living in the urban areas close to the hospital. Secondly, just like ART, medication for other conditions should be made available to patients free of charge. Out of pocket payments for drugs not on the ART schedule are a barrier to the poorer patients and in some instances the richer patients. As a result, patients forego the medication which can result in their clinical condition worsening.

Conclusion

The study explored the various access dimensions affecting uptake of anti-retroviral therapy at Chivhu General Hospital. The study revealed that both poor and rich patients face similar acceptability and availability barriers. However the cost of seeking care was more affordable for the richer patient groups. To ease the financial burden, patients suggested initiatives such as the removal of user fees, assistance with transport costs and widespread roll out of outreach programs to avert the transport cost.

In conclusion, the following are the access issues to be addressed in Chivhu,

- The high financial costs of seeking care in the form of transport costs, user fees and costs of medication.
- The need to instil a culture of respecting patients' confidentiality in the health care workers to enable patients to trust them more.
- The lack of adequate staff mainly doctors and the necessary facilities such as CD4 count machine to monitor effectiveness of therapy.
- Long waiting times and long queues to see the doctor.
- The general cleanliness of the facilities.

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Part D: Policy Brief

Access barriers to antiretroviral treatment in Zimbabwe, a case study of Chivhu Hospital

This policy brief is based on a study carried out in Chivhu, Zimbabwe, to investigate the factors affecting access to Anti-Retroviral Treatment (ART). This study was done from a user's perspective.

Introduction

Fourteen percent of the Zimbabwean population is infected with HIV (avert.org). Although the numbers infected are declining, more still needs to be done to lower the rate of infection, improve quality of life as well as prolong life expectancy for those living with the infection. One way of achieving this is the widespread rollout of antiretroviral therapy (ART). ART has been shown to improve quality of life, increase productivity and reduce the risk of transmission by reducing the body's viral load (Cardo, D. et al 2006). In response to the AIDS pandemic, the government of Zimbabwe availed antiretrovirals to those infected through its public health system. According to the 2010 WHO guidelines, 59% of those in need of treatment are receiving it (WHO 2011). Zimbabwe offers antiretroviral drugs (ARVs) free of charge. Although provision of ART is free of charge, patients have to pay for any other prescribed medication not on the ART program in addition to paying transport fees to get to the facility and other costs for food, phoning etc. It is against this background that this study was undertaken, with an aim of identifying the access barriers faced by patients as they receive antiretroviral treatment.

It is hoped that the findings will inform policy makers about how the health system can become more oriented to patient needs in order to overcome these barriers.

Research Objective

The research examined the access barriers faced by the users of ART services at Chivhu Hospital. The research also assessed whether these barriers differed for patients with higher or lower levels of wealth.

Methods

Data were collected by way of exit interviews using a semi-structured questionnaire. A total of 214 patients, aged above 18 years, participated in the study. All patients included in the study were receiving ART at the clinic located at the Chivhu General Hospital, which serves those patients living in Chivhu and the surrounding rural areas. The study used a comprehensive framework of access to investigate the three access dimensions namely acceptability, availability and affordability.

Study Findings

In order to get the free ART services, patients first have to pay a user fee at the Hospital. This presented a considerable barrier to accessing ART as most patients could not afford the fee. In contrast to other findings in the literature, stigma was not a significant barrier to access.

Availability of services The study findings suggested that there are considerable availability barriers to ART use.

- In coming to collect medication, patients spent at least two hours waiting for their medication.
- ART patients first had to queue with other patients at the outpatient department to make their payment then proceed to the ART clinic afterwards. Patients viewed this as time consuming.
- Only 3% of the patients had received home visits from health care workers and 80% of those who did not get visited said they would appreciate a visit from their health care workers.
- Patients spent an average of 60 minutes travelling to the facility, mostly by public transport. Presence of patient support services in the form of treatment buddies and support groups was very low.

Acceptability of services

- Poor cleanliness of facilities was a deterrent for use of ART for 95% of respondents. One patient commented and said, "We are so hesitant to visit the toilet whenever we come here. In addition nothing much is being done about the cleanliness of this place".
- Most patients (97%) agreed that providers respect confidentiality and that information was kept confidential at the facility. Despite this 62% of the patients felt they could not trust caregivers with sensitive information.
- 84% of patients did not feel they were being judged negatively in the community because they attend the ART clinic.
- Patients felt that health care workers explained their illness and medication to them (98%). A lower proportion of the patients however felt that providers undertake thorough examination (61%).

Affordability of services - Patients were divided into a poor and a less poor group using an asset index based measure of wealth. It was also assumed that households spending more than 20% of their budgets on health care may incur catastrophic health expenditure.

- 54% of the respondents incurred catastrophic health expenditure as a result of seeking care at the facility.
- 76% of poor patients had to borrow to finance health care in comparison to 47% of those who were rich.

- 25% of respondents said that the user fees were a deterrent to service use in addition to transport and food costs.

Conclusion

- ❖ Due to high transport costs and the time spent by patients at the hospital to collect medication or get checkups, most patients preferred to reduce visits to the hospital as much as possible.
- ❖ Removal of financial barriers and availing drugs does not necessarily translate to access to care. There is an interplay of various factors which include quality of care, state of facilities and staff attitudes which affect the continued use of ART.
- ❖ Dirty facilities were a deterrent to access.

Policy Recommendations

For ART to reach all the intended recipients, that is, everyone eligible for treatment regardless of their geographical location, socio-economic status and personal characteristics any factors that impede the equitable (fair) provision of the service should be removed. Building upon the findings of this study, the following actions should be taken towards ensuring equitable access to ART, bearing in mind that the challenges faced by patients in accessing and adhering to treatment change from time to time.

1. Remove user fees

Patients have to pay a user fee of \$1.50 which is unaffordable to most of them. Removal of the user fee could improve access to and adherence to therapy. Furthermore, patients should not pay for any other prescribed medications as is the case at the moment. This will go a long way in reducing cost barriers. Removal of the fees results in less congestion and less time spent at the facility as patients will not have to queue at the outpatient department.

2. Separate the ART clinic from the outpatient department

Separation of the two will result in patients spending fewer hours at the hospital. Having a separate ART clinic means that ART patients directly go to their clinic and they do not mix with other patients. This separation should be carefully, with input from patients and providers as a stand-alone ART clinic can result in stigmatisation of patients. This separation is efficient in terms of service provision as it reduces queues and congestion and it is more convenient to patients.

3. Improve on service provision

Cleanliness of facilities and provider patient relationships should improve. The hospital management should ensure that facilities are clean by making staff more accountable and

supplying them with the necessary cleaning materials. To improve on provider-patient relationships, staff should be supported to improve their actions and attitudes towards patients. In addition to close monitoring of staff, patient confidentiality can also be ensured by way of a clearly laid out code of conduct. Furthermore, frequency of consultation can be reduced by increasing the medication supplies given to adherent patients. This would save on transport costs and gives more convenience to the patient.

4. Increase geographical coverage of outreach services.

More areas surrounding the hospital should receive the mobile clinic facility in order to cut down on transport costs, reduce queuing at the facility and save patients from spending hours commuting to and from the facility. In addition, visiting patients at their homes will make caregivers aware of the specific needs of their patients as they interact on a personal basis. Family members should be taught to continue encouraging and supporting patients to adhere to their medication. Such support structures are quite essential in ensuring the continued uptake of antiretroviral therapy.

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Part E: Appendices

Appendix 1 ART Questionnaire

Date of interview

Interviewer name

Time interview started (hh:mm) [:] PM/AM (delete inapplicable)

Time interview ended (hh:mm) [:] PM/AM (delete inapplicable)

SECTION 1: SOCIO-ECONOMIC AND DEMOGRAPHIC DETAILS

1.1 Sex Male ()

Female ()

1.2 What was your age at your last birthday? Year born () Years ()

1.3 What is your current marital status?

Status	Tick the applicable
Married	
Living with partner	
Widow/widower	
Divorced or separated	
Never married (single)	
Other	
If Other specify	

1.4 Are you the the head of your household ? Yes.....No

1.5 What is YOUR highest level of education? If the person is NOT the House Hold Head (HHH) ask, What is the highest level of education of your HHH i.e. husband / father / mother etc.

Select one option only

Education Level	Respondent	Household Head
Completed Degree		
Completed diploma/certificate		
High School (Ordinary and Advanced Level)		
Primary School		
Other		
If other, specify		

1.6 Are you or the HHH currently employed? Yes..... No.....

1.7 If yes, what kind of job do you do?

Type of employment	Respondent	HHH
Civil Servant		
Private Sector Employee		
Small Scale Farmer		
Vendor		
Artisan		
Other, specify		

SECTION 2: UTILISATION OF HIV SERVICES AND COSTS OF THE DISEASE

2.1 When did you FIRST begin receiving antiretroviral (ARV) treatment? Month.....Year.....

2.2 How often do you collect your ARV treatment here at the clinic?

--	--

Frequency	Tick the applicable
Monthly or less	
2-monthly	
Other	
If other, specify	

2.3 Do you have fixed dates or appointments made in advance for collecting your medication?

Yes..... No.....

We are now going to ask you questions on how it could be difficult for you to stick to the ARV treatment schedule and how you might not always be able to make it for your appointments at the clinic.

2.4

	Yes	No
Did you miss taking any of your ARV tablets YESTERDAY?		
Did you miss taking any ARV tablets the day before YESTERDAY?		
Did you miss taking any ARV tablets 3 DAYS AGO? Specify the calendar day in relation to the day of the interview		
Apart from the last three days, have you ever missed taking any ARV tablets?		
Have you missed any of your medication refills in the last 6 months?		
If yes, how many visits did you miss? If no, go to 2.6. If yes go to 2.5		

2.5 Reasons for missing medication refills

	Yes	No

Lack of money		
Lack of time		
I felt better		
Inconvenient		
I could not take time off from work		
No transport		
Had no one to accompany me		
Too ill to travel		
Other responsibilities		
The treatment is not effective / does not make me feel better		
The queues in the facility are too long		
The staff are rude or uncaring		
The opening hours of the facility are inconvenient		
The queue was too long at the facility and I was told to return another day		
The pharmacy was closed and I was told to return another day		
Don't know/remember		
Other		
If other, specify		

2.6 At which times of the day do you take your medication?

MorningEvening

2.7 Who supports you in taking your ARV treatment each day? Indicate relationship e.g. sister, friend, children etc, can be more than one.

Relationship

Relationship

2.8 How often do you see the doctor/nurse for a check up?

	Yes	No
--	-----	----

Once a month		
Once every two months		
Other, specify		

2.9 Have you ever missed your appointment with the doctor/nurse in the past six months?

Yes..... No.....

2.10 If yes, how many times? Specify.....

2.11 What were the reasons for missing your appointment?

	Yes	No
It is not necessary to see a doctor/nurse as long as I am taking my medication.		
The doctor or nurse was not there and I was told to return another day		
Lack of money		
Lack of time		
Inconvenient		
I could not take time off from work		
No transport		
Had no one to accompany me		
Too ill to travel		
Other responsibilities		
The queues in the facility are too long		
The staff are rude or uncaring		
The opening hours of the facility are inconvenient		
The queue was too long at the facility and I was told to return another day		
Don't know/remember		
Other		
If other, specify		

2.12 How often do you have counselling sessions?

	Yes	No

Once a month		
Once every two months		
Other, specify		

2.13 Have you ever missed a counselling session in the past six months?

Yes.....No.....

2.14 If yes, how many times? Specify.....

2.15 What were the reasons for missing your appointment?

	Yes	No
Counselling is not necessary for me		
The counsellor was not there and I was told to return another day		
Lack of money		
Lack of time		
Inconvenient		
I could not take time off from work		
No transport		
Had no one to accompany me		
Too ill to travel		
Other responsibilities		
The queues in the facility are too long		
The staff are rude or uncaring		
The opening hours of the facility are inconvenient		
The queue was too long at the facility and I was told to return another day		
Don't know/remember		
Other		
If other, specify		

2.16 Besides ARVs, are you able to get the other health services you need from this facility? Yes/No

If NO go to 2.5 (If yes go to 2.6, if no go to 2.5)

Yes.....No.....

2.17 What services do you have to get elsewhere?

.....
.....

2.18 Have you ever been sick because of your HIV or because of your ARVs? Yes/No

If NO go to 2.24 (If yes go to 2.23, if no go to 2.24)

Yes.....No.....

2.19 If yes, where did you seek help?

	Yes	No
From this facility		
From another facility		
From a traditional healer		
I did not seek health care		
Other specify		

2.20 Do you take any herbal medications? Yes.....No.....

2.21 If yes, reason.....

SECTION 3: AFFORDABILITY

I am now going to ask you some questions about the financial resources you use as you seek health care as well as the difficulties you might face in seeking health care for your HIV/AIDS.

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

If no, go to 3.3

3.2 If yes, how much did you borrow? \$.....

3.3 In the last month did you have to sell personal or household items in order to pay for healthcare?

Yes No.....

3.4 How much time did you spend at the clinic last time you came to collect your ARV drugs?

HoursMinutes

3.5 How much time did you spend at the clinic last time you came to see the doctor/nurse for your ARVS?

Hours..... Minutes

3.6 In coming to receive treatment today, did you pay for the following and if so, how much?

Category	Amount \$ (If no money is spent, code 0)
Transport (one way)	
Hospital fees	
Medicines	
Accommodation if you need to stay the night nearby	
Food during visit	
Phoning or texting	
Other, specify:	

3.7 Did you find it easy or difficult to incur the above expenses?

Easy.....Difficult.....Neither easy nor difficult.....Don't know.....

3.8 Who is responsible for buying the food you eat?

Specify.....

3.9 Do you or the one who buys food afford to buy all the food needed?

Yes No

3.10 Have you spent any other money on health care in the past month (e.g. traditional medicines, herbal shops, special food, other providers (including traditional healers and private doctors) etc)?

IF YES, how much have you spent \$.....

SECTION 4: AVAILABILITY

4.1 Is this the closest clinic to your home that offers ARV treatment? Yes..... No

If yes go to 4.3

4.2 If NO, Why do you prefer this facility?

Reason

4.3 Are the opening hours of this clinic convenient for you?

Yes..... No..... Not sure..... Don't know

4.4 Which form of transport did you use to get here?

Transport mode	Yes	No
By foot		
Bicycle		
Public transport (Bus/Minibus)		
Own private car		
Other private car		
Ambulance or hospital transport		
Other		
If other, specify		

4.5 How much time did you spend travelling to the health care facility? (From leaving home to arriving at the facility)

Hours.....Minutes.....

4.6 Do you currently belong to a support group? Yes.....No.....

4.7 Do you have a treatment buddy? Yes..... No.....

4.8 Do you have a pillbox [show] for keeping your tablets? Yes.....No.....

4.9 Since you learnt about your HIV status, has anyone from the health service ever visited you at home for your HIV?

Yes..... No

4.10 If no, would you prefer to get visits from anyone who works at the health care centre? Yes..... No.....

Reason

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

	True	False	Don't know
It is acceptable to stop ARVs after gaining weight			
ARVs cure HIV/AIDS			
It is not necessary to come for checkups to the health care centre when you are healthy.			

4.12 Are you comfortable or free to come to the clinic to seek assistance when you do not have an appointment?

Yes..... No.....

Reason(s).....

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SECTION 5: ACCEPTABILITY

5.1 Have you told anyone besides the health care workers that you are HIV positive? Yes..... No.....

5.2 If yes, indicate the relationship.....

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

	Agree	Disagree	Not Sure

Do you feel that people in the community judge you negatively for attending this facility for your ARV treatment?			
For your ARV treatment what would you prefer: a) To see a nurse in a nearby clinic or b) To travel further to see a doctor			
For your ARV treatment what would you prefer: a) To reduce as much as possible the number of visits to the clinic b) To increase the number of visits to the clinic			
In this clinic are you able to talk to the doctors or nurses in private?			
Care providers do not treat patients with respect and dignity			
Care providers fully explain to patients their illness and medication			
Care providers undertake a thorough examination			
Care providers respect confidentiality when dealing with patients			
Care providers cannot be trusted with sensitive information			
The queues to see a doctor or nurse are too long at this facility			
The doctors and nurses (<i>health workers</i>) discussed the treatment fully with me			
It is a problem that the <i>health workers</i> DO NOT speak my language.			
I find it easy to tell the <i>health workers</i> when I have missed taking my tablets			
The <i>health workers</i> are too busy to listen to my problems			
Patient information is kept confidential in this clinic			
The health workers I see respect me			
The facilities (including waiting area and toilets) are dirty			
I do not mind being treated by providers of the opposite sex			

5.3 What do you suggest should be done to ensure that patients are adherent to the treatment programme?

.....
.....

5.4 What do you suggest should be done to improve the ARV service?

.....
.....

5.5 Are there any other comments that you would like to make?

.....
.....

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

We now want to ask you some questions about the characteristics of the house where you live and type of facilities available within your household.

6.1 Where do you live?

..... Village or community.

..... Area or township.

6.2 Which best describes the type of house in which you live?

	Tick the applicable
House or brick structure on a separate stand or yard or on farm	

Traditional dwelling/hut/structure made of traditional materials	
Dwelling/house/flat/room in backyard	
Town/cluster/semi-detached house (simplex, duplex or triplex)	
Flat	
Room/flatlet not in backyard but on a shared property	
Other	
If other, specify	

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6.3 What is the main material of your house's walls?

	Tick the applicable
Bricks & plaster/finished	

Bare brick/cement block	
Corrugated iron/zinc	
Wood	
Other	
If other, specify	

6.4 What is the main material of your house's roof?

	Tick the applicable
Tiles	
Corrugated iron/zinc	
Thatching	
Asbestos	
Other	
If other, specify	

6.5 How many rooms, including kitchens, does your house have? (Excluding bathrooms, sheds, garages unless people are living in them).

.....Rooms

6.6 What is the main source of drinking water for members of your household?

	Tick the applicable
Piped (tap) water in dwelling	

Piped (tap) water on site or in yard	
Borehole on site	
Neighbour's tap	
Public/communal tap (either free or paid)	
Water carrier/tanker	
Borehole off site/communal	
Flowing water/stream/river	
Stagnant water/dam/pool	
Well	
Other	
If other specify	

6.7 What type of toilet does your household use?

Type of toilet	Tick the applicable
Flush toilet (connected to sewage)	
Flush toilet (with septic tank)	
Pit latrine with ventilation pipe	
Pit latrine without ventilation pipe	
No facility/bush/field	
Other	
If other, specify	

6.8 What is the main source of energy for cooking in your household?

Option	Tick the applicable
Electricity from mains	

Electricity from generator	
Gas	
Paraffin	
Wood	
Other	
If other, specify	

6.9 Does your household have any of the following items in good working order?

Item	Yes	No
Landline phone		
Cell phone		
Radio		
Television		
Video recorder/DVD player		
Electric stove		
Bicycle		
Personal computer at home		
Fridge		
Car		

6.10 Does your household own cattle, livestock or chickens?

YesNo

6.11 In general how much does your household usually spend in a month? (Choose only one option)

Amount spent US\$	Tick the applicable
0 - 50	
50 - 100	
100 - 200	
200 - 500	
500 - 800	
800 and above	
Don't know	
Refuse	

6.12 Do you have anything else that you would like to tell us about your experience of seeking or receiving care at this facility?

.....

.....

.....

Thank you for your time.

Appendix 2: Ethics Approval Letter



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • Facsimile [021] 406 6411
e-mail: lamees.emjedi@uct.ac.za

12 November 2010

HREC REF: 521/2010

Mr W Siduna
Health Economics Unit
Public Health & Family Medicine

Dear Mr Siduna

PROJECT TITLE: ACCESS TO ANTIRETROVIRAL TREATMENT (ART) IN ZIMBABWE, A CASE STUDY OF CHIVHU HOSPITAL

Thank you for submitting your new study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the FHS HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until 15 November 2011.

Please send us an annual progress report (website form FHS 016) if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

lemjedi

Appendix 3: Journal Instruction for BMC Health Services Research authors

File formats

The following word processor file formats are acceptable for the main manuscript document:

- Microsoft Word (version 2 and above)
- Rich text format (RTF)
- Portable document format (PDF)
- TeX/LaTeX (use [BioMed Central's TeX template](#))
- DeVice Independent format (DVI)

Users of other word processing packages should save or convert their files to RTF before uploading. Many free tools are available which ease this process.

TeX/LaTeX users: We recommend using [BioMed Central's TeX template and BibTeX stylefile](#). If you use this standard format, you can submit your manuscript in TeX format. If you have used another template for your manuscript, or if you do not wish to use BibTeX, then please submit your manuscript as a DVI file. We do not recommend converting to RTF.

Note that [figures](#) must be submitted as separate image files, not as part of the submitted manuscript file.

Preparing main manuscript text

General guidelines of the journal's style and language are given [below](#).

Overview of manuscript sections for Research article

Manuscripts for Research article articles submitted to *BMC Health Services Research* should be divided into the following sections (in this order):

- [Title page](#)
- [Abstract](#)
- [Keywords](#)
- [Background](#)
- [Results and discussion](#)
- [Conclusions](#)
- [Methods](#)
- [List of abbreviations used](#) (if any)
- [Competing interests](#)
- [Authors' contributions](#)
- [Authors' information](#)
- [Acknowledgements](#)
- [Endnotes](#)
- [References](#)

- [Illustrations and figures](#) (if any)
- [Tables and captions](#)
- [Preparing additional files](#)

The **Accession Numbers** of any nucleic acid sequences, protein sequences or atomic coordinates cited in the manuscript should be provided, in square brackets and include the corresponding database name; for example, [EMBL:AB026295, EMBL:AC137000, DDBJ:AE000812, GenBank:U49845, PDB:1BFM, Swiss-Prot:Q96KQ7, PIR:S66116].

The databases for which we can provide direct links are: EMBL Nucleotide Sequence Database ([EMBL](#)), DNA Data Bank of Japan ([DDBJ](#)), GenBank at the NCBI ([GenBank](#)), Protein Data Bank ([PDB](#)), Protein Information Resource ([PIR](#)) and the Swiss-Prot Protein Database ([Swiss-Prot](#)).

You can [download a template](#) (Mac and Windows compatible; Microsoft Word 98/2000) for your article.

For reporting standards please see the information in the [About](#) section.

Title page

The title page should:

- provide the title of the article
- list the full names, institutional addresses and email addresses for all authors
- indicate the corresponding author

Please note:

- the title should include the study design, for example "A versus B in the treatment of C: a randomized controlled trial X is a risk factor for Y: a case control study"
- abbreviations within the title should be avoided

Abstract

The Abstract of the manuscript should not exceed 350 words and must be structured into separate sections: **Background**, the context and purpose of the study; **Results**, the main findings; **Conclusions**, brief summary and potential implications. Please minimize the use of abbreviations and do not cite references in the abstract. **Trial registration**, if your Research article reports the results of a controlled health care intervention, please list your trial registry, along with the unique identifying number (e.g. **Trial registration**: Current Controlled Trials ISRCTN73824458). Please note that there should be no space between the letters and numbers of your trial registration number. We recommend manuscripts that report randomized controlled trials follow the [CONSORT extension for abstracts](#).

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should be written in a way that is accessible to researchers without specialist knowledge in that area and must clearly state - and, if helpful, illustrate - the background to the research and its aims. Reports of clinical research should, where appropriate, include a summary of a search of the literature to indicate why this study was necessary and what it aimed to contribute to the field. The section should end with a brief statement of what is being reported in the article.

Results and discussion

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